

THE HOSPITAL RESETTLEMENT PROGRAMME IN NORTHERN IRELAND AFTER THE BAMFORD REVIEW

PART 1: STATISTICS, PERCEPTIONS AND THE ROLE OF THE SUPPORTING PEOPLE PROGRAMME

A REPORT FOR THE NORTHERN IRELAND HOUSING EXECUTIVE

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INTRODUCTION AND BACKGROUND

Introduction

The Review of Mental Health and Learning Disability in Northern Ireland, commissioned in 2002 by the Department of Health, Social Services and Public Safety (DHSSPS) from an independent committee led by Prof David Bamford, widely referred to as the 'Bamford Review', provided strong evidence of the need for comprehensive reform of services for learning-disabled people in Northern Ireland¹. In line with one of the Bamford Review recommendations, service developments for learning-disabled people since the mid-2000s were focussed on the resettlement of people living in a long-stay hospital. A key objective of the review report was²:

" ... to ensure that an extended range of housing options is developed for people with a learning disability".

The Northern Ireland Housing Executive (NIHE) played a significant role in helping to deliver the post-Bamford resettlement programme. Housing Executive officers worked alongside the Health and Social Care Board and Trusts in commissioning new services for learning-disabled people being resettled; a significant proportion of the social housing new build programme, which was planned by NIHE, was dedicated to the provision of housing for people who have additional support needs or who need to live in supported housing; the support element in these schemes was funded by the Supporting People Programme for which NIHE has administrative responsibility.

Research aims and objectives

This research was commissioned by NIHE in its role as the strategic housing authority and Supporting People administrative body for Northern Ireland. The overall aim of the research was to provide NIHE and its partners³ with an account of the way the resettlement programme had been managed, the role of the Supporting People Programme, and an insight into how and to what extent the lives of learning-disabled people who had been resettled from long stay hospitals⁴ had changed since taking up their new accommodation.

The original research objectives were:

- to undertake a brief literature review of relevant research and policy on the resettlement of learning-disabled people from Northern Ireland, Great Britain and the Republic of Ireland (see Part 2);
- 2. to provide an overview of the models of housing, care and support that have been adopted in NI to help sustain those who have been resettled into a more independent way of life, in comparison with the models available in GB;

¹ Review of Mental Health and Learning Disability (Northern Ireland) chaired by Prof David Bamford, (2005) *Equal Lives: Review of Policy and Services for people with a Learning Disability in Northern Ireland*, Department for Health, Social Service and Public Safety, Belfast

² Bamford, (2005), op. cit., page 8, para 1.15

³ The partners in this programme were: Northern Ireland Government Departments, statutory health and social care organisations, housing, care and support providers from the independent sector, regulatory bodies and others.

⁴ There were three long stay hospitals in Northern Ireland specialising in provision for people with moderate to severe learning disabilities and mental health issues - Muckamore Abbey Hospital, Antrim, operated by the Belfast H&SC Trust; Longstone Hospital, Armagh, operated by the Southern H&SC Trust; and Lakeview Hospital, Derry/Londonderry, operated by the Western H&SC Trust.

- to provide an insight into the socio-demographic profile and housing circumstances of people who had been resettled, focussing in particular on people who had been resettled since an enhanced version of the resettlement programme was launched on 1 April 2012;
- 4. to provide an overview of how resettled people perceived their quality of life and how their life had changed since settling in the community;
- 5. to give a balanced account of the impact of this scheme on the quality of their lives compared to their previous hospital settings as well as the impact on their family/carers;
- 6. to provide an estimate of the costs to the public purse of supporting and caring for learning-disabled people in the community compared to the hospital;
- 7. to contribute to a growing evidence base to guide future policy and good practice in addressing the housing and care needs of people with learning disabilities in long-term hospital and community settings.

The research programme

The Housing Executive's original intention was to achieve all of the research objectives in a single project. However, there were unforeseen difficulties in obtaining statistical information on the basis of which to profile the socio-economic characteristics and housing circumstances of the resettled population (objective 3); and it was not possible to identify a survey population of resettled people or construct a sample for interview (objectives 4 and 5). As a result the research was divided into two phases, each looking at the resettlement programme from a different perspective.

Phase 1 was re-designed to research and report on the institutional delivery of the resettlement programme and the role played by agencies involved in the planning and provision of housing, support and care services for learning-disabled people. This included:

- the main features of the learning disability resettlement programme⁵ focussing on issues affecting delivery of the programme since the Bamford Commission reported in 2005;
- the models of housing, care and support provision on which the resettlement programme was based:
- the characteristics, quality and costs of the housing and support services that were funded from the Supporting People programme; and
- the perceptions of policymakers, commissioners and service providers involved in the
 resettlement programme about the way resettlement was carried out, issues affecting the
 provision of housing and support, and the overall effectiveness of the programme from a
 policy and delivery point of view.

The main research questions for Phase 1 were as follows.

- How many learning-disabled people were there in Northern Ireland, and what proportion of them had been living as long-stay in-patients in hospital?
- What role did the different agencies play in resettlement?
- Were people resettled into accommodation that was appropriate for their needs and in a timely manner in line with the Bamford Commission's vision?
- Were those involved in policy, commissioning and service delivery generally content with the configuration of accommodation-based services for resettled people?

The description 'learning disability resettlement programme' was adopted here and elsewhere in the report to differentiate this aspect of hospital resettlement from a parallel programme that resettled people with mental health issues from the same three hospitals.

- How was independence promoted for people who were resettled?
- Alternatively, were some people resettled into institutional settings, which had been the subject of strong criticism by Bamford?
- What forms of housing with support funded from the Supporting People programme were provided to learning-disabled people generally, and to those who have been resettled from a long-stay hospital?
- What standards were achieved in this accommodation, and how much did it cost?
- Did stakeholders believe that resettlement was generally successful for the individuals concerned, and had betterment been achieved for them?
- Did stakeholders believe that the Bamford vision had been realised, and was value for money achieved in the way the programme was carried out?

Phase 1 of the research was completed in early 2014 and this report was submitted to the Housing Executive at that time. However, publication was deferred pending the completion of the second research phase in 2017.

The second phase of research was intended to report on the experiences of people who had been resettled from long stay hospitals. The research looked at the effectiveness of the resettlement process from their perspective, their levels of satisfaction with the outcome, and the impact on their lives that living in the community has had. Face to face interviews took place with twenty two learning-disabled people, their family members and the support staff working in housing support schemes where they were housed after resettlement. Phase 2 of the research is now complete and is reported in: Boyle F and Palmer J (2017), The Learning Disability Resettlement Programme in Northern Ireland: The experiences of learning-disabled people resettled from long stay hospitals in Northern Ireland, Northern Ireland Housing Executive.

Methodology for Phase 1

The methodology adopted for Phase 1 combined three different research elements:

- Desk research incorporating an online and library review of literature on the development of policy and practice in the resettlement of learning-disabled people. The review covered literature from NI, GB and the Rol. Key areas for examination included:
 - the evolution of resettlement policy in NI;
 - progress on resettlement in NI;
 - lessons from practice and contextual information for NI;
 - comparison with experience in GB and the RoI; and
 - an over-view of the approaches to independent living and models of housing, care and support available for learning-disabled people in GB for comparison with those found in NI.
- Data collection and analysis included:
 - data on the number, age and types of Supporting People-funded accommodation provided for learning-disabled people after resettlement in NI, in comparison with GB and Rol:
 - historic data on the progress made in resettling people since the Bamford report, and in particular in the three years after 1 April 2012;

- the characteristics of the housing and support services for learning-disabled people funded from the Supporting People programme generally, and of the particular services in which resettled people are living;
- information on the quality of housing and support services funded by Supporting People;
- the per capita and service-level revenue costs (Supporting People Grant only⁶) in housing and support services for resettled people.
- Consultations with policymakers, programme planners, service commissioners and senior managers involved in resettlement, and in the delivery of housing and support services to resettled people, to explore their views and perceptions of:
 - the pace of and influences on the rate of resettlement;
 - standards and issues in the provision of housing, care and support services;
 - views about the aims of the resettlement programme and the extent to which they have been or are being achieved.

The consultations with policymakers, programme managers and practitioners have been used to illustrate and inform parts of this report, and anonymised quotes have been used where relevant. Readers should note that each comment represents an individual's perspective on an aspect of the learning disability resettlement programme based on their particular experience from which trends and extrapolations should not necessarily be drawn. The researchers have used the results of interviews alongside documentary and data evidence as evidence on which to base the research findings and conclusions.

Structure of the report

Following this introduction, the report is divided into four parts:

- Part 1: Main Findings and Conclusions;
- Part 2: The resettlement programme in Northern Ireland;
- Part 3: A comparative perspective in resettlement policy in Great Britain and the Republic of Ireland.

There are five appendices:

- Appendix 1: interviews with policymakers, commissioners and service providers methodology and list of interviewees;
- Appendix 2: Semi-structured interview schedule;
- Appendix 3: Organisations providing supported housing and independent living services in Northern Ireland funded by supporting people grant;
- Appendix 4: models of housing support adopted in England for learning-disabled people and others with specialised needs - there is also an associated working paper that gives more detail⁷;
- Appendix 5: Members of the research team.

Key findings are highlighted in the body of the report in **bold type**. References to source material and sources of data are provided either in the body of the report or in the footnotes.

⁶ Information on social care funding and Housing Benefit was not available in time for incorporation into this report.

North Harbour Consulting (2009), Bamford Working Paper 2 - Models of housing and support used for learning-disabled people and others with specialised housing and support needs in England

PART 1: SUMMARY OF FINDINGS AND CONCLUSIONS

The introduction to this report identified ten research questions that were to be addressed in the research. This section of the report sets out the findings and conclusions in relation to each of the research questions. References are contained in the body of the report.

1.1 How many learning-disabled people were there in Northern Ireland, and what proportion of them had been living as in-patients in long-stay hospital?

The 2011 Population Census counted more than 40,000 people (2.2% of the Northern Ireland population) who were identified by the member of the household who completed the Census return as having a long-term 'learning, intellectual, social or behavioural difficulty'. The Census figure is more than double the number of learning-disabled people derived from a study of health and social care records by Prof. Roy McConkey *et al* in 2003 on which the Bamford Review and the development of subsequent policy was based. This difference is not accounted for by estimates of the rate of change in the number of learning-disabled people in Northern Ireland. McConkey *et al* had serious reservations about the accuracy of the health and social care data available to them on which their estimates were based. The authors suggest that planning for the learning disability resettlement programme in its various phases until 2011 may have been based on an underestimate of the numbers.

The study by McConkey *et al* identified 4,500 learning-disabled people who were diagnosed with severe or profound learning disabilities based on health and social care records. Around 300 people from this group were living in hospitals as long-stay patients. The implication of these figures is that a very large majority of people with severe or profound learning disabilities were living outside hospital in 2003.

The Bamford Report *Equal Lives* set out clear aims, objectives and guidelines for the delivery of better services for all learning-disabled people in Northern Ireland. The policy focus on resettling long-stay hospital in-patients was an important strand in the Bamford proposals, but the authors question whether more could have been done following the Bamford Review to improve services for learning-disabled people living outside a hospital setting. Policymakers, commissioners and service providers interviewed for the research commented on the shortage of accommodation and community services for learning-disabled people being resettled from hospital. These comments could apply equally to the availability of services for learning-disabled people previously living in community settings.

1.2 What role did different agencies play in the resettlement programme?

Planning and delivery of the learning disability resettlement programme involved two NI Government Departments (DHSSPS and DSD, now DfC), the Health and Social Care Board, the five Health and Social Care Trusts, the Housing Executive (both the capital planning and programme delivery team, and the Supporting People team), RQIA, selected housing associations and independent sector care and support providers as well as the private sector. Service and business plans, and investment proposals, were assembled at H&SC Trust level, and were then subject to scrutiny and approved at NI level.

Given the complexity of the programme and the number of stakeholders involved at both programme and scheme levels from the 1990s onwards, it is surprising that the research found no evidence of a joint resettlement plan and commissioning strategy being adopted with clear criteria and guidelines for potential services providers in the independent sector.

1.3 Were learning disabled people resettled into appropriate accommodation for their needs and in a timely manner in line with the Bamford vision?

There were long delays in the discharge of long-stay inpatients from the 1990s onwards. Successive resettlement programmes set targets but according to Bamford, the NIAO and those interviewed for this research these were frustrated by a number of factors including:

- lack of coordination between DHSSPS and the DSD;
- the absence of an overall resettlement plan;
- insufficient resources to fund alternative forms of provision;
- misalignment between health and housing funding streams;
- the absence of robust implementation mechanisms to hold Government Departments and agencies to account;
- the absence of a system to monitor performance against targets;
- the absence of formal procurement arrangements for new community-based services;
- a continuing perception that the needs of learning-disabled people could be met in their entirety by health and social services;
- an under-developed culture of involving learning-disabled people and family carers in decisions about the services available to them and that they wanted to receive. This lead to weak engagement by Trusts with patients and families, many of whom resisted proposals for resettlement.

This suggests that early stages of the resettlement programme were not well planned and managed, and that lessons from Bamford and other programme reviews were not learned. After 2012 there was a more effective framework for planning and commissioning new services for the learning disability resettlement programme. As a consequence, progress on the resettlement of those remaining in hospital was faster.

The main resettlement policy was that, wherever possible, people should be able to live in their own homes with the support they needed to help them live as independently as possible in the community. A variety of different types of housing, care and support service were developed for the resettlement programme. A profile of all the supported housing services for learning-disabled people funded by Supporting People in 2014/2015 was developed for the research (List 1), with a parallel profile of SP-funded services that were identified as being developed specifically for resettled people (List 2).

The most striking feature of the analysis of SP-funding for supported housing developed as part of the resettlement programme, however, is the relatively small number of services and bed spaces brought into management across NI as a whole in the period 2003 - 2011. Over the eight financial years between 1 April 2003 and 31 March 2011, an average of 1.5 new housing support services and as few as 6.25 bed spaces that are now identified by the SP team and the H&SC Board as being available for resettled people became available each year. Since 1 April 2012, an average of 6.5 services and 32 bed spaces has been brought into management each year. This is well below the target of 80 additional bed spaces to be developed each year up to 2020 recommended by the Bamford Review and needed to sustain resettlement.

The overall conclusion of the research is that some very good accommodation-based services were developed which fully met the needs of resettled people. However, not all accommodation-based services were of this standard. Interviewees referred to people living in congregate settings where there were more than the Bamford standard of up to five

people living together, and in one case up to 50 people living together, sometimes sharing accommodation and facilities. The data analysed for the research corroborates this finding.

These forms of congregate living did not conform to the Bamford principles. Other schemes were institutional, either because even though the service may have been designated as 'supported housing' the premises were more appropriate to residential care; or because the service ethos and delivery were outdated. Staff employed in some services continued to adopt traditional practices brought in from health and social care settings which undermined the principle of developing independence for residents.

1.4 Were all stakeholders generally content with the configuration of accommodation-based services for resettled people?

Stakeholders that took part in the consultative interviews organised as part of the research said that there were good, mediocre and poor services. There were said to be a number of obsolete heritage schemes dating from before the Supporting People programme was launched in 2003; and some services that had been commissioned and brought into management since 2003 in which traditional views of how accommodation for learning-disabled people should be configured had taken precedence over the Bamford principles. Some stakeholders said that there was an urgent need to review the suitability of accommodation that was not fit for purpose; and to develop a programme of remodelling or reprovision to which DHSSPS and DSD funding was attached.

1.5 Was independence promoted in the new setting for people who have been resettled, and if so, how was it promoted?

1.6 Alternatively, were people resettled into institutional or hospital-like settings which, irrespective of the models of housing, care and support adopted, were the subject of strong criticism by Bamford?

Participants in the interview programme all subscribed to the Bamford concept of supported living as a basis for promoting independence, where people have real choices about where they live, who they live with and what kind of life they can live. However, some interviewees said that this approach does not suit everyone - people with severe or profound disability for example, or those with challenging behaviours. This view runs counter to the evidence from the research and expert opinion in GB and the RoI set out in Part 3 of the report. The evidence from GB and RoI is supported by others of those who were interviewed for this research who said that people with a history of challenging behaviour placed in a supported living environment had developed new skills and had fewer episodes of challenging behaviour. It seems possible therefore that traditional attitudes to the development of services for learning-disabled people were still influencing some commissioning and referral practices during the resettlement programme.

There were also a number of practical reasons why supported housing was not available to people being resettled. There were anecdotal suggestions that care managers would sometimes refer someone to a residential care or nursing home because there is a vacancy available even if supported living would have been equally or more suitable. Cost factors were also said to be influential in such cases; or care managers may be overly cautious in their assessments of an individual's suitability for supported living.

1.7 What forms of housing with support funded from the Supporting People (SP) programme were developed for learning-disabled people generally, and particularly for those who were resettled from a long-stay hospital?

The report contains a profile of the types of accommodation funded by Supporting People and how these services were configured. Unfortunately, the research team was unable to establish from the information provided by NIHE and the H&SC Board exactly how many or what proportion of learning-disabled people resettled since Bamford, or indeed since the resettlement programme was revamped in 2012, had moved into SP-funded accommodation. In reviewing the SP data sets given in the body of the report, therefore, it was not possible to say how many people in the services included in either list had been resettled from hospital or had previously been living elsewhere.

In 2014, there were 151 SP-funded services for learning-disabled people in NI (List 1). Of these:

- there were 14 'legacy' services dating from the 1990s that received Special Needs Management Allowance (SNMA), a funding system which formally ended on 31 March 2002;
- Supporting People Grant (SPG) was paid to 137 services i.e. these were post-2003 schemes.

This list of all the SP-funded services for learning-disabled people contained a substantial number which appeared to represent congregate living. Either there were substantially more than five people living together in a single property, or more than three properties were grouped on a single site.

The total SP contract value for learning disability supported housing services was more than £16.5 million in the 2014/2015 financial year. The mean contract value was approaching £109,000 per annum; and the mean weekly unit price was just below £204.

29 out of the 151 SP-funded supported accommodation services for learning-disabled people were identified by NIHE's SP team and the H&SC Board as providing specifically for learning-disabled people resettled from long stay hospitals (List 2). The data show that only a few of the services identified as specifically for resettled people represented congregate living suggesting that the development of supported living services under the SP programme had responded positively to the Bamford Review recommendations.

The total SP contract value in the 2014/2015 financial year for services provided specifically for resettled people was £5.396 million (32.6% of the cost of all SP-funded learning disability services for 19% of all SP-funded learning disability services). The mean contract value was £186,000 (170% of the mean value of all SP-funded services for learning-disabled people); and the mean weekly price per bed space was £293 (270% the mean weekly cost per bed space in all SP-funded services for learning-disabled people). These services were more expensive per bed-space than the generality of SP-funded services for learning-disabled people.

1.8 How was this accommodation regulated and how were service standards monitored?

The research showed that there were a number of different approaches to regulating and monitoring the standard of accommodation and the quality of services being delivered to resettled learning-disabled people. Each agency involved in commissioning, service management or regulation had a different remit. As a consequence there was no over-view

of service standards, and no evidence to show whether the Bamford vision and objectives were being achieved in practice.

Registered housing associations were and remain subject to regulation by DSD (now The Department for Communities – DfC). There was (and still is) no independent regulatory framework for supported living and the NIHE Supporting People Department that funds these schemes does not have the necessary statutory powers to conduct formal inspections and enforce action. Residential care homes and domiciliary care services were and remain subject to registration and inspection by the RQIA, but accommodation in domiciliary care schemes is not subject to inspection. Some providers were undertaking service-level monitoring; and both H&SC Trusts and some providers had started to commission independent advocates to work with people who had been resettled, reporting more generally on whether services were being delivered effectively and appropriately for individual needs. However, commissioning of advocates was at an early stage in some Trusts.

In spite of the number of approaches to regulation and monitoring, there was no overview of service standards, and therefore no overall evidence was available to show whether the Bamford vision and objectives were being achieved in practice.

All of the services provided specifically for resettled people met Supporting People 'Minimum Quality Standards' based on provider self-assessment. However, six providers had been assessed as 'medium risk' against a series of political, operational and financial tests carried out by Supporting People as part of the team's approach to contract management, and one provider was assessed as 'high risk'. The high risk provider would have been required to manage quality issues by the SP team. RQIA enforcement action was also taking place in respect of this provider because it was a domiciliary and residential care provider in addition to its housing support activities.

Ten out of the 29 services specifically for resettled people were being provided by medium or high risk providers. Medium and high risk providers were working in more than one Trust area. These services operated in three out of the five H&SC Trust areas. The data provided by NIHE suggest that there were both performance and risk issues associated with the providers of a significant number of SP-funded services for resettled learning-disabled people.

1.9 Did stakeholders who were interviewed believe that resettlement was successful for the individuals concerned, and had betterment been achieved for them?

There is strong evidence from the interviews with policymakers, commissioners and service providers that progress had been slow in establishing mechanisms for assessing the betterment in peoples' lives following resettlement. Each H&SC Trust was developing its own approach, and there was no overall assessment of betterment.

There was a perception among those interviewed that although the resettlement programme had generally been a success from the perspective of resettled people, there had also been detrimental effects caused by programme delays and some resettlement services did not meet modern requirements nor conform to the Bamford principles. These are interviewees' personal views. However, in the absence of a coherent and coordinated programme of follow-up and evaluation, it is hard to see how those responsible for the resettlement programme can have had a clear idea of the impact on resettled people if the quality of services was not being consistently evaluated, and if one of the key aims – betterment - was not being monitored.

1.10 Did stakeholders believe that the Bamford vision had been realised and was value for money achieved in the way the programme was carried out?

There were mixed views among the people interviewed on the question of whether resettlement had been a success in public policy terms. A majority thought it was successful although implementation could have been better. It was seen as a success in terms of inter-Departmental cooperation; and Ministerial support for the programme was seen as significant in driving it forward. But there were reservations about whether a programme of this kind that is 'driven from the top' and which did not carry public opinion with it, was a success even if it was 'the right thing to do'.

Some interviewees preferred not to comment on the question of whether the resettlement programme represented good value for money. Those that did respond said that, purely in cost terms, it was more expensive than keeping people in hospital. When the social and economic benefits of the programme were taken into account, however, most interviewees thought that it did represent value for money but that value for money could have been improved if planning and commissioning had been better, if fully-costed model services had been developed as exemplars, and if a market for resettlement services had been developed through open procurement and competitive tendering.

PART 2 – THE RESETTLEMENT PROGRAMME IN NORTHERN IRELAND

2.1 LEARNING DISABILITY IN NORTHERN IRELAND

This section provides basic statistics on the definition and prevalence of learning disability in Northern Ireland and the characteristics of the learning-disabled population.

2.1.1 The legal definition of learning disability

The way that 'learning disability' has been legally defined has changed over the years alongside changing perceptions of learning disability itself. Prior to the 1990s, the term used in legislation and public administration was 'mentally handicapped'. In Northern Ireland, the term mental handicap is still used in the relevant legislation and is defined as:

"...a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning" ⁸.

The concept of mental handicap in public policy was, and to some extent may still be linked to a perception of learning-disabled people as having impairments that prevent them from participating in society, requiring care at home or in an institution. The counterpart of this perception in the wider community was that learning-disabled people were 'different' or 'sub-human' so that it was better if they were kept out of sight. As the following section shows, the majority of learning-disabled people in Northern Ireland were looked after by their families at home. Where this was not the case, however, they were often housed in hospitals and other institutions where they stayed for the remainder of their lives. This policy was justified on the basis that learning-disabled people were safeguarded while ensuring public safety.

Both the legal definition of mental handicap and the way learning-disabled people were looked after were questioned by the Bamford Review Committee (Bamford) following consultation with a wide range of interests, many of whom found the term 'mental handicap' denigrating. Bamford preferred the term 'learning disability' which was defined as:

" ... the presence of a significantly reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development" ⁹.

Bamford added that, in line with the *Equal Lives* model his working group was promoting, this definition should be put into the context of the person's social circumstances and the kinds of support they need in order to live a normal life. Nevertheless, the term 'mental handicap' is retained in the NI legislation in spite of the significant shift in thinking about learning disability, the rights of learning-disabled people, and the way that learning-disabled people should live their lives that have taken place in the past thirty five years.

⁸ Mental Health (NI) Order 1986, DHSS, quoted in Bamford, (2005) Equal Lives: Review of Policy and Services for people with a Learning Disability in Northern Ireland, Appendix H, page 171.

⁹ Bamford, (2005) *op. cit.*, p18, para 3.13

2.1.2 The prevalence of learning disabilities in Northern Ireland

The first significant source of information on the prevalence of learning disabilities across Northern Ireland's population is to be found in a study by Prof Roy McConkey and colleagues¹⁰, commissioned by DHSSPS as an input to the Bamford Review and published in 2003.

McConkey *et al* found an overall prevalence of people with learning disabilities of 9.71 per thousand head of population¹¹, equivalent to slightly less than 1% of the NI population. This figure was based on data taken from two main sources - Soscare¹² and Child Care Health System records. The combined data from these two sources showed 12,273 people with a learning disability known to health and social services in Northern Ireland in 2002¹³. However, McConkey *et al* had reservations about these figures because data from one health board¹⁴ were known to be missing. To compensate for this, adjustments were made to arrive at a further estimate. This put the total number of learning-disabled people in NI across all age groups at between 16,366 - 16,600 people¹⁵. The lower of these two numbers was used as the baseline figure by Northern Ireland Government Departments and agencies after 2003 as a basis for planning services for learning-disabled people¹⁶.

The McConkey report also provided a methodology for calculating the number and percentage of learning-disabled people according to their age and the severity of their impairment. Using the 16,366 figure as the base line ¹⁷, the results of this calculation are set out in Table 1.

Table 1: Number and percentage of learning-disabled people in the general population by age group and by severity of their disability, 2002¹⁸

Age Bands	Moderate	Moderate		Severe / Profound		Total	
	%	Number	%	Number	%	Number	
0 - 19	39.3%	6,432	10.5%	1,718	49.8%	8,150	
20 – 34	15.3%	2,504	6.4%	1,047	21.7%	3,551	
35 – 49	9.1%	1,489	5.8%	949	14.9%	2,439	
50+	9.0%	1,473	4.6%	753	13.6%	2,226	
TOTALS		11,898		4,468		16,366	
Percentage		72.7%		27.3%		100.0%	

Just over one quarter of all learning-disabled people were considered to have severe or profound levels of disability.

¹⁰ McConkey R, Spollen M and Jamison J (2003), Administrative Prevalence of Learning Disability in Northern Ireland.

¹¹ McConkey et al (2003), op. cit., page 3

¹² Social Services Client Administration and Retrieval Environment

¹³ McConkey et al (2003), op. cit., page 12, Table 5

McConkey thought that the discrepancy between Soscare and Census data arose because Soscare did not record all Trust patients who were in hospital. He also though it was possible that Muckamore Hospital had patients from other Boards who were not recorded in Soscare.

¹⁵ McConkey et al (2003), op. cit., page 12, Table 5

¹⁶ Interview with Neil Magowan, Head of Learning Disability Policy, DHSSPS, May 2014

¹⁷ McConkey et al (2003), *op. cit.*, page 13, Table 5b

Calculation by the research team based on McConkey's population figure and the percentage of people with moderate or severe/profound learning disabilities by age group that his team identified.

2.1.3 Where learning-disabled people were living in 2002/2003

McConkey found that nearly all learning-disabled people aged 19 years or under (around 8,150 individuals, or half the learning-disabled population in NI) were living with their families. Of those aged 20 years or over:

- between 390 and 470 people (c.3% of the learning-disabled population) people were in hospitals as either short- or long-stay patients (depending on data source used – see Table 2);
- between 1,700 and 1,900 people (c.12% of the learning-disabled population) were in residential care;
- around 6,125 people (c.37% of the learning-disabled population) were in other community settings including living with their families or in supported accommodation of some kind.

These estimates implied that hospital in-patients represented only a minority (13%) of Northern Ireland's learning-disabled people. Taking the figures as a whole, around 14,000 learning-disabled people (87% of the learning-disabled population in NI) were living with families or in other settings outside hospital.

McConkey's 2003 study gave a breakdown of the number of learning-disabled people living in hospital by health board area ¹⁹ in 2002 compared with 2001 Census data.

Table 2: Number of patients per originating Trust, 2002

Board	Based on SOSCARE Records	Based on the number of long stay in- patients identified in the 2001 Census
Southern HSSB	129	118
Western HSSB	41	39
Northern HSSB	69	90
Eastern SSHB	151	220
Combined NHSSB + EHSSB (Muckamore)	220	310
TOTALS	390	467

McConkey's estimates of the hospital population derived from health board records were significantly lower than the number of long-stay inpatients identified in the 2001 Census.

McConkey also provided an estimate of the proportions of learning-disabled people from each health board who were still living in hospital, by age group and by level of disability in 2002 derived from health board records²¹ (Table 3). Two thirds of those living in hospital were classed as having severe or profound learning disabilities.

There were four health boards in 2003 – the Southern Health and Social Services Board (SHSSB); the Western Health and Social Services Board (WHSSB); the Northern Health and Social Services Board (NHSSB); and the Eastern health and Social Services Board (EHSSB). A reorganisation of health and social care services created the Health and Social Care Board and five Health and Social Care Trusts on 1 April 2007.

²⁰ McConkey et al (2003), op. cit., page 16, Table 6

²¹ McConkey et al (2003), op. cit., page 18, Table 8

Table 3: Percentage of people living in hospital by age group and by severity of their disability

Age Group	Moderate Learning Disability	Severe / Profound Learning Disability
0 - 19	2%	4%
20 – 34	6%	13%
35 – 49	13%	25%
50 +	13%	24%
TOTALS	34%	66%

Combining the results from Table 1 and Table 3, it can be seen that **around 300 people in** hospital had disabilities that were rated as severe or profound, but a very large majority (c. 4,150) of people with severe or profound disabilities were living outside hospital. The question of what factors determined whether someone was hospitalised lie outside the scope of this research.

2.1.4 Trends

The McConkey report did not identify trends or make predictions about the future incidence of learning disability or the future numbers of learning-disabled people in the Northern Ireland population. However, Bamford suggested that, on the basis of general demographic and health statistics, there was likely to be an increase in the number of learning-disabled people²² as a result of:

- increasing life expectancy;
- people with complex health needs living into adulthood;
- more mothers giving birth later;
- increased survival rates for at-risk infants;
- a bulge in the numbers of learning-disabled people born in the 1950s and 1960s;
- a higher birth rate among ethnic minorities with an associated higher rate of learning disabilities in these populations.

Bamford also identified three trends that might tend to offset any increase on the number of learning-disabled people:

- better pre-natal care for expectant mothers with increased availability of pre-natal screening for congenital and other abnormalities²³;
- improved health care and early intervention for at risk infants leading to fewer becoming learning-disabled;
- the advent of gene therapy to correct or ameliorate congenital abnormalities.

Bamford concluded that it was impossible to predict the impact of these trends without further research²⁴. He noted, however, that learning disability policy in England was based on an assumed increase in the number of learning-disabled people of 1% per annum. He suggested that the figure might need to be 1.5% per annum in Northern Ireland given the higher birth rate compared with England.

²² Bamford, (2005), op. cit., page 21, paras 3.34 and 3.35

²³ However, the abortion of foetuses with congenital and other abnormalities is illegal in Northern Ireland unlike the remainder of the UK and would therefore not be a factor offsetting any increase in the number of learning disabled children born.

²⁴ Bamford, (2005), op. cit., page 22, para 3.36

Using Bamford's suggested 1% increase per annum benchmark for growth in the population of learning-disabled people as a basis for calculating the increase over McConkey's 2003 baseline number of 16,366 would mean that, in 2014, there could have been around 18,250 learning-disabled people in Northern Ireland (NI). If Bamford's higher annual percentage increase of 1.5% is used, then the number could have been around 19,250.

In publishing calculations of the likely population of learning-disabled people in NI, McConkey was aware that the data on which his work was based were unreliable. In retrospect, the figures may have been an underestimate. Applying McConkey's prevalence rate to the 2011 Census count of people in the general population in NI gives a figure of more than 27,000 learning-disabled people. However, the 2011 Population Census identified more than 40,000 people (2.2% of the Northern Ireland population) who were identified by the person completing the household's Census return as having a long-term 'learning, intellectual, social or behavioural difficulty' Table 4 identifies the number of people with a long-term 'learning, intellectual, social or behavioural difficulty' identified in the 2011 Census compared with the general population for Northern Ireland as a whole and for each of the five Health and Social Care Trust (H&SCT) areas.

NI and H&SC Trust Area	All usual residents by area	Number of usual residents with learning, intellectual, social or behavioural difficulty by area	Percentage of usual residents with learning, intellectual, social or behavioural difficulties by area (%)
Belfast Trust area	348,204	8,875	2.6%
Northern Trust area	463,297	9,178	2.0%
South Eastern Trust area	346,911	7,741	2.2%
Southern Trust area	358,034	7,258	2.0%
Western Trust area	294,417	7,125	2.4%
Northern Ireland	1,810,863	40,177	2.2%

The largest number of usual residents with learning, intellectual, social or behavioural difficulties was in the Northern Trust area, where there was no long-stay hospital. The smallest number and one of the lowest percentages was in the Southern Trust area, where Longstone Hospital was located and from which most long stay patients had been resettled by the end of 2011. The data therefore show that there was no obvious correlation between the existence of a long-stay hospital and the number and percentage of usual residents with learning, intellectual, social or behavioural difficulties resident in the area.

Extreme caution is needed when comparing McConkey's figures 2003 figures with the 2001 and 2011 Census data. The definition of a 'learning, intellectual, social or behavioural difficulty' adopted in the 2011 Census may well be wider than NHS definitions of 'learning disability' used in resettlement and other returns. In addition, the 2011 Census results are self-declared by the person completing the Census form and do not result from a clinical diagnosis²⁶.

http://www.ninis2.nisra.gov.uk/public/pivotgrid.aspx?dataSetVars=ds-3580-lh-63-yn-2009-2012-sk-134-sn-Health%20and%20Social%20Care-yearfilter--

The research team asked the Northern Ireland Statistics and Research Agency (NISRA) to say whether the definition of 'learning, intellectual, social or behavioural difficulty' used in the 2011 Census was the same as the definition used in the data on hospital inpatients. NISRA was unable to confirm this. We also asked whether the definition used in the data on in-patients was the same as the term 'learning disability' used by the Health and Social Care Board and Trusts in compiling resettlement statistics. Again, NISRA was unable to confirm whether or not that was the case.

Taking these two factors into account, the 2011 Census figures are likely to be larger than figures derived from health and social care sources. Nevertheless, they give a possible order of magnitude of Northern Ireland's population of learning-disabled people in 2012.

Census and other data published by NISRA show the number of people with a 'learning, intellectual, social or behavioural difficulty' who were hospital in-patients in 2012²⁷ with their average length of stay, by H&SC Trust area (Table 5). In compiling this table, the research team has assumed that the definition of 'learning, intellectual, social or behavioural difficulty' is consistent between the Table 4 and Table 5 data sets as a basis for comparison of 'the number of usual residents with a learning, intellectual, social or behavioural difficulty' and 'the number of hospital in-patients'.

Table 5: Number and percentage of learning-disabled people in hospital as an inpatient, with average length of stay, 2012

H&SC Trust	Number of usual residents with a learning, intellectual, social or behavioural difficulty (2011 Census)	Number of Inpatients ²⁸ with a learning, intellectual, social or behavioural difficulty (2012)	Inpatients as % of those with a learning, intellectual, social or behavioural difficulty	Inpatient: Average Length of Stay (months / years)
Belfast Trust area	8,875	1,123	12.7%	68.9 months / 5.7 years
Northern Trust area	9,178	0	0.0%	-
South Eastern Trust area	7,741	0	0.0%	-
Southern Trust area	7,258	174	2.4%	115 months / 9.6 years
Western Trust area	7,125	116	1.6%	52 months / 4.3 years
Northern Ireland	40,177	1,413	3.5%	73.2 months / 6.2 years

Table 5 shows that, by 2012, the largest number and highest percentage of people with a learning, intellectual, social or behavioural difficulty who remained as hospital in-patients were accommodated at Muckamore Hospital (Belfast H&SCT) where more than 1,100 people, representing 12.7% of the Belfast Trust area's learning-disabled population, and 79% of Northern Ireland's hospital-based population were living. The Southern H&SCT (Longstone Hospital) and the Western H&SCT (Lakeview Hospital) had relatively small proportions of the area's learning-disabled people in hospital following more rapid discharge and resettlement programmes. Two H&SC Trusts had no long stay hospital in their area so are shown as having a '0' population of in-patients. That does not mean, however, that the two Trusts did not have patients living in a hospital operated by one of the other Trusts.

Table 5 also shows that in 2012, 1,400 learning-disabled people (3.5% of the learning-disabled population) had been resident in hospital for more than 6 years on average. Bearing in mind that the figures for length of stay are averages taken over both short- and long-stay in-patients, the figures suggest that, by 2012, some long-stay learning-disabled patients had been living in hospitals for very long periods of time.

http://www.ninis2.nisra.gov.uk/public/pivotgrid.aspx?dataSetVars=ds-3580-lh-63-yn-2009-2012-sk-134-sn-Health%20and%20Social%20Care-yearfilter--

²⁸ The definition of 'in-patients' in this table includes both long and short stay patients.

2.2 THE LEARNING DISABILITY RESETTLEMENT PROGRAMME IN NORTHERN IRELAND – EVOLUTION AND PROGRESS

In this section of the report we trace the evolution of learning disability resettlement policy and progress in the resettlement of learning-disabled people in Northern Ireland from the early 1990s onwards.

2.2.1 The early years to 2002

Learning-disabled people began to be resettled from hospitals in Northern Ireland from the late 1970s onwards. This is similar to the pattern of resettlement that emerged in Great Britain (GB) and the Republic of Ireland (RoI) - see Part 2. Accurate records are not available for the early phases of the resettlement programme in NI²⁹. Bamford (2005) stated that:

"There is no accurate record of all services provided under the learning disability programme of care either by Health and Social Services Trusts or by a sub-contractor in the private or voluntary sector." ³⁰

Both Bamford and the Northern Ireland Audit Office (NIAO) reported that progress was relatively slow when compared with the pace of resettlement in Great Britain. NIAO records that, in 1992, there were 878 long stay patients in hospitals in Northern Ireland.³¹ In 1995, DHSSPS decided that all long stay learning-disabled patients still living in Muckamore, Longstone and Lakeview hospitals were to be resettled into the community³². In 1997, DHSSPS set a target that all patients in long stay hospitals were to be resettled by 31 March 2002³³. However, in the ten years 1992 to 2002, the NIAO records that the number of long-stay patients in NI hospitals fell from 868 to 453³⁴, a reduction of only 48%. According to the NIAO report, the proportion of learning-disabled people still in hospital in Northern Ireland (222 beds per million people) was higher than in England and Wales (15 beds per million), or Scotland (163 beds per million).

In parallel with the resettlement programme in NI, Bamford reports that there had been some growth in the provision of nursing home and residential care places for learning-disabled people³⁵. These services were commissioned by H&SC Trusts either as in-house provision or as provision by independent sector providers. Services for learning-disabled people began to be provided by people with a range of different disciplines other than medical qualifications. Bamford notes that these developments were uncoordinated and a number of difficulties arose as a consequence. The difficulties encountered included lack of information for families about where to go for different services; conflicting advice from different specialists; duplication of services; and gaps in service provision³⁶.

²⁹ See McConkey et al (2003), op. cit.

³⁰ Bamford et al (2005), op. cit., p24, para 3.51

³¹ Northern Ireland Audit Office (2009), Resettlement of long stay patients from learning disability hospitals, page 2, para. 4

³² Northern Ireland Audit Office (2009), op. cit., p9, para 1.7

³³ NIAO lists a number of dates and targets for completion of the resettlement programme. None of these were met. See Northern Ireland Audit Office (2009), *op. cit.*, page 16, para 2.3.

 $^{^{34}\,}$ This is higher than McConkey's estimate, and very slightly below the 2001 Census figure.

³⁵ Bamford, (2005), op. cit., page 24, para 3.52

³⁶ Bamford, (2005), op. cit., page 24, para 3.53

2.2.2 The Bamford Review

In 2002, DHSSPS commissioned an independent review of legislation, policy and provision for people with mental health issues and learning disabilities (the Bamford Review). The review generated ten reports of which Bamford, (2005) *Equal Lives: Review of Policy and Services for people with a Learning Disability in Northern Ireland* is the key text for this study. It seems possible that the decision to commission the Bamford Review was influenced by four factors:

- changing views about learning disability and the way learning-disabled people should be enabled to live their lives and the way services should be provided to meet their needs (these issues are discussed in Part 2 of the report);
- the failure to meet successive targets for the resettlement of learning-disabled people from long-stay hospitals referred to above;
- the need to comply with Section 75 of the Northern Ireland Act 1998³⁷ which placed a statutory duty on public bodies to promote equality of opportunity *inter alia* between persons with a disability and persons without; and
- the cross-departmental New Targeting Social Need programme³⁸ introduced in 2001, which aimed to tackle poverty and social exclusion through targeting efforts and available resources within existing programmes on people, groups and areas in greatest objective social need, with a primary aim of reducing social exclusion.

Bamford found that:

"... learning-disabled people in Northern Ireland do not enjoy equality of opportunity and are often excluded from the opportunities that other citizens enjoy. Their families frequently suffer high levels of social disadvantage and their caring responsibilities can place them under almost unbearable levels of stress. There is evidence of progress having been made, but in order to tackle these difficulties there is a need for major co-ordinated developments in support and services and a continuing change in attitudes over at least the next fifteen years." ³⁹

In setting out a vision for the future Bamford concluded that:

"... progress needs to be accelerated on establishing a new service model, which draws a line under outdated notions of grouping people with a learning disability together and their segregation in services where they are required to lead separate lives from their neighbours. The model of the future needs to be based on integration, where people participate fully in the lives of their communities and are supported to individually access the full range of opportunities that are open to everyone else." 40

The Bamford vision was based on five over-arching values (Figure 1).

³⁷ Northern Ireland Act 1998, Ch. 47, part vii, Equality of Opportunity, Section 75

³⁸ See, for example, DHSSPS (2001), *Tacking Equality and Targeting Social Need*

³⁹ Bamford, (2005), *op. cit.*, page 6, para 1.11

⁴⁰ Bamford, (2005), op. cit., Foreword

Figure 1: The 'Equal Lives Values' (authors' emphasis in blue)

Citizenship	People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen. Civil and human rights must be promoted and enforced.
Social Inclusion	People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community. Inclusion recognises both peoples' need for individual support and the necessity to remove barriers to inclusion that create disadvantage and discrimination.
Empowerment	People with a learning disability must be enabled to actively participate in decisions affecting their lives. People with a learning disability must be supported to have control, to have their voices heard, to make decisions about how to live their lives and about the nature of support they receive.
Working Together	Conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability. People with a learning disability must be central to planning and decision making processes.
Individual Support	People with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible. Service systems that are based on group approaches need to be remodelled to more fully recognise people's individual strengths and needs.

Bamford said that new policies were needed to put these values into practice and set twelve core objectives⁴¹. Three of these objectives are particularly relevant to this study:

- Objective 4: to enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social, work and leisure opportunities and form and maintain friendships and relationships;
- Objective 5: to ensure that all men and women with a learning disability have their home in the community, the choice of whom they live with, and that where they live with their family, their carers receive the support they need;
- Objective 6: to ensure that an extended range of housing options is developed for men and women with a learning disability.

In a chapter focussing on accommodation and support⁴², Bamford noted that many residential services created early in the resettlement programme were institutional in character and retained features of a hospital environment. To combat this trend, the report set out ten recommendations that were intended to govern how learning-disabled people leaving hospitals were re-housed (Figure 2).

Bamford noted that the responsibility for achieving these aims was not confined to health and social services organisations but needed to be shared across agencies in the public, private and voluntary sectors.

The Bamford Values and Objectives have been used in this research as a basis for reviewing the results of the post-Bamford resettlement programme.

⁴¹ Bamford, (2005), *op. cit.*, page 8, para 1.15

⁴² Bamford, (2005), *op. cit.*, pages 59 - 66

Figure 2: The 'Equal Lives Objectives' (authors' emphasis in blue)

Recommendation 1	By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the 5-year period from 2006 to 2011.
Recommendation 2	With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability.
Recommendation 3	With immediate effect, all new housing with support provision for people with a learning disability should be for no more than 5 individuals with a learning disability - preferably less - within the same household
Recommendation 4	By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than 5 people.
Recommendation 5	An additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings.
Recommendation 6	The Department for Social Development and the Department of Health, Social Services and Public Safety should develop clear assessments of future housing needs for people with a learning disability including those who currently live with their families and agree a continuous 3 year funding strategy to resource housing and support arrangements.
Recommendation 7	Housing planners should accumulate and disseminate detailed knowledge on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community.
Recommendation 8	A strategy should be developed by the Department for Social Development to increase opportunities for people with a learning disability to own their own homes where this is a safe and appropriate option.
Recommendation 9	Procedures and criteria for applying for Disabled Facilities Grants should be revised to tackle inconsistencies, reduce bureaucracy and reduce the hidden costs to carers.
Recommendation 10	Department for Social Development and the NI Housing Executive should establish mechanisms to ensure the increased use of floating support linked to an individual's needs rather than overly relying on accommodation based schemes.
Recommendation 10	mechanisms to ensure the increased use of floating support linked to an individual's need

2.2.3 Post-Bamford policy development up to 2011

Following the restoration of devolved Government in 2007 there was a renewed political focus on achieving a target date for completion of the resettlement programme ⁴³. The Bamford recommendations received strong Ministerial backing. The main emphasis of the programme focussed on people who had been admitted to hospital prior to 1 April 2006 and who had been in hospital for twelve months or more at 31 March 2007 ⁴⁴. This group was termed the 'Priority Target List' or 'PTL'. This remained the definition used as a basis for the resettlement programme in 2014. Annual targets for resettlement from the PTL programme were set for each Trust by DHSSPS from 2007 onwards.

In parallel with the resettlement of long stay learning-disabled people, there was an issue about the resettlement of people who were hospitalised for assessment and treatment after the names included in the 2007 PTL were agreed, but who also needed to be resettled. This list, known as the Delayed Discharge List ('DDL'), became a secondary element in the resettlement programme. To prevent that group becoming a new long stay population, DHSSPS and DSD jointly bid for funds to resettle this group alongside the PTL. In effect, two different discharge programmes were run in parallel after 2007/2008. The PTL list was to be

⁴³ Interview with Neil Magowan, Head of Learning Disability Policy, DHSSPS, May 2014

 $^{^{44}\,}$ DHSSPS (2009), Evaluation of the 2009 – 2011 Bamford Action Plan, page 38, para 5.5.43

resettled by March 2015, while resettlement of people on the DDL list was ongoing even though the policy intention was that there should no longer be a long stay resident population in hospitals after the end of March 2015.

The term 'long stay' as used in the Northern Ireland policy context does not therefore refer to the length of time that a learning-disabled person has lived in hospital or the likely length of stay⁴⁵. It refers to a definition developed for the post 1995 resettlement programme of the list of people that were to be resettled as part of the programme. Thus, in 2002, the term was defined as 'those patients in designated resettlement wards'. This changed in 2007 to 'those who had been admitted to hospital prior to 1 April 2006 and had been in hospital for 12 months or more at 31 March 2007'.

2.2.4 Progress on resettlement 2002 - 2011

Data from the 2009 NIAO report show the rate of resettlement activity for each year between April 2002 and March 2008 compared with the programme targets⁴⁶. This period encompasses the time during which the Bamford Review took place and the time immediately following publication of the *Equal Lives* report. No targets for resettlement were set in two of the seven years; the targets for the other five years were not met. Extrapolating the 5-year targets over the seven years, the number resettled is estimated by the authors of this report as being below the target numbers by more than 25% (Table 6).

Year	Target	Number resettled ⁴⁷
Apr 2002 – Mar 2003	35	25
Apr 2003 – Mar 2004	No number specified	30
Apr 2004 – Mar 2005	Minimum of 50	30
Apr 2005 – Mar 2006	Minimum of 50	30
Apr 2006 – Mar 2007	No number specified	40
Apr 2007 – Mar 2008	40	35
Apr 2008 – Mar 2009	60	Data not available
TOTALS	At least 235	Approximately 210
Extrapolated over 7 years	(235 / 5)* 7 = 329	(210 / 6) * 7 = 245 : Deficit 84 (26%)

Both the Bamford Review and Northern Ireland Audit Office reports identify reasons why the resettlement programme was slower than intended. The main factors were said to be:

- insufficient resources to fund alternative forms of provision;
- the absence of robust implementation mechanisms to hold Departments and agencies to account;
- a continuing perception that the needs of learning-disabled people could be met in their entirety by health and social services;
- an under-developed culture of involving learning-disabled people and family carers in decisions about the services available to them and that they wanted to receive.

⁴⁵ Source: Northern Ireland Audit Office (2009), *Resettlement of long stay patients from learning disability hospitals*, p26, para 3.2

 $^{^{46}}$ Northern Ireland Audit Office (2009), op. cit., page 14, paragraph 2.3 and page 26, Figure 4, paragraph 3.2

⁴⁷ The numbers are approximations taken from an unpublished bar chart provided by the NI Health and Social Care Board.

A 'post-Bamford' cross-departmental action plan for the period 2009 – 2011 was published covering both the mental health and learning disability resettlement programmes. An evaluation of the Action Plan subsequently carried out by DHSSPS shows that, between 2007 and 2011, 116 learning-disabled people were resettled from long stay hospitals – a reduction in the hospital population of 41%⁴⁸. A year by year breakdown between April 2009 and March 2011 is not available. Once again this performance did not meet the targets.

A further reason why performance on resettlement did not achieve the targets was that there was a slowdown in commissioning new accommodation-based services during the 2010/2011 financial year, when health service funding that had been secured as part of the 2008 – 2011 Comprehensive Spending Review (CSR) allocation was not available due to the impact of the banking crisis on Northern Ireland Government spending ⁴⁹. As a result, there was an under-spend on the housing allocation to the resettlement programme in that year because matching health funding was not available.

2.2.5 Policy development on Learning Disability 2011 / 2012

The target that all long-stay in-patients should be resettled by June 2011 was not met. There was a further Ministerial review of the programme in the second half of 2011 in response to the continuing delays in the programme. A new approach was developed for the 2012 - 2015 Comprehensive Spending Review programme. This required DHSSPS funding for resettlement to be aligned with DSD funding for the learning disability component of the social housing and Supporting People programmes. DHSSPS and DSD made a joint bid for resettlement programme funding to the Department of Finance and Personnel (DFP), based on a needs-based profile of all those in hospital that remained to be rehoused in mid-2011⁵⁰. The bids were successful. It was accepted by Ministers that the March 2013 target for completion of the PTL resettlement programme was not likely to be met. The target date was therefore reset to 31 March 2015 – the end of the CSR period.

An updated action plan covering the period $2012 - 2015^{51}$ was also approved. This contained for the first time actions to be taken under the heading 'Supporting People' in relation to improving social inclusion for people with disabilities, the resettlement of long stay patients from learning disability hospitals, commissioning new programmes of housing provision and a series of actions connected with education and training for learning-disabled people living in the community. A new learning disabilities service framework was published. This set out thirty three standards that aimed:

"... to improve the health and wellbeing of people with a learning disability, their carers and their families by promoting social inclusion, reducing inequalities in health and social wellbeing, and improving the quality of care." ⁵²

The standards included:

• the need for involvement by learning-disabled people in the choices and decisions about their health and social care needs;

⁴⁸ DHSSPS (2009), Evaluation of the 2009 – 2011 Bamford Action Plan, Annex A, Quantifiable Targets, page 72

⁴⁹ Interview with Aiden Murray, Assistant Director Learning Disability Services, Health and Social Care Board, May 2014

⁵⁰ This is the first reference that the research team has found to the development of a resettlement plan based on the aggregate needs as opposed to the numbers of learning-disabled people living as long-stay hospital in-patients.

DHSSPS (2012), <u>Delivering the Bamford Vision: The response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability: Action Plan 2012 – 2015</u>

⁵² DHSSPS (2012), <u>Learning Disability Service Framework</u>, Chapter 2, page 30

- information and communication between agencies and with learning-disabled people and their families;
- access to self-directed support, advocacy services and support to maintain employment opportunities and a range of meaningful day time activities for learningdisabled people;
- support to ensure that their accommodation needs were addressed.

For each standard, responsibilities for delivery are identified, as are the quality standards and performance indicators to be achieved. Standard 28, which refers to accommodation needs, stated⁵³:

"Person-centred support plans should identify the person's preferred living arrangements and these should be regularly reviewed. It is important that as family carers age they are supported to plan for the future to allow for a smooth transition to new care arrangements either within the family or in supported accommodation.

"Small-scale, supported living arrangements (5 persons or less) have been shown to offer a better quality of life for people with a learning disability as compared to congregated living arrangements.

"People living outside of family care should have a tenancy or occupancy agreement to offer them security of tenure along with an agreement to the number of support hours available to them individually.

"People should be involved in decisions about sharing their homes with others. As far as possible they should be offered a choice of accommodation in a locality of their choosing.

Participants in the consultative interviews that took place as part of the research said that the new resettlement plan and new structures agreed in 2011 and starting on 1 April 2012 were critically important:

- a new performance management framework was put into place;
- a revamped Programme Delivery Board was established;
- annual resettlement targets were set for each Trust;
- Trust performance was monitored regularly, and they were held accountable for meeting their targets;
- Trusts were required to make a monthly progress report to the Board; and
- progress was reviewed quarterly by the Programme Delivery Board with reports to the Minister.

On the commissioning side, a remodelled Northern Ireland-wide Supporting People Partnership Board was established bringing together representatives from the H&SC Board, the five H&SC Trusts, NIHE, DHSSPS and DSD, with five area boards (one for each Trust's geographical area) which were and remain responsible for considering needs and processing business plans and commissions for new accommodation-based services.

2.2.6 Progress on resettlement 2012 to 2015

The Health and Social Care Board provided the research team with data on the numbers of learning-disabled people resettled from the PTL and DDL lists between 1 April 2012 and 31 March 2014, with the number remaining to be resettled by 31 March 2015 (Tables 7 and 8).

⁵³ DHSSPS (2012), <u>Learning Disability Service Framework</u>, Chapter 10, page 117

Between 1 April 2012 and 31 March 2014, resettlement targets for the PTL were more than fulfilled. 116 people from the priority transfer list were resettled and 49 people remained to be resettled by March 2015. Almost half of those remaining to be resettled were living in Muckamore Hospital (Belfast Trust). Resettlement targets for the DDL were not met. At 31 March 2014, 24 people out of 30 remained to be resettled.

Table 7: Resettlement from the Priority Transfer List 2012 to 2014, by Trust, with numbers remaining to be resettled

Trust area of residence	Target to March 2013	Reported Resettled at 31 March 2013	Target to March 2014	Reported Resettled at 31 March 2014	Cumulative Target to March 2014	Cumulative Reported Resettled at 31 March 2014	Target to March 2015	Remaining to be resettled at 31 March 2014
Belfast Trust	13	9	25	30	38	39	24	23
Northern Trust	6	11	12	6	18	17	12	13
South Eastern Trust	10	10	5	8	15	18	13	10
Southern Trust	6	11	33	30	39	41	0	0
Western Trust	3	1	0	0	3	1	1	3
Northern Ireland	38	42	75	74	113	116	50	49

<u>Table 8: Resettlement from the Delayed Discharge List 2012 to 2014, by Trust, with numbers remaining to be resettled</u>

Trust area of residence	Cumulative Trust DDL Plans 2013/14 and 2014/15	Cumulative reported resettled at 31 March 2014	Remaining To be resettled by 31 March 2015
Belfast Trust	8	2	6
Northern Trust	10	2	8
South Eastern Trust	6	0	6
Southern Trust	2	2	0
Western Trust	4	0	4
Northern Ireland	30	6	24

2.2.7 Health and Social Care investment in resettlement since 1 April 2012

The H&SC Board also provided financial information from the five H&SC Trusts on the levels of revenue funding for the learning disability resettlement programme after 1 April 2012. The overall revenue cost over the three financial years 2012 – 2015 was £10.477 million. Table 9 provides a breakdown of the figures for each Trust.

Table 9: Learnin	g disability	care	costs	for	the	resettlement	programme	by	Trust,	2012	to	2014	(actual)	and	2015
(projected) ⁵⁴															

Trust	1 April 2012 to 31 March 2014	1 April 2014 to 31 March 2015 (estimate)	TOTAL: 2012 - 2015
Belfast Trust	£966,500	£1,264,320	£2,230,820
Northern Trust	£1,722,892	£874,519	£2,597,411
South Eastern Trust	£1,126,549	£1,697,373	£2,823,922
Southern Trust	£2,449,955	No resettlements	£2,449,955
Western Trust	No resettlements	£375,000	£375,000
Northern Ireland	£6,265,896	£4,211,212	£10,477,108

Table 9 reports revenue funding for new services for people resettled from the priority transfer and delayed discharge lists commissioned from 1 April 2012 (the start of the reorganised resettlement programme) onwards. The total expenditure to 31 March 2014 (£6.265 million) was the full year effect in 2014/15 of all schemes starting in 2012/13 and 2013/14⁵⁵. The Western H&SC Trust figure was zero because it had no resettlements in this period having completed the majority of its programme by 31 March 2012.

The total expenditure to 31 March 2015 of £4.211 million was the full year effect of all schemes funded to date for the year 2014/15. This was additional funding added to the figure of £6.266 million recorded in the previous column. The Southern H&SC Trust figure is zero because it had no resettlements in that year having completed its programme.

2.3 PERCEPTIONS OF THE RESETTLEMENT PROGRAMME – A POLICY AND DELIVERY PERSPECTIVE

A series of consultative interviews was carried out as part of the research with people who had responsibility for resettlement policy, programming and commissioning resettlement services, and those working in the fields of housing, care and support who oversaw service delivery. In this section we report their comments on resettlement policy and delivery.

2.3.1 Perceptions of progress on resettlement

All participants were asked a series of questions exploring their perceptions of the learning disability resettlement programme since the publication of the Bamford report in 2005. This time frame was divided into two parts – 2005 to 2009, when the Northern Ireland Audit Office's critical report *Resettlement of long stay patients from learning disability hospitals* was published; and subsequently from 2009 to 2014. Participants said that 2009 was not an ideal cut-off point for the earlier phases of resettlement because the major review of the programme in 2011 resulted in changes in the way the programme was managed from April 2012 onwards. Nevertheless, there was broad agreement that in the period 2005 to 2009, the need for priority to be given to resettlement was understood by all the agencies involved, but progress was very slow. Interviewees gave a number of reasons for the slow rate of progress.

⁵⁴ Trust data on actual and forecast expenditure was presented to the H&SC Board in different formats. The Board has provided an interpretation of the data to make them internally consistent.

⁵⁵ The H&SC Board informs the authors that Trusts use these years interchangeably in their submissions.

- lack of coordination between DHSSPS and the DSD;
- · misalignment between health and housing funding streams;
- the absence of an overall resettlement plan;
- the absence of a system to monitor performance against targets;
- the absence of formal procurement arrangements for new community-based services;
- weak engagement by Trusts with patients and families, many of whom resisted proposals for resettlement.

This list is similar to the list of factors causing delay identified by Bamford and the NIAO, suggesting that lessons were not learned from the earlier reviews. One participant explained that: "Bamford set the policy and direction of travel very clearly – the focus was on community care. The practicality of getting it done was the problem."

The official view given in the interviews was that all the participants in the Bamford Programme had confirmed to their respective Ministers in DHSSPS and DSD that the programme was on track to meet its targets. However, not all interviewees thought this was realistic. There were divergent views on the question of whether the March 2015 target date for completion of the resettlement of PTL patients was likely to be met. It was suggested by some interviewees that many of the people left in hospital from the PTL had acute and complex needs and needed nursing care; while others with challenging or forensic behaviours needed highly bespoke housing and care solutions that took time to develop and were expensive. Other factors including ongoing negotiations between hospital management and health sector trades unions about the redeployment of hospital staff were also referred to.

2.3.2 Issues affecting the rate of resettlement

Participants were then asked to say what they thought were the key issues affecting the rate of resettlement by choosing from a list provided by the interviewer. They were also asked to say which of the issues they had identified were the most significant. The results are set out in Table 10. All thirteen interviewees responded to this question.

Taking an over-view, one participant said:

"The key thing from the commissioner view is to ensure that funding is available to enable Trusts to deliver; then it has to be used; that requires interagency collaboration; then individuals must be resettlement ready. All the ducks have to be lined up between consultants, care managers, and providers for the transitional process – needs assessment, family ready and agreement, funding in place, and an available place."

Table 10: The most significant issues affecting the rate of development

Issue	Number out of 13 respondents who said this was 'Very Significant'
The level of resources allocated to the programme.	9
The availability of appropriate accommodation and support services in the right locations in the community.	9
The effectiveness of inter-department and inter-agency collaboration.	8
The targeting of resources to different aspects of the programme.	6
The availability of appropriate access to day care, educational provision, work and social activities for resettled people.	6
The difficulty of finding appropriate accommodation placements for residents.	5
The reluctance of residents and/or families for them to leave long stay hospital.	5
The availability of community support services for family carers.	4
The need for cultural change within the health and social care sector and the wider community to overcome low expectations of the ability of people with learning disabilities to leave hospital and live in the community.	3

Other factor(s) – 1 respondent each:

- NIMBY-ism: Community attitudes towards planning applications for supported housing and group living schemes and opposition to learning-disabled people living in their neighbourhood;
- the need to change staff attitudes and re-train staff moving from a hospital to a community setting.

2.3.3 Factors influencing successful delivery of the resettlement programme

Participants were asked to identify up to five factors which they believed had helped to promote the resettlement programme, and five factors which they felt had hindered the programme. Ten participants offered their views (Tables 11 and 12).

Table 11: Factors that helped to promote the resettlement programme

Factors promoting resettlement	No. out of 13 of respondents identifying each factor
Ministerial or political support for the resettlement programme	2
Introduction of clear targets and a performance management framework for the Trusts	2
The quality and commitment of staff (a) in a Trust and (b) in community-based services	2
The high profile given to early successes, and evidence that resettlement works from the perspective of learning-disabled people and their families	2

Other factor(s) – 1 respondent each:

- Joint working between the Board, Trusts, DHSSPS and the NIHE SP team;
- availability of services within the community

Table 12: Factors that hindered the resettlement programme

Factors hindering resettlement	No. out of 13 respondents identifying each factor
In a traditional society attitudes are slow to change – there is community resistance with ignorance still a factor; families are risk-averse, their concerns can be a barrier.	4
Negative local publicity in the media; local media have supported and/or prompted local MLAs to campaign against resettlement schemes in their constituencies.	2
Evidence of resistance by some consultants and Trust staff.	2

Other factor(s) – 1 respondent each:

- lack of strategic join-up between health and housing;
- lack of understanding in health and social care about what supported housing is;
- heightened financial risk for housing associations making them reluctant to take on new schemes;
- insufficient money in the system to make it as good as it could be;
- lack of capacity (to commission accommodation-based services interviewer) on the healthcare side;
- important information about individuals who had been resettled not passed on: "... some Trust staff are reluctant to share case histories, or work with a provider's staff team." (Provider manager).

2.3.4 The challenges faced by Trusts in resettling the people currently in hospital

Discussions between members of the research team and policy managers within DHSSPS and DSD before the formal interviews took place indicated that there were still significant challenges being faced by Trusts in resettling the people who were on the priority transfer list but who had still not been resettled in 2013 and 2014. People in this group were said to have complex needs or challenging behaviours. Finding appropriate placements and support was said to be difficult. This issue was followed up in the interviews with policymakers, commissioners and providers. There were a number of comments that explained the implications of needing bespoke solutions for most of the people who remained in hospital.

Table 13: Main difficulties in resettling people with complex needs and challenging behaviours

Main difficulties	No. of respondents identifying each factor
High unit cost – the cost of bespoke services compared with the available funding based on rates agreed for the programme as a whole at the outset.	6
Finding the right placement / appropriate accommodation / individual housing with bespoke care and support solutions for people who are challenging.	5
Community integration vs. community opposition even against people with low to moderate needs, so even more so for those with moderate / severe / challenging behaviours.	2
Access to specialised day time activities and facilities.	2

Other factor(s) – 1 respondent each:

- finding compatibility between tenants for new 'off the peg' or existing accommodation and support/care services, and associated safety issues;
- the level of staffing needed for people with complex needs;
- the resilience needed by provider staff to work with people who have complex needs, and the need to provide support mechanisms for staff;
- the need for specialised staff training on e.g. deprivation of liberty and human rights;
- scheme size and the number of bedrooms required for an individual who needs live-in staff;
- support and training for families and carers;
- development of services to prevent placement breakdown;
- the need for inter-agency collaboration on community safety issues;
- ensuring the confidence and competence of provider organisations in meeting complex needs;
- the absence of agreed cost models for the resettlement of people with complex needs.

One participant said:

"Each case is unique. Many people with complex needs cannot live in a congregated living setting because they do not want or cannot live with other people around them for safety reasons. Therefore the unit cost of any placement can be high."

As a result, the costs of resettling some individuals on a bespoke basis were said to be well above the revenue budget of £85 thousand per capita per annum from NHS and social care sources, £21 thousand per capita per annum from the Supporting People budget, plus Housing Benefit funding housing costs for people living in SP-funded supported accommodation.

The intention was that these costs would be an 'average' per capita over the lifetime of the resettlement programme. However, the figures were announced publicly at the outset of the programme so that Trusts commissioning in-house services, and independent sector providers, were given clear guidance on the prices they could charge. Interviewees said that this has meant that the intended 'swings and roundabouts' in which cheaper services commissioned early in the programme would allow funding for more expensive services commissioned later were not achieved.

2.3.5 Overview of roles and responsibilities

Participants were asked to say what they thought the role of the H&SC Trusts, and the Housing Executive's Capital Planning and Programming and Supporting People teams were in the planning and delivery of accommodation for people being resettled from long stay hospitals. All those taking part in the interviews gave an opinion.

Health and Social Care Trusts

Interviewees said that Trusts have statutory responsibilities for assessing the needs of learning-disabled people and for ensuring the provision of services to meet those needs. Within that, Trusts have a choice. They can:

- make direct provision themselves;
- procure services from the independent sector directly; or
- procure services through an intermediary such as the Housing Executive.

In each case, interviewees said that Trusts have a duty to ensure that the people they are resettling have accommodation that is appropriate for their needs. If supported housing meets their needs, then they also have a duty to ensure that the support the resettled person needs to retain a tenancy in the community is appropriate. Trusts therefore need a close relationship with the housing association and with the care or support provider to achieve these objectives. The Trust also has a responsibility to ensure consistency throughout the commissioning and procurement process on behalf of the individuals being resettled. Once the person is placed, the Trust's role is to undertake regular service and care reviews and to act on concerns arising from inspections.

Participants from the independent sector expressed concerns about whether, if Trusts have specified a particular type of bespoke provision, there should be a shared commitment with the provider to the future of the service in terms of risk sharing and funding to ensure that the service is sustainable. These interviewees said that they were concerned that overstretched health and social care budgets could, at some point in the future, leave the provider to meet the costs of provision as is happening in England where the level of funding for people with low to moderate learning disabilities has been reduced or cut (see Part 2).

The Northern Ireland Housing Executive planning and capital programme team's role

Participants said that the NIHE Capital Planning and Programming team had played a crucial role in the commissioning and procurement processes "... because more learning-disabled people than was previously the case" needed supported living in ordinary housing as opposed to being referred to residential and nursing care. The research team believes that this comment reflects a change in commissioning policy rather than a change in peoples' needs per se. The change in policy could have been influenced by the availability of funding from the SP programme to offset some of the H&SC costs associated with resettlement (see below).

The partnership between health and social care bodies and the Housing Executive was seen as critical because it unlocked capital funding and capacity for the development of new housing. NIHE's planning team was referred to as a 'facilitator', acting as an intermediary between Trusts and housing associations. The planning team was also seen as important alongside the Supporting People Partnership Board in monitoring progress on new developments and keeping development projects to time and budget. Housing and design is not health's area of expertise, so health sector interviewees said that there it was logical for the Trusts to involve housing professionals to ensure that there was close cooperation in designing and equipping schemes for specific needs and requirements.

The Northern Ireland Housing Executive Supporting People team's role

The link between Supporting People and the Trusts was said to be closer than links between Trusts and the Housing Executive's Capital Planning and Programming team. One participant said:

"... there is good collaboration with the Supporting People team and DSD, but we have questioned why Trusts have to take the lead in developing the business case for housing and support as this takes management resources from our side and that can cause delay".

Another participant, a provider, felt that commissioning was too strongly influenced by health and social care managers and practitioners rather than by housing practitioners.

Like the Housing Executive's planning team, the Supporting People team was seen as a facilitator with a role in enabling a scheme to proceed by committing revenue funding. One participant said:

"The presence of funding for resettlement within the Supporting People programme was highly significant in influencing the Trusts and the commissioning process to move people into supported housing rather than residential care".

While on the one hand this meant that the availability of funding from Supporting People promotes official policy in resettling people into their own homes, there was also a belief among several interviewees that SP funding gave Trusts a financial interest in commissioning supported housing even when it may not have been the best solution for the individual. It was suggested by one participant that: "... there is not really a shared understanding of what 'good practice' in supported living represents", so that the risk of blurred lines between care and support became a possibility.

This view was confirmed by another interviewee who, when asked why a new property development had been criticised by RQIA and the Supporting People team for incorporating a large industrial-scale kitchen and having an institutional feel, said that the design was appropriate for the high level of dependency shown by the people being settled there. This interviewee said that the service should have been commissioned as residential care if the

criterion of meeting individual need was being properly applied. However, the Trust involved had been keen to access funding from Housing Benefit and Supporting People in order to reduce its own financial commitment. This suggests that, in some circumstances, there may have been a process of cost transfer between social care and SP budgets taking place unless the boundaries between 'care' and 'support' were very clearly defined and needs assessment was matched with an appropriate commissioner specification.

2.3.6 The commissioning process for accommodation-based care and support services

Participants in the consultative interviews were also asked a series of questions about:

- the commissioning process for accommodation-based care and support services;
- the commissioning criteria for these services;
- how service standards were monitored.

In particular, interviewees were asked to say whether and to what extent they thought the housing, care and support services commissioned since 2007 met the requirements of the Bamford Review values and recommendations.

How accommodation-based services are commissioned

Ten participants answered the question. Two participants said that they did not know any details; one participant said they did not wish to comment.

Representatives of DHSSPS, DSD, NIHE and the H&SC Board tended to have a strategic perception of the commissioning process, whereas interviewees from Trusts and service providers tended to have a more detailed operational perspective. Examples of both structural and operational perspectives are set out in Figure 3. There appeared to be some variation in practice between Trusts.

Figure 3: The process for commissioning accommodation-based services

Respondent role	The commissioning process
DHSSPS / DSD / H&SC Board perspective	Commissioning structures start at area level through the Area Supporting People Partnership Boards which are chaired by a Health and Social Care Board staff member. Area SP Partnership Boards have representation from the H&SC Board, the Trust, Supporting People and others including the Probation Service NI. The need for capital and support funding is identified locally. If the need is assessed as being in line with policy, the agency that has brought the issue to the table will be invited to put a planning group together, develop a business for submission to the SP Commissioning Board (which has Northern Ireland-wide responsibilities). The Trust then confirms that people are ready for resettlement, that there is a strategic need and it is then signed off by NIHE to say that capital funding is available. If approved, funding is allocated to the planning team and the project starts on the ground.
H&SC Trust perspective	Three levels of responsibility were identified: planning, commissioning, and implementation. Planning: part of the resettlement process under the 3 year (2012 – 2015) plan involves identifying those who had been ready for resettlement for at least a year in 2007 that are the primary focus. Alongside the resettlement programme there is the normal process of admissions and discharges and similar issues about discharge have arisen for some of them as in the priority transfer list – i.e. there are some people admitted to hospital after January 2007 who have been identified as ready for discharge but there is nowhere for them to go (the Delayed Discharge List). Commissioning: Having assessed the health, care and housing needs of people on the PTL and DDL, the Trust needs to identify or develop appropriate services for them individually, then as a cohort. Some services are commissioned directly from a partner agency or from in-house providers; or there may be a vacancy in an existing scheme; or the family may have an option. Private and independent sector services are looked at first. If there is nothing suitable there, then the Trust will commission a new build service through the housing association development programme via the Housing Executive. For the latter, a business case is prepared in collaboration with the Trust's planning

department. That goes first to the Area Supporting People Partnership for review and approval. If approved, the Area SP Partnership allocates care funding for the required number of places, and the Trust liaises with the nominated housing association or tenders the services to private or voluntary sector care providers. The Trust then works with the housing association or provider to develop a cost model and the model of housing, care and support required. The association puts this into its bid for capital to the NIHE Capital Programme Planning Team, and to Supporting People for SP funding.

Implementation: This involves service development once a new service has been commissioned, and includes contracting and contract management with independent providers, or with the manager and team of a Trust-provided service. The other part of the role involves care management – assessment of individual needs, the care plan (possibly in conjunction with a housing plan and a provider's care/support plan); the referral process and a review of the process.

Supporting People

At project level, the Supporting People team is involved in scheme by scheme oversight during the planning process led by the Trust with the housing association. The SP team also oversees design principles, assistive technologies etc. Unlike the role of English SP administrative bodies, NIHE acts as a broker and mediator. The SP team also has a strong link with the NIHE Housing Benefit team in respect of the affordability of out-turn rents and welfare reform.

One participant from a Trust added that: "It is about going out to proven providers of other types of placement and talking to them about different services to meet the urgent and immediate challenges of people who are inappropriately placed. There is a lack of a real market in Northern Ireland. The problem is if you talk to the provider and they name the price, that approach is not going to drive best value."

Changes in the commissioning process

Participants were then asked to say whether there had been any significant changes in the way commissioning was carried out after 2007. Five participants said that there had been changes; five said that there had been few changes; and three people did not comment.

Those that said there had been significant changes in commissioning had senior roles in Government Departments, NIHE and a Trust. In this view there had been a number of changes in how the commissioning body and the process have worked, with stronger governance, more robust business cases, and better quality control in the period 2012 to 2014 than at any time in the past.

The participants who said that there had not been any significant changes worked for Trusts and service providers. One participant from a Trust said that there had not been any changes yet, but that:

" ... we are working up procurement processes for nursing homes and domiciliary care services in the community. So at the moment it is as we always have done. But more commissioning is now at Trust level rather than at Board level."

From this and similar responses it seems that there was a different understanding of what the term 'commissioning' meant between strategic and policy managers on the one hand and those with operational responsibilities on the other. For the policy and strategic managers, the term implied the whole process from needs-based planning to delivery of an operating service for resettled people. For those with operational responsibilities, the term appeared to be a synonym for 'procurement'. A senior manager's view was that:

"There is a commissioning process for services but we are unaware of any systematic account of how that is being specified. Commissioning is on a relationship basis, in other words, who you know)."

The criteria being applied to commissioning new services

Participants were asked to say what criteria have been employed in commissioning accommodation-based services since 2012. There were ten responses. One response referred to the Department for Finance and Personnel's *Guide to Expenditure Evaluation and Appraisal* (the 'Green Book')⁵⁶. Key questions addressed in the Green Book included:

- Is this proposal aligned with the resettlement policy and the Minister's commitment?
- Is it sustainable i.e. does it meet need from both the housing and care viewpoint?
- Is it not short term and does it fit a 30 year timescale for capital funding?
- Does it meet the needs of the particular individual, group or cohort?
- Is the proposal affordable and does it represent value for money?

Eight responses gave a more detailed, bottom-up account of how criteria had been developed. Many of the criteria related to the specification of the services needed to meet an individual's needs rather than the commissioning process overall. Four examples of interviewees' responses to this question are set out below.

"Specification, a rigorous tendering process involving housing associations, then usually quality criteria, marking, interviewing, decision and contract award."

"The development of commissioning criteria is case by case, depending on the individual needs being addressed. There have been a few tendering initiatives where the specification is specific to the needs and the type of service."

"Key issues are: suitability of the housing for the individual; the individual's risks and developing a risk plan; based on needs assessment, type of care and support package they need; the staffing they need."

"We adopt a 'horses for courses' approach. We assessed the needs of a number of individuals, and then went out to commission services for that particular group. This is ok for small scale commissioning, but not for large scale nursing homes etc. Therefore it has been piecemeal."

Only one Trust interviewee referred explicitly to a tendering process rather than a discussion with a provider of the kind referred to by some Trusts in the previous section on commissioning. A second Trust indicated that tendering is sometimes considered.

Promoting independence

When asked what they thought was the best solution for learning-disabled people being resettled in terms of maximising their independence, interviewees said that there are choices and options from large group living situations, hub and spoke schemes, small shared houses and single tenancies. These options were said to allow a choice between different services for different levels of dependency. None of the interviewees referred to the 2012 *Learning Disability Service Framework*.

Participants agreed that supported living, where people have had real choices where they live, who they live with and what kind of life they can live is most likely to promote independence and integration into the community. However, some respondents said that this approach does not suit everyone. First preference is a normal home, but some people require more space because of their challenging needs with controls over what they have access to for safety reasons – kitchens for example. A Trust cannot place any individual into

⁵⁶ Department of Finance and Personnel (2012), The Northern Ireland Guide to Expenditure Appraisal and Evaluation ('NIGEAE'): New DFP guidance on the appraisal, evaluation, approval and management of policies, programmes and projects

a setting that does not meet their assessed need. If, for example, they have very acute needs or challenging behaviours, Trust managers said that residential care or a nursing home may be the best solution.

There were also suggestions that care managers will sometimes refer someone to a residential or nursing home because there is a vacancy available even if supported living would have been equally or more suitable. Cost factors might be influential in such cases; or care managers may be overly cautious in their assessments of an individual's suitability for supported living.

2.4 THE ROLE OF SUPPORTED HOUSING FUNDED THROUGH SUPPORTING PEOPLE GRANT IN THE NORTHERN IRELAND LEARNING DISABILITY RESETTLEMENT PROGRAMME

Earlier sections of the report found that the learning disability resettlement programme in NI depended heavily on the availability of a number of different models of housing, care and support including nursing care, residential care, supported housing and others. The Bamford Review and successive policy statements from DHSSPS and DSD emphasised the role of supported housing in promoting independence for learning-disabled people. In the following section, we review the role that supported housing and supported independent living funded by the Supporting People programme played in resettlement.

2.4.1 The eligibility of different types of service for Supporting People Grant

Supporting People is a UK-wide programme of revenue funding for the housing support element in independent living services. The programme came into effect on 1 April 2003. It brought together into a single budget a number of pre-existing funding streams including Special Needs Management Allowance (SNMA), funding for older peoples' sheltered housing, Probation Grant, and funding for aids and adaptations in older and disabled peoples' homes. The new system also aimed to remove anomalies, in that some housing support services that were previously being funded from Housing Benefit (HB) had been held to be ineligible for HB funding by the Courts. For those supported housing schemes that were in operation at 1 April 2000, the SNMA they received was incorporated with the amount they were previously receiving for ineligible services from Housing Benefit into a system called 'Transitional Housing Benefit ('THB'). With further adjustments including an element for inflation, THB formed the basis for the initial payment of Supporting People funding (Supporting People Grant – 'SPG') to existing housing support services when that programme went live on 1 April 2003⁵⁷.

In an attempt to rationalise which services were eligible for funding from which Departmental budget (Housing Benefit and Supporting People Grant from DSD; domiciliary or residential care payments from DHSSPS), clear definitions of the services eligible for each source of funding were laid down with clear boundaries identified. The rules governing eligibility for Supporting People Funding in Northern Ireland are set out in *Northern Ireland Supporting People Guidance*, 2012⁵⁸.

⁵⁷ Note that a small number of schemes for learning disabled people had previously been registered as care homes. When the transition to SP funding took place, it was held that some of these services could not be de-registered because the accommodation was unsuitable for independent living, because the vulnerability of some residents meant that they required a residential care environment, or because there was no capital or revenue funding available to remodel accommodation or fund housing support for independent living. These schemes remained within an SNMA-funded portfolio.

⁵⁸ Department for Social Development (2012), Northern Ireland Supporting People Guidance

In Northern Ireland, the Supporting People programme provides revenue funding for the Northern Ireland Housing Executive, housing associations, Health and Social Care Trusts and voluntary and community sector organisations to provide housing-related support services to vulnerable people living in temporary and permanent accommodation. Support can be provided in any form of tenure: owner occupied accommodation, social housing or privately rented housing.⁵⁹ It is administered by the Housing Executive through its Supporting People team. The programme is overseen by the Supporting People Commissioning Board.

One of the underlying principles for the payment of SPG is that people living in accommodation-based or floating support services that are eligible for SP funding must be living in their own home. Normally, this means that they are owners or leaseholders, or have a tenancy or license agreement with all the rights and responsibilities associated with those forms of tenure. The Supporting People Guidelines state:

"The term 'own home' should be understood in terms of its common usage which implies the principles of control and autonomy for the individual. The management of the property in which the user resides must not constrain the freedoms of the service user beyond those associated with the normal terms of legal occupancy agreements and thereby create an institutional environment." ⁶⁰

The purpose of SPG must in all cases be to fund the provision of the 'housing-related support' (i.e. not any personal support or care) a vulnerable individual needs to:

"...develop or maintain the skills and confidence necessary to live as independently as possible in their chosen form of tenancy and to develop the ability to maintain a tenancy." ⁶¹

SPG is also used to fund the costs of intensive housing management (over and above 'normal housing management costs') arising, for example, as a result of the person's disability or because their accommodation is temporary and there is a high turnover of occupants as in the case of temporary accommodation for vulnerable single homeless people. The Guidance states that:

"Housing-related support must, by definition, provide support to the service user in relation to housing-related tasks⁶² ... Individuals must be supported to develop and maintain the skills and confidence necessary to enable a service user to live as independently as possible in their own home. In most instances services which undertake those tasks on behalf of a service user cannot be considered compliant with the principles of 'Supporting People' and are therefore not eligible for Supporting People Grant."⁶³

Nursing, personal and domiciliary care services, and specialised counselling, are therefore defined in the Regulations as 'ineligible services' for which SPG is not payable.

The Guidance goes on to say that support services can be provided in a complementary fashion alongside care or other services, but are not personal care. Services that are providing a mix of housing related support and either domiciliary or residential care must therefore be very clear which tasks are being funded from SPG and must not use SPG to subsidise normal housing management, health or social care, or counselling activities.

⁵⁹ Department for Social Development (2012), op. cit., page 8, para 4.1

⁶⁰ DSD (2012), op. cit., page 7, para 3.4

⁶¹ DSD (2012), op. cit., page 6, para 3.3

⁶² DSD (2012), *op. cit.*, page 8, Section 4.0

⁶³ DSD (2012), op. cit., page 7, para 3.8

Residential care homes are not eligible for Supporting People funding. They are described as 'excepted' accommodation in the Regulations which state:

Accommodation which is registered under 'The Registered Homes (Northern Ireland) Order 1992[2] where no funding (under Special Needs Management Allowance) was paid by the Department in relation to that accommodation during the financial year ending on 31st March 2003 is excepted accommodation for the purposes of Article 3 of the Housing Support Services (Northern Ireland) Order 2002.⁶⁴

However, if a registered care home was receiving SNMA up to 31 March 2003, they may continue to receive this funding provided that: "... payment of the allowance fits with the overall policy intention of the Supporting People programme to promote independent living." ⁶⁵

2.4.2 Support services for learning-disabled people currently funded by Supporting People Grant

Data on 2014 – 2015 funding of housing support services for learning-disabled people by the Supporting People programme was provided by the Housing Executive. Additional data on the SP-funded services used in the post-April 2012 resettlement programme was provided by the H&SC Board. Information from these two sources allowed the compilation of two lists of SP-funded accommodation-based services for learning-disabled people.

- List 1: contains all accommodation-based and floating support services designated for learning-disabled people being funded by SPG in the 2014 to 2015 financial year irrespective of whether or not they house resettled people. There are 151 services with 1,560 contracted bed spaces in the first list.
- List 2: contains a limited number of the List 1 services that are known to house one or more resettled people. There are 29 services with 273 units of accommodation (17.5% of all SP-funded bed spaces for learning-disabled people) in the second list.

It is worth noting at this point that data were not available to establish how many or what proportion of learning-disabled people resettled since Bamford, or indeed since the resettlement programme was revamped in 2012, had moved into SP-funded accommodation. In reviewing the SP data sets below, therefore, it is important to remember that at the time the research was carried out, it was not possible to be certain:

- whether List 1 included some services that were not included in the second list but which also provided accommodation-based support for resettled learning-disabled people;
- whether List 2 contained all the SP-funded services that provided for one or more resettled learning-disabled people;
- how many learning-disabled people resettled from a long stay hospital were supported by each SP-funded service provided with a service in the second list – there could have been a mix of people resettled from long-stay hospitals and other learning-disabled people who were previously living in another community setting – the family home or residential care, for example;
- which resettlement cohort (pre-2007, 2007 2011, or post-2012) resettled people supported by these services could be identified with;
- whether the people were resettled from the priority transfer list (i.e. waiting for resettlement since before 31 March 2007) or from the delayed discharge list (post-1 April 2007).

⁶⁴ Department for Social Development (2012), op. cit., page 16, para 6.1

⁶⁵ Department for Social Development (2012), *op. cit.*, page 16, para 6.1

In summary, it was not possible to say how many people in the services included in either list had been resettled from hospital or had previously been living elsewhere. The Supporting People team told the research team that it was confident that the vast majority of resettled people would have been included in the 29 services contained in List 2. However, there may have been others outside these schemes. The figures set out below should be taken as giving a general description of supported accommodation for learning-disabled people generally and for those who were resettled from a long-stay hospital.

A profile of List 1 - all SP-funded services for learning-disabled people

Of the 151 SP-funded services for learning-disabled people,

- 14 services received Special Needs Management Allowance (SNMA), a system which formally ended on 31 March 2000 when the Transitional Housing Benefit system came into operation;
 - in ten cases SNMA was paid to independent sector residential care homes;
 - in four cases, SNMA was being paid to shared or self-contained supported housing owned by a registered housing association.
 - Supporting People Grant (SPG) was paid to 137 services. Of these:
 - five were floating support schemes for learning-disabled people, two of which were operated directly by a Health and Social Care Trust (Belfast Trust and Western Trust);
 - four were unregistered adult placement schemes, of which two were operated directly by the Southern Trust, one payment was to a specialist voluntary sector provider, and the other appears to have been made to a private household;
 - the remaining 128 services were designated in NIHE records as 'shared or self-contained supported housing' of which 27 services were identified as being operated directly by a H&SC Trust.

Some services still received SNMA rather than SPG because they were legacy services that did not fully conform to the post-2003 SPG funding rules, or where accommodation or residents were unsuitable for independent living⁶⁶.

The SP data allow an analysis of service type, funding type, and level of funding for each service and provider, and for each Trust area. A list of providers is contained in Appendix 3. The data cover 26 providers, 151 different SP-funded services and 1,560 SP-funded bed-spaces. Tables 14 to 19 below show the figures.

In England, services that were funded by SNMA at 31 March 2003 and which did not fully comply with the requirements for SPG funding were transferred to the SP programme and were given three years, to 31 March 2006, to conform. Those that failed had SP funding withdrawn with effect from 1 April 2006. Different rules operated for pre-2000 services in Northern Ireland.

Table 14: Overview of the number of providers, services and bed-spaces by H&SC Trust area (2014/2015)

Trust Area	Number of SP-funded providers operating in Trust area ^{Note}	Number of SP-funded services in Trust area	Number of SP-funded bed spaces in Trust area
Belfast Trust	7	25	333
Northern Trust	11	36	363
South Eastern Trust	14	47	308
Southern Trust	8	27	314
Western Trust	8	16	242
NORTHERN IRELAND		151	1,560

Note The number of providers in this column does not sum to 26 because some providers operate in more than one Trust area.

The number of providers, SP-funded services and bed spaces found in each Trust area varies considerably. The three Trust areas in which one of the long-stay hospitals was located (Belfast Trust, Southern Trust and Western Trust) have fewer providers and services than the two Trust areas with no hospital.

The number of bed spaces in four of the five areas is broadly similar. The Western Trust has fewer SP-funded bed spaces than the other four areas because more of its reprovision programme was completed prior to 2012 and there was a higher proportion of people placed into residential and nursing care.

Table 15: Number and percentage of services provided by the independent sector and by Trusts in each H&SC Trust area

Trust Area	Number of Providers operating in Trust area Note	Number of SP-funded services in Trust area	Of which provided by Independent Sector	% provided by the Independent Sector	Of which, provided directly by Trust	% Provided by the Trust
Belfast Trust	7	25	18	72.00	7	28.00
Northern Trust	11	36	30	83.33	6	16.67
South Eastern Trust	14	47	42	89.36	5	10.63
Southern Trust	8	27	12	44.46	15	55.55
Western Trust	8	16	1 5	88.25	2	12.50
NORTHERN IRELAND		151	117	76.97	35	23.03

Note The number of providers in this column does not sum to 28 because some providers operate in more than one Trust area.

Almost one quarter of the services in receipt of SPG providing for learning-disabled people are operated directly by a Trust. There are variations between Trust areas. In the Southern Trust area, 55% of all SP-funded services for learning-disabled people are provided by the Trust; whereas in the Western Trust area 12.5% of these services are provided by the Trust; and in the South Eastern Trust area 10.6% of services are provided by the Trust. It is not clear whether these variations evolved because of different needs and circumstances, because of differences in Trust commissioning strategies, or because there was no overall philosophy and strategy for delivering the resettlement programme across NI as a whole.

Table 16 provides a breakdown of the number of bed-spaces provided by the independent sector and by Trusts, and of the mean number of bed-spaces per service, in each Trust area.

Table 16: Number and percentage of bed spaces provided by the independent sector and by Trusts in each Trust area

Trust Area	Number of Providers operating in Trust area	Number of SP- funded services in Trust area	Number of SP- funded bed spaces in Trust area	Number of SP-funded beds provided by Indepen- dent Sector	Mean number of bed spaces per Independent Sector service	Number of SP-funded beds provided by Trust	Mean number of bed spaces per Trust service
Belfast Trust	7	25	333	212	11.8	121	17.3
Northern Trust	11	36	363	312	10.4	51	8.5
South Eastern Trust	14	47	308	291	6.8	17	3.4
Southern Trust	8	27	314	156	13.0	158	10.5
Western Trust	8	17	242	178	12.7	64	32.0
NORTHERN IRELAND		152	1,560	1,149	9.8	411	11.7
Percentage			100.00	73.65		26.35	

There are a number of findings from Table 16:

- Trusts provide a slightly larger proportion of beds overall than their share of services (26.35% of beds compared with 23.03% of beds);
- the mean number of bed-spaces per service is higher in Trust schemes than in independent sector schemes (11.7 bed spaces per service in Trust schemes compared with 9.8 bed spaces per service in the independent sector);
- the mean number of beds in independent sector services funded by SP ranges from 6.8 beds per service in the South Eastern Trust area, to 13.0 beds per service in the Southern Trust area;
- the mean number of beds in Trust services funded by SP ranges from 3.4 beds per service in the South Eastern Trust area, to 32 beds in the two Western Trust area services;
- in the South Eastern Trust area, the mean number of beds in both independent sector and Trusts schemes is more or less in line with the Bamford requirement that services should not exceed 5/6 beds in size;
- in the Belfast, Southern and Western Trust areas, the mean number of beds in independent sector and Trusts schemes is well above the Bamford requirement;
- in three of the Trust areas (Northern Trust, South Eastern Trust and Southern Trust) the mean number of beds per service in the independent sector is higher than the mean number per service in Trust schemes.

The indications are that a significant number of services provided larger, congregate-type settings than the Bamford Review recommendations. However, the fact that a Supporting People funding contract may cover a large number of bed spaces in a single service does not necessarily imply a congregate setting. Other service models such as core and cluster, or dispersed houses with small numbers of people living in them, may have been adopted. Further work is needed to establish which services fully conform to the Bamford recommendations and which do not.

Table 17 provides data on the type of provider, type of service delivery and mean number of beds in each type of service.

Table 17: Provider, number of services, number and percentage of different types of service delivery and mean number of beds per type of service delivery for each Trust area

			Of which beds in:									
Trust Area	Number of Providers operating in Trust	Number of SP- funded services in Trust	Unreg Adult Placen	istered nents	Reside Care H		Shared Self – contai Suppo Housir	ned rted	Floatir Suppo	_	TOTAL	
	area	area	No. of beds	%	No. of beds	%	No. of beds	%	No. of beds	%	No. of beds	%
Belfast Trust	7	25	0	0.00	16	10.3	205	16.5	46	37.7	333	100
Northern Trust	11	36	0	0.00	26	16.7	325	26.2	12	9.8	363	100
South Eastern Trust	14	47	4	10.3	91	58.3	272	21.9	0	0.0	308	100
Southern Trust	8	27	35	89.7	3	1.9	284	22.9	0	0.0	314	100
Western Trust	8	17	0	0.00	20	12.8	157	12.6	64	52.5	242	100
NORTHERN IRELAND		152	53		123		1,30 4		80		1,56 0	100
% of all beds				2.5		10.0		79.7		7.8		100

The significant findings identified in this table are that:

- 10% of SP-funded bed spaces are in 10 registered care homes these are pre-2003 legacy SNMA-funded services that in England would have been remodelled within three years or funding would have been withdrawn;
- 80% are in forms of shared or self-contained supported housing there is a further analysis of these services below;
- 8% are in floating support services;
- 2% are in unregistered adult placements;
- there are variations in the proportion of learning-disabled people in each type of accommodation within the Trust areas – for example, 58% of all registered care home placements are in the South Eastern Trust area;
- there is considerable variation in the number of contracted beds in supported housing services receiving SPG in each Trust area.

Table 18 correlates the number of bed spaces in each service, in size bands, with the type of provider.

Table 18: Size bands (number of bed spaces) for shared housing schemes by provider and by Trust area

Trust Area		Independent Sector Providers : Number of services by number of beds						Trust Providers: Number of services by number of beds				
1-5	1-5	6 - 10	11 - 15	16 - 20	21 - 30	31+	1 - 5	6 - 10	11 - 15	16 - 20	21 - 30	31+
Belfast Trust	6	9	0	3	0	0	2	1	2	0	1	1
Northern Trust	23	3	2	1	1	1	2	1	0	2	1	0
South Eastern Trust	32	5	0	0	3	2	2	2	0	0	0	1
Southern Trust	4	4	1	2	0	1	5	5	0	2	3	0
Western Trust	2	5	1	4	1	1	0	0	0	1	0	1
NORTHERN IRELAND	67	26	4	10	5	5	11	9	2	5	5	3
Percentages by sector	57%	22%	3%	9%	4%	4%	39%	32%	10%	3%	6%	10%

The table includes:

- 78 services for between 1 and 5 people (51% of all SP-funded services for learning-disabled people) that apparently conformed to the Bamford requirements on the desirable maximum number of people living together in a single service;
- 35 services (23%) that had between 6 and 10 bed spaces which, depending on the
 actual living arrangements whether they have their own front door for example or
 are living in close proximity to a significant number of other learning-disabled people
 may have broadly conformed to the Bamford requirements;
- 21 services (14%) had between 11 and 20 bed spaces within the scheme, which again depending on the arrangements, might have been acceptable in some circumstances but was more likely to resemble congregate living;
- 18 services (12%) had 21 or more bed spaces;
 - in six cases there were more than 30 bed spaces in the scheme;
 - in two cases there were 50 or more bed spaces.
 - the likelihood is that these services were either mini-institutions or represent other forms of congregate living.

In total, one third of these services had 15 or more contracted bed spaces, and half had more than 5 bed spaces.

There is no evidence from Table 17 that Trusts were more likely than independent sector providers to be managing services with a large number of bed spaces. Nor does the table suggest that there was a preponderance of services with high numbers of bed spaces in any particular Trust area.

SP funding for learning disability housing support services in 2014 - 2015

Table 19 provides information on the contract value, mean contract value per service and mean weekly cost per bed space in SP-funded services.

Table 19: Total SP contract value for learning disability services, mean contract value, and mean weekly u	nit price by Trust
area	

Trust Area	Number of SP- funded services (2014/2014)	Total SP contract value (2014/2015)	Mean contract value	Number of contracted bed spaces	Mean no of bed-spaces per service	Mean weekly unit price
Belfast Trust	25	£2,254,642.00	£90,185.68	333	13.32	£162.39
Northern Trust	36	£4,190,756.00	£116,409.89	363	10.08	£222.02
South Eastern Trust	47	£4,367,983.00	£92,935.81	308	6.55	£227.03
Southern Trust	27	£3,585,585.00	£132,799.44	314	11.63	£216.16
Western Trust	17	£2,143,035.00	£126,060.88	242	14.24	£171.01
NORTHERN IRELAND	152	£16,542,001.00	£108,828.95	1,560	10.26	£203.92

The total SP contract value for learning disability support services in the 2014/2015 financial year was more than £16.5 million. The mean contract value was nearly £109,000 per annum; the mean weekly unit price was just below £204.

There was a correlation between the mean number of bed spaces per service in each area and the mean weekly unit price. This suggests that larger aggregations of bed spaces cost less per unit, but this was not necessarily reflected in the overall contract price, which was driven by the number of units as well as unit price.

A profile of the SP-funded services for learning-disabled people known to have been resettled from a long stay hospital (List 2)

Twenty nine out of 151 SP-funded supported accommodation services for learning-disabled people were identified by NIHE's SP team and the H&SC Board as providing for learning-disabled people resettled from long stay hospitals. Of these services:

- 25 services were provided by the voluntary sector and 4 were provided by a Trust;
- SPG funded all 29 services none were funded through SNMA;
- 27 were described as 'shared or self-contained supported housing';
- 2 were unregistered adult placements⁶⁷, one of which was provided by a voluntary sector provider, the other was provided by the Southern Trust.

Table 20 shows the number of providers, the number of services and the number of accommodation units for List 2 services containing resettled people, by Trust area.

⁶⁷ Registered adult placements are not eligible for SP Grant.

Table 20: Overview of the number of providers, services and bed-spaces by H&SC Trust area identified as specifically for resettled learning-disabled people (2014/2015 funding)

Trust Area	Number of SP-funded providers of services identified as for resettled people in area	% of SP- funded providers of all learning disability services working in the area	Number of SP-funded services for resettled people	% of all SP- funded learning disability services in the area	Number of SP-funded bed spaces for resettled people	% of all SP- funded learning disability bed spaces in the area
Belfast Trust	1	14.29%	1	4.00%	7	2.10%
Northern Trust	7	63.64%	14	38.89%	157	43.25%
South Eastern Trust	6	42.86%	8	17.02%	102	33.12%
Southern Trust	3	37.50%	5	18.52%	64	20.38%
Western Trust	1	12.50%	1	6.25%	16	6.61%
NORTHERN IRELAND			29	19.21%	346	22.18%

Note Number and percentage of providers not given as some providers work in more than one area

Comparing these figures Trust by Trust with the figures shown in Table 16:

Belfast Trust area

The Trust did not appear to have prioritised the provision of supported accommodation generally (Table 14) or specifically for the resettlement programme (Table 20). It had seven providers working in the area who provided housing and support for learning-disabled people, but only one service identified as specifically for resettled people.

Northern Trust area

The Trust focussed its provision of supported accommodation on the resettlement programme. Two thirds of the area's providers of supported housing for learning-disabled people were providing services identified as housing resettled people. It had 54% of all services in NI for learning-disabled people; and 43% of SP-funded bed spaces available for resettled people.

South Eastern Trust area

Almost 43% of the area's providers of supported housing for learning-disabled people were providing services identified as housing resettled people. However, only 17% of the services and 33% of the beds for learning-disabled people were provided for resettled people.

Southern Trust area

The Trust had not developed as many learning disability services as in some other Trust areas. The area had 17% of the SP-funded learning disability service providers overall, but 23% of the identified providers, 18.5% of services and just over 20% of bed-spaces available for resettled people.

Western Trust area

The Trust had not developed as many services as in some other Trust areas. The area had 17% of the SP-funded learning disability service providers, but only one service representing 8% of the identified providers and 6% of the services and bed spaces for resettled people.

It is noticeable that the three Trust areas within which a long stay hospital was located (Muckamore Hospital/Belfast Trust; Longstone Hospital/Southern Trust and Lakeview Hospital/Western Trust) had fewer SP-funded providers and services than the other two Trust areas.

The number of SP-funded bed spaces available for resettled people in four of the five Trust areas was fairly consistent at between 308 and 363. However, there were relatively few providers, services and bed spaces in the Western Trust area. Information obtained in the interviews suggested that patients from Lakeview Hospital were resettled before the other hospitals and prior to the 2012 resettlement plan being adopted. Perhaps as a consequence of this a significant proportion of resettled people from that hospital were placed in residential and nursing care settings.

The variations between the other Trusts may also be partly explained by commissioning policies which may have varied at different times during the post-2007 resettlement programme. Table 21 shows the date on which each of the services identified as being available to resettled people became operational⁶⁸.

Table 21: Operational date for services identified as specifically for resettled people – number of services by commissioning date by Trust

Trust Area	Became operational pre-2003	Became operational between 2003 and 2011	Became operational since 2012	Operational date not known
Belfast Trust	0	0	1	0
Northern Trust	2	5	6	1
South Eastern Trust	1	4	3	0
Southern Trust	0	3	2	0
Western Trust	0	0	1	0
NORTHERN IRELAND: Services	3	12	13	1
NORTHERN IRELAND: bed spaces	51	50	64	n/a
NORTHERN IRELAND: mean bed spaces per service	17	4.2	4.9	n/a

Table 21 shows that there was:

- an increase in the commissioning of services after the introduction of the Supporting People programme;
- a sharp fall in the mean number of bed spaces per service across NI as a whole after the introduction of SPG, reflecting the influence of the SP programme on implementation of the Bamford recommendations; and
- commissioning practices varied over time within and between Trusts⁶⁹ with more services commissioned in some Trust areas than others.

The Northern and South Eastern Trusts commissioned a small number of services that became operational within each time period. Southern Trust services became operational after the introduction of Supporting People programme in 2003. The single services included in this list commissioned by the Belfast and Western Trusts each became operational after the resettlement programme was revamped in 2012.

⁶⁸ This information is not currently available for all 152 supported accommodation services for learning-disabled people.

⁶⁹ Information on the date from which all the other SP-funded services for learning-disabled people became available is not available at present, but will be collected and analysed as part of phase 2 in the research programme.

Resettlement from Muckamore Hospital (Belfast Trust) was continuing at the time of the Phase 1 research. All resettlement activity in the Western Trust area was complete by 2012 and Lakeview Hospital was then closed. Similarly, resettlement of the PTL from Longstone Hospital was completed by the end of 2012 in the Southern Trust area, with smaller numbers of DDL people remaining to be discharged.

The most striking feature of this analysis is the relatively small number of supported housing services and bed spaces brought into management across NI as a whole in the period 2003 – 2011. Over the eight financial years between 1 April 2003 and 31 March 2011, an average of 1.5 services and 6.25 bed spaces that are now identified by the SP team and the H&SC Board as being available for resettled people became available each year. Since 1 April 2012, an average of 6.5 services and 32 bed spaces has been brought into management each year.

Table 16 above shows that, in List 1 services, around half of the SPG-funded accommodation had more contracted bed spaces than the Bamford recommendation limiting the ideal number to five. The Supporting People team provided information about the model of accommodation-based support adopted in each of the List 2 services identified as housing resettled people (Table 22).

Table 22: Number of SP-funded services, properties, bed spaces and mean number of bed spaces per property, by Trust area

Trust Area	Number of services identified as housing resettled people	Number of properties	Number of bed spaces	Mean number of bed spaces per property	Service model not known
Belfast Trust	1	2	7	3.50	0
Northern Trust	14	67	157	2.34	2
South Eastern Trust	8	58	102	1.76	0
Southern Trust	5	17	64	3.76	0
Western Trust	1	3	16	5.33	0
NORTHERN IRELAND	29	147	346	2.35	2

Almost all of the List 2 services that were identified as providing for resettled learning-disabled people fell within a narrow band of numbers of bed spaces—per—property. In most cases therefore, these services do not appear to require learning-disabled people to share accommodation. There are a small number of exceptions:

- In the Northern Trust area, there are two services that contain more than 5 beds in shared accommodation within a single property, and in one case there are 13 selfcontained units in a single property;
- In the South Eastern Trust area there is one service with 24 shared accommodation units across six properties, and two single-property services, one with 15 self contained units and the other with 18 self-contained units in the property;
- In the Southern Trust area, there is one service with 23 shared units in 4 properties;
- In the Western Trust area, the single scheme identified as providing for resettled people has a mix of 16 shared and self-contained units in a single property.

SP funding for housing support services specifically for resettled people

Table 23 provides information on the 2014-2015 contract value, mean contract value per service and mean weekly cost per bed space in SP-funded services that have been identified as specifically for resettled people.

Table 23: Total SP contract value for services specifically for resettled people, mean contract value, and mean weekly unit price by Trust area

Trust Area	Number of SP- funded services (2014/2015)	Total SP contract value (2014/2015)	Mean contract value	Number of contracted bed spaces	Mean no of bed-spaces per service	Mean weekly unit price
Belfast Trust	1	£144,872.00	£144,872.00	7	7.00	£398.00
Northern Trust	14	£2,266,341	£161,881.51	157	11.21	£277.60
South Eastern Trust	8	£1,820,807	£227,600.94	102	12.75	£343.29
Southern Trust	5	£990,376	£198,075.24	64	12.80	£297.59
Western Trust	1	£173,596.80	£173,596.80	16	16.00	£208.65
NORTHERN IRELAND	29	£5,395,993.56	£186,068.74	346	11.93	£299.91

- The total SP contract value for support services specifically for resettled people in 2013/2014 was £5.396 million;
- this amounted to 32.6% of the cost of all SP-funded learning disability services for 19% of all SP-funded learning disability services;
- the mean contract value was £186,000 (1.7 times the mean value of all SP-funded services for learning-disabled people);
- the mean weekly price per bed space was £293 (2.7 times the mean weekly cost per bed space in all SP-funded services for learning-disabled people);
- these services were more expensive than the generality of SP-funded services for learning-disabled people;
- the mean weekly cost per bed space in the Belfast and South Eastern Trust areas was well above the mean weekly cost per bed space in the other three trust areas.

2.5 EFFECTIVENESS OF THE RESETTLEMENT PROGRAMME

In this section we report on the quality of housing and support services that have been developed as part of the resettlement programme, and address the question of whether this provision meets the Bamford recommendations as seen from the perspective of the policymakers, commissioners and service providers whom we interviewed.

2.5.1 Assessing the quality of services

The interviews

In the course of the interviews⁷⁰, participants were asked to explain the processes by which the quality of the housing, care and support services provided for resettled people were being assessed. All thirteen participants replied to this question.

A number of different agencies have responsibility for monitoring aspects of service delivery in different settings. Each agency or role has a different approach although there may be overlap between them in some of the detail.

 $^{^{70}\,}$ A description of the interview process and a list of interviewees is provided in Appendix 1.

Service users, their families and advocates were identified by interviewees as the first line in the system. After that, the quality of services was said to be variously assessed by:

- Trust care management processes that monitored and reviewed services provided by the Trust and by independent providers;
- Trust in-house provision was also subject to Regulation 28, 29 and 30 visits by RQIA (covering residential, day care and nursing home care);
- Trust services were periodically monitored by Trust auditors;
- the quality of housing association services was monitored through housing associations internal management processes, externally through regulatory inspection by DSD (now DfC), and through contract management by Trusts in their capacity as care and support commissioners;
- the Supporting People department supervised the use of the Quality Assessment Framework version 2 (QAF2)⁷¹ which was designed for self-monitoring by housing support providers from both the statutory and independent sectors. The SP team then used the QAF2 results as a basis for contract management through monitoring of provider returns, announced performance visits and unannounced spot checks;
- The Regulation and Quality Improvement Authority (RQIA) registers nursing, residential and domiciliary care services and inspects care standards and financial probity in registered domiciliary care services, with the addition of an inspection of the accommodation provided in registered care homes.

The general view was that all publicly funded services should have a statement of purpose that incorporates performance indicators and agreed arrangements for how performance will be measured and evaluated. Commissioned services would then be governed by service level agreements, contractual arrangements, key performance indicators (KPIs), and performance reviews. These would be backed up by social worker and care manager visits to services, together with formal review meetings.

RQIA's expectation was and remains that where people are living in a registered service there should be regular reviews of the quality and appropriateness of the services they receive led by the Trust, irrespective of who the provider is. There was also an expectation that the care provider would carry out a monthly survey of residents' satisfaction with their accommodation and services, developing appropriate plans to deal with issues if there were areas of concern. However, interviewees said that, in practice, care management reviews were often led by the provider and this could mean that there was no independence of view in ongoing service reviews.

There was a complex interplay of oversight and regulatory arrangements governing SP-funded services, but there was no independent regulatory framework for SP-funded supported housing. The Supporting People Department did not have the necessary statutory powers or procedures to conduct formal inspections. These services were subject to contract management oversight by the Supporting People team, which came close to a monitoring and inspection process but was not governed by statutory powers⁷².

⁷¹ QAF2 is an updated tool designed to be used by providers for internal self-monitoring as well as by Supporting People teams as a contract management tool. It provides a standard for providers to measure themselves against when delivering services.

⁷² The Supporting People team had received legal advice that an interventionist approach to contract management and performance improvement in provider organisations could be deemed to make it a shadow director – i.e. someone who is not a director but who exercises control over a company and therefore assumes risk in connection with management of the company.

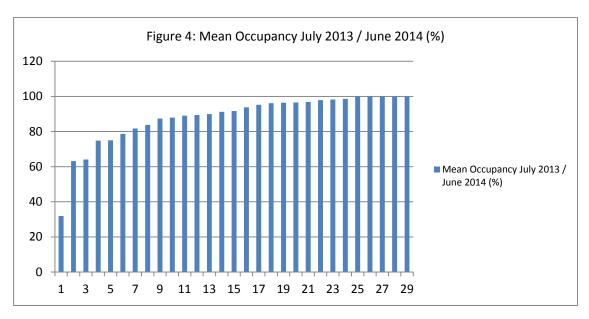
Some interviewees suggested that the SP team's QAF2 monitoring process is not identifying issues in either accommodation or support because it is partly based on self-monitoring by providers. RQIA was said to be 'filling the void' unofficially, reviewing housing support that was provided alongside domiciliary care on an informal basis during inspection visits, offering advisory recommendations rather than statutory actions to be taken. Concerns were expressed by some interviewees about whether or not this was legitimate.

What the Supporting People Programme data show

Data provided by the SP team allow an analysis of some aspects of provider management performance and service quality for the List 2 SP-funded services that were identified as providing accommodation-based support for resettled people.

All twenty nine services providing for resettled people were funded through 'Variable Block Contracts' in which the payment of SPG depended on the number of people provided with housing support at any one time within an overall contracted number of places. Although SPG payments were varied according to the current number of tenancies, the number of people actually supported by each service compared with the contracted number of places was an important indicator of provider service management. These are publicly-funded housing association schemes paid for in most cases by Housing Association Grant. One of the requirements of HAG funding is that accommodation must be well maintained and available for letting or in use at all times. For special needs supported housing services such as these, it would be reasonable to make a small allowance for people moving in and out of the service. However, rapid turnover of residents is not to be expected in learning disability services, and provider service management should be able to maintain occupancy levels of 95% - 100% in most cases. Anything below 85% is treated by the SP team as 'low occupancy'.

The mean occupancy level across the 29 List 2 services identified as providing for resettled people between July 2013 and June 2014 was 87.92%. Figure 4 shows mean occupancy (Y axis) between July 2013 and June 2014 across each of these services (X axis).



Fourteen services (48%) had mean occupancy levels over a twelve month period between 1 July 2013 and 30 June 2014 below 95%; eight services (28%) had occupancy levels below 85%, ranging from 31.87% to 83.72%. There were four low occupancy services in the Northern Trust area, and the single schemes in the Belfast and Western Trust areas were also experiencing low occupancy.

It is not clear whether the existence of a number of services with occupancy levels below 85% reflected lack of demand, weak liaison between providers and their referral agencies (Trusts and others), weak scheme management, or resulted from the provider's policy decision to reduce numbers in order to reduce social pressure among vulnerable residents some of whom may have challenging behaviours.

However, all of the services in this list met Supporting People 'Minimum Quality Standards' derived from the QAF2 self assessment process⁷³. The discrepancy between occupancy data and the results of self monitoring by providers may illustrate the shortcomings of the QAF2 process.

As part of its approach to contract management, NIHE also made an assessment of what it called 'Provider Risk'. The risk assessments on which this assessment was based were derived from a summary of the political, financial and operational risk associated with each provider of SP-funded services. There were thirteen providers of services in the list identified as providing support for resettled people. Of these:

- six providers were assessed by the SP team as 'low risk;
- · six were assessed as 'medium risk';
- one provider was assessed as 'high risk', and RQIA enforcement action was being taken in respect of care services delivered by this provider.

The risk assessments were summarised as a 'traffic light' system. Table 24 records the risk associated with the services that were provided by the thirteen providers operating in each Trust area.

Table 24: Supporting People 'Provider Risk Assessments by Trust area

Trust Area	Number of Providers operating in each Trust area ^{note}	SP-funded providers assessed as 'low risk'	SP-funded providers assessed as 'medium risk'	SP-funded providers assessed as 'high risk'	SP-funded providers who are also registered Dom. Care providers subject to RQIA enforcement action
		Green	Amber	Red	Red
Belfast Trust	1	1			
Northern Trust	7	3	3	1	1
South Eastern Trust	6	3	3		
Southern Trust	3		2	1	1
Western Trust	1	1			

Note: some providers operate in more than one Trust area. Northern Ireland totals would therefore be misleading.

Seven out of thirteen providers in this list were assessed as medium or high risk by the Supporting People team as part of its contract management processes. In some cases medium and high risk providers were working in more than one Trust area. Thus 10 out of the 29 List 2 services were being provided by medium or high risk providers. Note, however, that these services may not be typical of the entire list of 152 SP-funded services for learning-disabled people.

Level C in the Quality Assessment Framework vs 2 (QAF2), based on provider self-assessments of Assessment and Support Planning; Security, Health and Safety; Safeguarding and Protection from Abuse: Fair Access, Diversity and Inclusion; and Client Involvement and Empowerment. Level A is 'Excellent'; Level B means that the service can evidence good practice; Level C means that the service meets, and is able to evidence, the required minimum standard but there is scope for improvement. See: Supporting People (undated), Quality Assessment Framework Guidance, Northern Ireland Housing Executive, Section 2.2 and 3.1.

The data provided by NIHE suggest that there were both performance and risk issues associated with the providers of a significant number of SP-funded services for resettled learning-disabled people.

2.5.2 Are the Bamford requirements being met or do hospital-like conditions still remain?

Table 18 suggests shows that a significant number (48%) of List 1 SP-funded learning disability services contained more than 5 bed-spaces. 32% of all services contained eleven or more bed spaces. Although some of these services may have been based on patterns of dispersed accommodation, the figures are strongly suggestive that there were a number of examples of what Bamford called 'congregate settings' in these services.

The analysis of 29 List 2 services that were known to provide for resettled people suggests that, in that list, there were very few services that represented congregate living. Even in these services, however, there were a number where quite large numbers of self-contained rooms or flats were contained within a single property. This was not ideal from a 'best practice' perspective.

Participants in the interviews were asked whether all the community-based supported accommodation or care services that had been commissioned for learning-disabled people leaving long stay hospitals since 2007 met the recommendations on size, arrangements and conditions recommended in the Bamford report. Two participants, both of whom had a management role in the delivery of care and support services working for voluntary sector organisations said that all of their schemes followed the Bamford requirements on size, arrangements and conditions. Six participants said that not all the schemes they were associated with *did* conform to the Bamford requirements. Four of these comments are recorded below.

"The criterion that there should be no more than 5 people living together in one scheme is not met; nor is the requirement that there should not be more than three houses in one service. Bamford has influenced thinking, so more schemes are now in Bamford format but not the nursing home and residential care schemes from the past and some schemes that are still being developed. These are not covered by the same aspirations. Schemes with a smaller number of people at higher cost are at one end of the spectrum, but some residential care and nursing home schemes have not changed since Bamford."

"Bamford recommendations are followed in terms of what we see in plans, but not always when built. There was a recent example of an industrial kitchen built in a scheme with other institutionalised arrangements that was labelled as 'supported housing'. The specification for this scheme was too strongly influenced by health and social care practitioners ... Some heritage schemes are obsolete. Greater flexibility in the NIHE capital programme is needed to reconfigure schemes to bring them more into line with the Bamford principles."

"There are still some nursing homes and residential care homes that work on a fairly traditional model. There may also be converted residential care homes that have become Supporting People-funded environments that would not pass current HMO⁷⁴ and space standards. Some are still institutional in format, even though conditions have been improved in terms of en suite arrangements for example. These would not pass the current care home registration space standards. It will take time for these schemes to get up to standard. There are considerations of financial viability that work against modernisation. A service for 15 people is more economical and financially sustainable than a service for 3 to 5 people."

⁷⁴ HMO – Houses in Multiple Occupation.

"There is a significant number of former residential care homes converted into supported living where it would take a good understanding of the legislation to tell the difference from a registered care home. Some have been extensively remodelled and are qualitatively better but in others the improvements are marginal. And in some the accommodation would in any case not meet current standards for registered care. There are old residential homes, deregistered inappropriately; and new build supported housing services where RQIA does not have the remit to object to the physical standards but where it is clear that they would not meet the standards of a residential care home. But there are some very good schemes and those coming through the commissioning process are now much better."

The interviews with policymakers, commissioners and service providers suggested that there were still a significant number of services that were institutional in character; and there were instances where size criteria had not been fully met, and where ethos and delivery had not changed.

2.6 ATTITUDES TO RESETTLEMENT AND THE IMPACT ON THE RESETTLEMENT PROGRAMME

The research was intended to review the development of policy on resettlement and the way the resettlement programme has developed since the Bamford report. However, it has also uncovered wider issues that had an impact on the level and rate of resettlement and the resettlement process. These issues included attitudes towards learning-disabled people, their personal identity and rights, as well as the perceptions of the policy-makers, commissioners and providers who were responsible for delivering resettlement about the impact of resettlement on the learning-disabled people involved.

From the answers provided by interviewees, it is clear that changes in resettlement policy over the years had not always been accompanied by changes in the understanding of learning disability, or of the needs and rights of disabled people, whether by health and social care professionals or by the wider community. Almost all the people interviewed for the research commented on parental and family attitudes, community attitudes and the attitude of professional and nursing staff.

2.6.1 Parental and family attitudes

The interviews contained anecdotal evidence that conflicts sometimes arose between those charged with delivering the resettlement programme, and families who sometimes felt that a learning-disabled family member would be happier or better off in hospital⁷⁵. The Society of Parents and Friends of Muckamore ('Friends of Muckamore')⁷⁶ whilst fully supporting the resettlement of people who wanted to be resettled, noted concerns that those with the most complex care needs who received a high quality of care in Muckamore should not be resettled into the community where this was against the patients' and family wishes. Their concerns⁷⁷ ⁷⁸ included fears that:

Northern Ireland Audit Office (2009), op. cit., page 37, para 4.5; and page 38, para 4.8.

⁷⁶ The NI Audit Office (2009) *op. cit.*, page 27, footnote 29 noted that this group represents the views of those with family members in Muckamore – mostly Eastern and Northern Board residents, and that no major concerns had been raised at that phase by families in the Southern and Western Board areas and there were no formal family groups in these areas.

⁷⁷ Northern Ireland Audit Office (2009), *op. cit.*, page 38, para 4.7.

⁷⁸ Their concerns were also referenced in a NI Assembly debate, 9th February 2009. Carmel Hanna (SDLP) said: *Nevertheless, the Society of Parents and Friends of Muckamore Abbey informs us that a few individuals who have lived in Muckamore for up to 50 years would rather remain there* — it is their home. Some patients, and their families, do not wish to be pressurised into community care; they feel better cared for in their present setting.

- people moving out of hospital would not be accepted into the community and could be subjected to bullying and harassment;
- the level of care provided in Muckamore could not be replicated in the community;
 and
- that their family member's quality of life and access to recreational activities and day care facilities would diminish as a result of resettlement in the community.

They also had concerns about the potential higher cost of community care based packages and the longevity of funding packages in certain settings e.g. private nursing and residential homes.

In response to these concerns, the Health Minister gave a public assurance to families in 1995 that a member of their family living in hospital would only be resettled into the community if there was clear evidence of 'betterment'⁷⁹ for the patient, and provided that it was not against their wishes⁸⁰. This commitment was restated by successive Ministers and remained in place at the time of the research in 2014.

Interviewees suggested that, while this commitment had to be honoured, it had also been important to educate and persuade families about the benefits of resettlement. Some learning-disabled people who had lived in hospital on a long-term basis, and their families, saw positive changes in their friends' lives after resettlement and this helped to change attitudes to resettlement. In other cases, patients were said to have realised that there were very few people left in their ward, and this also influenced them to change their minds. It is clear that the attitudes of families — and indeed of learning-disabled people themselves — were a factor in determining the rate of resettlement and which individuals were resettled first.

2.6.2 Community attitudes

Interviewees said that there had been resistance from some communities to the resettlement of learning-disabled people in their neighbourhood. This took the form of campaigns to prevent the development of a scheme, and press campaigns that sought to denigrate the official policy on resettlement, both of which may have influenced opinion on local councils. There were said to have been instances where learning-disabled people who had been resettled were subjected to harassment by people in their local community. Trust managers said that they were working with local communities to obtain acceptance of the principles of integration, citizenship, and a sense of being part of that community so that the community became protective of people living in the area. This policy was said to be meeting with some success. Interviewees for the research suggest that there was less resistance to resettlement in 2014 than in earlier years.

2.6.3 The attitudes of professional healthcare staff

Resistance to the concept of resettlement for learning-disabled people is also said to have come from all levels of the health and social care sector. Consultants working in hospitals as well as some front-line staff were said to have been concerned about the ability of learning-disabled people to live outside a protective hospital environment. Interviewees suggested that these critical responses to resettlement were caused partly by out of date attitudes towards learning-disabled people, partly by a perceived loss of professional status, and partly

The term 'betterment' used here was also used in Equal Lives to indicate that if a person was resettled there would need to be an improvement in their circumstances outside hospital compared with their lives in hospital. This meant that resettlement of the individual was clinically appropriate, met the patient's needs, and had the potential to better the patient's life.

Northern Ireland Audit Office (2009), op. cit., page 2, para 3

by a fear that jobs would be lost if the resettlement of patients from the hospital they work in reduces the number of staff required. The research team was told by one interviewee that, in at least one Trust⁸¹, relatives of long stay patients who were employed as nursing and ancillary staff refused to co-operate with the resettlement programme. Hostility by staff towards resettlement caused delays in the completion of needs assessments and the discharge of patients.

Ministerial commitments were given to trade unions and staff that no job losses would be involved in the resettlement programme. A work-force review was carried out in 2009 – 2011, and programmes of retraining and re-orientation were put in place for hospital staff moving into residential care⁸²; but the problem was said to have remained as an issue in at least one Trust.

Further problems arose from the fact that Royal College of Nursing-qualified staff were reluctant to work outside a hospital setting if a transfer into social care meant that they would lose their RCN professional accreditation⁸³. One result of this was that nursing staff that were redeployed from hospital continued 'traditional' nursing practices in residential care and supported living environments. NIHE's Supporting People team, the RQIA and senior Trust managers were still working to resolve these issues at the time of the research.

Professional attitudes towards learning-disabled people were said to have been a barrier to effective resettlement even after a patient had left hospital. The Housing Executive and the RQIA both found that while a service might be commissioned as 'residential care' or 'supported housing' with specific service requirements, the service being delivered carried all the hall-marks of hospital-like institutional care because staff involved in planning and service provision had been influenced by traditional professional practices. Resolving this issue was identified by Bamford as being critical to the success of the *Equal Lives* approach.

"If institutionalised discrimination against people with a learning disability is evident in practice there remains an onus on Government and through them service commissioners and providers to address human rights and equality issues. It is our belief that in order to effectively address these issues services should be guided in future by the values on which the Equal Lives review is based: social inclusion, citizenship, working together and provision of individual support. In addition, efforts must be harnessed to change the attitudes and mind sets that support such discrimination and inequality ... legislative implementation needs to be combined with: education of service staff who may discriminate against people with a learning disability ... providing more integrated housing, education and day opportunities ... learning disability awareness training ... use of local and mass media ... involving people with a learning disability in the design, delivery and management of services."

⁸¹ Interview with a senior Trust manager

⁸² Interviews with health and social care policy-makers and commissioners undertaken as part of this research.

⁸³ Interviews with health and social care policy-makers and commissioners undertaken as part of this research.

⁸⁴ Interviews with health and social care policy-makers and commissioners undertaken as part of this research.

⁸⁵ These are ongoing issues which are discussed in Working Paper 5: Interviews with policymakers, commissioners and practitioners.

⁸⁶ Bamford, (2005), *op. cit.*, pages 30 - 31

2.6.4 The personal identity and rights of learning-disabled people moving out of hospital

Comments from external stakeholders referred to a number of issues relating to personal identity, documentation and access to personal finances for learning-disabled people living in long stay hospitals and those who had been resettled into the community. It appears that when learning-disabled people were admitted to hospital, their personal monies were lodged by the hospitals in population-wide funds rather than in individualised accounts. As a consequence, it was not always possible to account for the money belonging to individuals at the time they were discharged into the community, and an individual's money was not always transferred into a personal account.

Some factors relating to this issue centred on perceived or actual 'lack of capacity'⁸⁷ on the part of the person being resettled, lack of personal identification paperwork, and sometimes action by individual members of staff or staff teams who were *de facto* in charge of patient funds without any locus for doing so⁸⁸ and who had a vested interest in the system. In a number of cases the individual being resettled had no National Insurance number or other relevant documentation such as a Passport. This appeared to make the transfer of personal monies to personal accounts difficult. In response, one Trust has procured Birth Certificates and Passports for all those who have been resettled since 1 April 2012⁸⁹.

There are a number of issues here, albeit these were not part of this research. Firstly, there were questions around the retention (for long periods of time – in some cases decades) of individuals' funds, which the individual could not access or withdraw. Secondly, and of more relevance to this research, there were barriers to the withdrawal of this money by the individual being resettled at the time of resettlement or thereafter which could have had an impact on their ability to develop a degree of independent life in their local community. On occasions, it is alleged that the allocation of funds to individual accounts was actively obstructed by hospital staff.

Guidance was provided to HSC Trust staff about the transfer of patient's monies during and once resettlement was achieved ⁹⁰ for those individuals who were deemed to be incapable of managing their own financial affairs. For Belfast HSC Trust this noted that if the patient is resettled on a permanent basis, the 'Appointeeship' should be relinquished by Muckamore Hospital and transferred to the Trust with the responsibility for the patient, so that all the patient's savings and future benefits would be managed by the Trust.

At present there is no specific and separate mental capacity legislation in Northern Ireland - the Mental Health (1996) Order is the current legislation. The Bamford Review (Report – *A Comprehensive Legislative Framework*, 2007) recommended the development of a single legislative framework for the reform of mental health legislation and for the introduction of mental capacity legislation in Northern Ireland. The consultation period on a new Mental Capacity Bill has just ended (2nd September 2014). This would fuse mental health and mental capacity law into a single piece of legislation, with a view to introduction in the NI Assembly by January 2015 and enactment within the current mandate of the NI Assembly (by end of March 2016).

⁸⁸ Interview with a senior Trust manager

⁸⁹ Interview with a senior Trust manager

Belfast Health & Social Care Trust, Resettlement of Patients from Muckamore: Interim Guidance for Staff (in conjunction and agreement with Finance Staff) - Patients Community Resettlement (https://www.whatdotheyknow.com/request/165614/response/421924/attach/3/Muckamore%20Resttlement%20Patients%20Guidance%20for%20Staff%20May%202012.doc)

2.7 HAS THE LEARNING DISABILITY RESETTLEMENT PROGRAMME IN NORTHERN IRELAND BEEN A SUCCESS?

At the end of the interview, all participants were asked to say whether they thought that the resettlement programme had resulted in betterment in the lives of resettled people, whether it had been a success from a public policy standpoint, and whether it represented good value for money. These questions resulted in the most cautious answers from the interview participants.

2.7.1 Professional perceptions of how Betterment in the lives of learning-disabled people who have moved out of hospital is being assessed and whether participants believe it is being achieved

Interview participants were asked how 'betterment' in the lives of resettled people was being assessed. Seven respondents answered the question; six respondents said that they did not know how betterment is being assessed.

Comments on the way betterment is being assessed

"This was a big problem at the beginning. Our response was the twin approach – quality of life measures before and after they leave hospital, allied to the role of the independent advocate in helping them to express their feelings. Independent advocates have been commissioned by one Trust. Each trust has a separate contract."

"The trust has funding for additional advocacy services. These have been commissioned through a charity which is doing follow up quality of life indicators. Advocates will engage with people to assess quality of life prior to discharge, then after 3, 6, 9 and 12 months. This should have started two years ago but there was a lack of funding."

"We are not assessing it very well. Trusts have not been good at outcome measures."

"There is no formal process. We rely on the services and their managers to ensure that people are 'content'. There is very little info about people who are not happy, but when that happens steps are taken to look into it and if necessary find solutions."

"Not very robustly – through quality of life indicators derived from a number of different sources. SP is looking at outcomes and how developed from a housing perspective using the Bromford 91 , Reach 92 and Driving Up Quality Code 93 systems."

"That is difficult. In the past we did not make the connections between betterment, quality of life etc. But there has been very little investment in advocacy because the Board has not commissioned it. Other trusts have more. We should target it at people who lack capacity and those who have just left hospital."

Bromford Housing Group developed a system for monitoring the progress of tenants and residents receiving support and evaluating the success of the support provided to help people develop their ability to live independently following introduction of the Supporting People programme in 2003. See http://www.emeraldinsight.com/doi/abs/10.1108/14608790200200030

Warren S, Wood A and Maguire S (2013) *Reach: Support for Living an Ordinary Life – It's My Life*, Paradigm UK, Housing and Support Alliance and Pavilion Publishing. The Reach standards provide guidance for support providers and commissioners on how to meet their responsibilities to the people they support and the relevant regulatory bodies.

⁹³ Driving Up Quality Alliance (2013) *Driving Up Quality Code: Self Assessment Guide – A guide to help organisations work out what they need to get better at*, a response to the abuse of people living in the Winterbourne View residential care home.

From the responses set out above, there is evidence that:

- progress has been slow in establishing mechanisms for assessing betterment in peoples' lives following resettlement;
- each Trust is developing its own approach;
- no overall assessment of this critically important aspect of the learning disability resettlement programme had taken place at the time the research was carried out; but
- good practice developed by commissioners and providers in England is now being considered for adoption by the NI Supporting People team and others.

Interview participants were also asked whether they thought that the resettlement programme had been successful for resettled learning-disabled people and whether betterment in their lives has been achieved in ways advocated by Bamford. Ten respondents said that they believed the programme had been a success; three said that they did not know.

Selected comments from those who believed the programme has been a success

"We have been starting from a low base-line in hospital-based services. Muckamore was an old Victorian establishment, with wards, in a remote location, so betterment is anything that is better than that. The bottom line is a better environment with their own bedroom and bathroom, consideration given to peoples' dignity, choice, human rights (dependent on capacity), integration into communities." ⁹⁴

"In many instances, yes, the programme has been successful. The majority of people we see have more control over their lives and are receiving services that are more based on their needs. We are now seeing people living successfully in supported housing schemes with higher levels of need than some of those living in residential care."

"From what I have seen there are a number of success stories but this is not an unqualified 'Yes'. There are some exceptional projects. Some projects would need to be revisited and some do not pass the test."

"Many people who have been resettled have lived in hospital for 20 or 30 years. Many of them were not aware of what alternative options existed. The process in terms of the work of multi-disciplinary teams has given cognisance to the core principles of the programme – choice and options taken at the person's pace - but there is a group of hospital residents who should have been out years ago who wanted out. We have let them down."

"Generally, yes. There have been some failures and difficulties, but once resettled after a couple of years most people feel they have benefitted. A small number of families still feel they would have been better off in hospital but that is also changing."

<u>Selected comments from those who say they do not know whether the programme has been</u> a success

"It is hard for me to say as I don't review every individual. My sense is that the majority of people have better lives as a consequence of being resettled.

Authors' comment: This was not the only interviewee who implied that Human Rights were negotiable for people who lack capacity, although other interviewees were very committed to the principle of promoting Human Rights regardless of the level and nature of the disability.

"... I cannot say whether resettlement has been a success for every individual. This is not a one-off process. People don't just get resettled. The ongoing needs of each individual have to be considered. Their needs and requirements also change, so we need the capacity to make further changes."

"I have seen some services that have been developed by housing associations that have been a success, maybe for people with moderate learning disabilities. Overall, I don't know enough to say."

Overall, there was a perception that:

- the resettlement programme had been a success from the perspective of resettled people;
- the programme had taken too long to complete with adverse effects on the people still living in hospital as long-stay in-patients;
- some services do not meet modern requirements and do not conform to the Bamford principles.

However, these are personal views. In the absence of a coherent and coordinated programme of follow-up and evaluation, it is hard to see how those responsible for the resettlement programme can have a clear idea of the impact on resettled people if the quality of services is not being consistently evaluated, and if one of the key aims – betterment – is not being assessed.

2.7.2 The impact of the resettlement programme in public policy terms

Six interviewees said that the programme had been a success in public policy terms, although reservations were expressed. Of the remainder: two respondents said that they would prefer not to comment; two respondents said they did not know enough to comment; three made non-committal statements.

Selected comments on the effectiveness of resettlement in terms of public policy

"I like to think it has. It would be fairly unusual in NI where two Departments that have different remits have managed over a period of six years to deliver a programme on a consistent long term basis, and a shared set of priorities. Hopefully it will be renewed."

"Yes, because it is the right thing to do. The Minister has driven it in spite of lobbying from the other direction, shifting from disabled people being hidden to them being integrated and having rights."

"I don't know. There is still bias – some politicians do not grasp that this is policy and the way forward. Their attitude is that people should not be driven out of the hospital. The Antrim Press have run scurrilous articles about people being driven out, dying afterwards and committing suicide. So the policy is there but is not bought into by everybody."

"The resettlement programme has had a high profile in terms of moving people from a hospital into a house; but we need the rest of society to commit to improving the life experiences for people with learning disabilities, allowing their total involvement in the community. 'Destined', a voluntary organisation, drew up a charter and got shops and individuals to sign up in terms of jobs, participation in community life etc for learning-disabled people. We need the rest of Northern Ireland to drive the same agenda otherwise it falls back on health."

"There are still detailed issues that have to be resolved. People should no longer live in hospital just because that is where they can be accommodated rather than because they need assessment and treatment."

There were mixed views on whether the programme was a success in terms of public policy. It was seen as a success in terms of inter-Departmental cooperation. Ministerial support for the programme was seen as significant in driving it forward. But there were reservations about whether a programme of this kind that was 'driven from the top' and which did not carry public opinion could be termed a success even if it was 'the right thing to do'.

2.7.3 Value for money

At the end of the interview, participants were asked whether they thought that the learning disability resettlement programme represented good value for money. Eight participants said that the programme represented good value for money, although some said that value for money could have been better. One participant said that the programme had not been value for money. Four participants either said that they did not know or preferred to make no comment.

Selected comments on value for money in the resettlement programme

"Not in cash terms, but like all major policies that change the landscape, it was perceived as the right thing to do, and that is still the case. In ten years time, if peoples' lives are better, then it will be viewed as a success."

"So far as the money being spent on it is concerned – it is not a cheaper option than keeping people in hospital. Housing and supporting people in the community is more expensive. In the wider context and looking at the social and economic benefits that have been achieved, yes it is value for money – and of course the difference it makes to people's lives is very significant."

"That is a good question. The charge we usually face is that we are doing this on the cheap to save money. However, the reality is that resettlement is costing more than it used to cost to keep people in hospital. But it is good value for money if it adds to the quality of peoples' lives and upholds the principles of equality and inclusion."

"Yes, but it should have provided better value for money if the market had been broadened through a tendering process in advance. Also, with hindsight, staff skills should have been enhanced to give the programme impetus."

"No, because it is always going to be more expensive than keeping someone in a large hospital. But in terms of peoples' lives it has been very cost effective. I would want this for my relative. It is the right thing to do irrespective of the cost. But this last year, the costs will be very high as people with challenging issues are resettled."

"I do not have any evidence for or against. I do have concerns that the intended benefits have not been clearly articulated, so how do we evaluate the programme or 'betterment'."

Interviewees said that purely in cost terms resettlement was more expensive than keeping people in hospital. When the social and economic benefits of the programme were taken into account, however, then most thought that it did represent value for money. Several participants said that value for money could have been better if fully-costed model services had been developed as exemplars, and if a market for resettlement services had been developed through open procurement and competitive tendering.

PART 3: RESETTLEMENT IN GREAT BRITAIN AND THE REPUBLIC OF IRELAND

3.1 CHANGING APPROACHES TO THE PROVISION OF SERVICES FOR LEARNING-DISABLED PEOPLE IN GREAT BRITAIN

This section of the report reviews changing approaches to policy and the provision of services for learning-disabled people in GB and the RoI since the 1990s, as a basis for comparisons with and lessons for the resettlement process in Northern Ireland. Drawing on previous research by the Housing and Support Alliance⁹⁵, it also identifies the variety of different models of housing, care and support that have been adopted in England compared with the models that were found by this research in Northern Ireland. Appendix 4 provides more information about the English models of provision.

3.1.1 Policy on learning disability in Great Britain

In 1974 there were 10,496 places provided by the National Health Service in homes and hostels in the community ⁹⁶ across the UK, but there were still 55,150 beds in hospitals for the 'mentally handicapped'. The UK Government White Paper, *Better Services for the Mentally Handicapped* ⁹⁷ in 1971 advocated a 50% reduction in long stay hospital placements by 1991 through increasing the provision of local authority residential care places. However, progress in resettling people from hospitals into the community was slow in GB, as it was in NI.

By the 1980s it had become widely accepted that it was inhumane to keep learning-disabled people in hospitals for life. The seminal report *An Ordinary Life* (Kings Fund 1980)⁹⁸ promoted the concept that people with learning disabilities should live in ordinary houses, in ordinary streets and be part of ordinary communities. The *All Wales Mental Handicap Strategy*⁹⁹ (Welsh Office, 1983) advocated closure of long stay hospitals in ways that would enable people with learning disabilities to enjoy the full range of life opportunities and choices, have positive identities and roles in their families and communities, exercise choice and develop independence, self respect and self fulfilment.

Changing perceptions of learning disability began to place greater emphasis on the person's human rights, and the social barriers that exclude learning-disabled people from equal and full participation in community life. The concept of 'normalisation' was promoted as a way of changing societal attitudes.

"The reality that not all people are positively valued in their society makes social role valorisation so important ... It can help not only to prevent bad things from happening to socially vulnerable or devalued people, but can also increase the likelihood that they will experience the good things in life. Unfortunately, the good things in life are usually not

⁹⁵ The Housing and Support Alliance is a national charity and membership organisation working with people with learning disabilities, families, advocacy organisations, housing and support providers and commissioners.

 $^{^{96}}$ Hansard, 6 July 1976, (quoted in <u>Psychological Medicine</u> 1977, 7, 561 – 563)

⁹⁷ Department of Health and Social Security. (1971). Better Services for the Mentally Handicapped London: DHSS

⁹⁸ Kings Fund. (1980). An Ordinary Life: Comprehensive locally based residential services for mentally handicapped people, London: Kings Fund.

⁹⁹ Welsh Office (1983), All Wales Mental Handicap Strategy

Wolfensberger, W. (1992). A brief introduction to Social Role Valorization as a high-order concept for structuring human services. (2nd (rev.) ed.). Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agentry (Syracuse University).

accorded to people who are devalued in society. For them, many or most good things are beyond reach, denied, withheld, or at least harder to attain. Instead, what might be called 'the bad things in life' are imposed upon them, such as:

- 1. being perceived and interpreted as "deviant" due to their negatively-valued differentness. The latter could consist of physical or functional impairments, low competence, a particular ethnic identity, certain behaviours or associations, skin color, and many others;
- 2. being rejected by community, society, and even family and services;
- 3. being cast into negative social roles, some of which can be severely negative, such as 'subhuman', 'a menace', and 'a burden on society';
- 4. being put and kept at a social or physical distance, the latter most commonly by segregation;
- 5. having negative images (including language) attached to them;
- 6. being the object of abuse, violence and brutalization.

"This is why having at least some valued social roles is so important. In fact, a person who fills valued social roles is likely to be treated much better than people who have the same devalued characteristics, but who do not have equally valued social roles. This is because when a person holds valued social roles, attributes of theirs that might otherwise be viewed negatively are much more apt to be put up with, or overlooked, or dismissed as relatively unimportant." ¹⁰¹

Thinking also began to change about the nature of services for learning-disabled people, with a shift away from the 'medical model' of service provision which emphasised 'treatment', to a 'social model' where the focus became less about fixing the disability more about removing societal barriers so that disabled people could lead equal lives.

Resettlement outside hospital became the dominant policy throughout the UK from 1990 onwards. The NHS and Community Care Act (DHSS, 1990) was a watershed. The Act had a significant impact on the closure of long stay hospitals with a new focus on people with learning disabilities living in well-supported domestic settings that provided flexible care and that were responsive to user and carer needs and preferences. This shift towards a needs-based approach to planning and a mixed economy of services created a greater drive towards community based services. Long stay hospital closure activity increased as a result of the Act.

Despite the focus of the 1990 Community Care Act being on ordinary homes with support however, the majority of people moving-on from long stay hospitals were placed in residential care or group homes. In this period there was a reduction in local authority-run residential homes ¹⁰³ and an increase in residential care provision from the private and voluntary sectors. Whilst it was reported that many learning-disabled people moving out of institutions were experiencing a better quality of life, there were also concerns that too

The theory is well summarised using accessible language in: Osburn, J. (1998), An Overview of Social Role Valorization Theory, in The theory is well summarised using accessible language in: Osburn, J. (1998), An Overview of Social Role Valorization Theory, in The theory is well summarised using accessible language in: Osburn, J. (1998), An Overview of Social Role Valorization Theory, in The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux, 3(1), 7-12.

The medical model of disability sees disability purely as a problem of the individual. To put it simply, a disabled person is seen as faulty and in need of treatment through clinical intervention. As a result, disabled people are by definition dependent on others to decide on appropriate treatment and care, and how they should live their lives. The social model recognises that disabled people face disadvantage because their needs are not fully considered in the way that public policy is developed; because of the barriers that are created by an inaccessible physical and institutional environment; and because of direct and indirect discrimination.

Hatton, E. E. (2008). *People with Learning Disabilities in England*, Centre for Disability Research, Lancaster University

many people were living in large scale (i.e. 'congregate') settings that were still institutional in their approach.

A study by Emerson *et al* at Lancaster University ¹⁰⁴ concluded that quality of life for learning-disabled people was enhanced in smaller residential settings and that quality of life outcomes were poor in larger congregate type residential care. The type of services that had been developed as part of the long stay hospital closure programmes in England - large residential homes, hostels and NHS campuses - were found to be associated with poorer outcomes than smaller, more homely environments. The study also found that the Welsh and Scottish long stay hospital closure programmes had moved larger numbers of people directly into smaller, homely settings in comparison with the English programme.

In England, Scotland and Wales, strategies were developed that reflected these and similar research findings, and which focussed on independence, equality, rights, choice and control. In England, Valuing People: A new strategy for the 21st Century (Department of Health, 2001); In Scotland, The Same as You, A Review of Services for People with Learning Disabilities (Scottish Executive, 2000); and in Wales Fulfilling Lives (Learning Disability Advisory Group 2001) all strengthened the messages that people with learning disabilities needed real choice in where they lived; and that residential care should not be a default option. Valuing People explicitly stated that, with the right support, people with learning disabilities could live in ordinary housing regardless of the level of their disability.

This body of work had a significant impact on the development of public policy and the attitudes of those caring for people with learning disabilities. It influenced the thinking of the Bamford Review Group ¹⁰⁵. Caring moved away from intervention and 'looking after' the disabled person to a more enabling role that encouraged self-help and independence. It was recognised that life in a hospital setting deprived learning-disabled people of the opportunity to live in an ordinary house and to take part in activities in their local community. The personal identity and rights of people with learning disabilities within a long stay hospital setting were clearly not the priority. There was a new emphasis in policy on the resettlement of people from hospitals into the community where they could live a more normal life.

Despite these stronger messages, the shift away from residential care for people with learning disabilities only began to happen on any scale with the introduction of the *Supporting People Programme* in 2003, when funding incentives were made available to develop supported housing and supported independent living. Between 2003 and 2009 a total of 31,238 people with learning disabilities in England received a package of housing with support funded by Supporting People¹⁰⁶.

Even under the Supporting People programme, however, there were widely held assumptions that supported housing and supported living arrangements were only suitable for people with mild to moderate learning disabilities. Thus services developed under Supporting People were mainly targeted at these groups the Stay hospitals closed, it was people with profound and multiple learning disabilities and challenging behaviour that remained as the last people to move out. Because of the gap in local services for this group and the subsequent NHS Campus Closure Programme, the private sector filled these gaps.

Emerson E et al (1999) Quality and costs of residential supports for people with learning disabilities, Lancaster University

¹⁰⁵ Bamford (2005) *op. cit.*, page 16, para 3.6

Department for Communities and Local Government, 2009

¹⁰⁷ There was a similar comment from one of the people interviewed in Northern Ireland.

¹⁰⁸ Joseph Rowntree Foundation (2007), The impact of the supporting people programme on adults with learning disabilities. JRF: York

As a result there was actually an increase in in-patient and specialist healthcare provision for people with the most complex care needs. Between 2006 and 2010, while there was a 34% decrease in the number of inpatients in NHS learning disability provider services, there was a 15% rise in the number of inpatients living in independent sector learning disability provider services ¹⁰⁹. Essentially what was being developed was a new form of long stay hospital that meant people with learning disabilities were being placed away from their families and communities in the same way they had been in long stay hospitals in previous decades.

The *United Nations Convention on the Rights of Persons with Disabilities* (United Nations, 2006)¹¹⁰, to which the UK government is a signatory, sets international standards for the rights of disabled people to live in the community. *Improving the Life Chances of Disabled People* (Cabinet Office 2006) set out commitments across government to meet the policy aims of independent living for people with a disability. *Putting People First* (Centre for Policy on Ageing, 2008) was a multi-agency commitment to self directed support and personalisation that had resulted from a successful piloting of individual budgets for people with learning disabilities. *Valuing People Now* (DoH 2009) was a refreshed strategy for learning disability services that was linked to a 3 year delivery programme that included a NHS campus closure programme. *Valuing People Now* was supported by Public Service Agreement (PSA) 16, which measured the number of adults with a learning disability known to social services who were moving into settled accommodation outside NHS campuses or registered care homes.

Following the international banking crisis of 2008/2009, the UK Government decided to cut public spending. Funding for the Supporting People programme, which had been ring-fenced since 2003, was incorporated into the local authority Area Based Grants system. The ring fence was removed in the interests of bringing about: "... greater flexibility for local areas in delivering their own priorities for housing-related support and wider welfare and other services"¹¹¹.

After the 2010 general election, PSA 16 became obsolete. The Department of Health's Valuing People Implementation Team and the Department for Communities and Local Government's Supporting People Monitoring Team were dismantled. The Localism Act 2011 shifted emphasis to local authority-led decision making about planning, public services and housing policy. Welfare Reform has further restricted the availability of funding for housing and the income of people with mild to moderate learning disabilities. Taken together, all these factors have meant that those people with mild to moderate learning disabilities who have previously had housing-related support services paid for by Supporting People Grant are now being assessed under increasingly stringent adult social care criteria and in some areas are having services reduced or taken away. There is currently a loss of confidence within the supported housing sector which has tended to postpone the development of new services with little increase in the number of people with learning disabilities living independently¹¹².

¹⁰⁹ Improving Health and Lives Learning Disabilities Observatory (2011), People with Learning Disabilities in England, IHAL.

The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) came into force in May 2008. Under Article 19, States that are party to the Convention including the UK: "... recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in a normal life."

House of Commons Communities and Local Government Committee Session 1998 – 1999 (October 2009), Volume 1, paragraph 188

¹¹² Mencap (December 2012), Housing for People with a Learning Disability, London: Mencap

A view has developed among some commissioners and providers that supported living has become a service type with an associated funding pot reflecting institutional bias in the way vulnerable people should live rather than an ethos influencing the ways in which people can be supported to have real choice and control over their lives.

"The reality for many people accessing support from organisations is that there is often a worrying lack of control over who supports them, when the support is received and how this attends to what really matters to them as individuals. The care and support industry has placed so much importance on meeting minimum standards and professionalising that the most important aspects of care and support, such as human connection and listening to what people want and then doing it, have been lost." 113

Approaches such as the Reach standards are intended to ensure that there are clear aims and standards for supported living that promote self-determination, inclusion, personalised support and an 'ordinary life'. 114

With 30 years of policy that has directed and supported long stay hospital closure, all NHS long-stay hospitals finally closed in Wales in 2006 and in England in 2009. In Scotland, there were approximately 200 people still living in long-stay hospitals in 2014.

3.1.2 Republic of Ireland policy on learning disability

The Republic of Ireland (RoI) government first recommended an end to the admission of people with learning disabilities into psychiatric hospitals in 1984¹¹⁵. However, many people with learning disabilities continued to live in inappropriate psychiatric settings until the 1990s when a programme for moving the remaining people from these settings began¹¹⁶. In 1997 a strategy to move people with learning disabilities out of institutions was outlined in the report, *Services to Persons with a Mental Handicap/Intellectual Disability: Assessment of Need 1997-2001*¹¹⁷. This was followed by a *National Disability Strategy* launched in 2004 with a policy of enabling disabled people to access mainstream services. *The Congregate Settings Report*¹¹⁸ found that more than 4,000 people within the RoI lived in congregate settings (defined as institutional settings with more than 10 residents – a greater number than was adopted in Bamford's definition), of which 93% had a learning disability and 7% had a physical disability.

F. Kelly (2012) explored changes in provision in the period 1999 - 2009 for nearly 8,000 adults living in either congregate or community-based accommodation ¹¹⁹. Kelly found that, during this period, there was a marked rise in the numbers of people with learning disabilities living in community group homes in the Republic and that, by 2009, just under 50% of people with learning disabilities lived in community settings. The author concluded that:

" ... although there was a reduction in the number of places in congregated options over the decade, this was not uniform in that increased numbers of persons were living in new forms of congregated provision designated as specialist units."

¹¹³ Warren S, Wood A and Maguire S (2013) op. cit., page 5

¹¹⁴ Warren S, Wood A and Maguire S (2013) op. cit., page 1

¹¹⁵ G. Holt et al (2000). BIOMED-MEROPE project: service provision for adults with intellectual disability: a European comparison. Journal of Intellectual Disability Research

¹¹⁶ Department of the Environment, 2011

¹¹⁷ Irish Department of Health, 1997

¹¹⁸ HSE (2011). Time to Move on from Congregate Settings, HSE

¹¹⁹ Kelly F (2012), Changes in the provision of residential care for adults with an intellectual disability: a national longitudinal study

Kelly also found that:

"... despite unprecedented increased investment in services in this period, on average only 70 new places were created per annum – a 1 per cent increase on total places." 120

Kelly concluded that institutional models were likely to persist unless there was sustained investment in new models of provision that could be achieved through a planned transfer of resources.

The National Housing Strategy for People with a Disability 2011-2016 reinforced the drive to move people out of institutions with specific aims to:

"... promote and mainstream equality of access for people with a disability to the full range of housing options available suited to individual and household need... all people with disabilities, including those residing in institutions, are entitled to undergo an assessment of housing need".

As was the case in England, Scotland, Wales and (on the evidence of this research, in some cases in Northern Ireland), the Republic of Ireland replaced institutions with structures that replicated the behaviour of institutions, even if they were smaller in scale. Whilst these services may have improved outcomes over long stay hospitals, they often segregated people from their communities and did not offer a 'normal' life that included friendships, relationships and a community life. In a paper from the National Disability Authority, it was noted that:

"Greater usage of natural supports can potentially provide benefits for people with disabilities, in terms of their greater independence and for the State, in terms of more cost effective services". 121

In the Republic of Ireland there were still 147 people that needed to move on from hospitals at the end of 2010.

3.1.3 Lessons for Northern Ireland

As part of this research, interviews were conducted with Dr Simon Duffy¹²² of the Centre for Welfare Reform, and Professor Chris Hatton¹²³ of Lancaster University. The interviews explored where de-institutionalisation has worked in England, Scotland and Wales, where it has been less successful, and what needs to be done to promote real independence for learning-disabled people. The purpose of each interview was to identify the lessons learned from the resettlement programme that might benefit the process in Northern Ireland.

¹²⁰ Kelly F (2012), op cit.,

¹²¹ National Disability Authority. (2011). A Review of Literature on Natural Community Supports. NDA

¹²² Dr Simon Duffy is Director of The Centre for Welfare Reform; Chair of the Housing & Support Alliance; a policy advisor to the Campaign for a Fair Society; and Honorary Senior Research Fellow at the University of Birmingham's Health Service Management Centre.

¹²³ Chris Hatton is Professor of Psychology, Health and Social Care at the Centre for Disability Research, University of Lancaster; Co-Director of Improving Health and Lives - the Public Health England Specialist Learning Disabilities Public Health Observatory; and Regional Co-Director of the NIHR Research Design Service North West.

Dr Simon Duffy

Dr Duffy said that the early years of hospital closure in England were fixated on creating large units in the community and a new type of institution, albeit a smaller institution than existed with NHS hospitals. Supported living¹²⁴ did not register as an option with policy makers at the time. First phase solutions to hospital closure were 'immature'. In his view, deinstitutionalisation programmes were led by commissioning, procurement and tendering processes that commoditised housing and care solutions, instead of working around individuals to create appropriate and sustainable solutions.

Scotland began a hospital closure programme later than England and benefitted from the experience gained south of the Border. The programme had more of a rights-based approach. People with learning disabilities were obtaining their own homes, jobs and personalised support. In Scotland, the hospital closure programme developed approaches like *Inclusion Glasgow*¹²⁵ where personalised solutions were developed for the people with the most complex needs.

Dr Duffy believes that the style of change when closing hospitals is important. He says that it is difficult to bring about change in structures, especially within bureaucratic systems or where there is no vision, leadership or trust. The processes of change in England were often based on a lack of trust in people with learning disabilities, families and the people employed to support them. Whereas, in Lanarkshire, he saw leaders that had a vision and were able to share that vision with the wider community and find talented people whom they trusted to set up new housing and support services. This led to services that were set up around individual needs, and which have not become outdated models as many of the services set up as a result of closing institutions in England.

Reflecting on lessons learned from being involved in the closure of long stay hospitals in England and Scotland, Dr Duffy offered the following advice:

"Firstly, stop segregating people. Don't go into the business of building group homes as the solution. Reconnect people to their families and communities and support people to have love and relationships in their lives.

"Second, don't go down the commissioning and procurement route. There are obvious opportunities to link hospital closure with self- directed support, attach the funding and support to individuals, and work with care providers to develop Individual Service Funds. Too much power higher up in the process slows everything down. You need mechanical processes to devolve power and let people get on with it."

Professor Chris Hatton

Professor Chris Hatton had wide experience of the long stay hospital closure programmes in Wales and England. He said that in Wales, finance was a major driver for hospital closure. There were poor quality buildings that would have needed a great deal of investment to refurbish, and there would be a significant capital receipt in selling off hospital sites. Thus the initial approach of the *All Wales Strategy* was to build up community services for people with learning disabilities moving on from hospital. However, as these new services quickly became filled with people already living in the community, there was a change of approach. A command and control structure for closing hospitals was instituted, with funding attached to the programme.

¹²⁴ There is no legal definition of supported living, but the term refers to models of housing and support that are built around an individual or a group of individuals and that are separate from housing and personal/domiciliary care functions.

http://inclusion-glasgow.org.uk/

In England, Professor Hatton believes that the hospital closure programme has not resulted in the closure of institutions, with many smaller types of institution still being provided particularly for those with more complex needs. He believes the main reasons for this are that there is a deeply held belief that people with learning disabilities still need safety and separation from the community and as a consequence services have not been developed to meet peoples' needs in their communities. He pointed out that research clearly shows that the more individualised the approach to housing and support, the better the outcomes for individuals are.

Studies consistently show that living in smaller groups has better outcomes than living in larger groups; that challenging behaviour is a function of living in institutional environments; that retaining contacts with people they know and like is related to better quality of life; and that being part of a community, having connections, experiencing belonging and love all relate to better quality of life outcomes.

Professor Hatton offered the following reflections in thinking about the continuation of closing institutions in Northern Ireland.

"Leave behind the belief that learning-disabled people need institutions and don't build specialised houses. More imagination is needed in what we can do to support people - we need to develop better ways to take small scale innovations and scale up and introduce models like Shared Lives¹²⁶ and the Keyring Community Support Network model¹²⁷ 128.

"There are advantages if the care market has not been over developed and professionalised. Use this advantage to work with providers and staff to develop more natural models of support.

"Make sure there are enough good people to lead the process - invest in leadership and vision. Work alongside people with learning disabilities, families and staff, sharing the planning and process of move on.

"Experience has been that most families oppose closure of institutions but also report better outcomes and satisfaction with move-on services. This is evidenced in the Norwegian study of family attitudes to long stay hospital closure Family attitudes to de-institutionalisation: changes during and after reform years in a Scandinavian country". 129

"Northern Ireland has greater command and control potential because of its government structure so this should be used to its advantage in closing institutions. Northern Ireland has the advantage of dealing with segregated communities and can bring this knowledge and experience to avoid the segregation of people with learning disabilities.

3.1.4 The most successful models of housing, care and support from the perspective of resettlement and integration into community life

In the past, the options for someone leaving a long stay hospital were limited to either a nursing home, a residential care home or a return home to live with the family. In England, a wide variety of models of accommodation have been developed that offer greater choice and more opportunities for independence. Some of these have support or care 'built-in' as part of the service; others have separated out accommodation from care and support.

http://www.sharedlivesplus.org.uk/

http://www.keyring.org/Home

¹²⁸ These and other approaches to providing housing with support for learning-disabled people are described in the next section of this report, Appendix 4 and in more detail in Working Paper 2 accompanying this research report.

Lundeby, J. T. (2006). Family attitudes to deinstitutionalisation: changes during and after reform years in a Scandinavian country. Journal of Intellectual and Developmental Disability, 115-119.

Table 25 below compares the models of housing care and support that have been adopted in England with the models that have been identified in the research undertaken to date in Northern Ireland.

Table 25: Models of housing, care and support adopted in England compared with the models identified in Northern Ireland

Models adopted in England	Was the model identified in Northern Ireland in this research Note			
Provision of separate housing, care and support services				
Supporting People-funded Floating Support Services	Yes			
Rented social housing	Yes – Supporting People-funded services may be provided in either social or private rented housing			
Private Sector Renting				
Specialist Buy to Let, New Build and Refurbishment Schemes	Not identified so far			
Home Ownership				
Various approaches to home ownership exist including: family purchase of a house for the disabled person to live in; Buy to Rent; Privately Financed Shared Ownership; Company Ownership; Inheritance; Discretionary Trusts	It is inevitable that one or more of these approaches to home ownership exists in NI, but it was not part of this research to identify forms of home ownership.			
Housing, Care and Support Together (Accommodation Based Services)				
Supporting People-funded accommodation-based services	Yes			
Unregistered adult placements (now known in England as 'Shared Lives')	Yes			
Unregistered shared group homes	Not identified so far			
Extra Care, Sheltered Housing and Core and Cluster	Yes			
Residential Care	Yes			
Intentional Communities	Not identified so far. There is a debate in England about whether this approach is the right one.			
Other forms of support				
Supported Lodgings	Not identified so far			
Support Tenants	Not identified so far			
Community Support Networks – Keyring	Not identified so far			

Note: The fact that a model of housing, care and support has not been identified in this research does not imply that there are no examples in Northern Ireland.

Appendix 4 gives an over-view of the models of housing, care and support that have been adopted in England. A more detailed version of this appendix is available as a separate working paper that is circulated with this report. 130

North Harbour Consulting (2014), Bamford Review: Resettlement of learning-disabled people from long-stay hospitals; Working paper 2: Models of housing and support used for learning-disabled people and others with specialised housing and support needs in England. The working paper describes each type of housing, care and support service; how the service is accessed by a learning-disabled person; the pros and cons of each service; and how the service is funded. We are grateful to the Housing and Support Alliance for allowing us to draw on previous work they have undertaken in this field.

One way the inherent problems of shared group housing or living in large institutions can be overcome has been for people to have the opportunity to live with a family, in supported lodgings or with another tenant who provides them with support. Accommodation with a family, where sharing family life is part of the arrangement, is referred to as Shared Lives (formerly Adult Placement).

Accommodation in the home of a landlord where family life is not shared is known as Supported Lodgings. Confusingly some Shared Lives families are also called Supported Lodgings providers. This usually means that they offer a lower level of support which is often housing related. Shared Lives families can offer a full range of support including personal care. Supported Lodgings providers do not offer personal care. A support tenant shares the home of someone who has a learning disability. People using both type of scheme have to be over 18 years of age. There is no upper age limit. The two types of scheme are funded differently and are subject to different levels of support and supervision.

Even where some of these models of housing, care and support are to be found in NI, there is a wider question about whether approaches to independent living other than conventional supported housing are being promoted as policy. Further enquiries will be made as part of Phase 2 of the research. As Appendix 4 and the associated working paper demonstrate, there can be many advantages in adopting these models of provision if promoting independence is the goal.

APPENDIX 1

CONSULTATIONS WITH POLICYMAKERS, COMMISSIONERS AND SERVICE PROVIDERS

Research methods

A list of potential participants was agreed between the research team and the Project Advisory Group, with additional suggestions from the Northern Ireland Housing Executive ('NIHE') Research and Supporting People Teams. Participants were drawn from a cross-section of people involved in resettlement policy, planning, commissioning and service delivery.

Thirteen participants were contacted in advance by email, invited to take part and briefed on the purpose of the interviews. A short paper accompanied the initial email explaining the aims and methods of the research, together with a list of the themes to be covered. This was followed up where necessary by telephone. All those invited agreed to participate.

A semi-structured interview schedule was drafted within the research team and agreed with the NIHE research unit AND THE Project Advisory Group which included representatives from NI Government Departments, the H&SC Board and Trusts, the Housing Executive and provider organisations. A copy of the interview schedule is contained in Appendix A. The schedule was used to structure the interviews and was divided into four sections:

- the participant's role in planning or delivering the learning disability resettlement programme;
- progress in the resettlement of learning-disabled people from hospital since 2007¹³¹, and their comments on the key issues affecting the rate of resettlement;
- questions about the provision of accommodation and support for resettled people who
 does what, standards and benefits, and how quality is being assessed;
- views about the aims of the resettlement policy and whether they are being achieved in terms of the betterment of people after resettlement, and from a residents', public policy and value for money perspective.

Each participant's response to the questions was typed verbatim on an interview schedule, and an edited copy of the interview notes was subsequently sent to each participant for their approval.

The interview schedule provided a framework for discussion and the generation of comparative data based on each interviewee's personal responses to a series of specific questions and issues. The same questions were asked regardless of the participant's role in the resettlement process. This qualitative approach provided a valuable range of insights into expert opinion on the resettlement programme, its strengths and weaknesses.

The results of these consultations have been used to illustrate and inform parts of this report, and anonymised quotes have been used where relevant. Readers should note that each comment represents an individual's perspective on an aspect of the learning disability resettlement programme based on their particular experience from which trends and extrapolations should not necessarily be drawn. The researchers have used the results of interviews alongside documentary and data evidence to arrive at informed conclusions

¹³¹ The date <u>Equal Lives</u> was published

The participants

Thirteen people were interviewed. Participants included senior managers from:

- the two Government Departments most closely involved in the learning disability resettlement programme - the Department of Health, Social Services and Public Safety (DHSSPS), and the Department for Social Development (DSD);
- the Health and Social Care Board (the Board);
- four of the five Health and Social Care Trusts (the Trust(s));
- the Regulation and Quality Improvement Authority (RQIA);
- two provider organisations a charity specialising in the provision of services to learningdisabled people and a specialist registered housing association; and
- the Northern Ireland Federation of Housing Associations (NIFHA).

A list of people interviewed and their roles in the resettlement programme is attached in Appendix B. Additional interviews with service managers who have responsibility for front-line housing and support services, and a workshop for policymakers and commissioners to review research findings and preliminary conclusions, will be carried out in Part 2 of the research¹³².

Each participant described their role in the resettlement programme. Two participants said that their role lay primarily in the field of policy, with some overlap into programme funding; two participants said that their primary role was in managing the delivery of front line housing and support services; and two participants said that they were not directly involved in the programme but had responsibilities for regulation in one case and for representing housing association and managing agent interests on the other. The remainder said that their role involved a combination of commissioning, programme management and in some cases oversight of in-house and external service delivery.

Respondents were asked to respond in a personal capacity rather than giving an official departmental or organisational view. They were informed that their personal views would be treated in confidence and reported anonymously. In most cases respondents did give a personal view, although a small number of responses to some questions appeared to be non-committal. In reporting the results of these interviews, the majority of responses have either been aggregated or anonymised to uphold the guarantee of confidentiality and anonymity that was given at the start of each interview. At the end of each interview, the notes were edited and a copy was sent to the interviewee for agreement.

¹³² The research was planned as a single project divided into two parts – contextual research giving background on the learning disability hospital resettlement programme, and interviews with 50 resettled people and their carers. After the research started the Northern Ireland Housing Executive and the research team were informed that the second part of the research involving interviews with resettled people would require approval from the five H&SC Trust Research Ethics Committees. As a consequence the Housing Executive has decided in agreement with North Harbour Consulting (the research contractor) that the research will be divided into two separate contracts, the second of which will be retendered. References to 'Part 2' of the research should therefore be understood to mean that the intention is to carry out a number of tasks to augment the information reported as Part 1 of the research, subject to a successful retender by the current research team and subject to contract.

Participants in the consultation interviews

Name	Role	Responsibility within the resettlement programme
Neil Magowan	Head of Learning Disability Policy, DHSSPS	Policy on learning disability and, to a lesser degree, facilitating funding bids.
Stephen Martin	Deputy Director, Housing Policy Delivery, DSD	Responsibility for policy and funding for (a) HA development programme and (b) SP programme.
Aidan Murray	Assistant Director, Mental Health and Learning Disability Services, H&SC Board	Chair of the LD community integration project team; representative from the project team on the community integration programme board co-chaired by Fionnuala McAndrew and Brian O'Kane; represent the Board on the SP Commissioning Body which reviews plans and proposals; executive responsibility for the entirety of the Resettlement Primary Target List programme; seeking required funding from DHSSPS based on the number of people in the PTL; then have a role in accountability for delivery including the reshaping of hospital services post-resettlement.
Linus McLaughlin	Performance Manager, Performance Management and Service Improvement Directorate, H &SC Board	To identify the number of patients in the PTL list remaining to be resettled and agreeing this with the Trusts; to agree the resettlement plans 2012 – 2015; to set up and manage the process for monitoring progress against those plans and targets; to report progress to the Community Integration Programme Board.
Brian O'Kane	Acting Assistant Director, Supporting People, NIHE	SP's role is to commission capital and revenue supported accommodation inc housing. We give the Assistant Director, Development Programme, NIHE, a supported housing capital programme.
Dermot Parsons	Deputy Director, RQIA	Regulation of care services that people receive in their own homes – the 'care' part of 'care and support'; governance assurance of the processes that Trusts follow in resettling people.
John Veitch	Co-Director for Learning and Children's Disability Services, Belfast Trust	As co-director for LD and children's' disability services, responsible for all community based services within the Trust area, and for the hospital residents from Belfast, plus management of Muckamore Abbey Hospital – a regional hospital for LD forensic services, and the primary hospital from Belfast, Northern and SE Trusts.
Alyson Dunn	Assistant Director, Learning Disabilities, Northern Trust	Senior manager responsible for delivery of the programme of care service delivery. That involves a combination of planning, commissioning and operationalising services; and covers community based services, day services, respite services, residential services, and domiciliary care.
Carole Veitch	Operations Manager, Adult Disability Services, South Eastern Trust	Manager driving the hospital resettlement agenda within the Trust with links to the regional group, community services, and with responsibility for identifying individuals for resettlement.
Noreen McComiskey	Assistant Director, Learning Disability Services, Southern Trust	To deliver learning disability resettlement and develop new services.
Rosaleen Harkin	Assistant Director, Learning Disability Services, Western Trust	Oversee the implementation of the DHSSPS targets for the PTL and DD hospital cohorts.

Exhibit 55

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Deirdre McGuile*	Service Manager, Triangle HA	To deliver effective services in line with organisational values and mission and to ensure that there is a high standard f care and support. Triangle is also the housing provider.
Dirk Halfenberg	Assistant Director, NIAMH	The role is to oversee the operational running of the schemes in Armagh, Antrim and Belfast where we have resettled several service users from hospital. All have a service manager.
Cameron Watt	Chief Executive, Northern Ireland Federation of Housing Associations (NIFHA)	NIFHA represents HAs in NI. They are major care and support providers, directly and in partnership with managing charities and Trusts. This is an increasingly complex and risky area for NIFHA members. Funding streams and the future of SP are all issues that are regularly discussed. I have been involved with the CRISP Committee and have made an input into consultations.

APPENDIX 2

SEMI-STRUCTURED INTERVIEW SCHEDULE

Name of Inter	viewee					
Position						
Organisation N	lame		Ту	pe of Organisatior	1	
Location of int	erview				•	
Date of Intervi	ew		Ti	me of Interview		
Interviewer co	mments		-		·	
1.0 I would like	e to ask you	ı first about your owr	role in delive	ering the resettlem	nent programme	
1.1 In general	terms, wha	t is your role?				
1.2 Would you	describe y	ourself as one of the	following? SI	HOW CARD		
Policymaker	Planner?	Commission	Funder?	Service	Α	None of
?		er?		Provider?	combination of these?	these
If 'a combinati	on' or 'non	e of these' please exp	alain:		or triese:	
		onsibilities for aspec		ttlomont programi	mo do vou bavo?)
1.5 Specifically	, what resp	onsibilities for aspec	ts of the rese	ttiernent programi	ne do you nave:	
2.0 Progress	in the rese	ettlement of people	with learning	disabilities since	the nublication	of Faual Lives -
_		ices for People with a	_		•	
First, I'd like t	o explore	your perceptions of	the progress	that was made in	resettling peop	ole with learning
disabilities fro	m long stay	y hospitals in the for	ur years imm	ediately following	the publication	of Equal Lives in
		n Ireland Audit Offi 19. Please say whethe				
2.1 The rate of 2009. SHOW (ent was <u>lower</u> , at abo	ut the <u>same i</u>	evel as, or <u>nigner</u> t	nan expected be	etween 2005 and
Lower		At the same leve	I	Higher	Do	n't know
Do you have a	ny commer	nts on the rate of rese	ettlement in t	hat period?		
2.2 Does your	response re	elate to the whole of	Northern Irel	and or a particular	geographical ar	ea/areas?
Whole of NI?				Particular area(s)		
If a particular a	area, say wl	hich				
		our perceptions of the				-
	_	y hospitals in the fi in 2009. Please say v	-			•
		nent has been <u>lower</u> ,				_
2009 and 2014			, at about the	e <u>same level</u> as, o	r <u>migner</u> than ex	pected between
Lower		At the same leve	l	Higher	Do	n't know
Do you have a	ny commer	nts on the rate of rese	ettlement in t	his more recent pe	eriod?	
2.4 Once agai area/areas?	n, does yo	our response relate t	to the whole	of Northern Irela	and or a particu	llar geographica
Whole of NI?				Particular area(s)		
If a particular a	area, say wl	hich				
		the influence that ear		owing factors has	had on the rate	of resettlement

	Very significan t	Significan t	Slightly significan t	Not at all significant	Don't know
The level of resources allocated to the programme as a whole?	:				
The targeting of resources to different aspects of the programme?					
The effectiveness of inter-department and inter-agency collaboration?					
The need for cultural change to overcome low expectations of the ability of people with learning disabilities to leave hospital and live in the community?	ı				
Prompt: Where do low expectations come from?	Resident s	Families	Commiss ioners	Provider organisatio ns	Front line staff
The availability of appropriate accommodation and support services in the right locations in the community?					
The availability of appropriate access to day care, educational provision, work and social activities for resettled people?					
The availability of community support services for family carers?	;				
The difficulty of finding appropriate accommodation placements for residents?					
The difficulty of assessing and/or ensuring that residents were 'resettlement ready'?	:				
The reluctance of residents and/or families for them to leave long stay hospital?					
Other factor(s)					
2.6 Please identify up to five factors that yearsettlement of people with learning disabilities					the rate of
	Very significant	Significan t	Slightly significan t	Not at all significan t	Don't know
The level of resources allocated to the programme as a whole?					
The targeting of resources to different aspects of the programme?					
The effectiveness of inter-department and inter-agency collaboration?					
The need for cultural change to overcome low expectations of the ability of people with learning disabilities to leave hospital and live in the community?					
The availability of appropriate accommodation and support services in the right location in the community?					
The availability of appropriate access to day					

care, educational provision activities for resettled people	•	I							
The availability of con services for family carers?	nmunity suppor	t							
The difficulty of find accommodation placements		:							
The difficulty of assessing that residents were 'resettle	_	3							
The reluctance of resident for them to leave long stay	-	5							
Other factor									
2.7 Please comment on why	you have chosen	your five m	ost signi	ficant fa	ctors?				
2.8 Are there any other fac resettlement?	tors that you thin	k helped to	promot	e resett	lement or v	vhich ac	ted as	s barri	iers to
Promoted resettlement:									
Barriers to resettlement:									
2.9 What do you think are bodies in progressing resett	The second secon	int current i	ssues fo	or policy	makers, co	mmissio	ning a	and de	elivery
2.10 On the assumption the been resettled, what are the challenging behaviours or Criminal Justice system)?	e main difficulties	in resettling	people	with mo	derate to se	evere lea	arning	disab	ilities,
3.0 Questions about accomm	modation and sup	port							
3.0 Questions about accommod like to ask you	-		settlem	ent acco	mmodation	and sup	port.		
	some questions al	out post-re				and sup	port.		
I would now like to ask you	some questions alw accommodation en any chan	oout post-re schemes ar	e comm			and sup	pport.	ce	2009?
I would now like to ask you and 3.1 Please describe how new 3.2 Have there been seen as a second sec	some questions alw accommodation en any chan	oout post-re schemes ar	e comm	issioned				ce	2009?
I would now like to ask you and 3.1 Please describe how new 3.2 Have there been (Yes, go to 3.3; No, go to 3.4)	some questions al w accommodation en any chan	oout post-re schemes ar	e comm the	issioned				ce	2009?
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes	some questions all w accommodation en any chan l) hat were they?	schemes ar ges in	the	issioned	sioning p	process	sin	ce	2009?
I would now like to ask you and 3.1 Please describe how new 3.2 Have there been (Yes, go to 3.3; No, go to 3.4) Yes 3.3 If you answered 'Yes', wo	some questions all w accommodation en any chan l) hat were they? tly being applied f	schemes ar ges in or new sche	the No	issioned commiss the comm	sioning p missioning p endations o	process?	sin		
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r	some questions all w accommodation en any chan l) hat were they? tly being applied f	schemes ar ges in or new sche	the No	issioned commiss the comm	sioning p missioning p endations o	process?	sin		
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar	some questions all w accommodation en any chan l) hat were they? tly being applied f recent and heritag mford Report on L	schemes ar ges in or new sche e - now foll D services?	No No mes in t	issioned commiss the comm	sioning p missioning p endations o	process?	sin		
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar Yes 3.6 If you answered 'No', in 3.7 Do some schemes still of the same of the s	some questions all w accommodation en any chan l) hat were they? tly being applied f recent and heritag mford Report on L what ways do the	schemes ar ges in or new sche e - now folk D services?	the No No mes in to Yes to 3	the commesses, No to	sioning p missioning p endations o o 3.4)	process? orocess? on size, a	sin	emen	ts and
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar Yes 3.6 If you answered 'No', in 3.7 Do some schemes still of the same of the s	some questions all w accommodation en any chan l) hat were they? tly being applied f recent and heritag mford Report on L what ways do the offer similar arran	schemes ar ges in or new sche e - now folk D services?	the No No mes in to Yes to 3	the commesses, No to	sioning p missioning p endations o o 3.4)	process? orocess? on size, a	sin	emen	ts and
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar Yes 3.6 If you answered 'No', in 3.7 Do some schemes still esetting? (If Yes, go to 3.7)	some questions all w accommodation en any chan l) hat were they? tly being applied f recent and heritag mford Report on L what ways do the offer similar arran l; if No, go to 3.6)	schemes ar ges in or new sche e - now folk D services? y differ gements ar	the No mes in tow the layes to 3 No No No	the comments the comments to t	sioning p missioning p endations o o 3.4)	process? orocess? on size, a	sin	emen	ts and
I would now like to ask you and 3.1 Please describe how new 3.2 Have there been (Yes, go to 3.3; No, go to 3.4) Yes 3.3 If you answered 'Yes', wo answered 'No', in answered 'No', in answered 'No', in answered 'Yes', wo answered 'Yes', wo answered 'No', in answered 'Yes', wo ans	some questions all w accommodation en any chan l) hat were they? tly being applied f recent and heritag mford Report on L what ways do the offer similar arran l; if No, go to 3.6) hen will these sch	oout post-re schemes ar ges in or new sche e - now folk D services? y differ gements ar emes be rec nodels of h	the No mes in to No d condi	the commissions to itions to	sioning pendations of 3.4)	process? on size, a	sin	emen	ts and
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar Yes 3.6 If you answered 'No', in 3.7 Do some schemes still esetting? (If Yes, go to 3.7 Yes 3.8 If you answered 'Yes', w 3.9 What have been the	some questions all waccommodation en any chan l) hat were they? tly being applied frecent and heritage mford Report on L what ways do the offer similar arran (; if No, go to 3.6) hen will these schemost successful ration into communication i	schemes ar ges in or new sche e - now folk D services? y differ gements ar emes be rec nodels of h	the No mes in tow the Yes to 3 No No No ommiss ousing,	the commissions to ioned?	sioning principles of support	orocess? on size, a	sind arrang	emen ay ho	ts and ospital
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar Yes 3.6 If you answered 'No', in 3.7 Do some schemes still esetting? (If Yes, go to 3.7 Yes 3.8 If you answered 'Yes', w 3.9 What have been the resettlement and full integral 3.10 Is there now an extended.	some questions all waccommodation en any chan l) hat were they? tly being applied frecent and heritage mford Report on L what ways do the offer similar arran (; if No, go to 3.6) hen will these schemost successful ration into communication i	schemes ar ges in or new sche e - now folk D services? y differ gements ar emes be rec nodels of h	the No mes in tow the Yes to 3 No No No ommiss ousing,	the commissions to ioned?	sioning principles of support	orocess? on size, a	sind arrang	emen ay ho	ts and ospital
I would now like to ask your 3.1 Please describe how new 3.2 Have there bee (Yes, go to 3.3; No, go to 3.4 Yes 3.3 If you answered 'Yes', w 3.4 What criteria are curren 3.5 Do all schemes – new, r conditions set out in the Bar Yes 3.6 If you answered 'No', in 3.7 Do some schemes still setting? (If Yes, go to 3.7 Yes 3.8 If you answered 'Yes', w 3.9 What have been the resettlement and full integral 3.10 Is there now an extend as a result of the resettlement.	some questions all waccommodation en any chan hat were they? tly being applied frecent and heritage mford Report on Lawhat ways do the offer similar arran (r, if No, go to 3.6) hen will these schemost successful ration into community and community are settlement processettlement processettlemen	schemes ar ges in or new sche e - now folk D services? y differ gements ar emes be recondels of hoity life? rent types of ess itself begress itself begress ar emes be recondels of hoity life?	the No mes in too the Yes to 3 No No No No No No No No No No	the commissioned commissioned commissioned?	sioning pendations of 3.4) those foun	orocess? on size, a	sinderrange	emen ay ho	ts and ospital cive of needs

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move combined with the most appropriate models of housing, care and support etc.

- 3.12 What do you see as the role of the Northern Ireland Housing Executive in planning and delivering appropriate accommodation required to support the resettlement programme?
- 3.13 What do you see as the role of the NIHE Supporting People section in planning and delivering appropriate housing-related support required to support the resettlement programme?
- 3.14 What do you see as the role of Health and Social Care Trusts in supporting and overseeing the delivery of housing and support for resettled people?
- 3.15 How is quality in accommodation and support being assessed, and by whom?

How assessed?

By whom?

- 4.0 Views about the aims of the resettlement programme and the extent to which they have been achieved
- 4.1 What does the term 'betterment' as used in the Bamford Report on LD services mean for people who have been resettled from long stay hospitals?

Prompt: probe both physical and emotional betterment.

- 4.2 Can you give any examples?
- 4.3 How is the betterment of people who have been resettled being assessed?
- 4.4 What criteria are being used to make these assessments and who is making the assessment?

Criteria:

Who makes the assessment:

4.5 How have the values set out in the Bamford Report (2005) been reflected in the way resettlement has taken place?

Prompt: 'Citizenship', 'Social Integration and Inclusion', 'Empowerment', 'Working Together', 'Individual Support'

4.6 Has the resettlement programme been a success from the residents' perspective?

4.0 Has the resettlement pre	ogramme been a saccess monn	ine residents perspective:	
Yes		No	
4.7 Has the resettlement pro	ogramme been successful in pu	blic policy terms?	
Yes		No	
4.8 Has the resettlement pro	ogramme provided value for mo	oney to the public finances?	
Yes		No	
4.9 Do you have any final co	mments?		

Following the interview, we will proof read your answers then send them to you for comment to ensure that you are happy with their accuracy.

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APPENDIX 3

ORGANISATIONS PROVIDING SUPPORTED HOUSING AND INDEPENDENT LIVING SERVICES FUNDED BY SUPPORTING PEOPLE GRANT

Adult Supported Living (Mr & Mrs Brook)

Apex Housing Association

Autism Initiatives

Belfast Health And Social Care Trust

Board Of Social Witness

Camphill Community Clanabogan

Camphill Community Mourne Grange

Camphill Trust

FACT

Fold HA

Kilcreggan Homes

Mainstay DRP

Mencap

Northern Health And Social Care Trust

Northern Ireland Institute For The Disabled

Oaklee Care and Support Services

Orchard Grove

Positive Futures

Praxis Care Group

Prospects

South Eastern Health And Social Care Trust

Southern Health And Social Care Trust

The Cedar Foundation

The Croft Community

Triangle Housing Association

Western Health And Social Care Trust

APPENDIX 4

MODELS OF HOUSING AND SUPPORT FOR LEARNING-DISABLED PEOPLE AND OTHERS WITH SPECIALISED NEEDS THAT HAVE BEEN ADOPTED IN ENGLAND 133

Type of Service	Description
Supporting People-fund	· ·
Supporting People- funded accommodation- based services	Supporting People funding pays for services that support people to live independently, known as housing related support. This is delivered by staff in the individual's accommodation through accommodation-based support - staff based in the properties where tenants are living.
Supporting People- funded Floating Support Services	Floating Support services are generally offered to clients living in their own homes/tenancies. It enables them to gain skills and confidence to improve and develop skills to maintain their independence. It is not a service to do things for residents, but a service aimed at enabling people to take control of their lives and make their own decisions. The basic principles of the service are the same as for accommodation -based support.
Provision of separate ho	ousing, care and support services
Rented social housing	Renting an ordinary house from a local authority or housing association is an increasingly common choice for learning-disabled people. If necessary the property can be adapted if it is not already suitable. Properties can be let to one person, or two or three people may share a property either as joint tenants or possibly with each having their own tenancy. Floating support and domiciliary care can be provided to learning-disabled people in their own home so this is a common route to independent supported living.
Private Sector Renting	This is renting an ordinary street property from a private landlord. Charitable organisations letting out properties to a particular needs group are, for rent and housing benefit purposes, also classed as private landlords despite the fact they are not trading for profit.
Specialist Buy to Let, New Build and Refurbishment Schemes	There are a range of specialist housing providers who are able to buy, build or develop accommodation to a specific brief. They may use private or public capital, or raise mortgages to fund this.
	nent: A family or other relatives may be able to provide housing directly. The main w, but the list is not exhaustive.
Buy to Rent	Buy to rent is where a parent, or other close relative, buys (or builds) a property and then lets it out to their son or daughter or relation. The parents fund the acquisition commonly repaying the mortgage from the rent charged. This property may be any ordinary house, flat or bungalow – adapted if necessary. It can also be an annexe to the parent's home that is converted or a small bungalow built in the garden of the relatives own home.
Outright Purchase	Better off relatives may be able to buy a property, without borrowing, for their son or daughter to live in. In the long term the property could be: - Inherited on death of parent - Put into a Trust Gifted to a son/daughter now - Gifted or leased to a third party such as a Housing Association.
Privately Financed Shared Ownership	In the mainstream part-buy, part rent programme offered by some housing associations, part of the property is bought by the occupier and part rented from the association. Housing Benefit may be payable on the rent and the purchased share is eligible for Support for Mortgage Interest (SMI). Another option is for the part

¹³³ North Harbour Consulting is grateful to the Housing and Support Alliance for providing the information on which this table is based.

	purchased to be funded by relatives rather than SMI. It is also possible for parents to
	substitute their money for Social Housing or Home Ownership Long Term Disabilities (HOLD) Grant from the Homes and Communities Agency (HCA), which is used in combination with a loan by the housing association to fund the part they retain. This creates a privately financed Shared Ownership option, which is often more flexible than the Homes and Communities Agency regulated model.
Joint Ownership	Joint Ownership is where a group of people pool their resources to buy a property between them. This could be a group of families coming together to acquire a property for their children to share. Anybody who buys a house with a mortgage in conjunction with a husband or wife or partner is technically likely to be a 'joint owner'. This means they will be 'jointly and severally' liable for loan repayments. That is to say if one ceases to pay the mortgage for any reason the other remains liable for all the repayments, not just half. Joint Ownership is therefore commonplace. It is usual for two people to be joint owners but in legal terms it is equally simple for up to four people to be joint owners. So it is possible if unusual, if they have the resources, for up to four disabled people to be the joint owners rather than the parents (or other relatives). Where the owners are parents, those who live in the property will be tenants. There can be more than four joint owners but this is much more complex
Joint Ownership – Parents and Sons/Daughters	A variant on the Joint Ownership theme is for a parent to buy a property jointly with their son or daughter. The reason for doing this is usually not to increase resources but as a way of satisfying a lender that the person they are lending to has 'legal capacity'.
Company Ownership	An alternative to joint ownership for sharing is for a company to be set up to acquire or build property. One example involves 8 parents becoming shareholders in a company set up with the purpose of developing accommodation for people with learning disabilities. Some (or all) of the parents will be directors of the company.
Inheritance	If the property is inherited with the intention that it continues to be occupied by the disabled relative then the various benefits of continuing to live at home may be realised.
Discretionary Trusts	Discretionary Trusts have increasingly been seen as a key mechanism for making long-term financial provision for disabled relatives. Discretionary Trusts are a legal way of putting assets - money, shares and property - aside for a 'beneficiary'. Advice of a solicitor with expert knowledge of Trust law is required. To work in the way intended Trustees must have discretion as to how funds are used, the beneficiary should not be the sole beneficiary and must not have a right to the assets of the Trust.
Getting Housing, Care a	nd Support Together (Accommodation Based Services)
Unregistered shared group homes	This is a common form of provision for people with learning disabilities in ordinary or purpose built houses shared by a small number of disabled people. Typically this is 3, 4 or 5 people. Each person has their own bedroom, very occasionally two people may share. There will be an established and funded level of staff support, from visiting to 24 hour presence.
	The rest of the property is communal space used by tenants collectively and normally this will include at least a lounge, kitchen and dining area. There may be additional facilities like a sensory room, laundry, staff sleep-in room and some schemes will for example have en suite bathrooms rather than a shared bathroom. Staff may or may not also live in the group home.
	What distinguishes an unregistered shared house from a similar building which is designated as a registered care home is whether the care and operational arrangements require registration with the Care Quality Commission as an "establishment" or not.
	If personal care is provided (defined as physical and intimate touching and not including general social care or housing related support) the care provider will have

to be registered as a domiciliary care provider by the Care Quality Commission (CQC) but this is different from the whole building and service being registered as a care home. In this circumstance it is only the personal care element of the service that is regulated and monitored by CQC. This option includes three forms of specialist provision Extra Care, Sheltered **Housing and Core and** sheltered housing, Cluster extra care and 'core and cluster'. The first two are usually intended for older people aged 55 plus. They can be allocated to younger people with a learning disability but are particularly relevant for older people including those with learning and/ or physical impairments. There are sometimes reservations about thinking of sheltered housing as an option for disabled people as it implies grouping people together and a possible separation from the community. However, for some people, it is a positive choice. People can rent or choose to buy so this must also be a consideration for older people with a learning disability. It is not however, going to suit everyone. Extra care extends the basic sheltered concept. Core and Cluster is usually on a smaller scale than Extra Care, typically 8-20 self-contained flats and a staff flat or base within a single site dev elopement. **Residential Care** A residential care home is an "establishment" providing accommodation together with personal care. In the past there could be 20 or more people and services were inevitably institutional. More recent care homes are usually smaller, 4 - 8 people. Residential homes are owned and managed by public, private sector or charitable bodies. Some specialise in particular forms of provision, for example for people on the autistic spectrum or those with sensory impairment in conjunction with a learning disability. Care homes are registered with the Care Quality Commission (CQC) under the Care Standards Act 2000. Homes have to meet certain physical standards; they are inspected by the CQC whose reports are published (www.cqc.org.uk/). Staff are required to be trained to a certain level and staffing ratios are laid down. Intentional "Intentional communities" is a term used to describe a variety of planned residential **Communities** communities from eco villages and housing co-operatives to Kibbutzim and Ashrams. Typically members hold common social, religious or spiritual views and share responsibilities and resources. In the present context "intentional communities" refers to schemes of this type set up specifically to house disabled people who live together as part of a supportive community. Historically, intentional communities were often set up as small villages or farms in rural areas but some are newer developments in towns like Milton Keynes or may consist of a number of properties spread across an area. Other forms of support Shared Lives (SL) arrangements are distinguished by the following features: **Shared Lives** - They are part of organised SL Schemes that approve and train the SL Carers, receive referrals, match the needs of service users with SL Carers and monitor the arrangements - People using SL services have the opportunity to be part of the SL Carer's family and social networks - SL Carers can use their family home as a resource - SL agreements provide committed and consistent relationships - The relationship between the SL Carer and the person placed with them is of mutual benefit - SL Carers can support up to three people at any one time (two in Wales) - SL Carers do not employ staff to provide care to the people that they support Shared Lives Schemes originally offered long term accommodation and support but there has been growth in the last ten years of a range of other services including

	short breaks and day time support. Kinship support (where the Shared Lives family supports someone living in their own home) is the most recent area of growth and is offered in most areas of the UK.
Supported Lodgings	In Supported Lodgings, individuals receive a low level of (usually housing related) support and do not share in the family life of the landlord. Supported Lodgings Schemes are not registered with the Care Quality Commission as they do not offer personal care. Landlords do not undergo the same level of assessment as Shared Lives Carers and usually receive less support from the Scheme. They are more independent and are not subject to the same matching process. All the costs associated with placements are met by the person living in the accommodation.
Support Tenants	A support tenant shares the home of someone who has a learning disability (it might be a couple). They live with them as a friend or 'flat mate'. They share household tasks and bills just like any other unrelated friends sharing a house might. In addition the support tenant agrees, with the care or support provider, to do some additional things which help the person with learning disabilities live more independently than might otherwise be possible. The learning-disabled person will normally be the tenant or owner of the property. The support tenant is likely to be a lodger. This means they have no security of tenure. This helps to protect the more vulnerable, disabled resident.
Community Support Networks – Keyring	Community support networks are based on a small number of disabled people (up to about 10) who live in close proximity to each other providing friendship and support to each other. Each has their own home or flat although some may choose to share. One property in the network is occupied by a Community Living Worker, a part-time volunteer. The worker provides a small amount of practical help to each member of the network, for example, help with paying bills, correspondence, organising appointments, getting the right benefits. The worker's role is only to bring members together and help them form supportive relationships. There is also a Network Manager who supports Community Living Workers, and also helps tenants with specific, possibly complicated issues like benefits. Each Network Manager will look after three or four networks. There is also an out of hour's helpline. Keyring is a relatively low support option. Network members usually have an individual care package; the Network Manager and Community Living Worker and other members are not expected to be the sole basis of care and support although it is possible for some people they could be. Keyring is the leading charitable provider of this type of community network and the best starting point to check whether there is a suitable network nearby - www.keyring.org – and how to go about

APPENDIX 5

MEMBERS OF THE RESEARCH TEAM

JOHN A D PALMER

ROLF

John Palmer, Managing Director, North Harbour Consulting, is lead consultant and responsible for project management; desktop review of policy documents; NI data collection and analysis; designing themes and the analytical framework for interviews with policymakers and practitioners, resettled people and carers/family/advocates; interviews with policymakers and practitioners in NI; participation in interviewing resettled people and carers/families/advocates; editing working papers; writing the draft and final report; research management.

RESUMÉ

John has been a senior manager, policy analyst and researcher in the town planning and social housing fields including:

- senior lecturer at the Polytechnic of Central London (now University of Westminster) leading teaching
 and carrying out research in the School of the Built Environment on community planning, housing and
 social policy;
- management of the external research programme, and responsibility for 100+ general and special needs housing association performance audits across the Midlands for the Housing Corporation;
- chief executive of Ealing Family Housing Association (general needs housing); and Stonham Housing
 Association (special needs housing including physical and learning disability and mental health
 services).
- Since 1996, managing director, North Harbour Consulting Limited; completing more than 170 commissions mainly in research and management consultancy for public and non for profit organisations including: the Housing Corporation, the Northern Ireland Housing Executive, the NHS Executive and NHS Trusts, local authorities, general needs and specialist social landlords, and charities providing social welfare services.

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Palmer J A D and Watson L (1988), Hospital reprovision and the Private Finance Initiative: the procurement of supported housing for people with learning disabilities leaving long stay institutions, North Harbour Consulting and Pathways Research for East Berkshire NHS Trust and NHS Estates, West Midlands

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UNPUBLISHED RESEARCH

Palmer J A D with Paris C T (2002), Resource Allocation and the New TSN: A confidential review of needs-based resource allocation within the Northern Ireland Housing Executive, North Harbour Consulting for NIHE, Belfast Palmer JAD (2008), 'Stick, Twist or Bust': The impact of falling grant rates and the Government's 'efficiency agenda' on the ability of small and medium-sized housing associations in England to deliver new social housing, North Harbour Consulting for NIHE, Belfast

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FIONA BOYLE MA

ROLE

Fiona Boyle (FB), Senior Associate, Fiona Boyle Associates, is responsible for providing expert knowledge on policy, practice and agencies in the NI context; advising on desktop review, data collection and interviews with policymakers in NI; lead responsibility for conducting and reporting on interviews with resettled people, and carers/families/advocates; drafting working papers on these subjects; peer review of other working papers, draft and final report; participation in research management.

RESUMÉ

Fiona is the principal consultant with Fiona Boyle Associates. With a first class honours degree in Social Policy, Fiona has 23 years' experience of research, evaluation, lobbying and policy development in the statutory and voluntary sector. Her employment history has covered a broad range of social issues including housing and homelessness, legal studies, social security, poverty and social exclusion. Established in April 2002 as a full-time consultancy, Fiona Boyle Associates specialises in social research and evaluations, development of policy issues and lobbying government at local and national level. Clients have included: NI Assembly (Research & Library Services); Northern Ireland Housing Executive; Belfast City Council; General Consumer Council for N; NI Deaf Youth Association and Action on Hearing Loss NI; Care and support providers including Simon Community NI; Extern; Belfast Central Mission; Engage with Age; Atlantic Philanthropies; CARDI; Housing Associations and housing bodies including NIFHA, Housing Rights Service, SHAC, Oaklee Housing Association, Council for the Homeless NI, The Foyer Federation – NI

SELECTED PUBLICATIONS

F Boyle (2010) Assessment of the potential for equity release for older owner-occupiers, NIHE, Belfast F Boyle (2012) Sheltered housing in Northern Ireland, NIHE, Belfast

ALICIA WOOD

ROLE

Alicia Wood (AW), Chief Executive, Housing and Support Alliance is responsible for providing expert knowledge about current policy and best practice in housing, support and promoting independence for learning-disabled people; for advice on working with people who have learning disabilities to the same standards as would be required under the Mental Capacity Act 2005 which applies in England and Wales, but not yet in Northern Ireland; and communication with and involvement of learning-disabled people as active participants in consumer research; desktop review of key policy documents and research, and interviews with policy makers in GB and Rol; advising on the interview programme with resettled people and carers/families/advocates; drafting working papers on these subjects; peer review of other working papers, draft and final report; participation in research management.

RESUMÉ

Alicia is the Chief Executive of the Housing & Support Alliance, a national membership organisation that leads in developing and promoting community based approaches to housing and support. She is also a Fellow with the Centre for Welfare Reform; and a qualified Biodynamic psychotherapist who has worked with people with mental ill health and learning disabilities who have labels of 'challenging behaviour'. Alicia has worked in the statutory and voluntary sectors and has led strategies to create more housing for people with learning disabilities and managed a pilot project to test home ownership options and natural supports for people with learning disabilities. More recently, Alicia led on the national housing delivery plan for people with learning disabilities, working with the Department of Health, the Cabinet Office and the Department for Communities and Local Government. She has also led national development programmes for In Control, Paradigm and the NDTI working on housing, community development and personalisation.

SELECTED PUBLICATIONS

Alicia has written many publications including Reach Standards in Supported Living, Reach Out- personalising community and day services, Gadgets, Gizmos & Gaining Independence - the use of Assistive Technology by People with a Learning Disability and Choice Based Lettings and People with a Learning Disability.

MAHI - STM - 277 - 2338

STEVE HARRIS

ROLE

Alicia Wood will be assisted by Steve Harris, Senior Advisor, Housing and Support Alliance.

RESUMÉ

Steve is Senior Advisor at the Housing and Support Alliance. His background is in the management of residential care and supported living services in the statutory and voluntary sector. He has also worked on commissioning a wide range of services for Supporting People and Adult Social Care in local government including joint contracting between Supporting People and Adult Social Care. He has extensive knowledge and experience of delivering the full range of housing and support solutions for disabled people including private and social rented, new build with grant, ownership options, family investment options, specialist purchase, networks and dispersed networks, extra care, sheltered housing, support tenants, domiciliary care, supported living and assistive technology. He has worked with the Department for Work and Pensions, Department of Health, Department for Communities and Local Government and the Court of Protection on developing national housing and support policy initiatives.

COMMUNITY INTEGRATION PROGRAMME

Resettlement of Individuals with Learning Disabilities (Muckamore Abbey)

Initial Project Plan

Version 1 - 24 AUGUST 2011

1Document History

1.1Document Location

This document is only valid on the day it was printed.

The source of the document will be found on the HSCB "F" Drive

1.2Revision History

Revision	Summary of Changes	Changes marked
date		A STATE OF THE STA
24/08/11	Revisions from version 0.10	No
25/08/11	Additional distribution list added to 0.11 - no changes to content	
2/11/11	Draft removed – distribution list changed	

1.3Approvals

This document requires the following approvals.

Name	Signature	Title	Date o	f Version
		The state of the s	Issue	
Seamus Logan		AD of Mental Health, Social and Community Care, PMSI, HSCB	01/09/11	1
Aidan Murray	-	AD of Mental Health and Learning Disability , Social Care and Children, HSCB	01/09/11	1

1.4 Distribution

(Note: Versions 0.10 and 0.11 distributed for comment to Regional Resettlement Team 22/8/11 This document has been distributed to:

Name	Title	Date of	Version
		Issue]
Carolyn Harper	Director PHA	01/09/11	0.13
Dean Sullivan	Director of Commissioning	01/09/11	0.13
Fionnuala McAndrew	Director of Social Care and Children	01/09/11	0.13
Hugh McPoland	Director of Human Resources	01/09/11	0.13
John Compton	Chief Executive Health and Social Care Board	01/09/11	0.13
Louise McMahon	Director Performance and Service Improvement	01/09/11	0.13
Mary Hinds	Director of Nursing and AHP's	01/09/11	0.13

Michael Bloomfield	Head of Corporate Services	01/09/11	0.13

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Appendix 1: Summary Recurrent Financial Strategy

Appendix 2: Summary In-year Financial Strategy

Appendix 3: Roles, Membership, Accountabilities and Commitment

Appendix 4: Year 1 Key Milestones and Timeframes

Project Approach

3 Purpose of Project

The ultimate goal of the Community Integration Programme is to improve the quality of life for those with learning disabilities by providing a range of services that will support personal choice; move away from a service-led to needs-led approach and challenge and change mind-sets that may affect the individual's potential to become an integral and valued member of their community.

In order to achieve thisa structured project approach has been proposed through establishment of a Community Integration Team with responsibility to systematically drive and coordinate the resettlement of those who no longer require assessment and treatment from the hospital setting. The programme will adopt an approach of community service development and improvement to ensure individuals are offered increased choice and flexibility in relation to those who deliver the service, finances housing options and activities, increased opportunities for employment, and improved access to health care. Choices offered will be based on personalised assessment and care planning for each individual. There will be a much stronger emphasis on person-centred identification of needs and more creative commissioning of services

4 Project Scope

The project will aim to deliver the sustainable integration into the community of all individuals with learning disabilities who no longer require assessment and treatment in a hospital setting by March 2015. This will lead to closure of all long-stay wards, however, Muckamore Abbey Hospital Assessment and Treatment units will not be closed.

Although the emphasis of the project will be on Muckamore Abbey Hospital the approach used will be applied province-wide, therefore including individuals currently in Longstone Hospital, Armagh and Lakeview Hospital, Londonderry.

5 Exclusions

- 5.1 The project will identify issues and risks in relation to human resource needs, however, it will remain incumbent on the employing Trust to resolve staffing issues arising from the integration process.
- 5.2 Individuals who are under the age of 18 and currently in long-stay or delayed discharge beds are not included in the Community Integration Programme.

6 Project Objectives

High level objectives have been set for the project to;

- 6.1 Discharge all individuals who no longer require assessment and treatment safely and effectively into community settings within a 4 year period underpinned by an enhanced model of personalisation.. In total 239 individuals require integration into the community. The figure includes 182 patients in MAH, 49 patients in Longstone, SHSCT and 8 patients in Lakeview, WHSCT. (July 2011).
- 6.2 Systematically drive and co-ordinate the process of integration using a structured project management approach
- 6.3 Introduce an efficient, streamlined and consistent approach in relation to integration through development of a Community Integration Pathway
- 6.4 Develop and deliver a comprehensive communication strategy that will outline the rationale and proposed approach for community integration
- 6.5 Produce comprehensive, person-centred assessments and personalised care plans for each individual. (In some cases, a fully person centred plan may be developed on an ongoing basis throughout and after discharge). As needs change, individual plans will be subject to a process of ongoing review.
- 6.6 Review the needs of any individuals currently receiving treatment and / or care outside Northern Ireland with a view to determining the suitability for discharge and consider the need for future referrals outside Northern Ireland
- 6.7 Evaluate the Community Integration Programme in relation to improvement in the quality of life of individuals who have been discharged

7 Objectives and Associated Products

The project objectives are listed below along with associated products required to achieve these.

Table 1: Objectives and Associated Products

	Project Objective	Associated Product(s)
.1	Discharge all individuals who no longer require assessment and treatment safely and effectively into community settings within a 4 year period underpinned by an enhanced model of personalisation	All individuals resettled
2	Systematically drive and co-ordinate the process of integration using a structured project management approach	A Project Initiation Document A Comprehensive Project Plan A Project Reporting System
3	Introduce an efficient, streamlined and consistent approach in relation to integration	A Community Integration Pathway
4	Develop and deliver a comprehensive communication strategy that will outline the rationale and proposed approach for community integration	A Vision Document A Communication Strategy
5	Ensure comprehensive, person-centred assessments and personalised care plans are completed for each individual	A standardised tool for holistic person-centred assessment and care planning A completed assessment and personalised care plan for each individual
6	Review the needs of any individuals currently receiving treatment and / or care outside Northern Ireland	Review of needs per individual
7	Evaluate the Community Integration Programme in relation to improvement in the quality of life of individuals who have been discharged	An Evaluation Methodology

8 Resources

- 8.1 In order to drive and coordinate the programme and lead on community development strands required to apply the proposed model, two team posts will be funded for 3 years by the HSCB. The estimated cost is £0.117m each year for 3 years. This funding will be provided non-recurrently each year from the funding retracted from ward closures in the hospital..
- 8.2 The project will be lead by a programme manager from the HSCB Performance Management and Service Improvement Directorate in liaison with a HSCB Commissioner of Services and in partnership with HSC Trusts
- 8.3 The Community Integration Team will have the responsibility for monitoring the usage of funding that will be allocated to Trusts for the programme in each of the four years. In operational terms, this will involve reviewing and agreeing community integration costs with Trusts, the Housing Executive and voluntary organisations to ensure value for money and to confirm that funds are appropriately applied by Trusts for the specific needs of individuals.
- 8.4 In 2011/12, The Department allocated £6.4m Service Development funding for "Learning Disability resettlements". This funding was labelled as "non-recurrent for 3 years", but there is a working understanding with the DHSSPS that this will be recurrent funding subject to a review of how it is being applied at the end of three years. At this point in time, £1.3m of this funding has been indicatively allocated to community investment to prevent delayed discharges re-occurring, and hence at this stage it is not included as available for this programme. A demand and capacity review will be undertaken in community services to ascertain whether current investment in community services is sufficient to absorb the additional 239 people and hence release the £1.3m for community integration. Therefore at this stage, £5.1m of the service development funding has been earmarked for community integration. The Board has already taken 50% slippage on the service development moneys in 2011/12 to fund central pressures. It should be noted that the demand and capacity review may indicate a further requirement for investment in community services to help meet the needs of the 239 people who will be integrated into the community. While this potential need for additional investment can not be quantified at this stage, and hence is not included in the financial schedules accompanying this paper. This will have to be kept under review with the Department to ensure that additional funding will be provided if needed.
- 8.5 For the purposes of Investment Proposal Templates, the 2011/12 service development funding for community integration (£5.1m) has been allocated to Trusts based on the numbers of people within Oldstone and Finglass wards in Muckamore Abbey Hospital and after reviewing the numbers of delayed discharges by Trust in these wards.
 - A further amount of £1.0m has been allocated to the Board in 2011/12 for people who are integrated into the community as a result of Mental Health Tribunal decisions. For the

purposes of this paper it is assumed that £0.500m of this may be available for people who are integrated into the community from Muckamore Abbey Hospital under those directions.

- 8.6 In addition to the service development funding, it is proposed that funding will be retracted from Muckamore Abbey Hospital and Longstone Hospital to help meet the community integration. This retraction funding would be based on identified releasable direct costs associated with each ward to be closed, together with other appropriate indirect / overhead costs that can be released. In the past, funding was retracted from hospitals based on existing Departmental guidance. The Departmental guidance allowed for 10% retraction in the year of community integration, 20% in the year after community integration, 50% in the next year and 100% in the following year. With a planned approach to closing wards, however, it is proposed that a shorter timescale for retraction is adopted. The proposal is that 10% of identified funding would be retracted in the year of ward closure, 50% in the year following closure and 100% in the next year. To ensure that the full recurrent funding is available to the Board for funding community integration in the first year of each ward closure, it is proposed that the following practical approach is undertaken: 100% of the identified available funding should be retracted recurrently in the year of ward closure, with 90% of this amount nonrecurrently bridged back to the hospital in that year. In the following year, 50% of the identified available funding would be non-recurrently bridged back. No bridging would be required in year 3. This proposed retraction process would have to be agreed with Trusts in advance.
- 8.7 One final source of funding will be pre 2011/12 service development funding which has already been allocated to Trusts but which has not yet been committed because people remain in hospital while their integration into the community is being finalised. These people are still included in the hospital population numbers and hence it is correct to identify this funding as available. The exact amount of this funding will be assessed.
- 8.8 Existing voids in the system will be reviewed to ascertain if funding generated from this source could contribute to the community integration programme. It should be noted that the financial figures included in this paper are only indicative at this stage for a number of reasons:
- 8.9 Following the process of assessment and personalised care planning, the individual needs of patients may cost more than the indicative £85k care costs assumed for this process. Furthermore, an amount of £18k per person has been assumed for Supporting People funding from the Housing Executive. If individuals are not eligible for this funding, then the costs to Health and Social Care may increase above the £85k care costs assumed for this process and hence the additional recurrent gap in funding may grow;
- 8.10 Delays in the community integration process may mean that bridging funding is required for longer than the expected 3 years associated with ward closures;

- 8.11 Trusts may come up with additional cost pressures as a result of ward closures which have not been included here (e.g. costs of staff redundancy or costs associated with re-training of staff and site specific costs arising from securing and maintaining sites after closure);
- 8.12 In its proposals for closing 2 wards in Longstone in the future, Southern Trust has assumed that £1.2m efficiency savings will accrue to the Trust. For the purposes of this paper, however, the £1.2m has been assumed as being available for funding community integration.
- 8.13 In calculating the in-year amount for additional bridging funding each year, the following assumptions have been used. For year 1, in-year community integration costs will be 50% of the full year amount required (i.e. on average patients would be integrated into the community after 6 months). For years 2 to 4 in-year community integration costs will be 75% of the full year amount required (i.e. on average patients would be integrated into the community after 3 months).
- 8.14. In the past, local areas / Trusts would have expected to receive a share of retraction funding in proportion to their investment in a long stay hospital, and the Board would specify how this should be invested. The approach proposed in this paper prioritises the actual community integration costs as being the sole use of all retraction funding in the past, local areas / Trusts would have expected to receive a share of retraction funding in proportion to their investment in a long stay hospital, and the Board would specify how this should be invested. The approach proposed in this paper prioritises the actual community integration costs as being the sole use of all retraction funding. Further work will be required to consider the relative impact of this on LCG capitation shares of baseline learning disability investment.
- 8.15. The overall financial strategy shows a deficit in recurrent funding of £3.593m, with this occurring over year 2 (£0.632m), year 3 (£1.408m) and year 4 (£1.553m). This shortfall reflects that £1.3m of 2011/12 service development is being invested in community services rather than in funding the costs of community integration. It should be noted that the above figures for recurrent funding do not at this stage include any recurrent funding requirement for community services that may arise following the demand and capacity review of those services (see point 8.4 above)
- 8.16 There will also be a requirement for substantial non-recurrent finance in each year between years 2 and 5. The amount is variable over those 4 years and ranges between approximately £1.0m and £5.0m (Appendix 2). The Board would have to prioritise a source for this funding in each year as part of the financial strategy for community integration.
 - 8.17 Further detailed work is required to agree the timetable for community integration and ward closures, to agree the retraction process with Trusts and to ensure that the amounts for community integration costs, retraction funding and bridging funding are robust. It is proposed

that Departmental finance colleagues are kept apprised of the recurrent funding gap to ensure that this can be funded as required from 2012/13 onwards.

Summaries of funding schedules are outlined in full in Appendix 1

9. Approach

- 9.1 A ward by ward approach will be taken. Corresponding numbers of individuals within each area will provide annual targets for resettlement in liaison with the DHSSPS.
- 9.2 PRINCE 2 project management principles will be applied. These include:
 - · a finite and defined life span for the project;
 - an organisational structure with appropriate membership to represent all stakeholders. A Project Management Board, Community Integration Team, a Stakeholder and Reference Group and appropriate sub-groups to deliver key project objectives will be established
 - a reporting system
 - defined and measurable objectives, products and activities required to achieve these
 - an outline of resources.
- 9.3 The project will maintain a highly collaborative and transparent approach by including all key stakeholders in the planning, implementation, monitoring and evaluation of the outcomes of the project
- 9.4 A Community Integration Pathway will be developed in order to ensure a consistent, multidisciplinary approach is used. This will be accompanied by guidance on the approach, selection criteria, a tool for assessment and personalised care planning and an outline of expected timescales for the integration process to be completed
- 9.5 Each individual will have an up to date assessment and personalised care plan completed using an agreed, standardised person-centred assessment and care planning tool. The individual, their families and, where appropriate, advocacy services will be involved throughout the process and their views clearly recorded in relation to each individual's needs, wishes, the choices available and requirements to enable this to happen.
- 9.6 There may be objection to the discharge of individuals deemed ready to leave hospital.. No solution will be "imposed" on an individual and the Health and Social Care Board and relevant Trust staff will continue to work with those involved to achieve resolution to any such conflict to the satisfaction of all involved where possible

- 9.7 It is recognised that this programme will have an impact on community services and although not the direct responsibility of the Community Integration Team, the HSCB will complete a Demand Capacity Analysis in community Learning Disability services. The outcome of this work will guide future commissioning decisions.
- 9.8 A comprehensive plan will be developed following approval for project initiation and planning undertaken by the Community Integration Team

Community Integration Programme MAH (April 2011 – March 2012)

At this time the initial plan is to;

- 1. Close Finglass Ward
- Target patients in Oldstone who are already using this location as preparation and transition into the community. This will allow flexibility within this setting for transitional placement of others prior to discharge.
- Where individuals are currently undergoing the process of integration, i.e. where assessments are complete, placements agreed and funding allocated, the process should not be stalled or delayed.
- 4. Where individual needs indicate that a longer process of preparation and planning is required prior to discharge individuals may be relocated within the hospital to facilitate this and further ward closure.

Currently 49 patients in the SHSCT and 8 patients in the WHSCT are targeted for resettlement. Plans will be confirmed with the Trusts and included in the comprehensive project plan. All patients with residence in SHSCT and WHSCT currently in MAH will be resettled in 2011/12 and are included in the target numbers below

10 Target Numbers, Year 1, MAH

Table 1: MAH: Breakdown of Target Numbers per Trust 2011 / 12

MAH Location	NHSCT	SEHSCT	BHSCT	SHSCT	WHSCT	TOTAL
Current PTL	39	39	66	4	1	149
Phase 1 2011/12		-	-1			
Oldstone (PTL)	5	4	10	1	0	20 (Excl. x1 DD (SEHSCT))
Finglass (PTL)	5	8	6	0	0	19
Other (PTL)	2	0	0	3	1	6
Capitation	11	8	9	9	8	45
Net	+ 1	+ 4	+ 7	- 5	- 7	0
Actual 2011/12 (PTL)	12	12	16	4	1	45

Current DD (All wards)	6	16	10	0	1	33
Capitation (DD)	3	3	3	3	3	15
Net	- 3	- 13	- 7	+ 3	+ 2	- 18
Actual 2011/12 (DD)	3	8	3	0	1	15
Combined Actual	15	20	19	4	2	60

N.B. Figures include those previously funded in 2010/11 financial year

11 Key Milestones and Timescales (Year 1)

Key milestones with timeframes for Year 1 are outlined in Appendix 4

N.B. Milestones and Timescales will be expanded within the Project Initiation Document and the comprehensive Project Plan following discussion on details and approval by Project Management Board

12 Future Planning

This project is concerned with a new approach to the provision of integrated community living for people with learning disability who, until now, have spent long periods of continuous care in hospital. The project is not about closing the entire Muckamore Hospital site and current assessment and treatment facilities, together with other supporting services on the site, will remain.



APPENDIX 1

	YEAR 1	YEAR 2	YEAR 3	YEAR 4	YEAR 5	YEAR 6	YEAR 7	YEAR 8	YEAR 9	<u>:</u> ×
	2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	Total H
RECURRENT COSTS OF RESETTLING 239 PATIENTS Cost assumed to be £85k (plus £18k Supporting People) per patient	£5,100,000	£5,780.000	£5.440,000	£3,995,000	£0	€0	£0	£0	£0	£20,3 _{15,00}
out assumed to be cost (place black basperling i copie) per perior										MIS
RECURRENT AVAILABLE FUNDING SERVICE DEVELOPMENT FUNDING (£5.1m + £0.5m + £0.4m):	€6.000,000									£6, Q Q0,00
FUNDING AVAILABLE FROM RETRACTION :	£758,000	£3.489.571	£4,032,429	£2,442,000	£0	٤0	€0	£0	£0	£10,7 2 2,00
TOTAL RECURRENT FUNDING AVAILABLE	€6.758,000	£3,489,571	£4,032,429	£2,442,000	£0	£0	£0	03	£0	£16,722,00
RECURRENT SURPLUS / SHORTFALL IN FUNDING	£1,658,000	€2,290,429	-£1,407,571	-£1.553.000	£0	£0	£0	£0	€0	-£3. 59 6,00
Recurrent Funding c/f from previous year	-£1,658,000	£1.658.000	03	03	£0	£0	€0	£0	€0	£
RECURRENT SURPLUS / (SHORTFALL)	£0	-£632.429	£1,407,571	£1.553,000	€0	£0	£0	£0	£0	£3,593,00
ADDITIONAL RECURRENT FUNDING REQUIRED		£632,429		£1,553,000	£0	£0	£0	63	63	£3,593,00
		YEAR 2 2012/13	YEAR 3 2013/14	YEAR 4 2014/15						 X

	YEAR 1 2011/12	YEAR 2 2012/13	YEAR 3 2013/14	YEAR 4 2014/15			/EAR 7 2017/18	YEAR 8 2018/19	YEAR 9 2019/20		Total
IN-YEAR COSTS OF RESETTLING 239 PATIENTS Cost assumed to be £85k (plus £18k Supporting People) per patient	£2,550,000	£4,335,000	£4,080,000	£2,996,250	£0	€0	£0	£	0	£0	
IN-YEAR AVAILABLE FUNDING SERVICE DEVELOPMENT FUNDING :	£3,450.000										
FUNDING AVAILABLE FROM RETRACTION:	£758.000	€2,975.286	£3,346,714	£2,442,000	£0	£0	£0	£	0	£0	
Recurrent Funding c/f from previous year (IN-YEAR SURPLUS BELOW)		£1,658,000	£0	£0	£0	€0	€0	£	0	£0	
TOTAL IN-YEAR FUNDING AVAILABLE	£4,208,000	£4,633,286	£3,346,714	£2,442,000	£0	03	£0	£	0	€0	МАНІ
											1
IN-YEAR SURPLUS / (SHORTFALL)	£1,658,000	£298,286	£733,286	-£554,250	€0	03	£0	£	0	£0	Ω Θ
NON-RECURRENT BRIDGING FUNDING REQUIRED FOR HOSPITALS	£758,000	£3,056,757	£4,499,686	€3,871,157	€1,221,000	60	£0	Ę	0	€0	TM - 2
NON-RECURRENT FUNDING REQUIRED FOR ART	£117.000	€117.000	£117.000	£117,000	€0	£0	£0	£	0	60	277
TOTAL NON-RECURRENT FUNDING REQUIRED	£875.000	£3,173,757	£4,616,686	£3,988,157	£1,221,000	£0	£0	£	0	60	£13,87 4 ,600
BRIDGING FUNDING AT BOARD	£0	£400,000	£400,000	£400.000	€400,000	£400,000	€0	£	0	£0	23 5
USE OF IN-YEAR SURPLUS ABOVE	£1,658,000	£298,286	£0		£0	£0	£0	£	0	£0	ω
TOTAL FUNDING AVAILABLE FOR BRIDGING	£1,658.000	£698,286	£400.000	£400,000	£400,000	£400.000	£0	£	0	<u>£0</u>	£3,956,286
ADDITIONAL NON-RECURRENT FUNDING NEEDED FOR BRIDGING	03	£2,475,471	£4,216,686	£3,588,157	£821,000	60	£0	£0	€0		£11,101,314
TOTAL NON-RECURRENT FUNDING REQUIRED	03	£2,475,471	£4,949,971	£4,142,407	£821,000	£0	£0	£	0	£0	£12,388,8

Project Role	Membership Representation	Accountabilities Responsibility to members to;	Commitment
Sponsor Project Management Board	1 X HSCB PMSID (AD) – Seamus Logan (Chair) 1x HSCB Commissioner (AD) – Aidan Murray	Be accountable for the performance of the project. Provide support to the project. Promote the work of the project. Give strategic direction.	Quarterly and to attend extra-ordinary meetings
	1 x DHSSPSN! representative – Peter Deasley 5 x Trust (AD level): Bria Mongan (SEHSCT) John Veitch (BHSCT) (Co-Chair) Nigel Stratton (NHSCT) Bryce McMurray (SHSCT) Rosaleen Harkin (WHSCT) (SHSCT and WHSCT representation will be required on an temporary basis ending when resettlement of individuals associated with these Trusts has been completed) 1x NIHE – Colm McQuillian 1 x Clinical Director – Colin Milliken 1 X PHA - Molly Kane 1 x HSCB Finance - Adrian Walsh 1 x Independent Service Representative	Provide an ultimate decision-making forum for all major problems and issues. Ensure the project is aligned to corporate objectives. Approve the PID, project aims and objectives. project plans, changes and status reports. Provide quality assurance. Ensure full committed to resettlement and remove blockages with the full authority of the Chief Executive.	if required MAHI - STM - 277 - 2354

			45
Project Role	Membership	Accountabilities	Commitment
	Representation	Responsibility to members to;	

COMMUNITY INTEGRATION TEAM	1 x HSCB Programme Manager (Chair) – Joanne McConville 1x HSCB Commissioner– Iolo Eilian 1x Business Manager (MA) – Eilish Steele 2 x Programme Co-ordinators – To be appointed 5 x Trust Service Managers; (To be confirmed) BHSCT John McCart NHSCT Donna Morgan SEHSCT Carol Veitch SHSCT WHSCT Brian McGarvey 1x NIHE officer 1 X Trust Finance Representative (BHSCT) 1 x Human Resources Representative (BHSCT)	To produce the resettlement plan To run the project on a day-to-day basis using the agreed methodology outlined in the PID. To ensure the project delivers specified products to the required standard of quality and within the constraints of time and costs. To develop all necessary strategies to meet the project aims and objectives and to monitor and report on their effectiveness To report all issues and risks to the project lead and action taken to address these. To promote and raise awareness of the project amongst all stakeholders.	Monthly meetings as a minimum requirement and as necessary MAHI
STAKEHOLDER AND REFERENCE GROUP	1 X Staffside Representative Practitioners (Acute / Comm) Nursing SW AHP) 1X Society of Parents and Friends Advocacy Representatives Patient and Client Council representatives	To manage the resettlement budget To inform and advise the Project Team To act as advocates for patients undergoing resettlement	1 – 2 Monthly meetings and ad-hoc as required
	TILLI Group representatives Voluntary and Community Sector Representatives Primary Care Commissioner (GP, Dentistry, etc) (Additional as identified)	To report all issues and risks to the Project Team	2355

Appendix 4:

Year 1 Key Milestones and Timeframes

Key Miles	tone	Requirements	Time	Frame									-	
			Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar

f.		ja 13	í					7	1	2 0
Project Set-up	Formation of PMB, Project Team, Stakeholder and Reference Group				ji i					001
	Recruitmment of Community Integration Team Co-ordinators									
	Identification of baseline information on Muckamore, Comm services and target groups					X	ing and a second			
	Clarification of scope, objectives, risks, issues and timescales									
	Identification of reporting mechanisms	di								
	Production and Approval of the PID	Prince 3	K. W.							
	1	A July	le-							
Production of Comprehensive Project Plan	Development and agreement on approach, targets and phases	1								
	Approval Project Plan									
							94			
Production of Communication and Public Relation Strategy	Completion of stakeholder analysis, materials, approach									
	Delivery of Communication Strategy									

		Τ			r——	T	T		<u> </u>			ľ
Production of Human Resource, Training and Development Strategy	Identification of issues / concerns							689				
	Training Needs Analysis						.±1	pilling.				
	Approval of Strategy							The state of the s	1			
	Delivery of Strategy							4		_		
Production of Assessment and Care Planning Model	Identify current information captured						Mile W					
	Agree template for assessment and careplan											MAHI -
	Application of model and documentation	16		i _{lj.}								MIS
Active resettlement of individuals	Complete assessments and care plans (Target Group)		tan-									- 277
	Analysis of PCP's	-0.0										ا 2
	Identification of individual requirements for resettlement											357
	Development of individualised business cases											
	Agreement of individualised resettlement plans											ļ
		-										
Production of Evaluation Methodology	Identify appropriate evaluation methodology		ļ <u>-</u>									ראווטונ סס
	Apply on-going evaluation											



MUCKAMORE ABBEY HOSPITAL NON-RECURRENT/INYEAR BRIDGING IRO RESETTLEMENT PROGRAMME

INITIAL NON-R	NITIAL NON-RECURRENT BRIDGING ALLOCATED YEAR 1 YEAR 2 YEAR 3 YEAR 4 YEAR 5 YEAR 6 YEAR 7 YEAR 8 YEAR 9 YEAR 10 YEAR 11 TOTAL											VEAD 0	VEAR 10	VEAD 11	TOTAL
Hospital	Resettlement Ward	Total Retraction Amount		2011/12	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	FUNDING
Muckamore	Finglass ward costs	£758,000	Bridging amount		£379,000	£0	£	0							£379,000
Muckamore	Erne ward costs	£792,000	Bridging amount		£713,000	£396,000	£	0							£1,109,000
Muckamore	Ennis ward costs	£765,000	Bridging amount		£688,000	£382,500	£	0							£1,070,500
Muckamore	Greenan ward costs	£1,058,000	Bridging amount			£952,200	£529,000	0 f	E0						£1,481,200
Muckamore	Moylena ward costs	£866,000	Bridging amount			£779,400	£433,000	0 f	E0						£1,212,400
Muckamore	Rathmullan ward costs	£1,154,000	Bridging amount				£1,038,600	0 f	EO 6	£0					£1,038,600
Muckamore	Oldstone ward costs	£1,288,000	Bridging amount	:			£1,159,200	0 f	EO 1	£0					£1,159,200
Muckamore	Day care costs	£388,000	Bridging amount			£349,200	£194,000	0 f	20						£543,200
				£	£1,780,000	£2,859,300	£3,353,800	0 <u>f</u>	EO 1	£0 £	EO 1	EO £	0	£0 £	0 £7,993,100

ADDITIONAL N	NON-RECURRENT BRIDGING ALLOCATED														
			YEAR 1 2011/12	YEAR 2 2012/13	YEAR 3 2013/14		EAR 4 014/15	YEAR 5 2015/16	YEAR 6 2016/17	YEAR 7 2017/18	YEAR 8 2018/19	YEAR 9 2019/20	YEAR 10 2020/21	YEAR 11 2021/22	TOTAL FUNDING
Muckamore	Reinstate 10% Greenan	Bridging amour	nt		£105	,800									£105,800
Muckamore	Reinstate 10% Moylena	Bridging amour	nt		£86	,600									£86,600
Muckamore	Reinstate 10% Rathmullan	Bridging amour	nt				£115,40	0							£115,400
Muckamore	Reinstate 10% Oldstone	Bridging amour	nt				£128,80	0							£128,800
Muckamore	Erne and Ennis Ward pressures	Bridging amour	nt		£300	,000									£300,000
Muckamore	Additional Bridging Muckamore ward pressures	Bridging amour	nt				£1,156,00	0							£1,156,000
Muckamore	Non-recurrent bridging Daycare service	Bridging amour	nt					£388,00	00						£388,000
Muckamore	Non-recurrent bridging 2 wards staying open	Bridging amour	nt					£2,000,00	00						£2,000,000
			f	20	£0 £492	,400	£1,400,20	0 £2,388,00	00 :	£0 :	£0 :	£0 :	20	£0 £	0 £4,280,600

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			YEAR 1 2011/12	YEAR 2 2012/13			YEAR 4 2014/15	YEAR 5 2015/16	YEAR 6 2016/17	YEAR 7 2017/18	YEAR 8 2018/19	YEAR 9 2019/20	YEAR 10 2020/21	YEAR 11 2021/22		TAL NDING
Muckamore	Reinstate 10% Greenan	Bridging amoun	t £	0 £379,	000	£105,800	£0)	£0	£0	£0	£0	£0	£0	£0	£484,800
Muckamore	Reinstate 10% Moylena	Bridging amoun	t £	0 £713,	000	£482,600	£0)	£0	£0	£0	£0	£0	£0	£0	£1,195,600
Muckamore	Reinstate 10% Rathmullan	Bridging amoun	t £	0 £688,	000	£382,500	£115,400)	£0	£0	£0	£0	£0	£0	£0	£1,185,900
Muckamore	Reinstate 10% Oldstone	Bridging amoun	t £	0	£0	£952,200	£657,800)	£0	£0	£0	£0	£0	£0	£0	£1,610,000
Muckamore	Erne and Ennis Ward pressures	Bridging amoun	t £	0	£0	£1,079,400	£433,000)	£0	£0	£0	£0	£0	£0	£0	£1,512,400
Muckamore	Additional Bridging Muckamore ward pressures	Bridging amoun	t £	0	£0	£0	£2,194,600)	£0	£0	£0	£0	£0	£0	£0	£2,194,600
Muckamore	Non-recurrent bridging Daycare service	Bridging amoun	t £	0	£0	£0	£1,159,200	£388,0	000	£0	£0	£0	£0	£0	£0	£1,547,200
Muckamore	Non-recurrent bridging 2 wards staying open	Bridging amoun	t £	0	£0	£349,200	£194,000	£2,000,0	000	£0	£0	£0	£0	£0	£0	£2,543,200
			£	0 £1,780,	000	£3,351,700	£4,754,000	£2,388,0	000	£0	£0	£0	£0	£0	£0	£12,273,700

Exhibit 58

Muckamore Abbey Hospital
ADDITIONAL NON-RECURRENT PRESSURES FUNDING ALLOCATED

			YEAR 1	YEAR 2	YEAR 3	YEAR 4	YEAR 5	YEAR 6	YEAR 7	YEAR 8	YEAR 9	YEAR 10	YEAR 11	TOTAL
			2011/12	2012/13	2013/14		2015/16		2017/18	2018/19	2019/20	2020/21	2021/22	FUNDING
Muckamore	2 OTs at Muckamore BHSCT for LD Resettlement				£98,000	£98,000	£98,000							
Muckamore	Community OT appliances for resettlement				£112,500	£112,500								
Muckamore	Muckamore Assessment Team (Pump prime Community Forensics Team)				£57,849	£57,849								
Лискатоге	Advocacy for resettlement patients still in Muckamore						£45,000	£45,000						
Muckamore	Band 8a Resettlement Team			£59,000	£58,500	£59,000	£59,000							
Лискатоге	Constant supervision pressure				£1,000,000	£3,200,000	£1,200,000							

Muckamore	Non-recurrent funding for hospital staff resettling patients in community					£139,500								
Muckamore	Muckmamore pressure consultant and nurses					£398,000	£398,360							
Muckamore	Assistance with in-year costs of complex discharge patients						£217,000		£600,000					
Muckamore	Non-recurrent funding for resettlement patients still in Muckamore							£2,434,655	£1,031,000	£1,225,000				
Muckamore	Non-recurrent funding for Muckamore Abbey Hospital cost-pressure	•							£242,668			£3,000,000	£3,000,000	
Muckamore	FYE 18/19 Pressures - MAH Review										£1,500,000			
			£0	£59,000	£1,326,849	£4,064,849	£2,017,360	£2,479,655	£1,873,668	£1,225,000	£1,500,000	£3,000,000	£3,000,000	£20,546,381

Mental Health & Learning Disability Improvement Board 11/03/19 HSCB Board Room Co. Hall, Ballymena

Present

Marie Roulston, HSCB (Chair)

Oscar Donnelly, NHSCT

Marie Heaney, BHSCT

Bria Mongan, SEHSCT

Barney McNeany, SHSCT

Karen O'Brien, WHSCT

Phil Hughes, NHSCT (for Oscar Donnelly)

Alyson Dunn, NHSCT (for Oscar Donnelly_

Briege Quinn, PHA (for Mary Hinds)

Jerome Dawson, DoH

Lourda Geoghegan, RQIA

In Attendance

Valerie McConnell, HSCB

Apologies

Oscar Donnelly, NHSCT Mary Hinds, PHA

Action Notes

1	Welcome & Apologies	Apologies were noted and M Roulston outlined the purpose of the group for new attendees. L Geoghegan joined the meeting	
2	Last Meeting – Matters Arising	MH&LD ToR suggested amendments - To be tabled Meeting Schedule - Monthly meetings dates circulated LDSM BHSCT Project Lead - Action completed – post appointed to start 4 th April Assessment and Treatment ToR. Suggested amendments Action Completed. BHSCT Representative for A & T Study Visit (MH) Action Completed Children's LD Hospital – Iveagh – action completed	
3	Muckamore Abbey Hospital Action Plan	M Heaney gave an update on the police investigation and actions being taken in response to Independent Review recommendations including Adult Safeguarding, operational and inter-trust issues arising.	

In respect of discharge planning M Heaney advised that Trust Directors and Assistant Directors meet monthly to monitor progress; and the ADs are actively overseeing the discharge plans for people who are medically fit with a view to prioritising the Permanent Secretaries commitments.

A draft Regional action plan responding to the recommendations was tabled. J Dawson advised that a more strategic overview was required including an accommodation strategy. It was noted that, Dorsey and Lakeview are also experiencing some delayed discharges. V McConnell advised that she had received details of WHSCT and SHSCT delayed discharges, but hadn't yet been sent the Muckamore list. She advised that this was necessary to consider the specific issues that were contributing to delay. She also noted that a strategic plan would also need to consider what was required to prevent unnecessary hospital admissions in the future.

Requirement for Declaratory Orders may also be an issue. M Heaney advised that BHSCT have arranged meeting with DLS to see if these can be expedited. J Dawson indicated that he would raise with DoJ if their support with Courts was required.

M Heaney undertook to ensure that the Muckamore DD List was forwarded to HSCB/PHA ASAP.

V McConnell will draft strategic plan for consideration.

M Heaney

V McConnell

4	Learning Disability Service Model (VM)	LDSM March Highlight Report was tabled. V McConnell to circulate with action notes. It was noted that three of the Trusts had project managers in post and HSCB and other two Trust had people appointed but working notice. B Mongan asked about Independent Sector engagement. V McConnell advised that HSCB/PHA had proposed ARC (as the LD Provider umbrella organisation) be asked to join the steering group; however the Assistant Directors opposed this. They had undertaken to ensure that independent sector providers were engaged locally.	V McConnell
5	LD Acute Care Review (BQ)	B Quinn outlined arrangements for an urgent review of mental health assessment and treatment services as an accelerated work stream of the Learning Disability Service Model. Terms of Reference were considered. B Mongan queried why there was no Social Worker on the Expert Panel. B Quinn outlined considerations by the LDSM steering group, who felt that, as it was a mainly a clinical service the priority was for psychiatry, Psychology and LD Nursing expertise, and given that there is significant SW expertise on the Steering Group, the panel makeup was the most appropriate for the remit and purpose of the specific task. She also noted that there was a Family Carer representative on the expert panel, and that the TILLI groups set up specifically for the LDSM project would be involved. The ToR was considered and accepted.	

		ALD bed pressures (in the light of restricted admission to MAH) were noted. P Hughes cited the Adult MH Regional Protocol for hospital admissions as a useful model to be considered by LD.	
6	Direct Payment Legal Advice (MR)	M Roulston outlined recent legal advice from DLS that all family members directly employed by services users under Direct Payments / SDS arrangements require Access NI checks. Members noted the challenges and delays Trusts were experiencing in implementing this guidance. J Dawson urged pragmatism to avoid adverse impact on clients and families. A Dunn and B Mongan noted that NHSCT and SEHSCT were working through and addressing on a case by case basis.	
7	MHS Bench Marking (BMcN)	B McNeany highlighted the benefits of NHS Benchmarking for performance management and service planning. BHSCT has already adopted this and he has commenced work in SHSCT. Other Trust are keen to sign up. B Quinn has arranged a Workshop for the Trusts scheduled for 10 th May. B Mongan expressed an interest in attending. B Quinn will circulate workshop details to the Directors group. Individual Directors may wish to get a briefing from their ADS. A Dunn noted that the LD Assistant Directors were also considering the NHS Benchmarking system for LD. However, current data definitions may need tweaked / expanded to fit NI	B Quinn to send Workshop details to Directors.

		H & SC context. The LD ADs group were anticipating a cross Trust workshop in November to agree data definitions.	
8	MH Acute Care Pathway Review (Strathdee) Review (BQ)	B Quinn advised that the Expert Panel review was almost complete and that she and Dr S Bergan have met with them to take initial feedback. The first draft of the written report is expected at the end of March. She noted that there was some positive feedback about NI services (in comparison with other UK jurisdictions). The final report will be presented to the AMH Sub Group in the first instance then shared more widely round the system.	
9	Regional Bed Management Protocol (PH)	The mental Health Regional Bed Management Protocol was shared for information. This may serve as a template for the development of a similar protocol for adult learning disability. V McConnell and B Quinn will discuss with LD Assistant Directors with a view to identifying a working group to take forward.	V McConnell & B Quinn
10	Alcohol Acquired Brain Injury (MH)	M Heaney noted a lack of coherence in the way the system responds to people with Alcohol Acquired Brain Injury, with individuals falling between Brain Injury / Physical Disability / Mental Health / Addictions / Dementia services. Some end up in high cost social care settings because of the imperative to discharge from general hospital. There would appear to be an increase in the numbers of people presenting with AABI.	

		She suggested that a bespoke service needs to be commissioned with an agreed regional care pathway. HSCB/PHA will consider how to take this forward.	V McConnell / B Quinn
11	JR Enfield v WHSCT (KO'B)	K O'Brien outlined the outcome of the Judicial Review in this case that found against WHSCT and resulting in "ordinarily resident" rules as described in the English Care Act being applied to a person placed in NI supported housing scheme by an English local authority. This meant that WHSCT was being directed to pick up the care costs. There could be significant numbers of people in some services (such as Camphill Communities) that have an international clientele. V McConnell noted that if this is reciprocal then there are grounds for NI to transfer responsibility to other UK jurisdictions when people who have gone on ECR arrangements decide they do not plan to return to NI. K O'Brien sought the views of others as to whether or not it was worthwhile WHSCT challenging the ruling. It was agreed that clarity on reciprocal arrangements across jurisdictions was needed. Also clarity on the potential application to residential and nursing home placements. J Dawson will take this forward with colleagues in DoH.	J Dawson

12	Any Other Business	10,000 More Voices B Quinn noted that a survey of mental health service users and cares experience had been completed under the original 10,000 voices scheme some years ago. A rerun under 10,000 More Voices has commenced with a good response so far. Also a workshops to construct a survey template for front line staff was planned to commence in April. She will share the template with the MH & LD Improvement Board before the staff survey commences.	B Quinn
	Date of Next Meeting	2 – 4 pm 29 April 2019 Board Room, Co. Hall, Ballymena	

Mental Health & Learning Disability Improvement Board 24/01/19 HSCB Linenhall St, Belfast

Present

Marie Roulston, HSCB (Chair)
Oscar Donnelly, NHSCT
Marie Heaney, BHSCT
Bria Mongan, SEHSCT
Valerie McConnell, HSCB

Apologies

Barney McNeany, SHSCT Karen O'Brien, WHSCT

Action Notes

1	Welcome & Introductions	Apologies noted form Barney and Karen	
2	Last Meeting – Matters Arising	Marie R to consider ToR from CSIB for adaptation Marie R looked at CSIB ToR and they wouldn't meet requirements. Suggested ToR on agenda for discussion. Marie R to advise S Holland of newly formed group and put on agenda for Delivering Outcomes Board – Completed.	
3	Terms of Reference	Draft Terms of Reference for the MH & LD Improvement Board were considered. Oscar suggested including the groups and projects that will be reporting through to the Improvement Board be included.	

		Action: Valerie to draft suggested amendments and recirculate.	
		Meetings have been scheduled for the every other month for 2019. However, given the urgency and profile of the Muckamore Abbey Hospital agenda members felt that monthly meetings might be more appropriate. Action: Consult diaries to arrange a meeting in February.	Feb meeting of MH & LD Improvement Boar
4	Membership	Additional members required to enable the MH & LD Improvement Board to fulfil all of its functions was discussed. Mary Hinds (Director of Nursing and AHP, PHA) will be invited to join. Also Jerome Dawson, Acting Director of MH & LD Policy Unit, DoH.	Invite to Mary Hinds & Jerome Dawson.ms
		Action: Marie	
		It was felt that a medical representative was required.	
		Action: Marie R to discuss with Adrian Mairs (Director of Public Health Medicine, PHA).	
5	Muckamore Abbey Hospital – Update and Action Plan	1 st Draft of action plan considered. Includes; BHSCT actions to keep people safe; HSC Trust actions to expedite delayed discharges; HSCB/PHA & HSC Trust actions to review and modernise how acute care is delivered.	LD action plan re Muckamore Abbey.ms
		Action: Trust Directors to return to send suggested additions and amendments as tracked changes.	

6 Learning Disability Service Model (Project Board)

Valerie noted that Lorna Conn has been appointed as HSCB Social Care lead for Learning Disability (replacing Iolo Elian).

The Project Initiation Document (PID) outlining the governance structures for the development of a new Learning Disability Service Model (LDSM) was circulated in advance of the meeting for consideration. The MH & LD Improvement Board are identified as the Project Board, reporting through to TIG as the project is being funded from C & S Transformation fund. The Project Steering Group is established and includes the HSC Trust Assistant Directors / Co-Director.

The need to consider staff resilience and physical health care needs was noted. Valerie noted the Steering Group for the project included the Trust ADs, PHA Nursing colleagues, and a representative from the Bamford Monitoring Group and DoH. ARC had been engaged to develop a number of TILLI service user groups to facilitate input from service users, and a series of other stakeholder engagement mechanisms and events were planned. It was anticipated that priorities and work streams for the project would develop from these engagements and draw together work already underway (such as health care facilitators / health passports; Day Opportunities etc.

It was noted that the review of how acute care was delivered was already designated as an accelerated work stream for the project.

		Valerie noted funding for an 8a project Manager had been allocated to the five HSC Trusts and HSCB/PHA. SEHSCT and SHSCT have appointed; interviews are imminent for NHSCT and WHSCT and HSCB will be appointing from a waiting list. BHSCT has not yet commenced recruitment. Action: Marie H to discuss BHSCT Project lead with M Mitchell.	
7	LD Acute Care – Accelerated Work stream	A regional review of how acute care is delivered has commenced. Terms of Reference were shared. Briege Quinn (AD for MH & LD Nursing, PHA) is leading on this work. Some amendments were suggested, including making reference to Assessment and Treatment for people with LD experiencing mental health problems to ensure a clear focus on the need to consider community based treatment options as well as a critical review of the role and function of current hospital based provision. Action: Valerie to forward suggested amendments to Briege A study visit to a nurse lead Assessment and Treatment service in Gloucester has been identified as a potential model to meet NI needs. A study visit is planned for 15 Feb 2019. Most of the Steering Group members will be attending, however BHSCT AD cannot attend and has not yet nominated anyone form the Trust to go in her place.	Senior staff visit to LD Acute care service MH & LD Directors comment on ToR for I

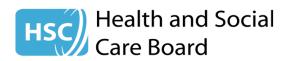
		Action: Marie H to identify BHSCT representative for the study visit.	
8	Mental Health Service Development and Improvement Projects	Valerie noted a number of Mental Health improvement projects initiated through the C & S Transformation fund: • Review of MH Acute Care Pathway • Review of Addictions Care Pathway. She will report progress to the Improvement Board. HSCB has appointed a Regional Trauma Network Manage (Geraldine Hamilton) and work on developing the Regional Trauma Network has picked up pace. Members were provided with the most recent highlight report for information. Trusts have received investment to recruit Trauma Specialists.	
9	Iveagh LD Children's Hospital – M Heaney	Marie H advised that Iveagh is an 8 bedded hospital unit providing LD inpatient care for children. She noted that originally provision was for four Trusts, with WHSCT opting to directly provide its own inpatient care for children with LD. Marie H is concerned the Iveagh is also accumulating delayed discharges, and has concern about its use as a care placement facility rather than an assessment and treatment unit. Of the current inpatients only 3 are in active treatment, with the remaining 5 medically fit for discharge, but with no suitable community placements available. The unit is experiencing staff shortages across all professions. She is therefore asking Trusts to expedite their discharges from Iveagh.	

		Marie R noted that this should probably be on the CSIB agenda, and considered under the review of Children's services requested by Seam Holland. Action: Marie R to put Iveagh on CSIB agenda and invite Marie H to the next meeting.	
10	Alcohol Acquired Brain Injury – M Heaney	Deferred to next agenda.	
11	Any Other Business	MH Funding Oscar asked about the £10m spend announced for Mental Health. Valerie advised that, in addition to the C&S Transformation funded projects for MH (and some LD), MH Inescapable pressures had been transferred into the C&S funding stream. This includes; 2nd tranche physical health care for AMH; Phase 2 Trauma Network; demography & inflationary pressures; prevent family breakdown; T3 addictions investment; and the roll forward of Psychological therapies funding withdrawn by DfC. WHSCT JR Enfield Judgement – circulated for infomation Karen forwarded copies of the judgement for the judicial review thsy had taken in respect of funding for a case placed in supported housing here by Enfild Council. The judgement ruled against the Trust but WHSCT may be appealing.	
	Date of Next Meeting	10am Monday 11 March 2019, Boardroom, Co Hall	
		(NB date being sought for meeting in February – TBC)	

ACTION PLAN: MUCKAMORE ABBEY HOSPITAL 2019

	ISSUE	ACTION	RESPONSIBILITY	LEAD OFFICER	DATE
1	Ensure the safety & wellbeing of inpatients at Muckamore Abbey Hospital	 Implement recommendations form the SAI Independent Review report 2018 Conclude Joint Protocol Adult Safeguarding Investigation with PSNI Take disciplinary action and report to NISCC / RCN as required 	Marie Heaney, BHSCT	TBC Mairead Mitchell, BHSCT	TBC
2	Accelerate the discharges of the remaining Resettlement population and delayed discharges	Review ToR and membership of Muckamore Resettlement Board to include new delayed discharge population	Marie Roulston HSCB (Chair) and Marie Heaney BHSCT	TBC Valerie McConnell / Lorna Conn HSCB Mairead Mitchell, BHSCT	TBC
		 Identify a senior lead officer to drive identification and development of suitable 	Marie Heaney BHSCT	TBC	TBC

3	Regional Review to modernise how acute mental health care for people with a Learning Disability in Northern Ireland 9accelerated work stream of the Learning Disability Service Modell Review)	Resettlement and delayed Discharge populations. Senior staff study visit to Glouster LD assessment & Treatment Service. Appoint independent expert panel to review current acute acer provision and latest evidenced based model of acute mental health care for learning disability patients Develop proposals for the modernisation of acute mental health care across NI Deliver action plan to modernise acute mental health care for people with	ria Mongan EHSCT scar Donnelly HSCT arie Roulston, SCB & Mary inds, PHA arie Heaney, HSCT ria Mongan, EHSCT scar Donnelly, HSCT Alyson Dunn, NHSCT Alyson Dunn, NHSCT aren O'Brien, HSCT Rosaleen Harkin,	/19
			WHSCT	



COMMUNITY INTEGRATION PROGRAMME

PROJECT MANAGEMENT BOARD

END STAGE REPORT

17th SEPTEMBER 2012

PRODUCTS AND SUB-PRODUCTS (As per PID)

PRODUCT	SUB-PRODUCT	PROPOSED END DATE
Discharge of Patients		March 31st 2015
	Outcomes Report for Inter-Trust Planning meeting	Monthly
	End Stage Report prior to PMB meeting	Bi-monthly
	Assessments and Care Plans on each individual	March 31 st 2013
Project Staffing	OTs	September 30 th 2012
	Proposal for additional staff requested from BHSCT	November 9 th 2012
Communication Strategy	Generic letter for relatives	June 2012 (achieved)
	Newsletter	June 2012 (achieved)
	Patient Information Leaflet	June 2012 (achieved)
	Press Release	June 2012 (achieved)
	Easyread Communication Strategy	Resolved – not required
	Newsletter 3 to be drafted	December 1st 2012
Evaluation of Quality of Life	Research proposal, terms of reference and process	December 31 st 2012
	Amended Quality of Life questionnaire	November 23 rd 2012
Procurement Process	Documentation	March 2013
	Process	March 2013
Community Integration Pathway	Generic process map for staff	September 30 th 2012 (Achieved)
	Patient pathway	November 30 th 2012 (Achieved)
	Community Integration File and Contents	November 30 th 2012 (Achieved)
	Audit on use of pathway	31st December 2012

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Demand Capacity Study	Template	December 31st 2012
Workforce Planning Strategy (BHSCT)		March 31 st 2015 (on-going)

PRODUCT / ISSUE	PROPOSED END DATE	ACTIVITIES	RESOURCES / RESPONSIB- ILITIES	ACHIEVEMENTS TO DATE / MITIGATING ACTION
Discharge of Patients	Mar 15	On-going discharge as per project plan Assessment and planning ongoing. No new discharges in from 30 th September to present. EDD for 5 BHSCT and 1 SEHSCT patient in December	Trusts	Contingency plan received from BHSCT. The proposal is to merge Erne and Ennis in March 2013 with 20 patients who it is not anticipated will be discharged. 2 further wards will be merged in 2013/14 but as yet a timescale for this is not indicated. This would result in a requirement to close 3 wards in the final year 2014/15. Therefore there is a high risk that the end date of March 2015 may not be achievable. This has not been confirmed by all Trusts. A planning meeting to be held in relation to mental health and learning disability resettlement at Director level on 7th December Finglass has closed due to staff shortages and therefore concerns about patient safety. Remaining patients have dispersed to Rathmullan, Oldstone, Erne and Killead. There is a danger that momentum will be lost on on-going planning for these patients as there are no meetings being held in Rathmullan and Killead
	March 2013	Assessments on all patients, including completion of questionnaire and discussion with next of kin	Trusts	The HSCB has requested that all assessments on PTL patients be completed by March 2013, essential for forward planning. Trusts have highlighted that an on-going nursing staff crisis has prevented nursing assessments being completed as the focus has been on care. Additional medical staff have also been requested in order to reach the timescales for full assessments. Work is ongoing in Erne and Ennis, however resettlement meetings in Killead have not commenced. At present there are no formal meetings set up in Moylena or Greenan which are targeted in 2013/14.

Project Staffing	Aug/Sept 12	2 x OT posts approved., money released from HSCB Requests made to HSCB for additional non-recurrent monies BHSCT have requested back-fill of nursing posts and increased	BHSCT / HSCB	OTs recruited. 1 x start date: 1 st November, 1x start date of 1 st December. These are inter-trust posts for MAH. HSCB have requested a proposal outlining additional staff requirements with costings
Communication Strategy	March 2015 (on-going)	Potential for legal challenge has been reported. A meeting with the Society of Parents and Friends was requested by S Logan. There was a good attendance and it was clear that virtually everyone had major concerns about resettlement The public and MLAs have expressed concerns about patients with offending behaviour	All project members	Queries and issues have been dealt with on an individual patient basis. Patients have individual meetings with care manager and ward staff at beginning of discharge process to ascertain preference and views Complaints received regarding requests for information from carers by care mangers via telephone. Staff advised to only contact carers to invite to meetings. The BHSCT has requested a framework from the
		leaving hospital to the extent that a placement has broken down Meetings to be held with patients / questionnaire completion Advocacy for carers/patients Freedom of Information requests have been requested from both the HSCB and Trusts. This has led to duplication		HSCB to outline action to be taken re communication relating to patients with offending behaviour BHSCT clinical director asked to provide details of the number of and what constitutes a patient presenting with offending behaviour Trusts to inform the HSCB of any requests made regarding patients in MAH

PRODUCT / ISSUE	PROPOSED END DATE	ACTIVITIES	RESPONSIB- ILITIES	ACHIEVEMENTS TO DATE / MITIGATING ACTION
Evaluation / quality of life / "Betterment"	On-going	Research proposal, scope and terms of reference to be developed for approval by PMB by NIHE representatives by December 2012. Amended simplified questionnaire with process for its use have been circulated and comments received. Meeting with HSCB and SHSCT service manager and advocacy held for feedback of implementation in the SHSCT	NIHE/ Co- ordinators	Draft Quality of Life questionnaire forwarded to NIHE. Agreement reached on responsibilities for development of proposal SHSCT have found completion of the questionnaire very beneficial on 3 monthly review following discharge. Further decision in relation to use of the Quality of Life questionnaire and start date to be made at PMB
Procurement Process	On-going	On-going meetings of procurement group Sub-group formed to develop documentation	Trust / HSCB	Ongoing meetings Baseline information template complete Tender documentation due for completion by December 31st 2012
Community Integration Pathway	November 30 th 2012	Development of Community integration pathway file completed This will collate information on patients, provide a tracking template to monitor progress and identify delays, rationale and action required	Project Manager / Trust key workers / clinical staff / stakeholders	Implementation of Community Integration Pathway in October 1st 2012. "About Me" patient booklets are being completed in liaison with SLT on all patients identified for discharge on an on-going basis
Demand Capacity Study	On-going	Group to be established Analysis of baseline information Development and completion of template	HSCB/ Trust representatives	Initial meetings held at HSCB level to agree scope, requirements and expected outcomes of study. Current information gathered and analysis to commence

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		Write-up and recommendations to be produced		Target date for completion of study – December 2012
Other issues	On-going	Request for confirmation letter relating to use of DSD monies for patients suitable for supported living made by Trusts	нѕсв	HSCB to send letter to Trusts
		Abbey Road development. 2 x business cases received in relation to plans for Abbey Road. I relates to Oldstone as a supported living facility and the other a previous case for a new development. Neither developments would be part of the hospital. As yet patients have not been confirmed for placement in these developments.		Further proposals would be required for a development other than Oldstone by HSCB
		On-going bureaucracy surrounding access of personal funds by patients due to lack of appointees for those with limited capacity		Trusts to resolve issue



Transforming care: A national response to Winterbourne View Hospital

Department of Health Review: Final Report

DH INFORMATION READER BOX

Policy	Clinical	Estates
HR / Workforce	Commissioner Development	M & T
Management	Provider Development	Finance
Planning / Performance	Improvement and Efficiency	Social Care / Partnership Working

Document Purpose	For Information		
Gateway Reference	18348		
Title	Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report		
Author	Department of Health		
Publication Date	December 2012		
Target Audience	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, GPs, Directors of Children's SSs		
Circulation List	Medical Directors, PCT PEC Chairs, PCT Cluster Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, Communications Leads, Emergency Care Leads, Voluntary Organisations/NDPBs		
Description	The report sets out the governments final response to the events at Winterbourne View hospital. It sets out a programme of action to transform services for people with learning disabilities or autism and mental health conditions or behaviours described as challenging.		
Cross Ref	Department of Health Review: Winterbourne View Hospital: Interim Report Winterbourne View Review: Concordat: A Programme of Action		
Superseded Docs	N/A		
Action Required	N/A		
Timing	N/A		
Contact Details	Mental Health, Disability and Equality Department of Health Room 313A Richmond House 79 Whitehall SW1A 2NS		
For Recipient's Use			

Transforming care: A National response to Winterbourne View Hospital

Department of Health Review: Final Report

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Ministerial Foreword

The scandal that unfolded at Winterbourne View is devastating.

Like many, I have felt shock, anger, dismay and deep regret that vulnerable people were able to be treated in such an unacceptable way, and that the serious concerns raised by their families were ignored by the authorities for so long.

This in-depth review, set up in the immediate aftermath of the Panorama programme in May 2011, is about the lessons we must learn and the actions we must take to prevent abuse from happening again.

It is also about promoting a culture and a way of working that actively challenges poor practice and promotes compassionate care across the system.

First and foremost, where serious abuse happens, there should be serious consequences for those responsible.

At Winterbourne View, the staff had committed criminal acts, and six were imprisoned as a result. However, the Serious Case Review showed a wider catalogue of failings at all levels, both from the operating company and across the wider system.

When failure occurs, repercussions should be felt at all levels of an organisation. Through proposed changes to the regulatory framework, we will send a clear message to owners, Directors and Board members: the care and welfare of residents is your active responsibility, so expect to be held to account if abuse or neglect takes place.

Yet Winterbourne View also exposed some wider issues in the care system.

There are far too many people with learning disabilities or autism staying too long in hospital or residential homes, and even though many are receiving good care in these settings, many should not be there and could lead happier lives elsewhere. This practice must end.

We should no more tolerate people being placed in inappropriate care settings than we would people receiving the wrong cancer treatment. That is why I am asking councils and clinical commissioning groups to put this right as a matter of urgency.

Equally, we should remember that not everything will be solved through action driven from the centre. Stories of poor care are a betrayal of the thousands of care workers doing extraordinary things to support and improve people's lives.

And while stronger regulation and inspection, quality information and clearer accountability are vital, so too is developing a supportive, open and positive culture in our care system.

I want staff to feel able to speak out when they see poor care taking place as well as getting the training and support they need to deal with the complex and challenging dilemmas they often face.

For me, this is the bigger leadership and cultural challenge that this scandal has exposed – and answering it will mean listening and involving people with learning disabilities and their families more than ever before.

As much as Winterbourne View fills us all with sorrow and anger, it should also fire us up to pursue real change and improvement in the future. It is a national imperative that there is a fundamental culture change so that those with learning disabilities or autism have exactly the same rights as anyone else to the best possible care and support. This Review is a key part of making that happen.

NORMAN LAMB
Minister of State for Care and Support

Maal

Joint Foreword

This report lays out clear, timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging. Our shared objective is to see the health and care system get to grips with past failings by listening to this very vulnerable group of people and their families, meeting their needs, and working together to commission the range of services and support which will enable them to lead fulfilling and safe lives in their communities

The Concordat which accompanies this report sets out our commitment to work together, with individuals and families, and with the groups which represent them, to deliver real change, improve quality of care and ensure better outcomes. Together we will set the strategic direction and measure progress. This requires real system leadership across all sectors, including elected councillors as well as across health and care to reduce inequalities.

The new health and care system brings a greater opportunity for people to work together more creatively to develop local innovative solutions. We commit to doing this.

Sir David Nicholson KCB CBE

Chief Executive NHS Commissioning Board Sarah Pickup

) he Sad Riday

President Association of Directors of Adult Social Services

Councillor David Rogers

Chair, Community Wellbeing Board

Local Government Association

Executive summary

- 1. The abuse revealed at Winterbourne View hospital was criminal. Staff whose job was to care for and help people instead routinely mistreated and abused them. Its management allowed a culture of abuse to flourish. Warning signs were not picked up or acted on by health or local authorities, and concerns raised by a whistleblower went unheeded. The fact that it took a television documentary to raise the alarm was itself a mark of failings in the system.
- 2. This report sets out steps to respond to those failings, including tightening up the accountability of management and corporate boards for what goes on in their organisations. Though individual members of staff at Winterbourne View have been convicted, this case has revealed weaknesses in the system's ability to hold the leaders of care organisations to account. This is a gap in the care regulatory framework which the Government is committed to address.
- The abuse in Winterbourne View is only part of the story. Many of the actions in this
 report cover the wider issue of how we care for children, young people and adults with
 learning disabilities or autism, who also have mental health conditions or behaviours
 described as challenging.
- 4. CQC's inspections of nearly 150 other hospitals and care homes have not found abuse and neglect like that at Winterbourne View. However, many of the people in Winterbourne View should not have been there in the first place, and in this regard the story is the same across England. Many people are in hospital who don't need to be there, and many stay there for far too long sometimes for years.
- 5. The review has highlighted a widespread failure to design, commission and provide services which give people the support they need close to home, and which are in line with well established best practice. Equally, there was a failure to assess the quality of care or outcomes being delivered for the very high cost of places at Winterbourne View and other hospitals.
- 6. For many people however, even the best hospital care will not be appropriate care. People with learning disabilities or autism may sometimes need hospital care but hospitals are not where people should live. Too many people with learning disabilities or autism are doing just that.
- 7. This is the wider scandal that Winterbourne View revealed. We should no more tolerate people with learning disabilities or autism being given the wrong care than we would accept the wrong treatment being given for cancer.

- 8. Children, young people and adults with learning disabilities or autism, who also have mental health conditions or behaviours described as challenging can be, and have a right to be, given the support and care they need in a community-based setting, near to family and friends. Closed institutions, with people far from home and family, deny people the right care and present the risk of poor care and abuse.
- 9. The Department of Health review drew on:
 - a criminal investigation with 11 individuals prosecuted and sentenced;
 - the Care Quality Commission review of all services operated by Castlebeck Care, the owners of Winterbourne View, and the programme of inspections of 150 learning disability hospitals and homes;
 - the NHS South of England reviews of serious untoward incident reports and the commissioning of places at Winterbourne View hospital;
 - an independent Serious Case Review commissioned by the South Gloucestershire Safeguarding Adults Board, published on 7 August 2012; and
 - the experiences and views of people with learning disabilities or autism and mental health conditions or behaviours described as challenging, their families and carers, care staff, commissioners and care providers.
- 10. An interim report was published on 25 June 2012. This final report of the review can be published now that the criminal proceedings have concluded.

Programme of Action

- 11. This report sets out a programme of action to transform services so that people no longer live inappropriately in hospitals but are cared for in line with best practice, based on their individual needs, and that their wishes and those of their families are listened to and are at the heart of planning and delivering their care.
- 12. The Government's Mandate to the NHS Commissioning Board¹ says:
 - "The NHS Commissioning Board's **objective** is to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people." (para 4.5)
- 13. We expect to see a fundamental change. This requires actions by many organisations including government. In summary, this means:
 - all current placements will be reviewed by 1 June 2013, and everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014;
 - by April 2014 each area will have a locally agreed joint plan to ensure high quality care and support services for all children, young people and adults with learning

¹ http://www.dh.gov.uk/health/2012/11/nhs-mandate/

- disabilities or autism and mental health conditions or behaviour described as challenging, in line with the model of good care set out at **Annex A**;
- as a consequence, there will be a dramatic reduction in hospital placements for this group of people and the closure of large hospitals;
- a new NHS and local government-led joint improvement team, with funding from the Department of Health, will be created to lead and support this transformation;
- we will strengthen accountability of Boards of Directors and Managers for the safety and quality of care which their organisations provide, setting out proposals during Spring 2013 to close this gap;
- CQC will strengthen inspections and regulation of hospitals and care homes for this
 group of people. This will include unannounced inspections involving people who use
 services and their families, and steps to ensure that services are in line with the
 agreed model of care; and
- with the improvement team we will monitor and report on progress nationally.
- 14. A full account of these actions, together with a range of further actions to support improvement of services including, for instance, steps to improve workforce skills, and strengthening safeguarding arrangements is set out in Parts 4-8. A timeline of the detailed actions is at **Annex B**.
- 15. Alongside this report, we are publishing a **Concordat** agreed with key external partners. It sets out a shared commitment to transform services, and specific actions which individual partners will deliver to make real change in the care and support for people with learning disabilities or autism with mental health conditions or behaviour that challenges.
- 16. This report focuses on the need for change, but there are places which already get this right. This shows that the change we intend to make is achievable. Alongside this report, we are publishing examples of good practice which demonstrate what can and should be done for all.

Part 1: Introduction

- 1.1 This Department of Health review responds to criminal abuse at Winterbourne View hospital revealed by the BBC Panorama programme in May 2011. It is equally concerned with the care and support experienced by all children, young people and adults with learning disabilities or autism who also have mental health conditions or behave in ways that are often described as challenging. For the purposes of this report, we describe this vulnerable group of people as "people with challenging behaviour".
- 1.2 There are currently an estimated 3,400 people in NHS-funded learning disability inpatient beds of which around 1,200 are in assessment and treatment units (usually known as A&T units)².
- 1.3 This report builds on the evidence and issues set out in the interim report published in June 2012³.
- 1.4 The picture from investigations and reviews, and from people who use services, their families, and the groups which represent them⁴ is of good services in some places, but too often they fall short. Too many people do not receive good quality care. The review found widespread poor service design, failure of commissioning, failure to transform services in line with established good practice⁵, and failure to develop local services and expertise to provide a person-centred and multidisciplinary approach to care and support.
- 1.5 Starting now and by June 2014, we must and we will transform the way services are commissioned and delivered to stop people being placed in hospital inappropriately, provide the right model of care, and drive up the quality of care and support for all people with challenging behaviour.
- 1.6 This is not easy. Developing the right range of services locally to build up necessary expertise is a complex task though that will be made easier with pooled budgets. But there is clear and readily available guidance and evidence for what works⁶. That guidance has been available for years. There are no excuses for local health and care

² There is poor quality data about the numbers of people with challenging behaviour. In the interim report we focused on the 1,200 beds in A&T units in the CQC Count me in Census 2010. In this report we have used the larger estimate of 3,400 people in NHS funded inpatient beds (from the same census). This is because some people may be in rehabilitation or other types of unit which provide A&T services and we also want to avoid inpatient services simply re-badging themselves.

³ Department of Health Review: Winterbourne View Hospital:Interim Report Interim Report: (June 2012) http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

⁴ see summaries of engagement with people with learning disabilities and families published alongside this report at www.dh.gov.uk/learningdisabilities

⁵ see Services for People with Learning disability and challenging behaviour or mental health needs 2007, Prof Jim Mansell.

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicandgudiance/dh_080129

6 see http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

Examples of good practice are published at http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

commissioners failing to come together to commission and design the services which will enable most people to live safely with support in their communities and prevent unnecessary admissions to hospital. There are no excuses for continuing to commission the wrong model of care.

- 1.7 The programme for change described below draws on actions in the interim report⁷ to which external delivery partners have already committed. A more detailed action plan will be agreed and monitored by the national Learning Disability Programme Board chaired by the Minister of State for Care and Support. The Board will measure progress against milestones, monitor risks to delivery, and challenge partners, to ensure all of these commitments are delivered.
- 1.8 In addition to this monitoring, the Department of Health will publish a progress report in one year, and again as soon as possible following 1 June 2014, to ensure that the steps set out in this report are achieved.

⁷ http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

Part 2: Winterbourne View hospital

- 2.1 When the interim report of this review was published in June, we were unable to comment on what happened in Winterbourne View hospital as criminal proceedings against former members of staff had not completed. Subsequently, all 11 individuals charged have pleaded guilty to all charges and have been sentenced (with custodial sentences for six former staff). The Crown Prosecution Service treated these offences as disability hate crimes, crimes based on ignorance, prejudice and hate, and brought this aggravating factor to the attention of the court in sentencing.
- 2.2 We now have a very detailed and compelling picture of the serious abuse suffered by patients at Winterbourne View hospital and the systematic way in which staff abused patients and misused restraint as punishment for what staff saw as bad behaviour.
- 2.3 The Serious Case Review (SCR) commissioned by South Gloucestershire Council Adult Safeguarding Board published on 7 August 2012 gives a compelling and comprehensive chronology of events at the hospital and we do not intend to duplicate that here.⁸
- 2.4 But now we have that picture, along with other reports shared as evidence to the SCR including reports from the police, the CQC, and the review by NHS South of England of commissioning of services at Winterbourne View hospital, we are able to draw firm conclusions about what went wrong.
- 2.5 Opened in December 2006, Winterbourne View was a private hospital owned and operated by Castlebeck Care Limited. It was designed to accommodate 24 patients in two separate wards and was registered as a hospital with the stated purpose of providing assessment and treatment and rehabilitation for people with learning disabilities. By the time the hospital was closed in June 2011, the majority of patients (73%) had been admitted to the hospital under Mental Health Act powers. Although thirteen were informal patients at admission, six of these were then detained under Mental Health Act powers after admission. On average, it cost £3,500 per week to place a patient in Winterbourne View.
- 2.6 Forty-eight patients had been referred to Winterbourne View by 14 different English NHS commissioners (there had also been a few placements from Wales); meaning that there was no one commissioner with a lead or strong relationship with the hospital. Similarly, South Gloucestershire Council, in whose area the hospital was located, was not party to the majority of referrals to Winterbourne View hospital.

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⁸ South Gloucestershire Safeguarding Adults Board *Winterbourne View Hospital: A Serious Case Review* by Margaret Flynn (2012) http://www.southglos.gov.uk/Pages/Article%20Pages/Community%20Care%20-%20Housing/Older%20and%20disabled%20people/Winterbourne-View-11204.aspx

- 2.7 This also meant that although a significant minority of patients were local to the hospital almost half of the patients at Winterbourne View were placed far away from their homes. Of 48 patients:
 - 13 were referred by commissioners located within 20 miles;
 - a further 12 patients were referred by commissioners between 20 and 40 miles away;
 - 14 patients were referred by commissioners between 40 and 120 miles away; and
 - 9 patients were referred by commissioners more than 120 miles away.
- 2.8 For just under half of the people in Winterbourne View, the main reason for referral was management of a crisis suggesting a real lack of planning for crises or local responsive services for people with this type of support need.
- 2.9 **People were staying at Winterbourne View hospital for lengthy periods**. The average length of stay at Winterbourne View was around 19 months but some patients had been there more than three years when the hospital closed and this in a hospital which was open for less than five years.
- 2.10 There is little evidence of urgency in considering discharge and move-on plans for Winterbourne View patients. It is worth noting for instance that 10 patients detained under Mental Health Act powers remained in Winterbourne View after their period of detention ended in one case for a further 18 months.
- 2.11 One of the most striking issues is the **very high number of recorded physical interventions** at Winterbourne View (ie of patients being physically held to prevent danger to themselves or others). The Serious Case Review notes that Castlebeck Care Ltd recorded a total of 558 physical interventions between 2010 and the first quarter of 2011, an average of over 1.2 physical interventions per day. One family provided evidence that their son was restrained 45 times in 5 months, and on one occasion was restrained "on and off" all day. It is very difficult to see how such high numbers of interventions could possibly be seen as normal.
- 2.12 Opportunities to pick up poor quality of care were repeatedly missed by multiple agencies. For instance:
 - Winterbourne View patients attended NHS Accident and Emergency services on 78 occasions while Winterbourne View was open but there was no process in place for linking these so that an overall picture emerged;
 - Between January 2008 and May 2011 police were involved in 29 incidents concerning Winterbourne View patients;
 - Between January 2008 and May 2011, 40 safeguarding alerts were made to South Gloucestershire Council but these were treated as separate incidents. 27 were allegations of staff to patient assaults, 10 were patient on patient assaults and three were family related incidents.
- 2.13 The Serious Case Review provides evidence **of poor quality healthcare**, with routine healthcare needs not being attended to for instance there were widespread dental problems and "most patients were plagued by constipation". Many patients were being given anti-psychotic and anti-depressant drugs without a consistent prescribing policy.

- 2.14 The Serious Case Review also sets out very clearly that for a substantial portion of the time in which Winterbourne View operated, families and other visitors were not allowed access to the wards or individual patients' bedrooms. This meant there was very little opportunity for outsiders to observe daily living in the hospital and enabled a **closed** and punitive culture to develop on the top floor of the hospital. Patients had limited access to advocacy and complaints were not dealt with.
- 2.15 There is strong and compelling evidence of **real management failure at the hospital.**The Serious Case Review says that on paper Castlebeck's policies, procedures, operational practices and clinical governance were impressive. The reality was very different:
 - for much of the period in which Winterbourne View operated, there was no Registered Manager (even though that is a registration requirement);
 - approaches to staff recruitment and training did not demonstrate a strong focus on quality. For example, staff job descriptions did not highlight desirability of experience in working with people with learning disabilities or autism and challenging behaviour – nor did job descriptions make any reference to the stated purpose of the hospital;
 - there is little evidence of staff training in anything other than in restraint practices;
 - although structurally a learning disability nurse-led organisation, it is clear that Winterbourne View had, by the time of filming by Panorama, become dominated to all intents and purposes by support workers rather than nurses; and
 - there was very high staff turnover and sickness absence among the staff employed at the hospital.
- 2.16 All this suggests that managers at the hospital and the parent company, as well as commissioners, regulators and adult safeguarding, had a number of opportunities to pick up indications that there were real problems at Winterbourne View, but failed to do so.
- 2.17 The very high number of recorded restraints, high staff turnover, low levels of training undertaken by staff, the high number of safeguarding incidents and allegations of abuse by staff all could have been followed up by the **hospital itself or by Castlebeck Care Ltd**, but were not to any meaningful extent. This failure by the provider to focus on clinical governance or key quality markers is striking, and a sign of an unacceptable breakdown in management and oversight within the company.
- 2.18 Equally it is striking that adult safeguarding systems failed to link together the information. NHS South of England's review highlighted the absence of processes for commissioners to be told about safeguarding alerts some commissioners were aware of concerns and failures to follow up concerns when commissioners became aware of them.
- 2.19 Despite the high cost of places at Winterbourne View (on average £3,500 per week) **commissioners** do not seem to have focused much on quality, or on monitoring how the hospital was providing services in line with its registered purpose ie. assessing the needs of individuals and promoting their rehabilitation back home. The lack of any substantial evidence that people had meaningful activity to do in the day, the way in which access by outsiders to wards was restricted, reports of safeguarding alerts (where

- these were shared with commissioners) should have been followed up rigorously, but were not. This amounts to a serious failure of commissioning.
- 2.20 The **CQC** acknowledged that they did not respond to the Winterbourne View hospital whistleblower and that neither they nor their predecessor organisations followed up on the outcomes of statutory notifications and clearly failed to enforce the requirement for there to be a registered manager.
- 2.21 The **Mental Health Act Commissioner** was notified on more than one occasion of incidents, and in its annual report in May 2008 referenced the need for action to improve but it was not followed up.
- 2.22 The **Police** have acknowledged that they took explanations from staff at face value. Avon and Somerset Constabulary police were involved in 29 incidents concerning Winterbourne View patients. Eight of the reported incidents were associated with staff using physical restraint on patients. The Police secured the successful prosecution of one member of staff prior to the Panorama programme.

What happened to people at Winterbourne View

2.23 Patients at Winterbourne View hospital were subject to horrific and sustained abuse, ill-treatment and neglect. The Serious Case Review has thrown down a challenge to health and social care commissioners to ensure that the individual patients and their families get the support they need to recover from their experience. The Department of Health supports that challenge.

Out of Sight: Stopping the abuse of people with a learning disability provides an update on what happened to Simon, one of the patients at Winterbourne View.

Simon's Mum said:

Simon is now back living near us, and he is loving every minute of his life. He is at the same residential care home he was in before he was sent away, but the service has been adapted so that it meets his needs. They have done this by developing a flat for him adjoining the care home, where he lives with his support team. It is his own space, an oasis of quiet and calm.'

Simon's package of care now costs about half as much as it did for him to be in Winterbourne View. The staff he has now have been wonderful and are truly dedicated. I know that not only is Simon happy, he is safe."

- 2.24 But we know that not every one who was at Winterbourne View has had the same experience as Simon. Indeed, the second Panorama programme broadcast on 29 October 2012 showed that some others who had suffered abuse have continued to be moved to hospitals far from home.
- 2.25 DH asked NHS South of England to coordinate follow up on what happened to the 48 English NHS patients who had been in Winterbourne View hospital. In March 2012:
 - 26 former patients had moved into a range of social care supported arrangements and 22 patients were in various inpatient facilities;
 - 19 had been subject to a safeguarding alert in their new location;

- 27 people had required support related to the trauma experienced at Winterbourne View hospital.
- 2.26 This exercise was repeated in September 2012. At that point:
 - Additional hospital discharges had taken place with 32 former patients in a range of social care settings and 16 patients in inpatient setting.
 - there were initial safeguarding alerts or active safeguarding procedures for six people at the time of the exercise.
- 2.27 Whilst one cannot generalise from such a small group of patients, the fact that two thirds of those in Winterbourne View are now in social care supported arrangements gives a strong indication of what is possible.
- 2.28 DH will continue to seek assurance about what has happened to this group of people.

Part 3: The picture beyond Winterbourne View

- 3.1 The events at Winterbourne View triggered a wider review of care across England for people with challenging behaviour. This included a programme of CQC inspections of nearly 150 learning disability services together with engagement by the Department of Health to seek the experiences and views of people with learning disabilities and people with autism some of whom had experienced care in hospital settings as well as families, organisations who represent the interests of this group of people, professionals and providers.
- 3.2 The interim report of the Department of Health review published in June 2012¹⁰ set out the findings:
 - too many people were placed in hospitals for assessment and treatment and staying there for too long;
 - they were experiencing a model of care which went against published Government guidance that people should have access to the support and services they need locally, near to family and friends;
 - there was widespread poor quality of care, poor care planning, lack of meaningful activities to do in the day and too much reliance on restraining people; and
 - all parts of the system have a part to play in driving up standards.
- 3.3 The interim report identified concerns about the quality of person centred planning, involvement of people and families in developing their care plan, and in ensuring personalised care and support.
- In addition, the interim report summarised published good practice guidance including the 1993 Mansell report, updated and revised in 2007¹¹, which emphasise:
 - the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers;
 - a focus on personalisation and prevention in social care;
 - that commissioners should ensure services can deliver a high level of support and care to people with complex needs or challenging behaviour; and
 - that services/support should be provided locally where possible.

⁹ The summary CQC report was published in June 2012. http://www.cqc.org.uk/public/reports-surveys-and-reviews/themed-inspections/review-learning-disability-services

http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

Services for people with learning disabilities and challenging behaviour or mental health needs October 2007, Professor Jim Mansell – see

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 080129

- 3.5 Three examples of good practice Salford, Tower Hamlets and Cambridgeshire were published alongside the interim report. 12
- 3.6 As a first step to driving redesign, the interim report set out the model of care which practice demonstrates will give the best quality of life and support and improve outcomes. This is summarised in here and set out in detail at **Annex A.**
- 3.7 In summary, the norm should always be that children, young people and adults live in their own homes with the support they need for independent living within a safe environment. Evidence shows that community-based housing enables greater independence, inclusion and choice, and that challenging behaviour lessens with the right support. People with challenging behaviour benefit from personalised care, not large congregate settings¹³. Best practice is for children, young people and adults to live in small local community-based settings.
- 3.8 Where children, young people and adults need specialist support the default position should be to put this support into the person's home through specialist community teams and services, including crisis support.
 - the individual and her/his family must be at the centre of all support services designed around them and with their involvement, highly individualised and personcentred across health and social care (including access to personal budgets and personal health budgets where appropriate);
 - people's homes should be in the community, supported by local services;
 - people need holistic care throughout their life, starting in childhood;
 - when someone needs additional support it should be provided as locally as possible;
 and
 - when someone needs to be in hospital for a short period, this should be in small inpatient settings as near to their home as possible.
- 3.9 This means that people with challenging behaviour should only go into specialist hospital settings exceptionally and where there is good evidence that a hospital is the best setting to enable necessary assessment and treatment not the only available placement. From the beginning, the reason for admission must be clearly stated and families should be involved in decision making. Where an individual lacks capacity and does not have a family to support them, the procedures of the Mental Capacity Act 2005 should be followed to ensure that decisions made are in her/his best interest and, if appropriate, an Independent Mental Capacity Advocate appointed.
- 3.10 Where someone is admitted to hospital the priority from the start should be rehabilitation and returning home. This requires a strong and continuing relationship between local commissioners and service providers and the hospital, focused on the individual patient's care plan, and a real effort to maintain links with their family and the home community. It also means for example, maintaining the person's tenancy of their home where relevant unless and until a more appropriate home in the community is found. Most of all, it is vital that families are involved in decision-making.

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http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

¹³ NICE clinical guidelines for autism recommend that if residential care is needed for adults with autism it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation).

3.11 Sending people out of area into hospital or large residential settings can cause real harm to individuals by weakening relationships with family and friends and taking them away from familiar places and community. It can damage continuity of care. It can also mean putting people into settings which they find stressful or frightening. This can damage mental health or increase the likelihood of challenging behaviour. There should always be clear and compelling reasons for sending any individual out of area. The individual and their family should always be involved and told these reasons. When this does happen, commissioners and the community team from the home area must keep in close contact with the individual and their family as well as the commissioner for the area where the individual is placed to assess progress and plan for their return to their own community.

Good Practice

The **Association of Supported Living** members contributed to a study on good commissioning in which they describe the ingredients to the successful outcomes they had achieved in moving people who at some point have been contained in institutions. Now everyone has a better life in community services which cost less. Prior to changes, costs ranged from £91,000 to £520,000 (for a private secure unit) per annum, following a move to supported living, high end costs reduced from £520,000 to £104,000 per annum.

- 3.12 The Government's Mandate to the NHS Commissioning Board makes clear that the presumption should always be that services are local and that people remain in their communities.
- 3.13 This model is achievable. It has been tried and tested and it works. The good practice examples published alongside the Interim Report are community-based and multidisciplinary. They can respond when someone presents with challenging behaviour, responding to that individual, their family, and care and support providers to seek explanations for the behaviour. That enables services working in partnership to develop interventions and support based on an understanding of the individual and their environment. Multidisciplinary approaches are essential because of the complexity of need and the way in which different perspectives contribute to agreeing appropriate interventions.

Part 4: The right care in the right place

- 4.1 A central part of our plan for action is to ensure that people with challenging behaviour only go into hospital if hospital care is genuinely the best option, and only stay in hospital for as long as it remains the best option. Our plan requires health and care partners to:
 - a. review all current placements, and support everyone inappropriately in hospital to move to community-based support;
 - in parallel, put in place a locally agreed joint plan to ensure high quality care and support services for all people with challenging behaviour that accord with the right model of care from childhood onwards; and
 - c. give national leadership and support for local change.
- 4.2 The patients at Winterbourne View were not listened to or believed when they told people about abuse. Their families were often not involved in decisions about where they were sent, parents and siblings found it increasingly difficult to visit and families' concerns and complaints often were not acted on. This failure to listen to people with challenging behaviour and their families is sadly a common experience and totally unacceptable. It leaves people feeling powerless.
- 4.3 We expect all actions in this programme to be appropriately informed by the views and needs of people with challenging behaviour and families in line with the NHS Constitution which can mean providing appropriate advice, information and support. This will happen at all levels, locally and nationally:
 - people with learning disabilities and families will be members of the Learning Disability Programme Board;
 - CQC will involve self-advocates and families in inspections and in their stakeholder aroup:
 - the NHSCB, LGA, and ADASS will involve them in planning and supporting changes in the way care is developed.
- 4.4 Changing attitudes to people with challenging behaviour is vital. Tackling disability hate crime is an issue the Department of Health takes very seriously. The Department is already taking steps to improve its understanding of disability hate crime and to deliver better outcomes for patients including those with learning disabilities.

4.a REVIEW ALL CURRENT PLACEMENTS AND SUPPORT EVERYONE INAPPROPRIATELY IN HOSPITAL TO MOVE TO COMMUNITY BASED SUPPORT

- 4.5 By 1 June 2014 we expect to see a rapid reduction in the number of people with challenging behaviour in hospitals or in large scale residential care particularly those away from their home area. By that date, no-one should be inappropriately living in a hospital setting. This is a three stage process which involves:
 - commissioners making sure they know who is in hospital and who is responsible for them:
 - health and care commissioners working together and with partners to review the care people are receiving;
 - commissioners working with individuals to agree personal care plans and bringing home or to appropriate community settings all those in hospital¹⁴.
- 4.6 DH will closely monitor progress in bringing these numbers down. The Government's Mandate to the NHSCB emphasises the expectation for a substantial reduction in reliance on inpatient care for these groups of people.
- 4.7 Progress in this area will be dependent on developing the range of responsive local services which can prevent admissions to hospital or other large institutional settings and allow any existing patients to be moved to better settings, closer to home. This may involve better use of existing Mental Health services with the right reasonable adjustments, or the commissioning of new, smaller and more local inpatient units where they are needed. But the emphasis should be on designing community services in line with the best practice model. We would expect to see a dramatic and sustained reduction in the number of assessment and treatment units and beds as a result of this shift.

Agreeing who should be reviewed and who is responsible for them

4.8 Commissioners need to make sure they know who is in hospital and who is responsible for them.

Key Actions:

The NHS Commissioning Board will:

- ensure by 1 April 2013 that all Primary Care Trusts develop local registers of all people with challenging behaviour in NHS-funded care;
- make clear to Clinical Commissioning Groups in their handover and legacy arrangements what is expected of them, including:
 - o maintaining the local register from 1 April 2013; and
 - reviewing individuals' care with the Local Authority, including identifying who should be the first point of contact for each individual.

¹⁴ For a very small number of people with complex needs, this can be a lengthy process. However, we expect this process to be carried out as quickly as possible. If, by this time, there are a very small number of cases where plans are agreed but not yet fully implemented, progress will be closely monitored.

Reviewing care and agreeing personal care plans

- 4.9 People should have the right care and support package to meet their individual needs. The care plans of all inpatients with challenging behaviour will be reviewed individually. Commissioners will assess whether they can create a better, community-based support package tailored as far as possible to each individual's needs.
- 4.10 People with challenging behaviours and their families will have the support they need to ensure they can take an active part in these reviews being provided with information, advice and independent advocacy, including peer advocacy.
- 4.11 Personal care plans should be enacted swiftly and safely. In many instances this will require the development of more personalised services in different settings so that individuals can be better supported at home or in the community. Although doing this can take time, the Department of Health expects it to be carried out with pace and a sense of urgency whilst always putting the interest of the individual first.
- 4.12 Where responsibility transfers from the NHS to local government, councils should not be financially disadvantaged. The NHS should agree locally how any new burden on local authorities will be met, whether through a transfer of funding or as part of a pooled budget arrangement.

Key Actions

By 1 June 2013, health and care commissioners, working with service providers, people who use services and families will review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual based around their and their families' needs and agreed outcomes.

Plans should be put into action as soon as possible, and all individuals should be receiving personalised care and support in the appropriate community settings no later than 1 June 2014.

4b. LOCALLY AGREED PLANS TO ENSURE HIGH QUALITY CARE AND SUPPORT SERVICES WHICH ACCORD WITH THE MODEL OF GOOD CARE

4.13 In parallel with the actions for people currently in hospital, every local area will put in place a locally agreed joint plan to ensure high quality care and support services for <u>all</u> people with challenging behaviour that accords with the model of good care. These plans should ensure that a new generation of inpatients does not take the place of people currently in hospital.

Commissioning the right model of care and challenging poor practice

- 4.14 We expect commissioners to work together to drive the move from hospital care to good quality local, community-based services, and account for how they do this. This involves:
 - better joint working between health and care; and
 - using the evidence on good practice.
- 4.15 Health and care commissioners are accountable for commissioning services to meet identified needs. It is essential that they work together to develop specific plans for improving health and care services for this particular group of people. This goes wider than health and adult social care; in particular, a strategic plan must also include children's services and specialist housing.

Gloucestershire County Council and NHS Gloucestershire have a (joint) strategic commissioning plan which includes bringing people back into the county. "For at least two years we have had a joint LA & NHS Learning Disability commissioning team (Gloucestershire CC and NHS Gloucestershire). We work from a common plan and as lead commissioner I head up the team of 8 people. We have commissioners from both health and social care. Health team members are directly engaged with complex people including people 100% funded by health and both LA and NHS colleagues work with people placed out of county".

Referrals for anyone needing additional assessment or treatment also go through this team to a specialist Learning Disability NHS service whose aim is to prevent admission for assessment and treatment. Social care commissioning colleagues in the team also access the NHS A&T service this way. This also means that if anyone's current services need additional resources to avoid breakdown, before the resources are allocated, the specialist NHS Learning Disability service would ensure this is necessary and value for money.

- 4.16 Local health and care commissioners and services should be commissioning integrated care care co-ordinated and personalised around the needs of individuals with a presumption that care should be local and that people should stay in their communities. This is more likely to happen if:
 - Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) take account of the health and care needs of people with challenging behaviour; and
 - health and care commissioners pool budgets.
- 4.17 Pooled budgets with shared accountabilities are likely to facilitate the development of more integrated care. They may help overcome the lack of strong financial incentives on a single commissioner to invest in community services (eg where the cost of investment in supported living in local communities falls to councils while savings from reduced reliance on hospital services go to NHS commissioners). There should be a clear presumption that budgets should be pooled and that health and wellbeing boards should promote collaborative working and the use of pooled budgets.
- 4.18 Commissioners need to work with providers of specialist services to ensure that community learning disability teams have the additional, intensive support they need to keep people out of hospital including in crises. They will also need to have access to local inpatient mental health services where these are genuinely required. This will reduce the need for hospital admissions out of area.
- 4.19 Finally, there is consensus that large hospital units are outdated and inappropriate and do not provide the care which people with challenging behaviour need. It is our clear expectation that commissioners should not place people in large hospitals. There may be a few people who need inpatient care, but this should be provided in smaller units and as close to home as possible. Any new, small specialist hospitals should only be built where JSNAs show a genuine unmet local need for such provision in a way which is consistent with good models of care. Local commissioners should have oversight of the services available in their areas and take the lead in discussing future need and what additional facilities are required. In addition, CQC will take account of the model of care in its revised guidance about compliance and in the registration and inspection of providers, as part of its new regulatory model.

Key Actions:

By April 2014, CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area. This could potentially be undertaken through the health and wellbeing board and could be considered as part of the local Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy (JHWS) processes.

The strong presumption will be in favour of pooled budget arrangements with local commissioners offering justification where this is not done. The NHSCB, ADASS and ADCS will promote and facilitate joint commissioning arrangements.

Evidence on best practice

4.20 Commissioning needs to draw on the evidence of what is best practice in the care of people with challenging behaviour. The Model of Care set out in this report is based on well established evidence. To strengthen the evidence base, NICE is developing further standards and guidelines for this group of people, to go alongside the standards already published on autism clinical pathways.

Key Actions:

By Summer 2015 NICE will publish quality standards and clinical guidelines on challenging behaviour and learning disability.

By Summer 2016 NICE will publish quality standards and clinical guidelines on mental health and learning disability.

4.21 NICE will also develop new quality standards on child maltreatment. They will focus on the recognition and response to concerns about abuse and neglect and effective interventions. These will support the use of the Government's statutory guidance, Working Together to Safeguard Children. 15

Prioritising children and young people's services

- 4.22 Children and young people with challenging behaviour can face particular difficulties and crises as they move from child to adult services. Integrating care and support around their needs and ensuring that they have access to the services identified in their agreed care plan is vital.
- 4.23 For children and young people with special educational needs or disabilities the Mandate to the NHS Commissioning Board sets out the expectation that children will have access to the services identified in their agreed care plan and that parents of children who could benefit will have the option of a personal budget based on a single assessment across health, social care and education. This means:
 - integrated planning around the needs of individual children; and
 - identifying best outcomes and measuring progress.
- 4.24 Local health and care commissioners need to plan strategically to develop local services that properly meet the needs of children and young people in the area where they live.

Good practice:

Ealing services for children with additional needs set up "The Intensive Therapeutic & Short Break Service (ITSBS). The service provides a viable model for significantly reducing challenging behaviour and securing home placement stability for a small but significant number of children and young people whose challenging behaviour would otherwise most likely result in a

¹⁵ https://www.education.gov.uk/publications/eOrderingDownload/00305-2010DOM-EN-v3.pdf

move to residential placements. Residential placement was avoided for all five young people who had been offered the service between 2008 and 2010. Residential placement has also been avoided for six out of the seven young people who were first offered the service between 2010 and 2011.

Key Actions:

The Department of Health will work with the Department of Education (DfE) to introduce from 2014 a new single assessment process and Education, Health and Care Plan to replace the current system of statements and learning difficulty assessments for children and young people with special educational needs; supported by joint commissioning between local partners (subject to parliamentary approval). The process will include young people up to the age of 25, to ensure they are supported in making the transition to adulthood.

Both Departments will work with the independent experts on the Children and Young People's Health Outcomes Forum to prioritise improvement outcomes for children and young people with challenging behaviour and agree how best to support young people with complex needs in making the transition to adulthood. This will report by June 2013.

4.25 Children and young people and their families need to be involved in this work.

4c. NATIONAL LEADERSHIP SUPPORTING LOCAL CHANGE

4.26 While changes to people's lives require action at a local level, with local commissioners and providers working together, change of this scale, ambition and pace requires **national leadership**. To provide leadership and support to the transformation of services locally, the LGA and the NHSCB will develop an improvement programme led by a senior sector manager. This will be in addition to the cross-government programme board.

Key Actions:

The Local Government Association and NHS Commissioning Board will establish a joint improvement programme to provide leadership and support to the transformation of services locally. They will involve key partners including DH, ADASS, ADCS and CQC in this work, as well as people with challenging behaviour and their families. The programme will be operating within three months and Board and leadership arrangements will be in place by the end of December 2012. DH will provide funding to support this work.

At a national level, from December 2012, the cross-government Learning Disability Programme Board chaired by the Minister of State for Care and Support will lead delivery of the programme of change by measuring progress against milestones, monitoring risks to delivery, and challenging external delivery partners to deliver to plan, regularly publishing updates.

4.27 Social care and health commissioners will be accountable to local populations and will be expected to demonstrate that they have involved users of care and their families in planning and commissioning appropriate local services to meet the needs of people with challenging behaviour. Families and self advocates have an important role to play in challenging local agencies to ensure that people have local services and the optimum model of care. There is a clear need both to challenge localities for failing to redesign services, and to provide practical support to help them do so.

Good Practice

There are many examples of good local practice in this area.

In **Salford**, in the last 5 years 16 people with a learning disability and behaviour that challenges living out of area have returned to their communities.

Beyond Limits have been commissioned by NHS Plymouth (now Devon CCG) to develop local personalised commissioning/provider processes and tailor-made services for people who have experienced long term, multiple placements and institutionalised living because their behaviours have challenged existing services. They are piloting this through facilitating planning for 20 people currently in out of area Specialist Assessment &Treatment Units and then providing support using personal Health Budgets.

- 4.28 Providers have a key role to play in redesigning service, working closely with commissioners, people who use services and families. The national market development forum within the Think Local Act Personal (TLAP) partnership will work with DH to identify barriers to reducing the need for specialist hospitals and by April 2013 will publish solutions for providing effective local services.
- 4.29 The Developing Care Markets for Quality and Choice programme will support local authorities to identify local needs for care services and produce market position statements, including for learning disability services.
- 4.30 The NHSCB will also work with ADASS to develop by April 2013 practical resources for commissioners of services for people with learning disabilities, ¹⁶ including:
 - model service specifications;
 - new NHS contract schedules for specialist learning disability services;
 - models for rewarding best practice through the NHS Commissioning for Quality and Innovation (CQUIN) framework; and
 - a joint health and social care self-assessment framework to support local agencies to measure and benchmark progress.

Key Action:

By March 2013 the NHSCB and ADASS will develop service specifications to support CCGs in commissioning specialist services for children, young people and adults with challenging behaviour built around the model of care in Annex A.

4.31 DH will ensure health and wellbeing boards have guidance and information to support them to understand the complex needs of people with challenging behaviour.

This will build on the guidance published in October 2012, *Improving the health and wellbeing of people with learning disabilities: an evidence-based commissioning guide for clinical commissioning groups.*<a href="http://www.improvinghealthandlives.org.uk/publications/1134/Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups

Part 5: Strengthening accountability and corporate responsibility for quality of care

5.1 Although 11 former members of staff at Winterbourne View have been sentenced in connection with the abuse of patients, this review has identified weaknesses in the system of accountability where leaders of organisations are not fully held to account for poor quality or for creating a culture where neglect and even abuse can happen.

Quality of care

- The primary responsibility for the quality of care rests with the providers of that care. Owners, Boards of Directors and Senior managers of organisations which provide care must take responsibility for ensuring the quality and safety of their services. The requirements set out in law include:
 - safe recruitment practices which select people who are suitable for working with people with learning disabilities or autism and behaviour that challenges;
 - providing appropriate training for staff on how to support people with challenging behaviour;
 - providing good management and right supervision;
 - providing leadership in developing the right values and cultures in the organisation;
 - having good governance systems in place; and
 - providing good information to support people making choices about care and support, including the views of people who use services about their experience.
- 5.3 We also expect boards to demonstrate good practice and comply with further legal requirements, which include:
 - Directors, management and leaders of organisations providing NHS or local authority-funded services must ensure that systems and processes are in place to provide assurance to themselves, service users, families, local Healthwatch and the public that essential requirements are being met and that they deliver high quality and appropriate care;
 - the Boards of care providers should understand the quality of the care and support services they deliver; and
 - organisations must identify a senior manager or, where appropriate a Director, to ensure that the organisation pays proper regard to quality, safety, and clinical governance for that organisation.

Key Action:

We expect Directors, management and leaders of organisations providing NHS or local authority-funded services to ensure that systems and processes are in place to provide assurance that essential requirements are being met and that they have governance systems in place to ensure they deliver high quality and appropriate care.

Sanctions to hold Boards to account when the quality of care is unacceptable:

5.4 There must be robust consequences for senior managers or Boards of Directors of services where through neglect the organisations they lead provide poor quality of care or where people experience neglect or abuse.

CQC's enforcement powers

- 5.5 CQC will take steps to strengthen the way it uses its existing powers to hold organisations to account for failure to meet legal obligations to service users. CQC registers providers at an organisational level. However, its inspections take place at the level at which services are delivered. As a result CQC has not always held organisations to account at a corporate level, but rather at the level of the regulated service. This needs to be addressed.
- 5.6 While most organisations providing care put in place governance arrangements that support safety and quality, some do not pay sufficient attention to this area. Where the leadership of an organisation allows a culture to develop that does not foster safety and quality in care, the people providing that leadership have to be held to account for the service failings. In the words of the serious case review, "Castlebeck Ltd's appreciation of events... was limited, not least because they took the financial rewards without any apparent accountability."
- 5.7 This is an unacceptable situation and must change. CQC already has powers to take action:
 - CQC is able to take tough enforcement action against organisations that do not meet
 the registration requirements, including stopping them from providing specific
 services or operating from specific locations. In the most extreme cases CQC can
 cancel a provider's registration, stopping it from providing any health or adult social
 care:
 - it is already an offence under the Health and Social Care Act 2008 not to meet the essential levels of safety and quality. This would include, for example, not making suitable arrangements to ensure that service users are safeguarded against the risk of abuse. As well as prosecuting the corporate provider for a failure to meet the registration requirements, CQC can prosecute individual directors or managers where the offence can be proven to have been committed by, or with the consent or connivance of, or attributable to any neglect on the part of that individual.
- 5.8 It is important that CQC makes full use of its existing powers to hold the corporate body to account. CQC will meet with executives of provider organisations when there are serious concerns about quality and safety issues to discuss their plans to deliver safe

and effective care. Since summer 2012, CQC has appointed corporate compliance managers to assess the quality and safety of care of large providers who operate across a large area.

Key Action:

CQC will take steps now to strengthen the way it uses its existing powers to hold organisations to account for failures to provide quality care. It will report on changes to be made from Spring 2013.

Fit and proper person test

- 5.9 CQC will also consider whether it is able to use its existing powers to carry out a fit and proper person test of Board members as part of the registration of providers. One option for this could be to require providers to nominate an individual Board member with responsibility for quality who would be accountable to CQC for the quality of care. If this person did not meet the fit and proper person test, CQC could insist that another Board member is nominated. CQC could not use its existing powers to bar an individual from being a member of the Board, since Directors are not required to register with CQC.
- 5.10 DH will explore how a stronger fit and proper person test for board members of health and social care providers can be introduced to make it comparable to fit persons' tests in other sectors. This will include looking at:
 - the tests applied by the Financial Services Authority, the Premier League and the Charity Commission, which look at an individual's past performance with regards to other regulatory systems;
 - prior involvement with other companies which may have had their licences revoked, withdrawn or terminated; and
 - if they or any business associated with them, has been suspended or criticised by a
 regulatory or professional body. Where individuals fail to meet these tests,
 regulators can deem them to be unsuitable to hold certain positions and
 organisations face regulatory action or risk being refused registration, where such
 persons are appointed. DH will examine if a similar approach could be applied to
 board members of health and social care providers.

Holding corporate bodies to account for poor care

- 5.11 There can be no excuse for Directors or managers allowing bullying or the sort of abusive culture seen in Winterbourne View. Individuals should not profit from others' misery.
- 5.12 DH will examine how corporate bodies, their Boards of Directors and financiers can currently be held to account under law for the provision of poor care and the harm experienced by people using those services.
- 5.13 There are a number of potential criminal offences for which a Board Director or Manager could be prosecuted:

- there are offences under general criminal law. For example, in cases where it is
 proved that an individual board member or manager has committed an offence
 against a person or aided and abetted the commission of any offence (such as an
 assault), then such individuals could also be prosecuted in accordance with general
 criminal law;
- organisations can be prosecuted for offences under the Corporate Manslaughter and Corporate Homicide Act 2007 if the service provider's organisation is managed in such a way that it caused a person's death. The track record of prosecution in such cases – despite new legislation being introduced expressly to address corporate failure – is thin.

Key Action:

The Department of Health will immediately examine how corporate bodies, their Boards of Directors and financiers can be held to account for the provision of poor care and harm, and set out proposals during Spring 2013 on strengthening the system where there are gaps.

We will consider both regulatory sanctions available to CQC and criminal sanctions. We will determine whether CQC's current regulatory powers and its primary legislative powers need to be strengthened to hold Boards to account and will assess whether a fit and proper persons test could be introduced for board members.

Developing leadership in Boards

5.14 Boards should ensure they have proper governance arrangements in place and take seriously their corporate responsibilities towards the people for whom they provide care. DH will explore with the National Skills Academy and the NHS Leadership Academy options to develop proposals on Board leadership development by March 2013.

Part 6: Tightening the regulation and inspection of providers

6.1 What happened at Winterbourne View raised profound questions about how regulation and inspection was working. As a result of Winterbourne View, and learning from their programme of inspecting nearly 150 learning disability hospitals, CQC is seeking to improve the way it regulates and inspects providers. In particular, CQC is committed to delivering on the recommendations set out in their Internal Management Review¹⁷, the findings of the Serious Case Review, the evaluation of their inspection of nearly 150 learning disability services¹⁸, and any relevant matters from the consultation on their strategy for 2013-16¹⁹ to ensure that its regulation of providers is robust.

6.2 This means:

- checking how services fit with national guidance;
- improving inspection; and
- improving information sharing.
- 6.3 Providers are already required to have regard to national guidance, as one of the requirements of regulation monitored by CQC. The model of care at Annex A sets out an agreed framework for best practice in this area. CQC will take action to ensure this model of care is considered as part of inspection and registration of relevant services in their new regulatory model which will be implemented in 2013. CQC will also include reference to the model of care in their revised guidance about compliance, which will also be published in 2013. Where services are not provided in line with this model of care, CQC will seek assurance that the provider's approach still delivers care in line with national guidance and legal requirements.

Key Action:

CQC will use existing powers to seek assurance that providers have regard to national guidance and the good practice set out in the model of care at Annex A.

- 6.4 In addition, CQC will:
 - share the information, data and details they have about prospective providers with the relevant CCGs and local authorities through their existing arrangements, who will, in turn, take account of the information and data shared by CQC when making decisions to commission care from the proposed service provider;

¹⁷ CQC Internal Management Review of the regulation of Winterbourne View (October 2011) http://www.cqc.org.uk/sites/default/files/media/documents/20120730_wv_imr_final_report.pdf

¹⁸ CQC Review of Learning Disability Services (June 2012)

http://www.cqc.org.uk/search/apachesolr_search/evaluation%20of%20learning%20disability%20services ¹⁹ CQC, The next phase: Our consultation on our strategy for 2013 to 2016 http://www.cqc.org.uk/sites/default/files/media/documents/cqc_strategy_consultation_2013-2016_tagged.pdf

- take steps now to strengthen the way we use existing powers to hold organisations to account for failures to provide quality care and report on changes to be made from Spring 2013;
- assess whether providers are delivering care consistent with the statement of purpose made at the time of registration, particularly in relation to length of stay and to whether treatment is being offered. Where it is not, CQC will take the necessary action (including, if necessary, enforcement action) to ensure that a provider addresses discrepancies either through changes to its services or changes to its statement of purpose;
- take tough enforcement action including prosecutions, restricting the provision of services, or closing providers down, where providers consistently fail to have a registered manager in place;
- take enforcement action against providers that do not operate effective recruitment procedures to ensure that their staff are suitably skilled, of good character and legally entitled to do the work in question. Operating effective recruitment procedures is a legal requirement and providers must be able to demonstrate to CQC that they have adequate procedures in place. Evidence of effective recruitment can include a provider showing it has requested criminal records checks for eligible employees (including any staff who regularly provide care or treatment) alongside checking references and qualifications. Where a provider has not requested criminal records checks on eligible employees, it will have to assure CQC that its recruitment procedures are still effective and that it can be evidenced that it is reasonable for the check not to have been made. Providers also commit an offence if they knowingly engage a person who is barred in activities such as providing healthcare or personal care. From 2014 the government will commence an explicit duty to check that a person is not barred before engaging them in these activities;
- continue to run the stakeholder group that helped to shape the inspection of 150
 learning disability services. It will continue to meet twice yearly and will be chaired
 by the CQC Chief Executive. CQC will review the role and function of the group as
 part of that work programme to make sure it continues to provide advice and
 critique on CQC's inspection and monitoring of providers;
- continue to make unannounced inspections of providers of learning disability and mental health services employing people who use services and families as vital members of the team;
- take a differentiated approach to inspections between different sectors of care
 provision to ensure the inspections are appropriate to the vulnerability and risk for
 the different care user groups (subject to the outcome of consultation on its new
 strategy);
- review, as part of its new strategy, the delivery of its responsibilities under s120 of the Mental Health Act 1983 for the general protection of patients detained under the Act which include wide powers to review the way in which the Act's functions and safeguards are working and investigating complaints by any person detained under the Act.

Key Actions:

CQC will take action to ensure the model of care is included as part of inspection and registration of relevant services from 2013. CQC will set out the new operation of its regulatory model, in response to consultation, in Spring 2013.

CQC will also include reference to the model in their revised guidance about compliance. Their revised guidance about compliance will be linked to the Department of Health timetable of review of the quality and safety regulations in 2013. However, they will specifically update providers about the proposed changes to the registration process in respect of models of care for learning disability services in 2013.

- 6.5 From 2013 arrangements for checking criminal records will become quicker and simpler with the introduction of a new service that will make criminal records certificates more portable. When the new service is running, the Department of Health will review the regulatory requirements about criminal records checks and consider whether providers should routinely request a criminal record certificate on recruitment.
- 6.6 Monitor will begin licensing non-foundation trust providers of NHS funded services from April 2014. Monitor will consider strengthening Board-level governance by including internal reporting requirements in the licensing conditions. This is in line with the recommendations from the Serious Case Review. Monitor and CQC are required to cooperate with each other and share information.
- 6.7 In its recent consultation document on licence conditions, Monitor proposed two requirements for providers to meet before they could obtain a licence:
 - a requirement for them to hold CQC registration; and
 - to confirm that their governors and directors, or equivalent people, are fit and proper persons.
- 6.8 The proposal is that these requirements would also appear in the licence conditions, making them on-going obligations which providers would have to continue to meet in order to continue to hold a licence. Monitor and CQC will be under a legal duty to seek to ensure that the conditions are consistent.
- 6.9 Ofsted, CQC, Her Majesty's Inspectorate of Constabulary (HMIC), Her Majesty's Inspectorate of Probation and Her Majesty's Inspectorate of Prisons will introduce a new joint inspection of multi-agency arrangements for the protection of children in England from June 2013. This approach, which is currently being piloted, will focus on the effectiveness of local authority and partners' services for children who may be at risk of harm, including the effectiveness of early identification and early help. The inspectorates intend to publish the arrangements for the inspections by April 2013.

6.10 Ofsted is responsible for inspecting children's homes, as well as boarding and residential provision in schools. Under new inspection frameworks published in September 2012 they will make judgements on the overall effectiveness, outcomes for children and young people, quality of care, safeguarding as well as leadership and management. Under the framework inspectors are expected to consider residents views on the service, to observe interactions between staff and children and young people and to obtain the views of relevant parties including social workers and the authorities responsible for placements.

Part 7: Improving quality and safety

- 7.1 Ensuring that commissioners are commissioning the right services, that organisations are properly accountable, and that regulation is most effective will tackle many of the systemic problems revealed by Winterbourne View. However, the Serious Case Review and the other evidence we have received make it clear that the programme of change must go wider.
- 7.2 The actions we have described so far are primarily for the Department of Health, commissioners and regulators to lead. However, this wider programme lays much greater weight on the responsibility of providers, professional bodies and others to lead. It covers:
 - making best practice normal;
 - improving the capacity of the workforce;
 - whistleblowing;
 - the Mental Health Act and Mental Capacity Act;
 - physical restraint;
 - medication; and
 - improving advocacy.

Making best practice normal

- 7.3 The fundamental responsibility for providing good quality care rests with providers. Representatives of provider organisations fully accept this. They have agreed to work together to develop options for improving quality, including bringing forward a pledge or code model based on shared principles along the lines of the TLAP Making it Real principles for learning disability providers.
- 7.4 Providers should involve people with learning disabilities and people with autism and their families in checking the quality of services.

Good Practice

Dimensions is a large social care provider that has made stringent efforts to monitor and improve quality and performance. It made a conscious decision to create a Compliance audit team separate from the operational management of services, believing that this tension would enable more objective and rigorous monitoring. The Dimensions Compliance team, together with a team of four Experts by Experience, work across each of the organisation's regions conducting service audits. The audits look at every aspect of the service from regulatory requirements, finance, health and safety and for evidence of better practice, including a two hour observation of staff interacting with the people they are supporting as well as on-going observation throughout the visit. The audit process gives a clear picture of what is happening in individual services and across the organisation, and forms part of the reporting of risk management up through its governance

structure, including the people it supports. The new systems are contributing to significant advances in quality and improved outcomes. Dimensions' intention is to promote best practice, ensure that it exceeds compliance requirements and demonstrate robust and rigorous processes of internal scrutiny in line with its vision and values.

7.5 Good practice guidance for the care of adults is well established²⁰. And there will be new statutory guidance in relation to children in long-term residential care.

Key Action:

The Department of Health and the Department for Education will develop and issue statutory guidance on children in long-term residential care (s85 and s86 of the Children Act 1989) in 2013.

Improving the capability of the workforce

- 7.6 Recruiting, training and managing the workforce is the responsibility of providers. The events at Winterbourne View highlighted that there are too many front-line staff who have not had the right training and support to enable them to care properly for people with challenging behaviour. This is a theme which has been reinforced by many of the families we have heard from.
- 7.7 It is crucial that staff who work with people with challenging behaviour are properly trained in essential skills. CQC will take enforcement action against providers who do not operate effective processes to ensure they have sufficient numbers of properly trained staff. Better skills and training are an important part of raising standards overall and we expect providers to ensure the people they employ are properly trained. However, the Department of Health, commissioners and other organisations will play an important role in setting expectations, creating standards and offering advice.
- 7.8 We expect commissioners to assure themselves that providers are meeting proper training standards. Contracts with learning disability and autism hospitals should be dependent on assurances that staff are signed up to the proposed Code of Conduct which the Department of Health has commissioned from Skills for Health and Skills for care, and minimum induction and training standards for unregistered health and social care assistants are being met.
- 7.9 From April 2013 Health Education England (HEE) will have a duty to ensure we have an education and training system fit to supply a highly trained and high quality workforce. HEE will work with the Department of Health, providers, clinical leaders, and other partners to improve the skills and capability of the workforce to respond to the needs of people with challenging behaviour and will examine ways to ensure that skills include knowing when and how to raise concerns, (in other words 'whistleblow') including on disability hate crime.

²⁰ see Services for People with Learning Disability and challenging behaviour or mental health needs 2007, Prof. Jim Mansell.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

- 7.10 HEE will expect that all new entrants are tested for their values and interpersonal skills, and will reach out into schools and colleges to ensure that young people with the right values consider a career in healthcare. HEE will ensure the values set out in the NHS Constitution lie at the heart of all it does.
- 7.11 It is crucial that staff who work with people with challenging behaviour should be properly trained in essential skills. HEE are committed to ensuring that non-professional members of the workforce (ie bands 1-4) receive continuing development and training to provide a skilled and highly motivated workforce.
- 7.12 It is not sufficient to have a well-trained workforce. There also needs to be good clinical and managerial leadership. The National Skills Academy for Social Care, on behalf of the Department of Health, published a Leadership Qualities Framework for Adult Social Care in October 2012. This builds on the principle that leaders that demonstrate the right values and behaviours at every level of the sector provide the best foundation for transforming social care.
- 7.13 There will be concerted effort across the system over the next year to ensure health and care professionals understand and are guided in achieving minimum standards, and aspire to best practice.

Key Actions

CQC will take enforcement action against providers who do not operate effective processes to ensure they have sufficient numbers of properly trained staff.

By December 2012 the professional bodies that make up the Learning Disability Professional Senate will refresh *Challenging Behaviour: A Unified Approach*²¹ to support clinicians in community learning disability teams to deliver actions that provide better integrated services.

By April 2013 the Academy of Medical Royal Colleges and the bodies that make up the Learning Disability Professional Senate will develop core principles on a statement of ethics to reflect wider responsibilities in the health and care system.

Skills for Care will develop by February 2013 a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour.

Skills for Health and Skills for Care will develop by January 2013 national minimum training standards and a code of conduct for healthcare support workers and adult social care workers. These can be used as the basis for standards in the establishment of a voluntary register for healthcare support workers and adult social care workers in England.

²¹ The Royal College of Psychiatrists and British Psychological Society and Royal College of Speech and Language Therapists: *A Unified Approach* (2007)

By end 2013 there will be a progress report on actions to implement the recommendations in *Strengthening the Commitment*, the report of the UK Modernising Learning Disability Nursing Review²².

Confidence in Whistleblowing

- 7.14 When things go badly wrong, and local management is reluctant to change, members of staff must feel it is safe for them to raise their concerns more widely and that they will be listened to. The interim report of this review set out action already taken to encourage whistleblowing²³. It also clarified roles within the system:
 - **Government:** in ensuring that the legislative framework in the Public Interest Disclosure Act is adequate;
 - **Employers**: in supporting staff to raise concerns by having a clear policy in place which makes it clear that staff who raise concerns will be supported and which provides ways to by-pass the immediate line management chain where necessary;
 - **CQC**: in monitoring concerns about patient safety raised with it and ensuring that timely referrals are made to the professional regulators where necessary; and
 - Professionals and other health and care workers: in raising concerns promptly.
- 7.15 CQC has strengthened its arrangements for responding to concerns that are raised with it by whistleblowers. Whistleblowing concerns are now monitored to ensure they are followed up and thoroughly investigated until completion and the information provided is included in regional risk registers, which list providers where 'major concerns' have been identified.
- 7.16 The Department of Health funds a free, confidential whistleblowing helpline for NHS and care staff and employers who need advice about raising concerns and for employers on best practice. The service, provided by Mencap, was extended for the first time to staff and employers in the social care sector. Mencap will shortly be announcing a campaign which aims to reduce the gap between those staff who know how to whistleblow and those who would feel comfortable in doing so.
- 7.17 In March 2012, we revised the NHS Constitution to include an expectation that staff will raise concerns, a pledge that concerns will be acted upon and an undertaking to give clarity around the existing legal rights to raise concerns. It is important that workers know to whom they can raise concerns and all employers should have a clear whistleblowing policy in place.
- 7.18 Where a doctor has good reason to think that patient safety is or may be seriously compromised by inadequate premises, equipment, or other resources, policies or systems, s/he has a duty to put the matter right if possible. Similar duties are laid on other professionals through their codes of conduct. In all cases, professionals must consider the wider implications of failing to report such concerns and the risks to patient safety.
- 7.19 The Department of Health has asked the LGA and NHSCB to take account of the recommendations of the Serious Case Review on whistleblowing. **Commissioners**

http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

²² Strengthening the Commitment' http://www.scotland.gov.uk/Publications/2012/04/6465/downloads

should ensure that organisations contracting with the NHS or a local authority include a condition of employment on its workers to report concerns where:

- a criminal offence has been, is being or is likely to be committed;
- a person has failed, is failing or is likely to fail to comply with any legal obligation to which he is subject;
- a miscarriage of justice has occurred, is occurring or is likely to occur;
- the health or safety of any individual has been, is being or is likely to be endangered;
- the environment has been, is being or is likely to be damaged; or
- information tending to show any matter falling within any one of the preceding paragraphs has been, is being or is likely to be deliberately concealed.

Improving safeguarding

- 7.20 Following consultation, **DfE is revising** *Working Together to Safeguard Children*, statutory guidance on how organisations, agencies and individuals working with children should work together to safeguard and promote their welfare. The guidance will be published in due course.
- 7.21 Events at Winterbourne View flagged the need to prioritise strengthening adult safeguarding arrangements. The Serious Case Review shows that adult safeguarding systems failed to link information. NHS South of England's review highlighted the absence of processes for commissioners to be told about safeguarding alerts and failures to follow up concerns when commissioners became aware of them. The Department of Health has already announced its intention to put Safeguarding Adults Boards on a stronger, statutory footing, better equipped both to prevent abuse and to respond when it occurs. By strengthening the safeguarding adults boards arrangements and placing health, NHS and the police as core partners on the boards we will help ensure better accountability, information sharing and a framework for action by all partners to protect adults from abuse.

Key Action:

The Department of Health will revise statutory guidance and good practice guidance to reflect new legislation and address findings from Winterbourne View, to be completed in time for the implementation of the Care and Support Bill (subject to parliamentary approval). In particular:

- Safeguarding Adults Boards will be put on a statutory footing, subject to parliamentary approval of the Care and Support Bill;
- local authorities will be empowered to make safeguarding enquiries, and Boards will have a responsibility to carry out safeguarding adults reviews;
- the Safeguarding Adults Board will publish an annual report on the exercise of its functions and its success in achieving its strategic plan; and
- the Safeguarding Adults Board core membership will consist of the LA, NHS and Police organisations, convened by the LA. Individual boards will be able to appoint other members in line with local need.
- 7.22 Local authorities should ensure that everyone involved in safeguarding is clear about their roles and responsibilities. All local authorities and their local safeguarding partners should ensure they have robust safeguarding boards and arrangements and have the

right information-sharing processes in place across health and care to identify and deal with safeguarding alerts. This requires a multi-agency approach including all partners. In recognition of the critical role of information sharing and multi-agency working in delivering successful outcomes for adults and children at risk, the Home Office is working in partnership with the Association of Chief Police Officers (ACPO), the Department of Health and the Department for Education to improve our understanding of the different local multi-agency models in place to support information sharing around safeguarding responses for vulnerable people.

- 7.23 Local areas need to work in partnership, including, where necessary with police and criminal justice agencies, to ensure that people returning to communities are supported adequately. This may include working with integrated offender management teams where appropriate.
- 7.24 NHS Accident and Emergency (A&E) staff need to be alert to adult safeguarding issues and have a clear understanding of what to do with any safeguarding concerns. The Department of Health will highlight to A&E departments the importance of detecting incidences of re-attendance from the same location /individual in their annual review of Clinical Quality Indicators.
- 7.25 ACPO recognise the importance of working together with statutory agencies, local authorities and safeguarding partners to enhance the service provided to vulnerable adults. ACPO has reviewed the overall learning from Winterbourne View and will ensure the following:
 - the one direct recommendation relating to the police regarding the early identification of trends and patterns of abuse has been fully recognised by Avon & Somerset Police. A specific workstream has been created by the force to identify a process to trigger early identification of abuse. The lessons learnt from the work undertaken will be disseminated nationally; and
 - all associated learning from the review will be incorporated into training and practice, including Authorised Professional Practice.

Applying protections of the Mental Health Act and the Mental Capacity Act

7.26 Nearly three-quarters of people at Winterbourne View hospital (73%) were detained under the Mental Health Act 1983. But it is clear that the principles and safeguards of the Mental Health Act were not properly applied. This was also true for some of the people who were informal patients, who also had their freedom and movement constrained. Some of the people we met said they and their families were given little say in where they were sent. This does not fit with the principles of personalisation in the NHS Constitution or the principles of the Mental Health Act 1983 and Mental Capacity Act 2005.

Key Actions:

The Department of Health will work with CQC to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards (DOLS) provisions to protect individuals and their human rights and will report by Spring 2014.

During 2014 the Department of Health will update the Mental Health Act Code of Practice and this will take account of findings from this review.

Raising understanding of good practice and reducing the use of physical restraint

- 7.27 Physical restraint should only ever be used as a last resort and never used to punish or humiliate.
- 7.28 The CQC inspections revealed widespread uncertainty on the use of restraint, with some providers over-reliant on physical restraint rather than positive behaviour support and managing the environment to remove or contain the triggers which could cause someone to behave in a way which could be seen as challenging. In Winterbourne View, bullying, punishment and humiliation were disguised as restraint.
- 7.29 We need both to take enforcement action where restraint is used improperly or illegally and to clarify and spread better understanding on how to use restraint properly. Where CQC finds evidence of inappropriate or illegal use of restraint it will take enforcement action.

Key Actions:

The Department of Health will, together with CQC, consider what further action may be needed to check how providers record and monitor restraint.

With external partners, the Department of Health will publish by the end of 2013 guidance on best practice on positive behaviour support so that the physical restraint is only ever used as a last resort where the safety of individuals would otherwise be at risk and never to punish or humiliate.

7.30 This will include:

- a set of agreed values to promote change and raise standards to minimise the use of physical intervention;
- looking at different methods of restraint;
- a training framework for commissioners to enhance the skills of the workforce; and
- identification of information and data needs.

This work will look more widely than people with challenging behaviour and apply to anyone in the health and social care systems who may be subject to physical intervention.

Addressing the use of Medication

7.31 We have heard deep concerns about over-use of antipsychotic and antidepressant medicines. Health professionals caring for people with learning disabilities should assess and keep under review the medicines requirements for each individual patient to determine the best course of action for that patient, taking into account the views of the person if possible and their family and/or carer. Services should have systems and policies in place to ensure that this is done safely and in a timely manner and should carry out regular audits of medication prescribing and management, involving pharmacists, doctors and nurses.

Key Actions:

The Royal College of Psychiatrists, the Royal Pharmaceutical Society and other professional leadership organisations will work with ADASS and ADCS to ensure medicines are used in a safe, appropriate and proportionate way and their use optimised in the treatment of children, young people and adults with challenging behaviour. This should include a focus on the safe and appropriate use of antipsychotics and anti-depressants.

The Department of Health will explore with the Royal College of Psychiatrists and others whether and how to commission an audit of use of medication for this group. As the first stage of this we will commission, by summer 2013, a wider review of the prescribing of antipsychotic and antidepressant medicines for people with challenging behaviour.

Improving information, advice and advocacy

7.32 Good information and advice, including advocacy, is important to help people with challenging behaviour and their families to understand the care available to them and make informed choices. But it is clear that there is a very wide variety in the quality and accessibility of information, advice and advocacy, including peer advocacy and support to self-advocate.

Good Practice

In Dudley the local authority is working with independent advocacy organisations and commissioners to develop a quality framework which we hope will be widely adopted.

Key Actions:

The Department of Health will work with independent advocacy organisations to:

- identify the key factors to take account of in commissioning advocacy for people with learning disabilities in hospitals so that people in hospital get good access to information, advice and advocacy that supports their particular needs; and
- drive up the quality of independent advocacy, through strengthening the Action for Advocacy Quality Performance Mark and reviewing the Code of Practice for advocates to clarify their role.
- 7.33 It is vital that people who make complaints about their care, or the care of a family member are listened to and are given the support (including advocacy as appropriate) and advice they need to make that complaint. This includes complaints about abuse and disability hate crime.
- 7.34 The Care and Support White Paper²⁴ states that all providers are required, by law, to have a clear and effective complaints system, and this is monitored by the CQC. If a provider or local authority does not resolve a complaint to the satisfaction of the user, that person can ask the Local Government Ombudsman to investigate. The Ombudsman will be clearly signposted through the new national information website for care and support.
- 7.35 The Department of Health accepted the recommendations made by the Equality and Human Rights Commission, which includes putting in place robust and accessible systems so that residents living in institutions can be confident of reporting harassment by staff or other residents.
- 7.36 The Department for Health is strengthening the ways in which people can give feedback on their care and support. This Government supports the development of websites which allow those who use services and their family or carers, to give feedback to providers and commissioners about any poor, or indeed good practice.
- 7.37 The Department of Health will work with the LGA and Healthwatch England on involving people with learning disabilities and their families in local Healthwatch organisations. A key way for local Healthwatch to benefit from the voice of people with learning disabilities and families is by engaging with existing local Learning Disability Partnership Boards, and, for children and young people, Parent Carer Forums. LINks (local involvement networks) and those preparing for Healthwatch can begin to build these relationships with their Boards in advance of local Healthwatch organisations starting up on 1 April 2013.

²⁴ Caring for our Future: reforming care and support, http://www.dh.gov.uk/health/2012/07/careandsupportwhitepaper/

Part 8: Monitoring and reporting on progress

- 8.1 How will government, the public, people with challenging behaviour and families know we are making progress? Transparency of information and robust monitoring are critical for delivering transformed care and support. This involves:
 - auditing current provision;
 - developing better information for the future; and
 - national monitoring through the Learning Disability Programme Board, including service user and family representation.

Auditing current provision

8.2 In pursuing this review, it became clear that there is a lack of clarity on the number of people with challenging behaviour in hospital settings or who is responsible for them. There have been improvements, but much more needs to be done to establish a baseline.

Key Action:

By March 2013 the Department of Health will commission an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay. The audit will be repeated one year on to enable the learning disability programme board to assess what is happening.

Developing better information systems

8.3 The Department of Health intends to establish key performance indicators (on, for example, numbers of people in hospital, length of stay, incidents of restraint, and number of safeguarding alerts) which will enable the Learning Disability Programme Board and local services to monitor progress.

Action:

The Department of Health, the Information Centre for Health and Social Care and the NHSCB will develop measures and key performance indicators to support commissioners in monitoring their progress from April 2013.

The Department of Health will develop a new learning disability minimum data set to be collected through the Information Centre from 2014/15.

The NHSCB and ADASS will implement a joint health and social care self assessment framework to monitor progress of key health and social care inequalities from April 2013. The results of progress from local areas will be published.

Monitoring and transparency

8.4 We will monitor progress through the Learning Disability Programme Board. It will also be essential for the process to be transparent and open to scrutiny.

Key Actions:

The cross-government Learning Disability Programme Board will measure progress against milestones, monitor risks to delivery and challenge external delivery partners to deliver to the action plan of all commitments (Annex B). CQC, the NHSCB and the head of the LGA, ADASS, NHSCB development and improvement programme will, with other delivery partners, be members of the Programme Board, and report on progress.

Regular updates to the Programme Board will be published on the Department of Health website, with all other papers and minutes for that Board.

The Department of Health will work with the improvement team to monitor and report on progress nationally, including reporting comparative information on localities. We will publish a follow up report by December 2013 and repeat this by December 2014.

Part 9: Conclusion

- 9.1 For too long, people with challenging behaviour have as highlighted by Mencap and the Challenging Behaviour Foundation been too much out of sight. Although there is ample authoritative guidance across health and care, and examples of good practice around the country, in too many places the needs of this highly vulnerable group of people are not being addressed. It is easy to see why families and groups who support people with challenging behaviour are sceptical about what will happen this time to deliver the transformation of care which people deserve.
- 9.2 But we believe that the package of timetabled actions set out in this report and the accompanying Concordat, together with the commitment by national and local leaders to monitor and report on delivery against these will deliver real change. And this will be enabled by the reforms to health and care systems which give greater power to individuals and local communities to develop services which genuinely respond to local needs.

Annex A: The model of care

There are too many people challenging behaviour living in inpatient services for assessment and treatment and they are staying there for too long.

The closure of most long-stay hospitals in the 1980s and 1990s, and the recent closure of NHS campuses, means most people with learning disabilities, including those with behaviours that challenge now live in the community with support. But some still live (for short or longer periods) in NHS funded settings. Assessment and treatment units emerged as the most likely solution to meeting the needs of people with learning disabilities and complex mental health/behavioural issues post-institutional closure. However, there were opposing views between 'building based' services and increasing support to people in their natural communities as the preferred option.

Good practice guidance on supporting people with learning disabilities, autism and those with behaviour which challenge includes the 1993 Mansell report, updated and revised in 2007. Both emphasise:

- the responsibility of commissioners to ensure that services meet the needs of individuals, their families and carers;
- a focus on personalisation and prevention in social care;
- that commissioners should ensure services can deliver a high level of support and care to people with complex needs/challenging behaviour; and
- that services/support should be provided locally where possible.

Evidence shows that community-based housing enables greater independence, inclusion and choice and that challenging behaviour lessens with the right support. The Association of Supported Living's report *There is an Alternative* describes how 10 people with learning disabilities and challenging behaviour moved from institutional settings to community services providing better lives and savings of around £900,000 a year in total.

The CQC *Count me in* 2010 census showed only 2 learning disabled patients on Community Treatment Orders compared to over 3,000 mental health patients – suggesting a greater reliance on inpatient solutions for people with learning disabilities than for other people needing mental health support.

CQC found some people were staying many years in assessment and treatment units. Annex B estimates that, in March 2010, at least 660 people were in A&T in Learning Disability wards for more than 6 months.

This report sets out how the model of care set out in the Mansell reports fits with the new health and care system architecture focusing on key principles, desired outcomes for individuals, and a description of how the model should work in practice.

Key principles

The key principles of high quality services for people with learning disabilities and behaviour which challenges are set out below:

For people:

- 1. I and my family are at the centre of all support services designed around me, highly individualised and person-centred;
- 2. My home is in the community the aim is 100% of people living in the community, supported by local services;
- 3. I am treated as a whole person;
- 4. Where I need additional support, this is provided as locally as possible.

For services:

- Services are for all, including those individuals presenting the greatest level of challenge;
- 6. Services follow a life-course approach i.e. planning and intervening early, starting from childhood and including crisis planning;
- 7. Services are provided locally;
- 8. Services focus on improving quality of care and quality of life;
- 9. Services focus on individual dignity and human rights;
- 10. Services are provided by skilled workers;
- 11. Services are integrated including good access to physical and mental health services as well as social care;
- 12. Services provide good value for money;
- 13. Where inpatient services are needed, planning to move back to community services starts from day one of admission.

Outcomes

A high quality service means that people with learning disabilities or autism and behaviour which challenges will be able to say:

- 1. I am safe:
- 2. I am treated with compassion, dignity and respect;
- 3. I am involved in decisions about my care;
- 4. I am protected from avoidable harm, but also have my own freedom to take risks;
- 5. I am helped to keep in touch with my family and friends;
- 6. Those around me and looking after me are well supported;
- 7. I am supported to make choices in my daily life;
- 8. I get the right treatment and medication for my condition;
- 9. I get good quality general healthcare;
- 10. I am supported to live safely in the community;
- 11. Where I have additional care needs, I get the support I need in the most appropriate setting;
- 12. My care is regularly reviewed to see if I should be moving on.

This is about personalisation, starting with the individual at the centre, living in the community. The first level of support for that individual includes the people, activities and support all people need in their every day lives – family, friends, circles of support, housing, employment and leisure.

Most people with learning disabilities or autism will need more support from a range of sources: their GP or other primary care services, advocacy, a care manager or support worker and could include short breaks. That support may change as needs change, and this will involve assessments of physical or mental health needs or environmental needs (such as loss of a parent, a relationship breakdown, unemployment) to identify what support should be provided.

For people who need further support – including where they have behaviour which challenges – the intensity of support should increase to match need. That should include intensive support services in the community, assessment and treatment services (which could be provided in a safe community setting), and, where appropriate, secure services. But the aim should always be to look to improvement, recovery, and returning a person to their home setting wherever possible.

Responsibility for safety and quality of care depends on all parts of the system working together:

- i. **providers** have a duty of care to each individual they are responsible for, ensuring that services meet their individual needs and putting systems and processes in place to provide effective, efficient and high quality care;
- ii. **commissioners** (NHS and local authorities) are responsible for planning for local needs, purchasing care that meets people's needs and building into contracts clear requirements about the quality and effectiveness of that care;
- iii. **workforce**, including health and care professional and staff who have a duty of care to each individual they are responsible for; and
- iv. **system and professional regulators** who are responsible for assuring the quality of care through the discharge of their duties and functions.

To achieve these outcomes a revised model of care as set out below needs to be delivered.

Roles and responsibilities

Good services meeting the needs of everybody must include:

<u>Information</u>

Councils, elected councillors, health bodies and all care providers, whether
from the public, for-profit or not-for-profit sectors should provide good quality,
transparent, information, advice and advocacy support for individuals, families and
carers.

Community based support

 Councils and health commissioners should ensure that general services (GPs, hospitals, libraries, leisure centres etc) are user-friendly and accessible to people with learning disabilities/autism so they can access what everyone else can access.

- Community based mental health services for this group should offer assertive outreach, 24-hour crisis resolution, a temporary place to go in crisis and general support to deal with the majority of additional support needs at home.
- Housing authorities should include a wide range of community housing options shared, individual, extra care, shared lives scheme, domiciliary care, keyring, respite.
- **Social care commissioners** should ensure the availability of small-scale residential care for those who would benefit from it (eg because they have profound and multiple disabilities).
- Councils and employment services should offer support into employment.
- Councils and providers of services should enable a range of daytime activities.
- **Councils** should roll out personal budgets for all those who are eligible for care and support including those with profound and multiple disabilities and/or behaviours seen as challenging.
- Where appropriate, health commissioners should fund continuing health care.
- Health and social care commissioners should focus on early intervention and preventive support to seek to avoid crises (eg behavioural strategies). Where crises occur, they should have rapid response and crisis support on which they can call quickly.

Commissioning, assessment and care planning

- **Health and social care commissioners** should develop personalised services that meet people's needs. Key factors include;
- involving individuals with support where needed and families at all stages;
- planning for the whole life course, from birth to old age, starting with children's services;
- developing expertise in challenging behaviour;
- developing partnerships and pooling resources to work together on joint planning and support with integrated services – including:
 - multi-disciplinary teams to perform assessments, care planning, care assessment, care management and review,
 - o joint commissioning ideally with pooled budgets, and
 - shared risk management;
- Health and social care commissioners should use all available information from joint strategic needs assessments (JSNAs) and local health and wellbeing strategies to commission strategically for innovation and to develop person-centred community based services;
- Health and social care commissioners should commission personalised services tailored to the needs of individuals, ensuring a focus on improving that individual's health and well-being and agreed outcomes. Progress towards delivering outcomes should be regularly reviewed;
- **Health and social care commissioners** should start to plan from day one of admission to inpatient services for the move back to community;
- Health and social care commissioners should ensure close coordination between the commissioning of specialised services including secure services, and other health and care services;

- Social care bodies have ongoing responsibility for individuals, even where they are
 in NHS-funded acute or mental health services, including working with all partners to
 develop and work towards delivering a discharge plan;
- Health and social care commissioners should audit provision to assess which services are good at supporting people with challenging behaviour (the Health Self Assessment Framework is an effective way to monitor outcomes);
- Health and social care commissioners should develop effective links with children's services to ensure early planning at transition and joint services. The SEND Green Paper proposal for an integrated health, education and care plan from 0-25 will also help to ensure that children's services are similarly thinking about a young person's transition to adult services at an early stage.

Service Providers

- All service providers (community, residential, health, care, housing public, forprofit and not-for-profit providers) have a duty of care to the individuals for whom they provide services and a legal duty to refer. This includes ensuring that:
 - o people are safe and protected from harm;
 - o their health and well-being are supported;
 - o their care needs are met;
 - o people are supported to make decisions about their daily lives;
 - o people are supported to maintain friendships and family links.

Providers should:

- provide effective and appropriate leadership, management, mentoring and supervision. Good leadership is essential in setting the culture and values;
- have a whole organisation approach to Positive Behaviour Support training;
- recruit for values and ensure that staff have training for skills mandatory training
 which can include training on value bases when working with people with learning
 disabilities, positive behaviour support, types of communication including non-verbal
 communication, active support and engaging in meaningful activities and Mental
 Capacity requirements. Best practice includes involving people with learning
 disabilities and families in the training;
- operate good clinical governance arrangements;
- monitor quality and safety of care;
- Work with commissioners to promote innovation new and different ideas, especially for the most challenging.

Assessment and treatment services

- Health and care commissioners are responsible for commissioning assessment
 and treatment services where these are needed. The focus should be on services
 (which can be community based) rather than units. Where a person is at risk (or is
 putting others at risk) in a way that community support cannot help and needs to be
 moved to a safe place, commissioners should focus on this being provided close to
 home.
- **Health and care commissioners** should look to review any placement in assessment and treatment services regularly, and focus on moving the individual on into more appropriate community based services as soon as it is safe for the individual to do so.

- Social care services should be closely involved in decisions to admit to assessment and treatment services.
- All assessment and treatment services providers must comply with statutory guidance on the use of physical restraint.

Prisons and secure services

- **Social care services** should work closely with prison and secure services to ensure person centred planning and health action planning and to plan for appropriate provision when people move on from prison or secure services.
- Offender management processes should include health screening programmes that identify an offender's learning disability and any physical and/or mental health issues.

<u>Workforce</u> should demonstrate that they are providing quality care and support which includes:

- personal and professional accountability;
- training in working with people with complex needs and behaviour which challenges;
- developing good communication and involving advocates and families'
- monitoring an individual's progress and reviewing plans; and
- good understanding of the legislative framework and human rights;
- Taking action to report any concerns identified.

System and professional regulators

As a regulator, the Care Quality Commission (CQC) should:

- monitor whether services are meeting essential standards;
- take enforcement action if a provider is not compliant;
- monitor the operation of the Mental Health Act 1983.

Professional regulators such as the Nursing and Midwifery Council (NMC) and General Medical Council (GMC), have a role to play to protect and promote public safety. They do this by:

- setting and maintaining professional standards; and
- investigating and taking appropriate action where concerns are raised about registrants, which can include the registrant being removed from the register and where appropriate being referred to the Independent Safeguarding Authority (ISA).

The professional regulators have produced a leaflet to help the public to ensure that they receive the care and treatment from professionals who meet the right standards.

Annex B: Timetable of Actions

This Report sets out a range of national actions which the Department of Health and its partners will deliver to lead a redesign in care and support for people with learning disabilities or autism and mental health conditions or behaviours viewed as challenging.

The Department of Health is committed to working with partners to monitor progress, hold all players to account for delivery, and ensure better experiences and improved outcomes for this very vulnerable group of people.

No.	Date	Action
1.	From June 2012	CQC will continue to make unannounced inspections of providers of learning disability and mental health services employing people who use services and families as vital members of the team.
2.	From June 2012	CQC will take tough enforcement action including prosecutions, restricting the provision of services, or closing providers down, where providers consistently fail to have a registered manager in place.
3.	From June 2012	CQC will take enforcement action against providers who do not operate effective processes to ensure they have sufficient numbers of properly trained staff.
4.	From November 2012	The cross-government Learning Disability Programme Board will measure progress against milestones, monitor risks to delivery and challenge external delivery partners to deliver to the action plan of all commitments. CQC, the NHSCB and the head of the LGA, ADASS, NHSCB development and improvement programme will, with other delivery partners, be members of the Programme Board, and report on progress.
5.	From December 2012	The Department of Health will work with the CQC to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards provisions to protect individuals and their human rights and will report by Spring 2014.
6.	From December 2012	The Department of Health will, together with CQC, consider what further action may be needed to check how providers record and monitor restraint.
7.	From December 2012	The Department of Health will work with independent advocacy organisations to identify the key factors to take account of in commissioning advocacy for people with learning disabilities in hospitals so that people in hospital get good access to information, advice and advocacy that supports their particular needs.
8.	From December 2012	The Department of Health will work with independent advocacy organisations to drive up the quality of independent advocacy, through strengthening the Action for Advocacy Quality Performance Mark and reviewing the Code of Practice for advocates to clarify their role.
9.	From December 2012	A specific workstream has been created by the police force to identify a process to trigger early identification of abuse. The lessons learnt from the work undertaken will be disseminated nationally. All associated learning from the review will be incorporated into training and practice,

No.	Date	Action
		including Authorised Professional Practice.
10.	From December 2012	The College of Social Work, to produce key points guidance for social workers on good practice in working with people with learning disabilities who also have mental health conditions;
11.	From December 2012	The British Psychological Society, to provide leadership to promote training in, and appropriate implementation of, Positive Behavioural Support across the full range of care settings.
12.	From December 2012	The Royal College of Speech and Language Therapists, to produce good practice standards for commissioners and providers to promote reasonable adjustments required to meet the speech, language and communication needs of people with learning disabilities in specialist learning disability or autism hospital and residential settings.
13.	By end of December 2012	The Local Government Association and NHS Commissioning Board will establish a joint improvement programme to provide leadership and support to the transformation of services locally. They will involve key partners including DH, ADASS, ADCS and CQC in this work, as well as people with challenging behaviour and their families. The programme will be operating within three months and Board and leadership arrangements will be in place by the end of December 2012. DH will provide funding to support this work.
14.	By end December 2012	By December 2012 the professional bodies that make up the Learning Disability Professional Senate will refresh <i>Challenging Behaviour: A Unified Approach</i> to support clinicians in community learning disability teams to deliver actions that provide better integrated services.
15.	By January 2013	Skills for Health and Skills for Care will develop national minimum training standards and a code of conduct for healthcare support workers and adult social care workers. These can be used as the basis for standards in the establishment of a voluntary register for healthcare support workers and adult social care workers in England.
16.	By February 2013	Skills for Care will develop a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour
17.	By March 2013	The Department of Health will commission an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay. The audit will be repeated one year on to enable the learning disability programme board to assess what is happening.
18.	By March 2013	The NHSCB will work with ADASS to develop practical resources for commissioners of services for people with learning disabilities, including: model service specifications; new NHS contract schedules for specialist learning disability services; models for rewarding best practice through the NHS; commissioning for Quality and Innovation (CQUIN) framework; and a joint health and social care self-assessment framework to support local agencies to measure and benchmark progress.
19.	By March 2013	The NHSCB and ADASS will develop service specifications to support CCGs in commissioning specialist services for children, young people and

No.	Date	Action
		adults with challenging behaviour built around the model of care in Annex
		A.
20.	By March 2013	The Joint Commissioning Panel of the Royal College of General Practitioners and the Royal College of Psychiatrists will produce detailed guidance on commissioning services for people with learning disabilities who also have mental health conditions.
21.	By March 2013	The Royal College of Psychiatrists will issue guidance about the different types of inpatient services for people with learning disabilities and how they should most appropriately be used.
22.	By 1 April 2013	The NHSCB will ensure that all Primary Care Trust develop local registers of all people with challenging behaviour in NHS-funded care.
23.	By 1 April 2013	The Academy of Medical Royal Colleges and the bodies that make up the Learning Disability Professional Senate will develop core principles on a statement of ethics to reflect wider responsibilities in the health and care system.
24.	By 1 April 2013	The National Quality Board will set out how the new health system should operate to improve and maintain quality.
25.	By 1 April 2013	The Department of Health will work with key partners to agree how Quality of Life principles should be adopted in social care contracts to drive up standards.
26.	From 1 April 2013	The NHSCB will make clear to CCGs in their handover and legacy arrangements what is expected of them in maintaining local registers, and reviewing individual's care with the Local Authority, including identifying who should be the first point of contact for each individual.
27.	From April 2013	The NHSCB will hold CCGs to account for their progress in transforming the way they commission services for people with learning disabilities/autism and challenging behaviours.
28.	From April 2013	Health Education England will take on the duty for education and training across the health and care workforce and will work with the Department of Health, providers, clinical leaders and other partners to improve skills and capability to respond the needs of people with complex needs.
29.	From April 2013	CQC will take action to ensure the model of care is included as part of inspection and registration of relevant services from 2013. CQC will set out the new operation of its regulatory model, in response to consultation, in Spring 2013.
30.	From April 2013	CQC will share the information, data and details they have about providers with the relevant CCGs and local authorities.
31.	From April 2013	CQC will assess whether providers are delivering care consistent with the statement of purpose made at the time of registration.
32.	From April 2013	Monitor will consider in developing provider licence conditions, the inclusion of internal reporting requirements for the Boards of licensable provider services to strengthen the monitoring of outcomes and clinical governance arrangements at Board level.
33.	From April 2013	The strong presumption will be in favour of pooled budget arrangements with local commissioners offering justification where this is not done. The NHSCB, ADASS and ADCS will promote and facilitate joint

No.	Date	Action
		commissioning arrangements.
34.	From April 2013	The NHSCB will ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism receive safe, appropriate and high quality care. The presumption should always be for services to be local and that people remain in their communities.
35.	From April 2013	Health and care commissioners should use contracts to hold providers to account for the quality and safety of the services they provide.
36.	From April 2013	Directors, management and leaders of organisations providing NHS or local authority funded services to ensure that systems and processes are in place to provide assurance that essential requirements are being met and that they have governance systems in place to ensure they deliver high quality and appropriate care.
37.	From April 2013	The Department of Health, the Health and Social Care Information Centre and the NHSCB will develop measures and key performance indicators to support commissioners in monitoring their progress.
38.	From April 2013	The NHSCB and ADASS will implement a joint health and social care self assessment framework to monitor progress of key health and social care inequalities from April 2013. The results of progress from local areas will be published.
39.	From April 2013	The Department of Health will work with the LGA and Healthwatch England to embed the importance of local Healthwatch involving people with learning disabilities and their families. A key way for local Healthwatch to benefit from the voice of people with learning disabilities and families is by engaging with existing local Learning Disability Partnership Boards. LINks (local involvement networks) and those preparing for Healthwatch can begin to build these relationships with their Boards in advance of local Healthwatch organisations starting up on 1 April 2013.
40.	By Spring 2013	The Department of Health will immediately examine how corporate bodies, their Boards of Directors and financiers can be held to account for the provision of poor care and harm, and set out proposals during Spring 2013 on strengthening the system where there are gaps. We will consider both regulatory sanctions available to CQC and criminal sanctions. We will determine whether CQC's current regulatory powers and its primary legislative powers need to be strengthened to hold Boards to account and will assess whether a fit and proper persons test could be introduced for board members.
41.	From Spring 2013	CQC will take steps now to strengthen the way it uses its existing powers to hold organisations to account for failures to provide quality care. It will report on changes to be made from Spring 2013.
42.	By 1 June 2013	Health and care commissioners, working with service providers, people who use services and families, will review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual based around their and their families' needs and agreed outcomes.
43.	By Summer 2013	Provider organisations will set out a pledge or code model based on shared principles - along the lines of the Think Local Act Personal (TLAP)

No.	Date	Action
		Making it Real principles.
44.	By Summer 2013	The Department of Health, with the National Valuing Families Forum, the National Forum of People with Learning Disabilities, ADASS, LGA and the NHS will identify and promote good practice for people with learning disabilities across health and social care.
45.	By summer 2013	The Department of Health will explore with the Royal College of Psychiatrists and others whether there is a need to commission an audit of use of medication for this group. As the first stage of this, we will commission a wider review of the prescribing of antipsychotic and antidepressant medicines for people with challenging behaviour.
46.	By June 2013	The Department of Health and the Department for Education will work with the independent experts on the Children and Young People's Health Outcomes Forum to prioritise improvement outcomes for children and young people with challenging behaviour and agree how best to support young people with complex needs in making the transition to adulthood.
47.	In 2013	The Department of Health and the Department for Education will develop and issue statutory guidance on children in long-term residential care.
48.	In 2013	The Department of Health and the Department for Education will jointly explore the issues and opportunities for children with learning disabilities whose behaviour is described as challenging through both the SEN and Disability reform programme and the work of the Children's Health Strategy.
49.	In 2013	The Department of Health will work with independent advocacy organisations to drive up the quality of independent advocacy.
50.	In 2013	The Department for Education will revise the statutory guidance Working together to safeguard Children.
51.	In 2013	The Royal College of Psychiatrists, the Royal Pharmaceutical Society ad other professional leadership organisations will work with ADASS and ADCS to ensure medicines are used in a safe, appropriate and proportionate way and their use optimised in the treatment of children, young people and adults with challenging behaviour. This should include a focus on the safe and appropriate use of antipsychotic and antidepressant medicines.
52.	By December 2013	The Department of Health will work with the improvement team to monitor and report on progress nationally, including reporting comparative information on localities. We will publish a follow up report by December 2013.
53.	By end 2013	The Department of Health with external partners will publish guidance on best practice around positive behaviour support so that physical restraint is only ever used as a last resort where the safety of individuals would otherwise be at risk and never to punish or humiliate.
54.	By end 2013	There will be a progress report on actions to implement the recommendations in <i>Strengthening the Commitment</i> the report of the UK Modernising learning disability Nursing Review.
55.	By end 2013	CQC will also include reference to the model in their revised guidance about compliance. Their revised guidance abut compliance will be linked to the Department of Health timetable of review of the quality and safety regulations in 2013. However, they will specifically update providers about

No.	Date	Action
		the proposed changes to our registration process about models of care for learning disability services in 2013.
56.	From 2014	The Department of Health will work with the Department for Education to introduce a new single assessment process and Education, Health and Care Plan to replace the current system of statements and learning difficulty assessments for children and young people with special educational needs; supported by joint commissioning between local partners (subject to parliamentary approval). The process will include young people up to the age of 25, to ensure they are supported in making the transition to adulthood.
57.	By April 2014	CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area. This could potentially be undertaken through the health and wellbeing board and could be considered as part of the local Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy (JHWS) processes.
58.	No later than 1 June 2014	Health and care commissioners should put plans into action as soon as possible and all individuals should be receiving personalised care and support in appropriate community settings no later than 1 June 2014.
59.	In 2014	The Department of Health will update the Mental Health Act Code of Practice and will take account of findings from this review.
60.	By December 2014	The Department of Health will publish a second annual report following up progress in delivering agreed actions.
61.	From 2014/15	The Department of Health will develop a new learning disability minimum data set to be collected through the Health and Social Care Information Centre.
62.	By Summer 2015	NICE will publish quality standards and clinical guidelines on challenging behaviour and learning disability.
63.	By Summer 2016	NICE will publish quality standards and clinical guidelines on mental health and learning disability.

Glossary

ACPO Association of Chief Police Officers

A & E Accident and Emergency
A & T Assessment and Treatment

A4A Action for advocacy

ADASS Association of Directors for Adult Social Services
ADCS Association of Directors of Children's Services

BBC British Broadcasting Corporation CCG Clinical Commissioning Groups

CQC Care Quality Commission

CQUIN Commissioning for Quality and Innovation

DfE Department for Education DH Department of Health

DOLS Deprivation of Liberty Safeguards EOF Education Outcomes Framework

GP General Practitioner

HEE Health Education England

JHWSs Joint Health and Wellbeing Strategies JSNAs Joint Strategic Needs Assessments

LA Local Authorities
LD Learning Disability

LGA Local Government Association
LINKS Local involvement networks
NHS National Health Service

NHSCB National Health Service Commissioning Board NICE National Institute for Health and Clinical Excellence

NQB National Quality Board

Ofsted Office for Standards in Education, Children's Services and Skills

RCGP Royal College of General Practitioners

RCPsych Royal College of Psychiatrists SAB Safeguarding Adults Boards

SCR Serious Case Review
TLAP Think Local Act Personal

WINTERBOURNE VIEW – TIME FOR CHANGE

Transforming the commissioning of services for people with learning disabilities and/or autism

WINTERBOURNE VIEW - TIME FOR CHANGE

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FOREWORD

The Winterbourne View scandal, exposed by the Panorama programme, shocked the nation. It led to the Government pledge to move all people with learning disabilities and/or autism inappropriately placed in such institutions into community care by June this year. Not only has there been a failure to achieve that movement, there are still more people being admitted to such institutions than are being discharged. This has caused anger and frustration.

In light of the need to achieve progress Simon Stevens, the CEO of NHS England, asked me to consider how we might implement a new national framework, locally delivered, to achieve the growth of community provision needed to move people out of inappropriate institutional care.

Only by a big expansion of such community provision can we achieve a move from institution to community. So we need a mandatory national commissioning framework that delivers that expansion, pooled budgets, and a focus on the individual's needs not the system boundaries. The role of the many voluntary and community organisations that both advocate for and provide services for people with learning disabilities and/or autism is crucial to that aim, as are the individuals themselves, their families, clinicians, managers and professionals across the health service and in local councils, who need to work together to achieve a dramatic turn-around.

In tackling this challenge it became clear to me that we need both a major expansion of community delivery driven by better commissioning but also, crucially, the empowerment of people with learning disabilities and/or autism and their families. That means a clear and robust Charter of Rights and an effective "Right to Challenge", backed by strong advocacy and support, that enables citizens to demand change. We also propose that community based providers have the right to propose alternatives to inpatient care from commissioners. And we support a major expansion of the right to request a personal budget; again we believe this underpins an empowerment of the individual citizen to have care and support appropriate to them.

In other words we need to drive change from the top through better commissioning and from the bottom up through empowering people and families to challenge the system.

Underpinning a shift to community provision and away from inappropriate institutional care are exciting proposals for workforce development and a new social finance fund. In developing community provision we need social finance to support capital development so we propose a "life in the community social investment fund" which will support the provision of working capital, investment in housing and an investment readiness partnership fund. This is a new proposal but we recognised that developing community provision needs the funding that social finance can provide and I urge Government and NHS England to push ahead with funding to make this happen promptly.

The steering group were clear about the crucial importance of workforce and skills development. This must happen alongside developing community facilities. We were particularly impressed with the momentum around the idea of the Academy set out on this Report. We must ensure that momentum for change is built on by all those involved.

And finally, as well as a mandatory national framework for commissioning that is locally delivered we must have active decommissioning of inappropriate institutional care and closures of such institutions.

The timetable and process requires further discussion but a twenty-first century approach to the care and support of people with learning disabilities cannot be based on long-term care in an institution.

In putting together this report I want to thank all my colleagues on the steering group, and all those I have met or spoken to, and those who submitted many comments and documents. Even when critical we recognised this came about through the anger of those who have seen a system fail them.

In 1851, the American physician and philanthropist Samuel Gridley Howe wrote about the "evils" of institutional care. He wrote, "all such institutions are unnatural, undesirable and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society."

That essential truth underpins our proposals for change and we know they have widespread support. We recognised that as a nation when we closed the old mental health asylums and we must recognise it again here.

I have recommended to the chief executive of NHS England that my steering group be brought together again in 6 months to review progress on our recommendations and that we have a formal stock take of actions taken in 12 months' time. We can act as a driver for change but clearly it is the institutions themselves that must deliver these recommendations. And deliver them they must.

Over the past few years people with learning disabilities and/or autism have heard much talk but seen too little action, and this forms the backdrop to our recommendations and our desire to see urgent action taken now to make a reality of the Winterbourne pledge. They deserve better and this Report provides recommendations on that essential road map for change.





Sir Stephen Bubb

EXECUTIVE SUMMARY

About this report

- 1. This report is the product of NHS England asking Sir Stephen Bubb, chief executive of charity leaders body ACEVO, to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism. This came after a pledge made in the wake the Winterbourne View scandal to enable people with learning disabilities and/or autism inappropriately placed in hospital to move to community-based support by June 2014¹ was missed.
- 2. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, providers and academics).
- 3. Whilst originally tasked with drawing up recommendations for a commissioning framework, it was clear to the steering group that any such framework formulated by NHS England would need to be accompanied by related action from others (including most obviously central and local Government), and our recommendations reflect this. Our starting point is that it is not acceptable in the twenty-first century for thousands of people to be living in hospitals when with the right support they could be living in the community, and that to force change we need both more 'top-down' leadership (from NHS England, local government, central government and other Arms-Length Bodies), and from the 'bottom up' more empowerment for people with learning disabilities and/or autism and their families. Our recommendations are aimed at both.
- 4. The failure to meet the Winterbourne View pledge above means there is now a great deal of anger and frustration surrounding this issue. In responding to this report, NHS England and its partners need both to act with urgency, and to be realistic about the timeline for success, so that they do not promise yet another 'false dawn'.

The problem

5. Some people with learning disabilities and/or autism who present challenging behaviour and/or complex mental health problems may need to be admitted to inpatient settings to be assessed and treated – particularly if they are liable to detention under the Mental Health Act on the recommendation of mental health professionals or a court. But many are admitted when their admission could have been prevented had they

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1 Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)

received better support in the community, and many stay in hospital too long, when with the right support in the community they could be discharged. The result is that for many years too many people with learning disabilities and/or autism have been, and continue to be, in inappropriate inpatient settings – often a very long distance away from family and home.

- 6. We must see a step change on two fronts: a) putting in place the community-based support to safely discharge people currently in inpatient settings (of whom the latest NHS England data collection showed there were 2,600)², and crucially b) supporting children, young people and adults in the community to prevent admissions in the first place (focusing on a much larger number, most urgently perhaps some 24,000 adults in England who present severe challenging behaviour³).
- 7. By a very long way, this report is not the first time anyone has considered these issues. Many have done so, over many decades. So why has there not been more progress? Our view is that:
 - It is not that we don't know 'what good looks like'. That has been
 described many times, from Professor Mansell's⁴ authoritative report
 in 1993 onwards.
 - Nor is it that we don't know what kind of commissioning we need to secure that good care. The Concordat published after the Winterbourne View scandal set out the necessary key steps very clearly (starting with pooled budgets and joint local commissioning plans), and has been followed by a range of further analysis and guidance.
 - Instead, it is that we make it too hard for stakeholders across the system to make change happen, and too easy to continue with the status quo. And we do not give enough power or support to the people most eager and best placed to make things change starting with people with learning disabilities and/or autism themselves and their families.
- **8.** Our recommendations therefore aim to make it easier (or mandatory) to do the right thing, harder (or impossible) to do the wrong thing, and to empower and support the agents of change.

Recommendations

Strengthening rights

1. The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning. The Charter should clarify existing rights, and set out new rights we propose below. The mandatory commissioning framework later in our recommendations should require all commissioners to invest in services that make these rights 'real' and easily used.

- 2 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/
- 3 K. Lowe et al, Challenging Behaviours: prevalence and topographies. *Journal of Intellectual Disability Research*, 51, 625–636 (2007)
- 4 J. Mansell, Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs (1993), and revised edition (2007)

- The Government should respond to 'the Bradley Report Five Years On',⁵
 to ensure that people with learning disabilities and/or autism are better
 treated by the criminal justice system.
- 3. People with learning disabilities and/or autism and their families should be given a 'right to challenge' decisions to admit or continue keeping them in inpatient care. They should receive independent expert support to exercise that right, including high-quality independent advocacy.
- 4. NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism, including all those in inpatient care and appropriate groups living in the community but at risk of being admitted to inpatient care.
- 5. The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital, so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.

Forcing the pace on commissioning

- 6. The Government and NHS England should require all local commissioners to follow a mandatory commissioning framework. The funding and responsibility for commissioning services for this group should be devolved as much as possible from NHS specialised commissioning to Clinical Commissioning Groups. Learning from the strengths (and weaknesses) of the Better Care Fund, a mandatory framework should then require the pooling of health, social care and housing budgets, and mandate NHS and local government commissioners to draw up a long-term plan for spending that funding in a way that builds up community services, makes the Charter of Rights above real, and reduces reliance on inpatient services. NHS England, central Government and local government representatives such as the Local Government Association and Association of Directors of Adult Social Services should support and assure the drawing up of local commissioning plans, and unblock systemic barriers (including Ordinary Residence rules and eligibility for Continuing Health Care). There should be a named lead commissioner in each area, working collaboratively with a provider forum and people with learning disabilities and/or autism and their families.
- Community-based providers should be given a 'right to propose alternatives' to inpatient care to individuals, their families, commissioners and responsible clinicians.

Closures of inpatient institutions

8. The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities. This active decommissioning should be driven by a tougher approach from the Care Quality Commission, local closure plans, and closures led by NHS England where it is the main commissioner. NHS England should come to a considered, realistic view on what is possible – but then it should

5 G. Durcan, A. Saunders, B. Gadsby & A. Hazard, *The Bradley Report five years on:* an independent review of progress to date and priorities for further development (2014)

set out a clear timetable not just for reductions in admissions or inpatient numbers, but for closures of beds and institutions.

Building capacity in the community

- 9. Health Education England, Skills for Care, Skills for Health and partners should develop a national workforce 'Academy' for this field, building on the work already started by Professors Allen and Hastings and others⁶. The Academy should bring together existing expertise in a range of organisations to develop the workforce across the system.
- 10. A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient settings and build capacity in community-based services. The Investment Fund, seeded with £30 million from NHS England and/or Government, could leverage some £200 million from other investors to make investment more easily accessible to expand community-based services.

Holding people to account

11. Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level. Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning organisation) should be collected and published. Both local commissioners and national bodies (including NHS England, DH, the LGA and others) should be held to account for implementing our recommendations above – local named lead commissioners by local people, NHS England and central Government, and national bodies through existing governance structures (such as the Transforming Care Assurance Board chaired by the Minister for Care and Support).

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ABOUT THIS REPORT

- 1. After the Winterbourne View scandal, the Government and a large number of partners signed a Concordat pledging action on care for people with learning disabilities and/or autism who present behaviour that challenges and/or complex mental health problems. The Concordat promised: "health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014". It envisaged a "rapid reduction in hospital placements for this group of people", and "the closure of large-scale inpatient services". But that pledge was missed.
- 2. Following the failure to meet that pledge, NHS England developed a programme plan and asked Sir Stephen Bubb, chief executive of charity leaders body ACEVO, to make recommendations for a national commissioning framework under which local commissioners would secure community-based support for people with learning disabilities and/or autism.
- 3. Sir Stephen was supported by a steering group of representatives from the voluntary sector, the NHS and local government, Gavin Harding MBE as co-chair of the Department of Health's Transforming Care Assurance Board, individuals with learning disabilities and/or autism, and family members of people with learning disabilities and/or autism. Over the course of its work, the group engaged with a range of stakeholders (from people with learning disabilities and/or autism and their families to commissioners, voluntary sector organisations who work with and/or represent people with learning disability or autism and their families, providers and academics). The membership of the steering group is set out in the appendices.
- 4. When we refer to community based services we mean smaller more personalised services within a community setting where there is good access to local amenities and services. People supported are able to exercise choice and control over where they live, who they live with and who supports them and truly feel that where they live is their home. The label applied to the service such as supported living or registered care should in no way impact on the quality or feel of the service provided.
- 5. The steering group was supported through focus groups with individuals with learning disabilities and/or autism and their family carers, and by an expert reference group on social investment. The latter group was supported by research on the potential role for social investment from Resonance Ltd, which formed the basis for much of our thinking on social investment and which is being published alongside this report.⁸

⁷ Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)

⁸ Resonance, Winterbourne View and Social Investment (2014)

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- In formulating this report, over several months the steering group met with or heard from a wide range of stakeholders. We held workshops with people with learning disabilities and/or autism, with providers and with commissioners. We looked at the considerable volume of work already undertaken on this issue - the reports by Professor Mansell of 1993 and 2007,9 the review by the Department of Health undertaken after the Winterbourne View scandal,10 the subsequent Concordat signed up to by stakeholders across the system,11 Ensuring Quality Services by the LGA/NHS England, 12 and reports and guidance by a very wide range of organisations, including but not limited to the Joint Improvement Partnership hosted at the Local Government Association, Think Local Act Personal, the National Development Team for Inclusion(NDTI), the Royal College of Psychiatrists and the British Psychological Society, the Housing and Support Alliance, Skills for Care, the Challenging Behaviour Foundation, the Challenging Behaviour National Strategy Group and others. A number of organisations spoke to us or submitted evidence directly, including the Ideas Collective, CHANGE, Shared Lives Plus, and Prof. Richard Hastings at the University of Warwick. We have drawn heavily on their ideas and views, and are hugely grateful for their engagement.
- 7. Whilst we were originally tasked with making recommendations for a national commissioning framework for NHS England, it is clear to us that any such framework formulated by NHS England must be accompanied by related action from others most obviously, local and central government and by a stronger rights framework. Our recommendations reflect this.

⁹ J. Mansell, Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs (1993), and revised edition (2007)

¹⁰ Department of Health, Transforming Care: a national response to Winterbourne View hospital (2012)

¹¹ Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)

¹² LGA & NHS England, Ensuring Quality Services (2014)

THE PROBLEM WE ARE CONFRONTING

Where we are now

- 1. The problem we are dealing with is, we believe, well understood. It has been well described a number of times, by people with learning disabilities and/or autism themselves, their families, charities and campaign groups, the Department of Health, professional organisations, the Local Government Association and NHS England. We summarise it here for clarity, rather than as a new addition to the debate.
- 2. Some people with learning disabilities and/or autism who present challenging behaviour may need to be admitted to inpatient settings to be assessed and treated particularly if they are liable to detention under the Mental Health Act on the recommendations of mental health professionals or a court. But
 - a) many are admitted when that could have been prevented had they received better support in the community,
 - **b)** many stay in hospital too long, when with the right support in the community they could be discharged.

The result is that for many years, at any one time far too many people with learning disabilities and/or autism could (and still can) be found in inappropriate inpatient settings.

- 3. After the Winterbourne View scandal, the Government and a large number of partners signed a Concordat which promised: "health and care commissioners will review all current hospital placements and support everyone inappropriately placed in hospital to move to community-based support as quickly as possible and no later than 1 June 2014". It envisaged a "rapid reduction in hospital placements for this group of people", and "the closure of large-scale inpatient services".¹³
- 4. Since then, hundreds have been transferred out of inpatient care NHS England's quarterly data collections show that between 30 September 2013 and 30 September 2014, 923 people were transferred out of inpatient care. But crucially, numbers admitted have been consistently higher than numbers transferred out with 1,306 individuals admitted over the same period.¹⁴
- 5. Individuals with learning disabilities, their families, commissioners and clinicians, will still say that many of those inpatients could be discharged, or that their admission could have been prevented, if there were better

¹³ Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)

¹⁴ NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/

support available in the community. And NHS England's care reviews are still finding significant numbers of people in inpatient settings who could and should be discharged with the right community-based support in place. Too often, people are still placed in inpatient settings a very long distance from family and home.

- 6. The pledge in the Concordat is still valid. We still need to do better both at
 - a) Putting in place the community-based support to safely discharge people currently in inpatient settings (of whom the latest NHS England data collection showed there were 2,600),¹⁵ and
 - b) supporting people in the community to **prevent admissions** in the first place with that early intervention starting at the earliest possible stage in childhood, but most urgently with better support provided to adults in the community with severe challenging behaviour (of whom there are much larger number, perhaps some 24,000 people in England ¹⁶).
- 7. Stakeholders were clear to us that this latter need to focus on early intervention and prevention cannot be overlooked. The intense focus on the 2,000–3,000 people currently in inpatient settings is welcome, but it must not be at the expense of catering for the larger number at risk of admission. Failure to do better for them will result in failure to reduce inpatient numbers overall.

Where we need to get to

- 8. Again, there is broad consensus on what the world should look like for people with learning disabilities and/or autism who present behaviour that challenges. It has been described repeatedly by people with learning disabilities and/or autism themselves, their families, Professor Mansell (in 1993 and again in 2007),¹⁷ the Department of Health (in its 'model of care' published after the Winterbourne View scandal),¹⁸ the Winterbourne View Joint Improvement Programme (in *Ensuring Quality Services*),¹⁹ the NDTI (in the DH-funded *Guide for commissioners of services for people with learning disabilities who challenge services*)²⁰ and others. Again, we summarise 'what good looks like' here for clarity rather than with the intention of adding anything new to the debate:
 - The presumption should be that people live in their own homes, not in hospitals. A hospital, whatever the quality of the care it provides, is not a home.
 - The system needs to respect and uphold the rights of people with learning disabilities and/or autism (general human rights and rights
 - 15 NHS England, Quarterly 'Assuring Transformation' data, published at www.england.nhs.uk/ourwork/qual-clin-lead/wint-view-impr-prog/
 - 16 K. Lowe et al, Challenging Behaviours: prevalence and topographies. *Journal offfIntellectual Disability Research*, 51, 625–636 (2007)
 - 17 J. Mansell, Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs (1993), and revised edition (2007)
 - 18 Department of Health, Transforming Care: a national response to Winterbourne View hospital (2012)
 - 19 LGA & NHS England, Ensuring Quality Services (2014)
 - 20 NDTI, Guide for commissioners of services for people with learning disabilities who challenge services (2010)

- specific to people with disabilities), ensuring that they are able to exercise choice and control over their lives and that they are treated with dignity and respect.
- Services need to support people as human beings to lead whole lives (rather than simply as 'patients' who need to be treated for medical problems).
- Support needs to be provided over the whole life course, from birth
 to old age, and we should seek to intervene early to prevent crises rather
 than simply responding to them.
- The system needs to combine highly personalised support with reasonable adjustments that ensure access to universal services.
- Services need to incorporate building blocks that we know to be crucial to success, such as: multi-disciplinary community learning disability teams able to provide support with communication, physical and mental health and social needs; care coordinators; support for families to look after family members at home, including short break services; high-quality independent advocacy services; appropriate housing; access to education, work and meaningful activities; extra support in times of crisis; access to Positive Behavioural Support and highly-skilled staff throughout the system (all set out in more detail in the Mansell reports, ²¹ the joint report of the Royal College of Psychiatrists, British Psychological Society and the Royal College of Speech and Language Therapists in 2007, ²² or the NHS England/LGA guide *Ensuring Quality Services* ²³).
- Where a spell in inpatient settings is truly necessary, it should be
 as local as possible, and enable speedy resolution to crises in a way
 that builds resilience for the individual and their family.
- People with learning disabilities gave us a strong message that a good system will be co-designed with, and employ, people with learning disabilities and/or autism and their family members.
- 9. There is also broad agreement about some of the mechanisms required in commissioning practice if we are to have services that meet the above, and these were clearly spelt out in the Transforming Care Concordat that followed the Winterbourne View scandal. They included:
 - Pooled budgets and joint commissioning, accompanied by strong local leadership. The Transforming Care Concordat stated: "the strong presumption will be in favour of pooled budget arrangements...
 CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area."²⁴
 - 21 J. Mansell, Services for People with Learning Disabilities and Challenging Behaviour of Mental Health Needs (1993), and revised edition (2007)
 - 22 Royal College of Pyschiatrists, British Pyschological Society and Royal College of Speech and Language Therapists, *Challenging Behaviour: a unified approach*
 - 23 LGA & NHS England, Ensuring Quality Services (2014)
 - 24 Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)

- Personalisation. The Concordat pointed to the importance of personal care plans for each individual, and pledged that inpatients "should be receiving personalised care and support in community settings".²⁵ Subsequent work, such as Think Local Act Personal and the NDTI's 2014 report on personal health budgets for people with learning disabilities,²⁶ has pointed to the potential benefits of personal budgets as a tool for achieving personalised care.
- Contracts that incentivise or require best practice. The Concordat
 pledged a range of actions to make it easier to: reward best practice
 through the NHS commissioning for quality and innovation (CQUIN)
 framework, embed Quality of Health principles in NHS contracts and
 Quality of Life principles in social care contracts, and hold providers
 to account.²⁷
- Support for commissioners. There has been widespread recognition that local commissioners do not always have the capacity or capability to lead the kind of service transformation hoped for, and the Concordat led to a range of actions to support commissioners, ranging from practical tools (such as toolkits or service specifications) to guidance (such as that by the Royal College of GPs and Royal College of Psychiatrists²⁸) to workshops as currently being run by the Joint Improvement Programme. People with learning disabilities and/ or autism and their families have argued strongly that they and their local groups should be partners in commissioning decisions.
- Provider and workforce development. Again, there has been widespread agreement that for more people with learning disabilities and/or autism who display challenging behaviour to be supported successfully in the community, community-based providers and workforces will need support and development. A large number of pledges in the Concordat focused on workforce development, with actions ranging from guidance for social workers to minimum training standards for healthcare support workers to guidance for commissioners on workforce development.²⁹

Why has there not been more progress?

- 10. As the above makes clear, this steering group is not the first time anyone has thought about this issue, by a very long way. For decades people have argued for change and described what good care looks like, and how we can commission it. The Winterbourne View scandal made the need for change even clearer, and resulted in a wide range of commitments from Government and others. But the problem remains. Why?
 - 25 Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)
 - 26 Think Local Act Personal & the NDTI, Personal Health Budgets: including people with learning disabilities (2014)
 - 27 Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)
 - 28 Joint Commissioning Panel for Mental Health, Guidance for commissioners of mental health services for people with learning disabilities (2013)
 - 29 Department of Health, Winterbourne View Review: Concordat: a programme of action (2012)

- 11. Our view is that progress has been so slow not because we haven't described what good looks like, or how we need to get there, but because it has been too hard to do the right thing and too easy to do wrong thing, and the people most eager to change the system (people with learning disabilities and/or autism and their families, enthusiastic providers, clinicians and commissioners) have had too little power or support to do so.
- 12. Clinicians are being asked to admit fewer people who present challenging behaviour to inpatient settings, and to discharge others, on the basis that they can be appropriately supported in the community. Many clinicians would like to do just that, and some manage it – but too often they do so in spite of the system, not because of it. They are being asked to keep people in the community or discharge to the community when many will worry that the community-based support on offer is insufficient, or not there at all. They do not want to see individuals unsupported in the community, and many will have seen precisely that happen with subsequent placement breakdown and a need for readmission. They are being asked to take this approach when many work for providers that are not financially incentivised to have a culture and a drive to get people supported in the community, but that instead have an incentive to keep inpatient beds full. And clinicians are being asked to do this when the people who have the expertise to suggest to them realistic communitybased alternatives are often unable to, because they lack access to information about the individual's needs.
- 13. Both health and social care providers are being asked to expand their community-based capacity to support people who present behavioural challenges in order that they are not admitted in the first place, or can be safely discharged from inpatient settings. Many would like to do just that, and some manage but again, too often despite the system not because of it. Providers are being asked to invest significant sums of money in new staff, training and sometimes new or altered accommodation, months in advance of them taking on new clients and being paid for their care. They may not have the capital to make that upfront investment. Sometimes they are asked to put those services in place at impossibly short notice. And they are asked to make the upfront investment when they are fundamentally not confident that commissioning or clinical behaviour will change, and that there will be predictable revenue streams to pay for their investment.
- 14. People with learning disabilities and/or autism and their families are being asked to play a central role speaking up for their rights, acting as partners in designing packages of support, perhaps managing personal budgets, challenging poor practice, being directly involved in the appointment of their care staff. Some do. But too often they experience it as an exhausting battle against the system. Others do not know what their rights are, don't have the support to express or use them. Still others do not know what good community-based potential alternatives could be created for them, and know only the community services that have failed them before.
- **15.** Frontline staff are being asked to behave differently to think more often of people as people and citizens with rights(not just patients with problems), to engage individuals or their families in care more, to be aspirational about what people can achieve, to make greater use of Positive

Behavioural Support. Many do – but again, less because of the system than in spite of it, because we are asking them to do so without a great deal of support or training, and without incentivising the organisations they work for to make it a priority.

- 16. And commissioners (CCGs, local councils and NHS specialist commissioners) are being asked to collaborate across organisational boundaries to transform a highly complex system, taking risks in the process. Some have, but again, too often in spite of the system not because of it. Because they are being asked to do all this when many have limited time and capacity to give to the issues, lack expert support, are constrained or slowed down by organisational disputes over who pays for what and whose responsibility an individual should be, and may lack the backing from local leaders that they need to push through change and negotiate compromise between different interests. And they are being asked not to put people in inpatient beds when often those beds have been paid for on a block contract, come at no marginal cost, and feel like the safe option.
- 17. We need to make it easier (or mandatory) for all these stakeholders to do what we are asking of them. We need to make it harder (or impossible) for them to settle for the status quo that we are agreed must stop. And we need to empower the agents of change those commissioners, providers, clinicians and above all, people with learning disabilities and/or autism and their families, who are battling for things to be done differently. That is what any new commissioning framework needs to do, and what our recommendations aim to achieve.

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RECOMMENDATIONS

Strengthening rights

- The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning
 - 1.1. We have heard, loud and clear, the message from people with learning disabilities and/or autism and their families that the system needs to do a better job of respecting and upholding their rights, and listening to what they have to say. This is about doing what is fundamentally the right thing, respecting people's human rights as a point of principle. But it is also about empowering people who could help change the way the system works for the better, but who too often struggle to make themselves heard. In the context of the problem described in the previous chapter, it is about empowering the agents of change.
 - 1.2. People with learning disabilities and/or autism and their families have an array of rights in law or Government policy through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on.
 - 1.3. But in our engagement with stakeholders over the course of our work, we heard that the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.
 - 1.4. In some cases, people with learning disabilities and/or autism and their families may not be aware of the rights they already have, or may not have access to the support they need to exercise those rights (such as access at the right time to an advocate or lawyer for instance, during a crisis, at point of admission, or when in an inpatient setting).
 - 1.5. In other cases, there are doubts over whether the rights of people with learning disability are being respected in practice as originally intended. For instance, as the Government has recognised,³⁰ there have been occasions where the safeguards in the Mental Health Act have not been properly applied, leading to the recent consultation on updating the Mental Health Act Code of Practice.
 - 1.6. There are also serious concerns about the treatment of people with learning disabilities and/or autism by the criminal justice system, and whether their rights are being properly upheld.

In 2009, the 'Bradley Report'³¹ described a widespread lack of awareness of the issues faced by people with a learning disability and communication difficulties in the criminal justice system. Since then, there has been significant progress, but the 'Bradley Report Five Years On', ³² published this year, found more needs to be done and made nine recommendations for action. This area was outside our remit to explore in detail, but we recognise how fundamentally important it is. We recommend that the Government respond to the recommendations of the 'Bradley Report Five Years On', setting out how cross-government action will tackle the issues raised.

- 1.7. To make the rights that people with learning disabilities and/or autism and their families already have feel real, we recommend that the Government should set out a Charter of Rights for people with learning disabilities and/or autism and then require commissioners to shape local services around those rights.
- 1.8. Any such charter should build on existing work (such as the 'We Have the Right' statement put together by people with learning disabilities with support from CHANGE for the purposes of this report, or the Challenging Behaviour Charter drawn up by the Challenging Behaviour National Strategy Group, both of which can be found in the appendices). The Charter of Rights should clarify the rights people already have, and the support they can access to use them. It should clarify how professionals (commissioners, clinicians and others) should respect those rights including in respect to upcoming changes to the Mental Health Act Code of Practice.
- 1.9. To give the Charter of Rights 'teeth', local commissioners should be required to base their local commissioning plans on it, and to set out how they will make those rights real for instance, by:
 - ensuring information is accessible and available in a range of formats (including easy read) and adapted for individual needs;
 - commissioning high-quality independent advocacy services for people with learning disabilities (including people with complex needs), brokerage support, and supporting self-advocacy and family advocacy groups. Particularly for individuals who do not have family, or do not have a supportive family, such support is critical;
 - offering personal budgets and strong support for people with learning disabilities and/or autism and their families to use them;
 - ensuring that at key moments (such as prior to admission) people
 with learning disabilities and/or autism and their families know
 their rights, know what support they can access to exercise them,
 and know how to access that support;

³¹ Lord Bradley, The Bradley Report (2009)

³² G. Durcan, A. Saunders, B. Gadsby & A. Hazard, The Bradley Report five years on: an independent review of progress to date and priorities for further development (2014)

- employing and working in genuine partnerships with people with learning disabilities and/or autism and family carers throughout the system in drawing up commissioning plans, in hiring staff, in ensuring providers meet high quality standards, in scrutinising and holding commissioners to account, sitting on provider boards of director, and so on. Some of this good practice commissioners could require through the contracts they let to providers, and NHS England should show leadership by employing people with learning disabilities and/or autism at a central level to help drive service transformation.
- 1.10. Action to make this Charter of Rights 'real' should be central to the mandatory commissioning framework we set out below.
- 2. People with learning disabilities and/or autism should be given a 'right to challenge' their admission or continued placement in inpatient care
 - 2.1. In addition to making existing rights feel more 'real', we propose extending the rights of people with learning disabilities and/or autism and their families starting with a 'right to challenge'.
 - 2.2. A 'right to challenge' would allow a person with learning disabilities and/or their family to challenge a decision to admit them to hospital or keep them there, should they so wish. Such a right should be accompanied by free support from an independent, multidisciplinary team, including 'experts by experience' - family carers or people with learning disabilities who have had experience of inpatient services or been at risk of admission themselves. Building on the process already developed through NHS England's existing programme of care and treatment reviews and reviews by NHS England's Improving Lives Team, together they would ask what assessment, treatment or safeguarding was to be undertaken/was being undertaken in an inpatient setting that could not feasibly be done in the community. The independent support would help individuals and families understand what community-based alternatives might be possible. Based on the presumption set out in the Mandate from the Department of Health to NHS England after the Winterbourne View Scandal ("the presumption should always be... that people remain in their communities"), the review triggered by this right to challenge would only recommend admission/continued placement in hospital if it concluded that the assessment, treatment or safeguarding could only be effectively and safely carried out in an inpatient setting.
 - 2.3. We recognise that many individuals with learning disabilities and/or autism will not feel able to challenge the decisions taken regarding their care, particularly if they are in inpatient settings. In such cases, it is essential that the commissioners paying for their care take the responsibility to challenge the appropriateness of their admission or continued placement in inpatient settings. We expect all commissioners to ensure a care and treatment review is undertaken with the permission of the patient or their carer in order to confirm if inpatient treatment is appropriate.

- NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism, along with support to manage those budgets
 - 3.1. The 'right to challenge' outlined above should be allied to an extension of rights to have a personal budget (or personal health budget),³³ building on existing rights for those eligible for Continuing Health Care and social care funding. A right to have a personal budget (or personal health budget) should be considered for:
 - People who are inpatients and those at risk of admission:
 If an independent review linked to a 'right to challenge' found that an individual could avoid admission or be discharged with the right package of assessment, treatment, support and safeguarding in the community, the individual and their family should have a right (but not an obligation) to a personal budget (or personal health budget) to put that package in place.
 - People with learning disabilities and mental health needs.
 For instance, people with learning disabilities who are on the Care Programme Approach would be a readily identifiable group who might benefit.
 - Children and young people with learning disabilities.
 Children and young people who have significant health needs could be offered personal budgets (or personal health budgets) to enable them to remain living in the community and avoid out of area placements.
 - 3.2. Personal budgets and personal health budgets encourage a change in thinking. Instead of commissioning services for groups, support is designed for one person at a time, based on a whole-life care plan that focuses on what matters to the person and their family. As now, people should be able to take their budget in a variety of ways as a direct payment, as a notional budget, or as a budget managed by a third party (known as an individual service fund in social care).
 - 3.3. Local areas will need national support to make this extension a reality, and the centre (the Department of Health, NHS England and national partners) will need to invest in that support. This should include:
 - Ensuring close links with the Integrated Personal Commissioning programme, to support local areas to pool funding across health and social care.
 - Publishing the number of people taking up personal budgets (or personal health budgets) and the impact on their lives, so local health and social care commissioners understand progress and can be held to account.

- Putting in place a national support programme for local commissioners, to enable them to actively promote personal budgets (or personal health budgets) as an option for these groups.
- Ensuring that the other recommendations of this report are implemented in ways that encourage and promote uptake of personal budgets and personal health budgets.
- 4. The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital, so that people do not lose their homes on admission and end up needing to find new suitable accommodation to enable discharge.
 - 4.1. We heard that on being admitted to hospital, it is common for people with learning disabilities and/or autism to lose their tenancy. Not only can that be distressing for the individual, the need further down the line to find suitable accommodation can cause delays to discharge. It was not in our remit to look into this issue in detail, but we recommend that the Government explore ways to protect the tenancies of people with learning disabilities and/or autism when they are admitted to hospital, so that they can return to the same home on discharge if they wish to.

Forcing the pace on commissioning

- The Government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework
 - 5.1. The basic pillars of what is required at a local level from NHS and local authority commissioners has already been described (and committed to by a range of partners) through the Transforming Care Concordat and elsewhere, namely:
 - One shared vision, driven forward by active senior leadership, based on the presumption that hospitals are not homes, and that people should be supported to live in the community.
 - One pooled budget, allowing maximum flexibility for commissioners to fund what individuals truly need, and aligning the financial incentives on all commissioners to invest in community-based provision.
 - One robust plan for commissioning on a whole life-course basis, supporting early intervention and support (from early childhood onwards), expanding the provision of community-based support and care, and reducing the number of inpatients and inpatient provision. That plan should be based on a robust understanding of current and future need, a range of existing best practice guidance, and active engagement with people with learning disabilities and/or autism, their families and providers.
 - 5.2. Many local commissioners (in local councils and clinical commissioning groups) are enthusiastic about making this shift happen, and there is much good practice to draw on. But a great

many local commissioners do not have the three pillars above in place. The most recently published stocktake by the Winterbourne View Joint Improvement Programme³⁴ found many areas were not pooling budgets, commissioners, providers and families continue to cite disputes over who should fund what as a reason for inappropriate placements, and the growing number of people in inpatient settings suggests that in many areas, what local plans were drawn up did not meet the scale of the challenge. We have heard that common causes include:

- Lack of local leadership, and weak accountability. Where local
 commissioners have been successful in expanding communitybased provision and reducing the need for inpatient beds, active
 senior leadership backing has often been cited as key to their
 success. But where that leadership has been lacking, the national
 organisations do not appear to have been able to hold local
 commissioners to account, and nor do people with learning
 disabilities and/or autism or their families.
- Systemic barriers. Local commissioners have pointed to a number of systemic barriers to success, such as inconsistent application of rules around Continuing Health Care (CHC) funding, Ordinary Residence rules, NHS Responsible Commissioner rules and difficulties engaging with specialist, secure (forensic) commissioners.
- Insufficient support, assurance and challenge. Commissioning services for people with such complex needs is a highly-skilled job, but we heard that commissioning capacity has reduced in many areas, and that in some areas that lack of capacity is a significant obstacle to progress. The Concordat has resulted in a wide range of useful support for commissioners, from the Joint Improvement Partnership (JIP) and others. But there needs to be more 'on-the-job' support for, and challenge or assurance of, the drawing up of local commissioning plans to ensure that they are sufficiently robust. Critically, there must be a strong role for people with learning disabilities and/or autism and their families in providing that support and challenge.
- 5.3. To overcome these barriers, we believe national organisations such as NHS England, departments across Government, other Arms-Length Bodies and the LGA need to play a more robust leadership role unblocking barriers and devolving funding, setting out a mandatory framework for local commissioners to follow, and providing more support and assurance to local commissioners as they do so.
- 5.4. NHS England should devolve the budget and responsibility for commissioning services for this group as much as possible from NHS specialised commissioning to Clinical Commissioning Groups (CCGs), so that local commissioners are more clearly incentivised

to ensure there is adequate community-based provision, and admitting an individual to a secure bed is never the 'easy option' for local commissioners. NHS England and its partners at a national level should also remove the systemic barriers that make it harder for local commissioners to invest more in community-based provision and to disinvest in inpatient beds, such as the difficulties local commissioners report having as a result of Ordinary Residence rules, Responsible Commissioner rules and eligibility for Continuing Health Care funding.

- 5.5. Through a mandatory framework, NHS England should require local NHS commissioners to pool their spending with commissioners of social care and housing services for adults with learning disabilities who present behaviour that challenges, and mandate them to produce a single, outcomes-focused plan for using that spending, covering a period of a number of years. Clearly, the successful engagement of local government is critical here. Whilst NHS England cannot mandate local authorities to commission in a particular way, it should seek to work with others (the LGA, ADASS, DCLG, DH) to ensure that the commissioning framework is fit for purpose from a local government perspective, and that the local authorities are fully engaged as equal partners in the drawing up of joint local plans. The NHS should also make the pooling of budgets dependent on that engagement.
- 5.6. Local plans should be required to follow a basic mandatory framework, answering questions such as:
 - What the measurable objectives the plan aims to achieve
 (e.g. what improvements in health, wellbeing and independence
 we want to see, what reduction in need for inpatient provision
 we want to see, or what reduction in use of 'out-of-area'
 inpatient placements, over what timeframe).
 - How those goals will be achieved (taking into consideration what we know to be key to success, as set out in existing literature such as the Mansell reports³⁵ and *Ensuring Quality Services*,³⁶ and including how the rights of people with learning disabilities and/ or autism and their families will be made real, as above, and how the local workforce will be developed, as below).
 - How the plan ensures local services take a whole life-course approach. Appropriate services need to be available for children, young people and adults, with efforts to prevent the need for inpatient services starting in early childhood, and an effective approach in place to managing transition from children's services or residential education to community-based adult services. We heard throughout our work that more effective support for children and better transition between children's and adults' services will be critical earlier intervention in childhood and improving the transitions between will be critical.

- Who is responsible for success, including at senior leadership level, and with a single lead commissioner clearly identified.
- What analysis of current and future need has been undertaken.
- How these plans have been co-produced with people with learning disabilities and/or autism and their families, providers and clinicians. Local providers should be brought together in a forum to collaborate with one another and with commissioners to ensure comprehensive local services are available.
- 5.7. The commissioning framework should also describe the kind of approach to commissioning we need to see. For instance, we believe commissioners need to:
 - Take a more proactive, long-term approach planning what kind of services will need to be in place for people from childhood onwards, rather than reacting to crises as they emerge.
 - Take a more collaborative approach to engaging with providers. Commissioners need to stimulate the market, encouraging the entry and development of smaller, more innovative providers. They also need to engage with providers more proactively in planning services for individuals and for the population as a whole, giving providers greater opportunities to put forward alternative options. The commissioning framework should make clear that this is both entirely permissible under procurement law and to be actively encouraged.
 - Take a more outcomes-based approach, so that payment is increasingly linked to outcomes for people, rather than hours of support provided.
- 5.8. Alongside the commissioning framework set out above, there needs to be more support and assurance from NHS England, the Department of Health and the LGA, who should build on the work of the Winterbourne View Joint Improvement Partnership and provide more intensive, 'on-the-job', action-focused support to local commissioners, helping them to draw up and implement commissioning plans as above, and to extend the uptake of personal budgets. To ensure that local plans are realistic and robust, NHS England and the LGA should also scrutinise and assure them. This process should also involve scrutiny by panels (at local and national level) of people with learning disabilities and/or autism and their families. Local commissioners that submit plans which are insufficiently ambitious or robust should be given extra support to improve them.
- 5.9. In pursuing this agenda, NHS England and its national partners should learn from the strengths and weaknesses of the Better Care Fund,³⁷ which also mandated the pooling of budgets, and
- 37 The Better Care Fund is a £3.8 billion budget, pooling health and social care funding, to support transformation and integration of health and social care services. More detail can be found at www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/

- the drawing up of local joint plans with support and assurance from the centre.
- 5.10. Alongside the model above, the commissioning framework should include measures to facilitate swift, safe discharge from inpatient settings back into the community, such as a standard contract that includes financial incentives for inpatient providers to focus on discharge planning. Currently, the way in which many inpatient providers are contracted gives them no financial incentive to focus on discharge planning from day one (and indeed they may be financially incentivised to keep as many beds full for as long as possible). That should change, so that contracts incentivise the kind of behaviour we want from inpatient providers including planning for the earliest possible, safe discharge from the point of admission.
- Community-based providers should be given a 'right to propose alternatives' to inpatient care
 - 6.1. We heard that a barrier to discharge is often that responsible clinicians in inpatient settings will be concerned that appropriate support is not available in the community, and struggle to see how an appropriate community-based support package (potentially including continued assessment, treatment and safeguarding) could realistically be put into place. That can then lead to decisions that it is too early to discharge, or start planning for discharge. To tackle this, community-based providers considered by local commissioners to be of sufficient quality and reliability, and given permission by individuals or their families, should be given the ability to understand the detailed needs and wishes of people in inpatient settings (through access to information, clinicians or the individual and their family), upon which basis they can put forward a potential package of community-based support for consideration by the individual, their family, the commissioner and the responsible clinician. This should be an opportunity for people who can put together innovative solutions - providers, voluntary organisations, support brokers, advocates - to take the initiative.

Closures

- 7. The commissioning framework should be accompanied by a by a closure programme of inappropriate institutional inpatient facilities, driven by tougher registration requirements, local closure plans, and leadership by NHS England
 - 7.1. We are clear that there must be closures of inpatient institutions:
 - The presumption, in the twenty-first century, ought to be that people with learning disabilities and/or autism live in the community, not in hospitals
 - People with learning disabilities and/or autism and their families have been very clear that this is what they want. Some, such as the self-advocacy groups who submitted their views to us via CHANGE, argued that all hospitals for people with learning disabilities and/or autism should be shut. Others believe some

hospitals should remain open, providing a high-quality, locally-integrated service more clearly focused on assessment, treatment and discharge – but they want the number reduced. Some suggested that it is learning disability-specific mental health facilities which should be closed, with universal mental health services making the necessary adjustments to be inclusive of people with learning disabilities alongside others. Whatever the precise way forward, the consensus in favour of significant closures is clear.

- This is also an assumption already signed up to by stakeholders across the system via the Concordat that followed Winterbourne view. The Concordat was clear that currently too many people with learning disabilities and/or autism are admitted to inpatient settings when admission could have been avoided, too many stay too long, and so too many are in inpatient settings at any one time. The corollary is that we have too many inpatient beds, some of which should be closed.
- 7.2. So we are crystal clear that there must be closures. But we are also clear those closures must be implemented in the right way:
 - A guiding principle should be 'above all, do no harm' closures must be accompanied by more and better community-based support in place, and must be driven by what is best for people with learning disabilities and/or autism and that alone.
 - We must not close down one set of institutions only for another to appear. People with learning disabilities and/or autism and their families were clear that small residential care homes and group homes can be 'institutions' in that they can be places where people don't choose who to live with or how to spend their time and don't feel like home. We have also heard fears that some inpatient hospitals could simply 'rebadge' as residential care or nursing homes. We need to ensure that the community services we replace hospitals with are genuinely what people with learning disabilities and/or autism want, and the CQC needs to be vigilant against allowing hospitals simply to go on providing the same institutional care under a different label.
 - To say we should close inpatient wards is not the same as saying we do not need all the people who work in them, with the expertise that they have. Whilst care in inpatient settings is of variable quality, in places people are providing assessment, treatment and support to the highest standard. Some of that assessment, treatment and support can and should be provided in the community, in people's own homes. The packages of support people need to live in the community are likely to require input from professionals such as support staff, psychologists, occupational therapists, psychiatrists, nurses, some of whom are likely now to be employed in inpatient providers. The shift in care we are seeking is more likely to require professionals to work in different ways and different settings than to stop being involved altogether. The professionals working in inpatient

- settings need to be part of the solution, and part of the remit of the national Academy we propose below must be to help make that happen as part of a managed transition.
- 7.3. Given the consensus that we currently have more inpatient provision than we should need, we propose that the CQC should act as a market entry regulator and work with local commissioners to determine any future registrations of planned local assessment and treatment or inpatient units. It should announce that after a transitional period, it will significantly raise the quality threshold that inpatient settings will need to meet, including measures such as size of institution and average length of stay taken into account in regulatory judgments (recognising that appropriate length of stay will vary according to need). Any inpatient settings that fail to meet the bar should be considered in breach of the relevant fundamental standards. The approach needs to be ambitious, overt and public, such that it sends a clear message to providers about what the future holds.
- 7.4. Earlier in this report we proposed a mandatory commissioning framework for commissioners of health and social care services, with local commissioners required to draw up a plan for reducing reliance on inpatient beds, and that plan then scrutinised and assured by national system leaders with the involvement of people with learning disabilities and/or autism and their families. Part of that planning process should include a forecast for the number of inpatient beds each area believes it should have, based on a population needs assessment. This should be developed in partnership with others people with learning disabilities and/ or autism and their families. A plan to actively decommission any beds surplus to that requirement, together with the transfer of skilled staff into community services where appropriate, can then follow. These local closure programmes should be implemented in close collaboration with people with learning disabilities and/ or autism, their families and providers.
- 7.5. Finally, NHS England, as a direct commissioner of many inpatient services, should also decommission inpatient services that it currently pays for that are surplus to need. It should seek to start doing this at the earliest opportunity, sending a clear signal to the provider market about the direction of travel.
- 7.6. NHS England should set out a clear timeline for a closure programme of institutions which do not accord with the model of care that the Government committed to following the Winterbourne View scandal³⁸. We have heard differing views on what that timeline should look like. The Housing and Support Allowance suggested to us that the number of people with learning disabilities and/or autism in inpatient settings could be reduced to 1,500 and admissions reduced 75% by 2018. Groups of people with learning disabilities brought together by CHANGE called for an end to admissions

in three years, and all institutions specifically for people with learning disabilities to be closed after that – though some people with learning disabilities also said that they wanted better-quality, smaller and more local inpatient services to remain. Some local areas will be able to achieve change quicker than others. The picture is mixed. NHS England should come to a considered, realistic view on what is possible – but then it should set out a clear timetable not just for reductions in admissions or inpatient numbers (as has been tried unsuccessfully to date), but for closures of institutions.

Building capacity in the community

- 8. Health Education England, Skills for Care, Skills for Health and partners should develop as a priority a national workforce 'Academy' in this field, building on the work already started by Professors Allen and Hastings and colleagues
 - 8.1. We will only successfully prevent people with learning disabilities and/or autism and challenging behaviour needing to be admitted to inpatient settings, and discharge those currently in hospitals, if we can achieve a major expansion, and major improvement in quality, of community-based support services (including robust preventative and pro-active care that starts before problems manifest, care coordination and brokerage, advocacy, appropriate housing, care and support, multi-disciplinary community learning disability teams, crisis support and respite services). Without that expansion and improvement in quality, people will continue to have crises and be admitted to inpatient institutions, and many people with learning disabilities and/or autism, their families, clinicians and commissioners, will continue to be nervous about discharge from hospital back into the community.
 - 8.2. We heard a consistently strong message that building the skills of the workforce (from care assistants to doctors and nurses to commissioners) should be a major priority here. Critically, this support should be available to family carers too, who should be recognised as fundamental partners in care.
 - 8.3. As a result of the programme of work set in train following the Winterbourne View scandal, we now have a significantly enhanced and growing corpus of best practice guidance on working with people who display challenging behaviour (the Concordat has led, for instance, to a wide range of new or updated guidance for commissioners, social workers, clinicians, healthcare support workers, universal services on reasonable adjustments and more). There are also academics, trainers, providers and commissioners across the country with real expertise in supporting people with challenging behaviour in the community. There is a range of guidance on how local commissioners and providers can embed this good practice through workforce development.
 - 8.4. What is needed now is a concerted programme of action to spread that expertise and codified good practice across the workforce, significantly expanding on the provision already available.

The proposal put together by Professor Richard Hastings and Professor David Allen for an 'Academy' to deliver that³⁹ is persuasive, particularly in its articulation of the need for a programme of action that:

- has two clear goals: firstly, supporting the system transformation
 that we hope to see in the immediate future in localities across
 the country as we build capacity in community services and
 reduce reliance on inpatient provision, and secondly, supporting
 the continued long-term development of the workforce in
 services for people with learning disabilities and/or autism
 who display challenging behaviour.
- achieves those goals through:
 - a programme of training and development available
 to stakeholders across the system (local leaders of
 commissioning agencies and provider organisations, provider
 staff, clinicians, families and carers, individuals with learning
 disabilities themselves). This needs to focus both on providers
 of long-term care and support, but also on the community
 'infrastructure' that providers, people with learning
 disabilities and/or autism and their families need to be able
 to rely on, particularly to manage crises community learning
 disability teams, psychologists and psychiatrists able to assess
 people where they are living and develop appropriate support
 plans, and so on.
 - quality kite-marking or accreditation (of training providers and of support providers, whose variable quality we heard is a major issue for commissioners and people with learning disabilities and/or autism and their families) and
 - supporting the continued development of a bank of evidence, best practice, minimum standards, toolkits and guidance.
- brings together and helps coordinate (rather than seeking to replace or replicate) the large number of organisations and individual experts already working to build the skills of the workforce in this area – including many people with learning disabilities and/or autism themselves and their families.
- 8.5. We believe any such programme of action should include a clear role for people with learning disabilities and/or autism and their families, who should be employed to help deliver it.
- 8.6. We are also clear that any programme along these lines needs to be action-focused at least in the immediate future, as much a national taskforce or action programme as an 'academy', closely aligned to the mandatory change programme that we set out above. But whatever the name, we have heard a clear consensus (from people with learning disabilities and/or autism and their families, providers, commissioners, clinicians, academic experts) that there

is a pressing need for urgent and significant investment in workforce development in this field. We therefore recommend that Health Education England, Skills for Care, and Skills for Health build on the momentum generated by Professor Hastings' and Professor Allen's proposal, working with them and stakeholders across the system (including in the self-advocacy movement and the voluntary sector), to fully scope out the gaps in training and development of staff caring for those with a learning disability and/or autism who display challenging behaviour, and then develop a national academy along these lines to expand and develop existing good practice and to fill the identified gaps.

- A 'Life in the Community' Social Investment Fund should be established
 to facilitate transitions out of inpatient facilities and build capacity in
 community-based services.
 - 9.1. The conundrum we currently face is that people with learning disabilities and/or autism, their families, clinicians and commissioners are nervous of keeping people out of inpatient settings, or discharging them more quickly, in the absence of stronger community-based services. Providers of community-based services, on the other hand, are nervous of investing in expanding their offer in the absence of greater certainty that those services will be called on by commissioners and clinicians.
 - 9.2. The risk we are asking providers of community-based services to take here is significant: for any one person with learning disabilities who displays behaviour that challenges, a support provider may need to recruit and train a number of support workers. In some cases, where suitable accommodation might not be available, a housing provider might need to make adaptations to existing stock or even invest in new buildings. The local community learning disability team might need to invest in recruiting and training more staff (nurses, psychologists, psychiatrists, GPs, speech and language therapists, occupational therapists) to provide support as and when it is needed. This recruitment, training and occasionally investment in property would need to happen months in advance of a person moving in or starting to receive the support, and the provider(s) being paid for delivering it.
 - 9.3. We can reduce the risk that we are asking providers to take by reforming commissioning and clinical practice, so that providers have greater confidence that if they invest in expanding community services, there will in fact be take-up. Our hope is that our other recommendations will do that. A mandatory framework should shift commissioning practice particularly by requiring commissioners to engage with providers in drawing up local plans, to pool budgets and thereby make for more flexible revenue streams, and to set clear targets for shifting care out of inpatient settings and into the community. Strengthening the rights of people with learning disabilities and/or autism and their families should make it easier for people who want and can be cared for in the community rather than inpatient settings to avoid admission or speed up discharge.

Our proposed reforms to the commissioning of inpatient settings should do the same. But even with these changes to commissioning practice, we will still be asking providers to take a big risk by investing large sums of money in expanding community provision, without certainty that those services will be called on or adequately commissioned. And we are making this ask of a set of providers, often in the voluntary or public sectors, many of whom do not have significant capital of their own to invest, and who are unable, unused or unwilling to access capital from investors.

- 9.4. We therefore believe there is a strong case for making such investment capital more easily available, so that community-based services can be expanded more quickly.
- 9.5. We recommend that the Government should allocate £30 million from LIBOR fines or other sources to a 'Life in the Community' Social Investment Fund in other words, an investment vehicle with a social mission to improve outcomes for people with learning disabilities and/or autism who display challenging behaviour in the community.
- 9.6. That investment fund should use its capital to leverage that of other investors, so that the pool of capital ultimately available would be multiples of whatever endowment it received from NHS England or the Department of Health. Research commissioned for this steering group and published alongside this report⁴⁰ suggests that public investment of the order of the above could leverage investment from others such that the size of the fund might ultimately reach some £200 million. Over time, funds received from the sale of any public sector inpatient units could also be channelled into this fund. Sitting alongside a mandatory commissioning framework, and a national academy aimed at developing the skills of the workforce across the system, it should catalyse an injection of investment into community-based services during the period of transformation we envisage over the next few years. It should do this by addressing three needs:
 - a) Above all, a need for working capital to enable a range of providers to scale up community-based services in advance of that support being commissioned and made use of including services that can help make transitions happen, such as independent advocacy and brokerage.
 - b) In some local areas and for some individuals, a need for capital to secure suitable housing – a need which may grow if we are to see the kind of shift from inpatient provision to community-based support that we hope to achieve.
 - c) A need to build up investment-ready partnerships or consortia of local providers, from across the public, private and voluntary sectors. Building successful community services is likely to involve a significant degree of partnership working between a range of individual organisations in one local area, and it is also

likely to require smaller, more innovative providers to be able to engage with commissioners.

- 9.7. To address these two capital needs, the Government-backed fund we are proposing should start by exploring three potential interlinked solutions, namely:
 - a) A 'payment for outcomes' fund, whereby investment would be advanced to community-based services upfront, for example to fund working capital to increase staffing teams and also some specialist property adaptations, and the investors would be repaid their investment by commissioners when and only when a reduction in inpatient provision had been safely achieved because more people were being successfully supported in the community. The research commissioned for this report suggests that seed funding of £10 million from NHS England and/or the Government could result in a £30 million payment for outcomes fund. Clearly, any outcomes-based commissioning would need to be carefully designed to avoid perverse incentives, learning from other outcomes-based commissioning models across public services.
 - b) A linked social property fund, whereby a fund would acquire properties and refurbish them if necessary, before leasing those properties to housing providers. The research commissioned to support this report suggests that seed funding of £10 million from NHS England and/or the Government could result in a social property fund of up to £200 million. 42 For such a fund to work, it will be essential to ensure that any future welfare reforms do not inadvertently make it uneconomic to build or adapt homes for people with learning disabilities and/or autism by capping housing benefit for this group at a level too low to justify investment in their housing. We are also clear that this fund must be to finance the building or acquisition of homes to suit individual needs - not to build homes that risk becoming a new set of smaller institutions. This will be achieved by ensuring that the fund is focused on its social impact mission from the start, as well as being a viable and scalable investment vehicle.
 - c) Additionally, a £10 million 'market development fund', building on similar initiatives by the Cabinet Office, which would support the building of local partnerships or consortia and support them to be 'investment-ready', as well as supporting smaller, more innovative providers to expand their services.
- 9.8. Excerpts from the Resonance report can be found in the appendices, setting out how the 'payment for outcomes' fund and linked social property fund could work in more detail.

Holding people to account

- 10. Action on the recommendations above should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level. Data on key indicators (such as admissions rates, length of stay, delayed transfers, number of beds by commissioning authority) should be collected and published. Both local commissioners and all relevant national bodies should be held to account for implementing our recommendations above.
 - 10.1. Local commissioners should be held to account by local people, including those with learning disabilities and/or autism and their families (for instance through learning disability partnership boards or similar). They should also be held to account by NHS England.
 - 10.2. National bodies should be held to account through existing governance structures that include people with learning disabilities and/or autism (such as the Transforming Care Assurance Board co-chaired by the Minister for Care and Support and Gavin Harding MBE).

APPENDIX 1 MEMBERSHIP OF THE STEERING GROUP

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Steve James Avenues Group

Vicki Raphael National Valuing Families Forum

Vivien Cooper Challenging Behaviour Foundation

APPENDIX 2 'WE HAVE THE RIGHT' STATEMENT

In June 2014, CHANGE and Lumos organised an event to discuss closing institutions for people with learning disabilities. 100 people with learning disabilities attended, from 35 self-advocacy groups. CHANGE then consulted with this group in drawing up a document – 'We Have the Right' – submitted to the steering group responsible for this report. The text of the document is below, and available at www.changepeople.org/blog-and-news/we-have-the-right-have-your-say-on-institutions-now/.

"People with learning disabilities have the same rights as everyone else. No one should be made to live where they don't want to live, just because they need support.

Yet tens of thousands of people with learning disabilities in Britain do not have this right and they should.

Institutions should be closed and replaced with ways of supporting people with learning disabilities which allow us to live in ordinary homes, in our community, with the people we choose.

Institutions aren't just big buildings. Some small buildings like residential care homes and group homes are really institutions, because they are places where people don't get to choose who to live with and how to spend their time and they don't feel like home. No kind of institution should be seen as acceptable.

Before someone moves into an institution, they and their independent advocates should have the right to challenge that decision and to keep on challenging it.

To challenge decisions, people with learning disabilities need to have more power. We could have more power if we are able to:

- Have high quality easy read information that is quality checked by employed people with learning disabilities.
- Have Access to a personal budget (such as a Direct Payment) or a Personal Health Budget.
- Have trained and properly independent advocates to support us to make decisions and a person who looks after our personal budget money (broker) to support us to spend our money differently.
- Be employed and work in support of other people with learning disabilities as advocates, peer supporters, service planners commissioners and inspectors.

- Support self advocacy organisations to become sustainable, find ways to employ people with learning disabilities and develop peer-topeer working.
- Have powerful representation from employed people with learning disabilities at every point where decisions are made about us.
- Make the people who have made decisions about us explain why they
 have made that decision at regular meetings which commissioners
 and directors have to attend.
- We want to be involved in the development of a clear transition plan supporting people with learning disabilities to move from institutions into community based living.
- That every Joint Strategic Needs Assessment and Local Health and Wellbeing strategy is made to show clearly how it considers the needs of people with learning disabilities, and steps they are taking to ensure people with learning disabilities have greater power.
- Councils and the NHS must be made to stop admitting anyone else with learning disabilities into residential care and nursing homes within the next 3 years.
- Councils and the NHS must be told that all residential care homes and nursing homes must close within 10 years, and people with learning disabilities supported to move into their own home, living with only the people they choose to live with.
- CHANGE and the self-advocacy groups want to come up with a definition of institution."

APPENDIX 3 CHALLENGING BEHAVIOUR NATIONAL STRATEGY GROUP CHARTER

Members of the Challenging Behaviour National Strategy Group⁴³ believe that better support and services could be provided for children and adults who are perceived as challenging, and have developed a charter which sets out the rights of these individuals and the action that needs to be taken. The text of the Charter is reproduced below and is also available at www.challengingbehaviour.org.uk/strategy-group/charter.html.

Rights and values

- People will be supported to exercise their human rights (which are the same as everyone else's) to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability.
- All children who are at risk of presenting behavioural challenges have the right to have their needs identified at an early stage, leading to co-ordinated early intervention and support.
- **3.** All families have the right to be supported to maintain the physical and emotional wellbeing of the family unit.
- 4. All individuals have the right to receive person centred support and services that are developed on the basis of a detailed understanding of their support needs including their communication needs. This will be individually-tailored, flexible, responsive to changes in individual circumstances and delivered in the most appropriate local situation.
- **5.** People have the right to a healthy life, and be given the appropriate support to achieve this.
- People have the same rights as everyone else to a family and social life, relationships, housing, education, employment and leisure.
- 7. People have the right to supports and services that create capable environments. These should be developed on the principles of positive behavioural support and other evidence based approaches. They should also draw from additional specialist input as needed and respond to all the needs of the individual.

- 8. People have the right not to be hurt or damaged or humiliated in any way by interventions. Support and services must strive to achieve this.
- People have the right to receive support and care based on good and up to date evidence.

Action to be taken

- 1. Children's and adults' services will construct long term collaborative plans across education, social and health services and jointly develop and commission support and services to meet the needs of children and adults with learning disabilities, their families and carers.
- 2. Local Authorities and the NHS will develop and co-ordinate plans to:
 - Reduce the exposure of young children with learning disabilities to environmental conditions that may lead to behavioural challenges.
 - Promote the resilience of young children with learning disabilities who face such environmental conditions.
 - Provide early intervention, support and services that will meet the individual needs (including communication needs) of young children who are showing early signs of developing behavioural challenges.
- Active listening to the needs of the family will lead to the provision of appropriate and timely support, information and training.
- 4. People will be supported to have a good quality of life by individuals with the right values, attitudes, training and experience.
- 5. The NHS and services will proactively plan to ensure that people receive the same range, quality and standard of healthcare as everyone else, making reasonable adjustments when required. People will have an individualised health action plan and be supported to have access to annual health checks to ensure all health needs are met.
- 6. People and their family carers will receive support and services that are timely, safe, of good quality, co-ordinated and seamless. They will be proactively involved in the planning, commissioning and monitoring of support and services including both specialist and general services.
- 7. A person-centred approach that enables and manages the taking of risk will be used to ensure that people have access to family and social life, relationships, housing, education, employment and leisure.
- 8. Local authorities and the NHS will know how many children and adults live in their area and how many they have placed out of area. On the basis of information from person-centred plans all agencies will plan and deliver local support and services.
- **9.** Services will seek to reduce the use of physical intervention, seclusion, mechanical restraint and the inappropriate or harmful use of medication with the clear aim of eliminating them for each individual.
- 10. All services and agencies will strive to improve continually, using up to date evidence to provide the best support, care and treatment to deliver positive outcomes for individuals.

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APPENDIX 4 SUMMARY OF RECOMMENDED SOCIAL INVESTMENT STRUCTURES FROM WINTERBOURNE VIEW AND SOCIAL INVESTMENT (2014)

To provide input to the steering group chaired by Sir Stephen Bubb, Resonance were commissioned by Big Society Capital and the Social Investment Business to produce a report on the potential role for social investment in transforming care for people with learning disabilities and/or autism. Their report, *Winterbourne View and Social Investment*, is available at www.resonance.ltd.uk.

Winterbourne View and Social Investment recommends a hybrid approach which uses two linked investment structures in a complementary way:

1) A 'Payment for Outcomes' Fund to provide working capital funding to providers in order to scale up projects and staffing teams as well as specialist property adaptations, ultimately funded by longer term savings to health budgets, and financed by social investment. 2) A linked Social Property Fund to help providers respond to increased property needs if provision was significantly scaled, providing a more standardized leased housing option across the sector, promoting plurality of providers and localised housing/ support choices for individuals, and acting as a focus and catalyst for action.

Winterbourne View and Social Investment argues that whilst the two structures could, in principle, be developed independently, and one could exist without the other, in practice there are strong reasons to develop the two in a coordinated and complementary way. The report argues that Government seed investment/support is needed to kick-start this, providing leadership, confidence to investors and sector stakeholders and an acceleration of timelines. The report further argues that whilst better commissioning alone might in itself reduce net inflows to in-patient facilities, without this investment impetus, constraints on providers will continue to imply thousands of individuals remaining in this situation for decades to come, and the likelihood of future "Winterbourne View" scenarios recurring.

'Payment for Outcomes' Fund

The purpose of this element of the structure would be to help providers to fund the transitional costs of supporting a resident into their new home (advocacy/brokerage and staff mobilisation) and any required adaptations

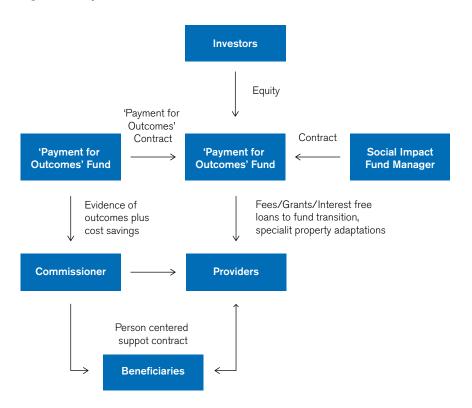
that are above and beyond a standard specification which can be economically provided by a housing provider (including a Social Property Fund) which may be necessary for some tenants but not others. Examples of this could be the conversion of a bedroom to a wetroom, all room air conditioning, or significant strengthening to the fabric of a building.

This funding vehicle (which could take on a number of different legal forms, but is referred to simply below as the Special Purpose Vehicle or "SPV") would have a payment-for-outcomes contract with the NHS England (and other commissioners as they are willing) where payments would be triggered by clear delivery of sustained support and specific positive outcomes for individuals, which would be expected to be at a meaningfully reduced cost in the longer term compared with the inpatient facility.

For example, if the expectation was that, in time, a resident could be supported at a cost of £1500pw in the community, compared with £2500pw in the inpatient facility, then a one-off payment of, say, 50% of this expected saving would be paid to the SPV in the event of the provider achieving the positive 'outcome' for the resident of successfully making this move. In this scenario, assuming a sharing of 50% of the expected saving over a 12 month period, a payment of £26,000 would be paid – an amount which could cover the specialist property adaptations, transitional cost of the provider and a financial return to investors in the 'Payment for Outcomes' Fund. The report notes that at this stage all figures around expected savings are indicative and for illustration purposes only, but the authors point to anecdotal evidence of annual expected savings per individual of anywhere between £50–125k.

The generic structure of a 'Payment for Outcomes' Fund is set out below:

Figure 1: 'Payment for Outcomes' Fund



Winterbourne View and Social Investment argues that this structure:

- Meets the needs of the sector to help individuals based on their research, the authors believe that the immediate need is for providers to have the working capital and commissioning clarity to scale up provision from the relatively small numbers who are currently being transferred out of inpatient facilities. A 'Payment for Outcomes' Fund focuses on these two issues directly. It gives providers the data and contracting certainty to plan for scaling up activity, and the capital to do it, rather than simply attempting to respond to shorter term, ad hoc commissioner requests.
- Makes best use of Government support the main intervention from Government would be to ensure that an attractive 'Payment for Outcomes' contract could be offered. This might involve in the short term some payments which were overlapping (eg if block contracts for inpatient beds could not be immediately unwound) but would ultimately be driving towards savings for Government in this area.
- Fits with reasonable investor requirements the report argues there
 is an increasingly developed market of investors who are interested
 in investing in these structures. For example, there is now an impact
 investment fund which is dedicated to the purpose of investing into
 'Payments for Outcomes' Funds (The Results Fund).
- Can be practically delivered 'Payments for Outcomes' Funds are still a relatively new investment innovation and can take a considerable time to develop. However, as the costs funded by the 'Payments for Outcomes' Fund would be approximately 8–12% of the property acquisition costs, initially a Fund of just £5–10m would be required to complement the first phase of the linked Social Property Fund discussed further below. This could focus on an initial cohort, and coalition of willing commissioners and providers which could then be further expanded and replicated.

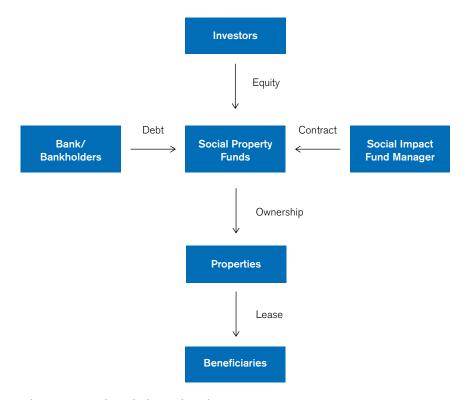
There are a number of more detailed issues which would need to be addressed in the next phase of development of such a structure, which are dealt with in the *Winterbourne View and Social Investment* report.

Social Property Fund

The purpose of this element of the structure would be to give further impetus to the supply of specialized housing, in a scenario where providers were significantly scaling up activity from current levels.

The fund would acquire properties, and cover all acquisition costs and any refurbishment to bring them up to an agreed specification as set out in a Framework Agreement, but not very specialist adaptations necessary for individual tenants, which would be separately covered by the 'Payments for Outcomes' Fund described above. The fund would lease the properties it acquired to an initially small but inclusive group of approved providers with the relationship managed through the Framework Agreement. The financial return to investors would be based on the fund being paid Local Housing Allowance rates (or variations thereon) for rental but would also include capital gain on the property (if any).

Figure 2: Social Property Fund



The report authors believe that this structure:

- Meets the needs of the sector to help individuals the report authors found a general unwillingness or inability from many providers to take on significant levels of debt. Another recurring theme is that complete reliance on a pure private capital model for housing may drive provision models back to the scale and perverse incentives that have arguably helped create the "Winterbourne View problem". It is therefore necessary to think towards a social investment structure which bridges this gap. A property fund makes a clear distinction between the providers of investment capital to fund property assets, the users of those assets, and the providers of support (even if the last two may be the same in many cases). It is also an inherently "open" structure which can provide a diverse range of housing and support providers with access to those assets on appropriate terms.
- Makes best use of Government support a fund structure should not require government guarantees of the investment vehicle or additional subsidies. It would seek to offer investors a risk adjusted return on their investment as a market based solution to the capital need of this initiative. However, it could be seeded by initial investment from identified Government funding sources which would provide initial impetus and encourage private sector investment.
- Fits with reasonable investor requirements a property fund is a transparent and recognizable structure for investors. It can take initial "seed" investment from a small number of initial founding investors (including Government) and use this to attract further investment, potentially up to large amounts (£100−300m) which would be very difficult for individual service providers to raise on their own balance sheets.

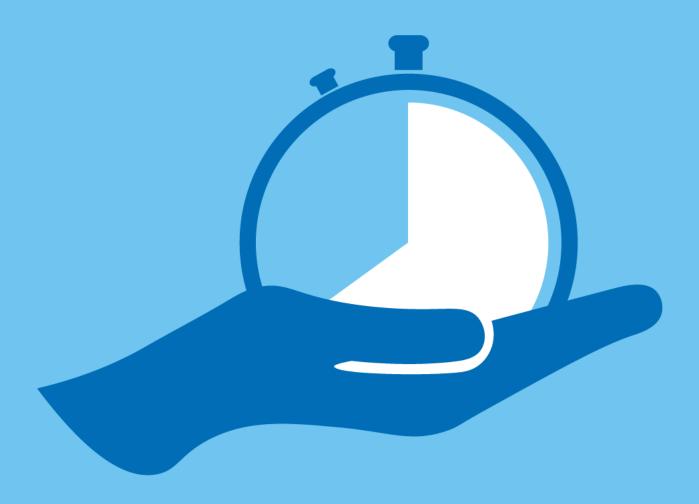
Can be practically delivered – there are established models for property
funds which can be delivered within reasonable budgets and timing,
and which can move from initial smaller scale structures to larger scale
structures in due course. By avoiding direct Government guarantees
and subsidy, and by dealing with specialist property adaptations
through the linked 'Payment for Outcomes Fund', it is also inherently
scalable to address large scale capital needs for the sector.

There are a number of more detailed issues which would need to be addressed in the next phase of development of such a structure which are dealt with in the *Winterbourne View and Social Investment* report.

WINTERBOURNE VIEW – TIME IS RUNNING OUT

The 6 month independent review of the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb

July 2015





WINTERBOURNE VIEW - TIME IS RUNNING OUT

ACEVO is the Charity Leaders Network. As the Association of Chief Executives of Voluntary Organisations, we are the leading voice of the UK's charity and social enterprise sector. We provide support and representation for members ranging from leaders of small community based organisations to those of the nation's best known charity brands.

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Thanks

The authors of this report would like to thank the transforming care and commissioning steering group and all those who contributed to our work and this report. All mistakes contained herein are our own.

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FOREWORD

When *Winterbourne View – Time for Change* was published in November 2014, still more people with learning disabilities and/or autism were being admitted to inpatient facilities than being discharged. This is despite a promise from Government to close institutions such as Winterbourne View. *Time for Change* has been widely supported but I understood the deep scepticism of people with learning disabilities and/or autism and their families that anything would actually change. I am acutely aware that we do not just want more reports.

I believe that things have changed, and that we will see the closure of inappropriate institutions and the scaling up of community provision that has been needed for so long. The leadership being displayed by NHS England's CEO, Simon Stevens, does give me that optimism. The Government endorsed my report and moved forward with a consultation on its recommendations, including the 'right to challenge' for people with learning disabilities and/or autism and their families. That is a step change.

The report laid out a clear roadmap of action – a new national framework in which commissioners choose community-based provision over hospitals. The programme would deliver closures and enable providers to work in partnership to offer new facilities, to ensure community support and independence for people with learning disabilities and/or autism. In particular I argued that people with learning disabilities and/or autism must have a central role in designing the care that will best meet their needs. And they should be able to challenge decisions when it does not.

There has been progress since the publication of my report. We have seen a definite shift in the direction and commitment to change which was not apparent when I started the review. At last we have an acceptance that institutions must close and I congratulate Simon Stevens on making his promise to the Public Accounts Committee that NHS England will produce a closure timetable. We expect this to be published in October.

The last Government were swift to move on the recommendations to strengthen the rights of people with learning disabilities and/or autism and their families. A consultation has been made through the Green Paper *No voice unheard, no right ignored,* which has seen over 400 responses. I look to the new Care Minister, Alistair Burt, to move on introducing legislation that will enshrine peoples' 'right to challenge' in law.

The number of people being discharged from institutions is now greater than those being admitted. At the end of May 2015, over 1,700 Care and Treatment Reviews had been conducted. However it remains abundantly clear that a 'revolving door' of discharges and admissions will continue unless a closure and transition programme is acted on.

NHS England has made it a top strategic objective to improve the health outcomes for people with learning disabilities, by implementing new service models that provide care for people in their communities rather

than in hospital. The Care Act is a landmark piece of legislation, and the Green Paper is progress that should not be underestimated.

But the pace of change remains slow, and this is unacceptable. While a priority for NHS England, the Transforming Care programme has not yet delivered anything tangible in terms of new community facilities or closures. This is worrying; robust community provision does not appear overnight. And yet the closure of institutions can only happen when there are sustainable alternatives built up by commissioners and providers.

In responding to *Time for Change*, the Transforming Care partners committed to a series of actions. I accepted Simon Stevens' proposal that my steering group be reconvened in 6 months to review progress and that a formal stock take of actions be taken in 12 months. So this report is a warning call – my steering group was clear on the changes that need to take place. Where positive step changes have been made, I have recognised the success. Where delivery has been lacking, my appraisal will be severe.

I will be reviewing the adequacy of closure plans when published. The Transforming Care programme recently announced five 'fast-track' sites where services will be shifted away from hospitals. These sites will help shape the service model that is being developed to re-design care across England. A programme of action is clearly starting to take shape. But we must expect a closure programme to cover the country and not just five areas. We know that people with learning disabilities and/or autism are often in hospitals very far from their families – a nation-wide programme is therefore essential.

The scaling up of community provision is a fundamental part of this programme. Yet there has been little to no discussion with providers and stakeholders outside of the Transforming Care partners. Lack of communication from the centre prevents local commissioners and providers from readying themselves for change, or even being aware that they will be expected to respond to a new service model.

That is why I have set up a Provider Delivery Taskforce, alongside the Voluntary Organisations Disability Group and Housing and Support Alliance. This will work with excellent providers of community-based care (using NHS England and LGA's own 'Ensuring Quality Services' guidelines) to make sure they can be responsive and proactive in transitioning people out of institutions. But that is not enough.

Time for Change was clear that building this capacity in the community is an absolute priority. But the two recommendations made to this effect – workforce development, and investment in community-based services – have seen little progress. This is unacceptable and risks undermining the work being done elsewhere to create a new framework of care for people with learning disabilities and/or autism.

So I am now calling on NHS England to establish a **Transition Taskforce** which will be mandated to work with providers, commissioners, people with learning disabilities and/or autism and families to set out the national framework for scaling up community provision. It will plan for 'shovel ready' schemes that can be sustainably established to allow for the closure of institutions and the appropriate transition of individuals into

the community. The Taskforce will examine the financial models that are needed, as well as how to secure a skilled workforce.

This will build on the excellent services that are already provided by charities and social enterprises, many of which pioneer innovative ways to support the wellbeing and independence of people with learning disabilities and/or autism outside of hospital settings. For example, there is wide-ranging good practice for staff training and Positive Behaviour Support. I am clear that restrictive practices, such as the use of mechanical restraint or seclusion have no place in the 21st century of care for people with learning disabilities and/or autism, and this report gives recommendations to that effect. Given that it will take time to effectively transition care from institutions into the community, there must be steps taken now to ensure people are receiving the best support.

Since November, I have visited and spoken to a number of providers, as well as institutions about *Time for Change*. Any closure programme will lead to concern within this sector, especially the workforce, around whether such a shift can and will be managed effectively. Individuals with learning disabilities and/or autism, their families and carers cannot be isolated from the Transforming Care programme; they must be at its core.

I want to thank all of my colleagues on the steering group, and all those I have met or spoken to. In November, I cautioned NHS England and its partners to be realistic about the timeline for success – to not promise another 'false dawn.' However the call for urgent action remains and I will be holding Transforming Care to account on its commitment to deliver lasting change.

I will review further progress at the year anniversary of the publication of *Time for Change* – the steering group will be reconvened on 7th December 2015. I expect to see change being delivered on the ground. This is the opportunity for us, as a nation, to provide the care that people with learning disabilities and/or autism deserve and have been denied for so long.



Stephen Dubb

Sir Stephen Bubb

EXECUTIVE SUMMARY

About this report

- 1. When *Winterbourne View Time for Change* was published in November 2014, still more people with learning disabilities and/or autism were being admitted to inpatient facilities than being discharged. This is despite a promise from Government to close institutions such as Winterbourne View.
- 2. The report laid out a clear roadmap of action a new national framework in which commissioners choose community-based provision over hospitals. The programme would deliver closures and enable providers to work in partnership to offer new facilities, to ensure community support and independence for people with learning disabilities and/or autism. In particular Sir Stephen argued that people with learning disabilities and/or autism must have a central role in designing the care that will best meet their needs. And they should be able to challenge decisions when it does not.
- 3. A joint response was made by the Transforming Care programme in *Transforming Care for People with Learning Disabilities Next Steps.*Sir Stephen is now leading an independent review of the work of the Transforming Care partners Department of Health, NHS England, Health Education England, Care Quality Commission, Association of Directors of Adult Social Services, and Local Government Association to ensure sufficient action is being taken to improve the way services for people with learning disabilities and/or autism are delivered.
- 4. This report is Sir Stephen's six month review. The steering group was reconvened on 6th July 2015, and ongoing engagement has been had with those partners that have taken responsibility for acting on recommendations, as outlined in the Transforming Care response. Each stakeholder has submitted an update on their work, for review by Sir Stephen and the group. This report records those responses and offers a reflection on where we are, and where we need to be.

The missing pieces

- 5. NHS England has made it a top strategic objective to improve the health outcomes for people with learning disabilities, by implementing new service models that provide care for people in their communities rather than in hospital. The Care Act is a landmark piece of legislation, and the Department of Health's Green Paper on the rights of people with learning disabilities and/or autism *No voice unheard, no right ignored* is progress that should not be underestimated.
- 6. But the pace of change remains slow, and this is unacceptable. While a priority for NHS England, the Transforming Care programme has not yet delivered anything tangible in terms of new community facilities or closures. This is worrying; robust community provision does not appear

- overnight. And yet the closure of institutions can only happen when there are sustainable alternatives built up by commissioners and providers.
- 7. There are two areas where it is clear that not enough progress has been made. The first is a question of leadership. In the six months that have passed since *Time for Change*, very little has been communicated to key stakeholders about the particulars of how transformation will be achieved. Communication needs to move beyond the walls of the state providers, individuals and local stakeholders must be brought in as equal partners as a matter of urgency. Transformation will only be delivered through a robust, transparent process in which stakeholder engagement is taken seriously. High quality independent advocacy is often cited as a powerful tool, and yet there is little evidence of how this will be funded, delivered and made available to all.
- 8. It is also clear that while we have the promise of a closure programme, little attention has been given to the need for gearing up the capacity and response of providers. It will be impossible to deliver a closure programme without ensuring robust community provision. While Care and Treatment Reviews are being rolled out as a tool for assessing individual circumstances, decision-makers will be powerless to recommend anything other than an inpatient bed if they lack the tools or avenues to do otherwise. This is a simple point, but absolutely critical to squaring the circle of care services.
- 9. In response ACEVO has teamed up with Voluntary Organisations Disability Group and Housing & Support Alliance to establish a Provider Delivery Taskforce to get on and do what needs to be done to identify good provision, and how to scale it up. Providers will work to the *Ensuring Quality Services* guidance and champion the effective delivery of the services needed to transform care for people with learning disabilities and/ or autism.
- 10. Social investment also has a crucial role to play. *Time for Change* was accompanied by a report *Winterbourne View and Social Investment* which laid out potential models for using social investment to drive the transformation programme. But this review has identified a failure to scope social investment fully, the commitment made in the Transforming Care response. This must be seen as a failure on the part of the Transforming Care programme to act on the practical questions of implementation. A closure programme requires the retraining of staff, the development of community-based facilities, a transition programme and alternative investments to underpin change. Moving forward, it is the job of the partners to link up the work streams that have been taken on in response to *Time for Change* and provide a seamless new model of care for people with learning disabilities and/or autism. Failure to give due attention to any of the pieces will have significant consequences elsewhere.

Key recommendations

Strengthening rights

- 11. This report recommends that the new Government introduces new legislation swiftly following the Green Paper consultation that ended in May. The Transforming Care progress report says that it will publish a response to the Green Paper by the autumn, but a 'right to challenge' needs to be enshrined in law, so that individuals and their families and/or advocates are truly empowered to question the care they receive.
- 12. 'The Bradley Report five years on' made it clear that there is still progress to be made for people with learning disabilities and/or autism in our courts and prisons. This report reiterates the call for a cross-government response, from the Ministry of Justice to Department of Health. Without this, people with learning disabilities and/or autism will not receive the support they need at all stages of the criminal justice system.

Closures

13. This review expects a closure programme to be published in October 2015. This programme will need to demonstrate strong leadership and set out a clear plan for the whole country. Without this, the Transforming Care programme will not be able to deliver on meaningful and lasting change to the way care and support is designed and delivered for people with learning disabilities and/or autism.

Building capacity in the community

- 14. This report recommends that NHS England and its partners establish a Transition Taskforce, independently chaired. This would include providers, commissioners, individuals with learning disabilities and/ or autism and families to lead on the national framework for scaling up community provision. Unless these key stakeholders can come together to work on a practical scheme for making sure there is sufficient support in place, sustainably funded, then Transforming Care will fail to deliver any meaningful transformation at all.
- **15.** *Time for Change* called on NHS England and the Government to establish a 'Life in the Community Fund' to facilitate transitions out of inpatient facilities. This report recommends that the Government move quickly to act on social investment options for building up the community provision, as this a crucial part of moving care out of inpatient facilities.
- **16.** This report recommends that the Care Quality Commission (CQC) should undertake a review of restrictive practices with a view to banning physical restraint methods, such as the emergency response belt.
- 17. The Government must also review the scope of the CQC to have powers for reviewing the care provided to individuals with learning disabilities when cared for in supported living. It is essential that people with learning disabilities and/or autism are given full protection.

ABOUT THIS REPORT

- 1. Last year, the Government failed to meet its pledge to support everyone with a learning disability and/or autism inappropriately placed in hospital to move to community-based support no later than 1st June 2014. In response, NHS England developed a programme plan to accelerate change. As part of this Sir Stephen Bubb, chief executive of the charity leaders network ACEVO, was asked to make recommendations for a national commissioning framework under which local commissioners could secure community-based support.
- 2. Sir Stephen chaired the Transforming Care and Commissioning Steering Group, comprised of representatives from the third sector, NHS and local government. Over the course of its work, the group was supported by a range of stakeholders, from people with learning disabilities and/or autism and their families, to commissioners, third sector organisations who work with and/or represent people with learning disabilities and/or autism, providers and academics. The membership of the steering group can be found in the appendices.
- **3.** The steering group's report *Winterbourne View Time for Change* was published in November 2014. It outlined a roadmap for action
 - A closure programme for in-patient care institutions;
 - A Charter of Rights for people with learning disabilities and/or autism and their families:
 - A 'right to challenge' for people with learning disabilities and their families, and the right to request a personal budget;
 - A mandatory framework for local decision-makers to follow that sets out who is responsible for which services and how they will be held to account;
 - Improved data collection and publication, including key indicators such as admission rates, length of stay, delayed transfers and the number of beds by commissioning organisations;
 - Improved training and education for NHS, local government and provider staff;
 - A social investment fund to build capacity in community-based services.
- 4. A joint response was made by the Transforming Care programme in *Transforming Care for People with Learning Disabilities Next Steps.*Sir Stephen is now leading an independent review of the work of the Transforming Care partners Department of Health, NHS England, Health Education England, Care Quality Commission, Association of Directors of Adult Social Services, and Local Government Association to ensure sufficient action is being taken to improve the way services for people with learning disabilities and/or autism are delivered.

- 5. This report is Sir Stephen's six month review. The steering group was reconvened on 6th July 2015, and ongoing engagement has been had with those partners that have taken responsibility for acting on recommendations, as outlined in the Transforming Care response. Each stakeholder has submitted an update on their work, for review by Sir Stephen and the group. This report records those responses and offers a reflection of where we are, and where we need to be.
- **6.** This will be followed by a formal twelve month review, drawing from engagement with a wide range of stakeholders. This reflects the wide remit of *Time for Change*. While originally asked to make recommendations for a national commissioning framework for NHS England, it remains clear that any such framework must be accompanied by action from others local government and providers and by a stronger rights framework for people with learning disabilities and/or autism, and their families and carers.

A CHANGING LANDSCAPE

Where we are now

- Much has happened since November 2014. The Care Act has come into force, Simon Stevens has promised a closure programme to the Public Accounts Committee, and NHS England has announced a range of new initiatives for forcing the pace of change.
- 2. It is clear that we are no longer just describing the problem. There has been a step change in the approach of the Transforming Care programme and firm commitments made to accelerate change and deliver a new framework of care for people with learning disabilities and/or autism.
- 3. The Transforming Care response to *Time for Change* outlines how the programme will look to reduce a reliance on inpatient care nationally.¹ Its commitments include –

TIME FOR CHANGE RECOMMENDATION

TRANSFORMING CARE PROGRAMME COMMITMENT

People with learning disabilities and/or autism should be given a 'right to challenge' their admission or continued placement in inpatient care

To roll out Care and Treatment Reviews for people in inpatient settings and at the risk of admission.

The Government and NHS
England should force the pace on
commissioning by requiring local
commissioners to follow a mandatory
framework.

To set out a model for health and care services for children and adults with a learning disability and/or autism who have a mental illness or behaviour that challenges, to describe –

- outcomes to be achieved:
- the kind of services that should be place;
- the standards that those services should meet.

A 'Life in the Community' Social Investment Fund should be established to facilitate transitions out of inpatient facilities and build capacity in community-based services. To build on the Resonance report, by identifying a region, locality or cluster of localities to test the feasibility of different social investment models.

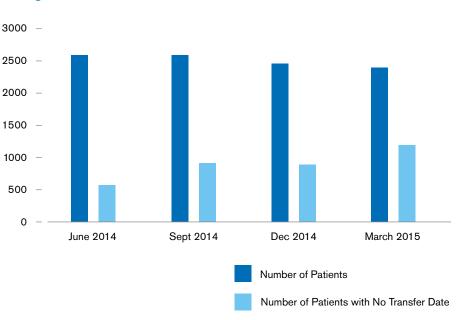
Health Education England, Skills for Care, and Skills for Health should fully scope out the gaps in training and development of staff caring for those with a learning disability and/or autism, and then develop a national academy to expand existing good practice and fill identified gaps.

To carry out scoping work to identify current gaps in the provision of workforce development.

- **4.** On the 3rd July, the Transforming Care partners published a progress report. It reiterates the priority areas that make up the programme of action that it has committed to
 - Empowering individuals;
 - Getting the right care in the right place;
 - Workforce;
 - Regulation and inspection;
 - Data and information.²
- 5. This programme of action is underpinned by the NHS England Business Plan 2015 16. One of its top priorities for improving health is to transform care for people with learning disabilities by
 - "improving the health outcomes for people with learning disabilities, by rolling out care and treatments reviews and implementing new services models."
- 6. Time for Change recommended that a new commissioning framework should be accompanied by a closure programme of institutional inpatient facilities, to reduce the number of inpatient beds and catalyse the development of community provision. At a Public Accounts Committee evidence session in February 2015, Simon Stevens said that "care will have to be re-provided in a more radical way," and that this means some facilities will need to close. He said that details of a closure programme could be expected in around six months. 5
- 7. The guiding principle of this recommendation has been "above all, do no harm." Time for Change was clear that a closure programme must be accompanied by better community-based support and provision that has the capacity to transition people out of institutionalised care. Without an effective transition programme, there can be no firm assurances that people with learning disabilities and/or autism will receive the care that they need and want.
- 8. NHS England has announced waves of locally targeted pilots to encourage the adoption of good practice and to test innovation. This includes the Integrated Personal Commissioning programme which went live 1st April 2015. It will bring together health and social care budgets at the individual level by supporting NHS bodies, councils and voluntary organisations to partner and submit innovative plans for the transformation of the care of certain services, including those for people with learning disabilities.
 - 2 Progress Report from the Transforming Care Delivery Board (2015)
 - 3 NHS England, Building the NHS of the Five Year Forward View NHS England Business Plan 2015 – 2016 (2015)
 - 4 http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/public-accounts-committee/care-for-people-with-learning-disabilities/oral/18031.html
 - 5 http://data.parliament.uk/writtenevidence/committeeevidence.svc/ evidencedocument/public-accounts-committee/care-for-people-with-learningdisabilities/oral/18031.html
 - 6 Winterbourne View Time for Change (2014)

- 9. The Transforming Care programme has also announced five 'fast track' sites that will bring together organisations across health and care to transform care specifically for people with learning disabilities. They will receive additional 'technical' support from NHS England and have access to a £10 million 'transformation fund' to accelerate change. These are promising overtures. But has it resulted in any change?
- 10. The Department of Health's response to the Winterbourne View scandal (the 'Concordat') recognised that failings were widespread across the care system. A data collection process Assuring Transformation is now being embedded to ensure that public awareness of those commitments made in the Concordat is transparent and robust. Responsibility for collecting this data did sit with NHS England, but has recently passed to the Health and Social Care Information Centre (HSCIC).
- 11. The data shows a slight decrease in the number of people registered as being in inpatient facilities (see fig. 1).⁷

Figure 1



^{*}March 2015 data collected by HSCIC

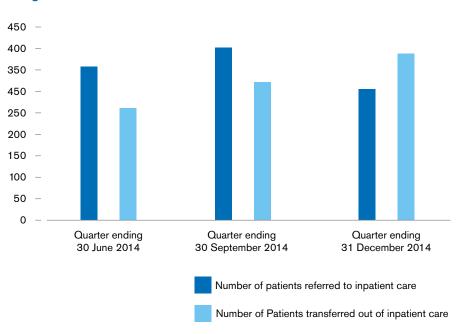
- **12.** However, it is important to note that the HSCIC data does not include responses from 47 CCGs. While a slight momentum has been built over the last six months, the pace needs to improve drastically.
- 13. The data also tells us that nearly half of inpatients do not have a set date for transfer back to the community. The main reason given for this on an individual basis is that a clinical decision has been made to not pursue a transfer date. It is absolutely essential that such a decision is based on the ability of an individual to live successfully in a community setting, rather than the significant hurdles that still exist in transitioning people into community settings. These include risk aversion among clinicians, financial disincentives to discharge, a lack of independent advocacy as well as the 'catch 22' situation in which an individual's behaviour is negatively affected by being in an inpatient facility.⁸
- 14. The Transforming Care programme needs to deliver a robust framework for overcoming these systemic barriers. This needs to incentivise decision-makers to focus on discharge planning from the outset and enable providers to plan for the earliest possible, safe discharge from the point of admission.⁹
- **15.** Data collections show the number of people being referred to inpatient facilities compared to that being discharged. Until the end of 2014, NHS England collected quarterly data (see fig. 2).¹⁰

⁸ Resonance, Winterbourne View and Social Investment (2014)

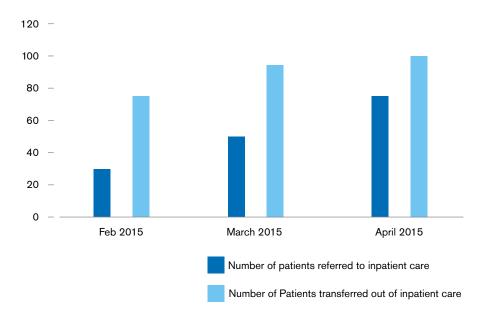
⁹ Winterbourne View - Time for Change (2014)

¹⁰ NHS England, Quarterly 'Assuring Transformation' data, published at http://www.england.nhs.uk/ourwork/qual-clin-lead/ld/atd/

Figure 2



Data collected by the HSCIC shows progress on a monthly basis in 2015.11



16. Since *Time for Change* was published, the trend has been for discharges to outnumber referrals. But this data also shows the number of people being referred to inpatient facilities rising overall. While this may be impacted on by the number of CCGs reporting back, this should not be the picture we are seeing six months on.

The missing pieces

- **17.** There are two areas where it is clear that not enough progress has been made. The first is a question of **leadership**. In the six months that have passed since *Time for Change*, very little has been communicated to key stakeholders about the particulars of how transformation will be achieved.
- 18. There has been a flurry of public announcements in the lead up to this six month review, such as the five fast tracks sites, but little has been put in place to prepare providers and local stakeholders for what actions and responsibilities they will be taking on. Communication needs to move beyond the walls of the state providers, individuals and local stakeholders must be brought in as equal partners as a matter of urgency.
- 19. From this review, it is clear that the Transforming Care programme has moved forward in identifying where the gaps are in current provision, and it has started to outline a new commissioning model to draw up local closure plans. But transformation will only be delivered through a robust, transparent process in which stakeholder engagement is taken seriously.
- 20. It is also clear that while we have the promise of a closure programme, little attention has been given to the need for gearing up the capacity and response of providers. It will be impossible to deliver a closure programme without ensuring robust community provision. While Care and Treatment Reviews are being rolled out as a tool for assessing individual circumstances, decision-makers will be powerless to recommend anything other than an inpatient bed if they lack the tools or avenues to do otherwise. This is a simple point, but absolutely critical to squaring the circle of care services.
- 21. The risk of a 'revolving door' therefore persists. People readmitted to inpatient facilities because they have been discharged to unsustainable or inappropriate alternative provision does nothing to improve standards or drive a truly preventative solution. This is crucial given the projected growth in the number of people with learning disabilities requiring community-based support over the next 10 years, which has been estimated to be between 37,000 and 52,000 by 2030.¹²
- **22.** A practical programme for building up community provision needs to take place in tandem with the closure programme. This does not seem to be happening.
- 23. In response ACEVO has teamed up with VODG and Housing & Support Alliance to establish a Provider Delivery Taskforce to get on and do what needs to be done to identify good provision, and how to scale it up. Providers will work to the *Ensuring Quality Services* guidance and champion the effective delivery of the services needed to transform care for people with learning disabilities and/or autism.

24. But this also requires a firm response from the Transforming Care programme. This report recommends that NHS England and its partners establish a Transition Taskforce, independently chaired. This would include providers, commissioners, people with learning disabilities and/or autism and families to lead on the national framework for scaling up community provision. Unless these stakeholders can come together to work on a practical scheme for making sure there is sufficient support in place, sustainably funded, then Transforming Care will fail to deliver any meaningful transformation at all.

STRENGTHENING RIGHTS

- The Government should draw up a Charter of Rights for people with learning disabilities and/or autism and their families, and it should underpin all commissioning.
 - 1.1. Time for Change was clear that, as a point of principle, the rights of people with learning disabilities and their families must be upheld at all stages of their care. This does not just mean improving the current system; people need to be empowered to help change the system to make sure their rights are fundamental to the decisions made about their care.
 - 1.2. The Care Act has now come into force this enshrines in law the principle that individual wellbeing be the central concern when designing care and support. It will underpin adult social care commissioning by incorporating the essential elements of social and economic wellbeing and making sure decision-makers consider individuals' views, wishes and beliefs.
 - 1.3. Time will tell if the Care Act as it is currently drawn will prove clear and persuasive enough to ensure that this principle comes to underpin every individual's care.
 - 1.4. But the Care Act only applies to decisions made by local authorities. Individuals with complex needs will need support from across health and social care. While much has been said about the importance of joint commissioning between the two, it is equally clear that the principle of wellbeing needs to apply across the board. The Department of Health's Green Paper *No voice unheard, no right ignored* has consulted on this question by asking whether NHS commissioners should share new local authority duties around promoting individual wellbeing.¹³
 - 1.5. While the principle of wellbeing is critical to ensuring that there is a step change in the way services are designed for people with learning disabilities and/or autism, *Time for Change* is clear that more commissioner-led decision-making alone will not effect change. Individuals with learning disabilities and/or autism and their families need to be clear on their rights, at all times, else there will be a barrier to them effectively engaging with their care.

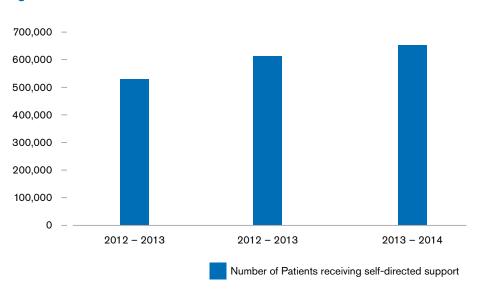
- 1.6. This is why *Time for Change* recommended that a Charter of Rights be specifically drawn up for people with learning disabilities and/or autism. The Care Act enshrines the principal of wellbeing in law, and draws together disparate legislation that came before. But for individuals with learning disabilities and/or autism and their families, it remains one of many laws or policies that must be navigated when assessing and delivering care.
- 1.7. There is yet to be seen a Charter for Rights for people with learning disabilities and/or autism. This would be a clear and universally accessible document that clarifies the rights people already have, and outlines the support they have access to, including independent advocacy, for using them.
- 1.8. Legislation like the Care Act could give this Charter 'teeth,' by mandating commissioners to base their plans on the rights and wellbeing of individuals. This would be included in the Charter, but would not in itself provide the package of information that they should be able to access easily. Without this, we will continue to hear from individuals and families that they feel powerless to engage with or challenge decisions.
- 1.9. The steering group recognises that the Department of Health's Green Paper has consulted on this issue. In fact, it goes beyond *Time for Change* by suggesting that individuals receive a 'personalised summary of rights that are relevant to their individual circumstances' as soon as reasonably practical following the start of discussions about a potential admission.¹⁴
- 1.10. We look forward to hearing what responses the consultation has had on this question. While this would be an important part of making sure individuals with learning disabilities and/or autism are informed about specific circumstances as and when they happen, there is still a need to bring together all the rights that exist under the Mental Health Act Code, Care Act *et al* across the fields of health and social care.
- 1.11. This should include a clear statement of rights, such as the right to a personal budget, the right to trained and independent advocates, and the right to support to exercise human rights.
- 1.12. A Charter of Rights is the first recommendation of the *Time for Change* report. Aptly so; a Charter is a simple change, but is absolutely non-negotiable. Only by setting out a Charter of Rights will the Transforming Care partners sufficiently tackle the widespread lack of awareness of the issues faced by people with a learning disability and enable individuals to become 'agents of change.'¹⁵

- 2. The Government should respond to the 'The Bradley Report five years on'.
 - 2.1. *Time for Change* recommended that the Government respond to the recommendations of 'The Bradley Report five years on,' to set out how cross-government action will tackle the issues raised.
 - 2.2. The Transforming Care programme did not commit to leading on this recommendation but people with learning disabilities and/or autism will continue to receive inappropriate care in the criminal justice system if no action is taken. 'The Bradley Report five years on' made it clear that there is still progress to be made. This report reiterates the call for a cross-government response, from the Ministry of Justice to Department of Health. Without this, people with learning disabilities and/or autism will not receive the support they need at all stages of the criminal justice system.
- 3. People with learning disabilities and/or autism should be given a 'right to challenge' their admission or continued placement in inpatient care.
 - 3.1. The Care Act recognises that individuals have the expertise of lived experience. They are best-placed to judge their own wellbeing. A Charter of Rights is about enabling them to describe what this looks like for them. *Time for Change's* second recommendation looks to extending the rights of people with learning disabilities and/or autism and their families they should have the 'right to challenge' any decision to admit an individual to an inpatient facility, or to keep them there.
 - 3.2. This needs to apply across a person's care journey, from the point of admission to any decisions to change or continue a form of care. This right would be accompanied by free support from an independent 'multi-disciplinary' team, including 'experts by experience' family carers or people with learning disabilities who have had experience of inpatient services or been at risk of admission themselves.¹⁶
 - 3.3. NHS England's response has mainly been around the rollout of Care and Treatment Reviews. These are part of a strategy to ensure that the individual is central to any decisions made about their care. They bring together the commissioner, an independent clinician, 'expert by experience,' and the individual receiving the care. The stated aims of a Care and Treatment Review include ensuring the person is safe, that they are getting good and effective care, exploring whether a plan is in place for their future and assessing whether their care and treatment could be provided in the community.
 - 3.4. Individuals who were inpatients on 1st April 2014 who did not have a discharge plan have been receiving Care and Treatment Reviews to review the appropriateness of their care. As at the end of May 2015 over 1,700 Care and Treatment Reviews had been completed.¹⁷

- 3.5. These reviews offer a critical platform on which to assess an individual's care with their interests, and the expertise of independent stakeholders, at the heart of the process. They look set to ensure that proper discussions are had around the options and risks that are relevant to particular individuals at particular times. *Time for Change* recognised that many individuals with learning disabilities and/or autism will not feel able to challenge the decisions taken about their care, particularly if they are in inpatient settings. This means that it is right that there is a responsibility on the part of commissioners to ensure a Review is undertaken, with the patient's permission.
- 3.6. But the 'right to challenge' is not just about mandating the NHS or local authorities to actively question and discuss the options available to an individual. Any mechanism for providing a 'right to challenge' must enable individuals and their families to challenge decisions themselves, and provide them with the support and information to do so.
- 3.7. As the Department of Health's Green Paper indicates, there are many facets to this. Alongside a review to challenge admissions to inpatient settings, individuals may seek transfers or discharges once admitted and look to request discharge planning if it is not already in place on admission.¹⁸
- 3.8. One of the most important counters to re-institutionalisation is to empower people to ask what aspect of their care, if anything, is preventing them from being supported outside of an inpatient facility. Individuals do have the right to request a Review; this would be exactly the sort of information that a Charter of Rights could describe and enable.
- 3.9. This report recommends that the new Government introduces new legislation swiftly following the consultation that ended in May. The Transforming Care progress report says that it will publish a response to the Green Paper in the autumn, but a right to challenge needs to be enshrined in law, so that individuals and their families are truly empowered to question the care they receive.

4. NHS England should extend the right to have a personal budget (or personal health budget) to more people with learning disabilities and/or autism, along with support to manage those budgets.

Figure 3



- 4.1. At the end of March 2014, 62% of all those eligible for community based services were accessing care and support through a personal budget across England (see fig. 3). 19 Use of personal budgets has seen a steady rise year-on-year.
- 4.2. This is set to increase at pace with the Care Act now enshrining the right to have a personal budget in law from April 2015. This represents a cultural change that commissioning services need, towards designing care for one person at a time, based on a whole-life care plan that incorporates the principle of treating individuals as experts in their own needs and interests.
- 4.3. Again, the Care Act only applies to social care in this instance.

 But it is clear that personalisation is high on NHS England's agenda given the promise to rollout personal *health* budgets beyond Continuing Health Care in the year to come.
- 4.4. But the split between health and social care remains a barrier to meaningful personalisation. *Time for Change* recommended that the extension of this right be linked closely with the Integrated Personal Commissioning (IPC) programme, to support local areas to pool funding across health and social care.²⁰ The only way to drive personalisation is to blend health and social care funding at the level of the individual and allow them to direct how the money is used.

¹⁹ Health and Social Care Information Centre, *Community Care Statistics, Social Services Activity, England – 2013 – 14, Final release* Available at: http://www.hscic.gov.uk/searchcatalogue?productid=16628&topics=0%2fSocial+care&sort=Relevance&size=10&page=1#top

²⁰ Winterbourne View - Time for Change (2014)

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4.5. Four out of the nine IPC demonstrator sites will include people with learning disabilities in their plans. This is a crucial opportunity to prove that there has been a step change in delivering individualised care, from describing what it looks like to action. Local areas will need support from the national partners to make sure they are publishing the number of people taking up these budgets and the impact on their lives so that lessons can be learnt and commissioners held to account.

The Government should look at ways to protect an individual's home tenancy when they are admitted to hospital.

- 5.1. *Time for Change* included this recommendation to emphasise the wide-ranging consequences for people who are admitted to inpatient settings. While the Transforming Care response has not treated it specifically, it is clear that if the programme of action works effectively, such issues will arise from considering the needs and concerns of individuals with learning disabilities and/or autism.
- 5.2. It can not be the case that people run the risk of having nowhere to live when they are discharged from hospital. Section 47 of the Care Act created a duty for local authorities to work with housing associations to ensure that a person's tenancy remains secure while they are an inpatient.
- 5.3. The Transforming Care partners are starting to articulate a robust programme for care across health and care. It is clear that the rights, values and beliefs of individuals will play a much bigger role in the design of care. But they must be careful to not miss the detail. By not protecting an individual's home tenancy, decision-makers will risk delaying a discharge further down the line because time will have to be given to finding suitable accommodation.
- 5.4. The issue of housing will require greater partnership working, and a model which ensures commissioners and providers can predict future needs, respond to immediate concerns and plan in a timely manner. Services continue to be too reactive, dealing with crises as and when they emerge. This flies in the face of the prevention and personalisation agendas that the Transforming Care partners purport to lean on. Well thought out discharge plans that are in place at the point of admission are therefore crucial.

FORCING THE PACE ON COMMISSIONING

- The Government and NHS England should force the pace on commissioning by requiring local commissioners to follow a mandatory framework.
 - 6.1. When *Time for Change* was published the basic pillars of an effective commissioning framework were recognised a shared vision, pooled budgets, active engagement and a robust understanding of need.
 - 6.2. Visions have come before Valuing People, Fulfilling Potential.

 Transforming Care can benefit from these, but must move radically if it is going to deliver the change that is needed. It needs to finish the job.
 - 6.3. The key to this will be the model of care it lays out. Personal budgets, the 'right to challenge,' and capacity-building in the community will mean little if commissioners do not have the mechanisms to shift services out of inpatient facilities. NHS commissioners and local authorities should not have to take risks, or go against the grain, to provide individuals with care outside of a hospital setting.
 - 6.4. Time for Change recommended a mandatory framework; a system in which it is impossible for the status quo to remain. Through partnership working the national partners can ensure that a commissioning framework speaks to commissioners across health and care on an equal level.
 - 6.5. Progress has been made. The Transforming Care programme recently announced that it would be working in five 'fast track sites' to bring together health and care organisations with the technical support they need to change services. It is claimed that these sites will help to shape an approach that can then be delivered across England. It is good to see that Transforming Care is committing proactive support for local commissioners, including a 'transformation fund' this will enable local decision-makers to submit plans that are robust, pro-active and sustainable.
 - 6.6. But this approach will fall short without strong leadership and a clear communication of outcomes. Local commissioners need to be engaged in what good looks like, any model will need a whole life-course approach and objectives must be clearly measurable. The programme must not isolate itself within five sites this would work against the key principle of personalised care and fundamentally fail to promote the collaborative attitudes that are needed to help people back into their communities.

- 6.7. Nearly 60% of people in inpatient facilities are more than 20 km away from their home postcode; 18.2% have been identified as placed over 100km away.²¹ Working in five areas will likely require local commissioners to work further afield to ensure that provision is available where and how individuals need. This applies to the IPC programme as well as the fast track sites local plans must join up and this requires strong leadership and assurance from the centre.
- 6.8. In their response to *Time for Change*, the Transforming Care partners committed to supporting local areas to adopt good practice at pace.²² This is important a transition plan for moving people out of inpatient facilities requires great consideration, but 'complexity' can only be an excuse for so long.

7. Community-based providers should be given a 'right to propose alternatives' to inpatient care.

- 7.1. Enabling providers to take an active role in peoples' care would be a strong indication of a step change in commissioning culture. But this has not been achieved. There has been no commitment within the Transforming Care programme to allow quality local providers to work with individuals and their families to actively propose potential packages of community-based care.
- 7.2. Transforming Care has committed to testing innovation and 'getting the basics right.'²³ Ensuring providers are part of the drive to form innovative solutions should be a basic staple of any new model that seeks to incentivise the system away from filling hospital beds. *Time for Change* has called for providers, with the permission of individuals and families, to have a right to put forward potential support options; at the very least providers need to be core partners for transformation.
- 7.3. The fast track sites identified by the Transforming Care programme have committed to co-production of learning, and sharing of expertise. This review will assess closely whether community providers are given the platforms they need to showcase excellent care services, and to work with individuals to develop those services around their needs.

²² Transforming Care for People with Learning Disabilities - Next Steps (2015)

CLOSURES

- The commissioning framework should be accompanied by a closure programme of inappropriate institutional inpatient facilities, driven by tougher registration requirements, local closure plans, and leadership by NHS England.
 - 8.1. The latest Learning Disabilities Census report showed that patients have an average length of stay of 547 days; in 2013, the average was 542 days.²⁴ This is a damning indication of how little real movement has been achieved over this time. The Concordat was clear that too many people with learning disabilities and/or autism are admitted to inpatient settings when admission could be avoided, too many stay too long, and so too many are in inpatient settings at any one time.²⁵
 - 8.2. That is why there needs to be a closure programme working alongside a new model for commissioning services. Otherwise, a surplus of beds will continue to delay change.
 - 8.3. In February 2015, Simon Stevens announced that a closure programme would be issued by autumn 2015. NHS England is committed to delivering a transition plan for inpatient facilities, drawing on the IPC programme that has been live since April 2015.
 - 8.4. Six months on from *Time for Change*, this review looks forward to the programme from Transforming Care. To be effective it will have to draw together a new commissioning framework with local closure plans that can actively decommission bed surpluses, transfer skilled staff into community services, recruit train and support the workforce in the community and work in close collaboration with people with learning disabilities and/or autism, their families and providers.
 - 8.5. This programme will have to be clear, and demonstrate strong leadership. We already have one failed timetable for transfers; NHS England cannot repeat the mistakes of the Concordat.

BUILDING CAPACITY IN THE COMMUNITY

- 9. Health Education England (HEE), Skills for Care, Skills for Health and partners should develop as a priority a national workforce 'Academy' in this field, building on the work already started by Professors Allen and Hasting and colleagues.
 - 9.1. Despite its vision to shift care out of hospitals and have more people supported in their communities, the community workforce has shrunk significantly in the past five years. On top of this, NHS England has lost 1,500 learning disability nurses since 2010.²⁶
 - 9.2. Building the skills of the workforce was a major priority for *Time for Change*. There is no dearth of best practice guidance for local commissioners and providers to embed into workforce development, but there needs to be concerted programme of action to support the long-term development of the workforce in services for people with learning disabilities and/or autism.
 - 9.3. The Transforming Care response was to commit to a first step in developing a workforce which provides person-centred care support a scoping exercise to identify current gaps in provision. But there has been little evidence of action.
 - 9.4. HEE is a Transforming Care partner. In responding to this review, HEE has reported on its activities over the last six months. The emphasis so far has been to generate an appropriate governance structure for this workstream. This includes a national delivery network with representation from thirteen local education and training boards to support local delivery. It plans to established a Workforce Expert Advisory Group to be chaired by Baroness Sheila Hollins.
 - 9.5. The programme of action will include the development of a learning disability skills and competency framework, which will rolled out early next year after piloting. This includes spreading Positive Behaviour Support (PBS) training at scale, as part of the work to reduce restrictive practices.
 - 9.6. Given this outline of action, this review will work closely with the partners to ensure that it remains action-focused. If it falls behind, any new service model that is introduced will fall at the first hurdle and prove unable to provide individuals with care in the community.

- 9.7. Excellent community provision needs an excellent workforce which can deliver services and respond to crises. Providers should be able to work with community teams to ensure that when extra support is needed, they are not forced to place individuals in inpatient facilities. Commissioners should be rewarding providers who invest in workforce training, and deliver excellent outcomes.
- 9.8. One of the most shocking aspects of the Panorama programme that exposed Winterbourne View was the evidence of physical abuse and neglect of people with learning disabilities. In the wake of this scandal, the Care Quality Commission (CQC) undertook 150 unannounced inspections of NHS and independent care services. These uncovered wider concerns about standards of care. It is clear that some institutions use physical restraint, including use of the emergency response belt. This report recommends that the CQC should undertake a review of restrictive practices with a view to banning physical restraint methods such as the emergency response belt. This would help drive transformation at the pace we need to ensure the work of HEE and its partners can be embedded within commissioning practices. Just as community provision will not be built up without the scaling back of inpatient facilities, a comprehensive commitment to PBS training and techniques will not be achieved without the scaling back, or banning, of restrictive practices.
- 9.9. The Government must also review the scope of the CQC to have powers for reviewing the care provided to individuals with learning disabilities when care for in supported living. It is essential that people with learning disabilities and/or autism are given full protection.

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- A 'Life in the Community' Social Investment Fund should be established
 to facilitate transitions out of inpatient facilities and build capacity in
 community-based services.
 - 10.1. Time for Change was clear transformation will only happen if there is investment to help community-based providers expand. The steering group commissioned a report Winterbourne View and Social Investment from Resonance, a social impact investment company. This laid out inter-linked solutions for the capital needs of providers, centred on a Government-backed vehicle with a social mission to improve outcomes for people with learning disabilities and/or autism.
 - 10.2. In the response to *Time for Change*, the Department of Health has taken responsibility for scoping this idea further. However, six months on there has been no evidence of any action to implement such an exercise, or build on the significant body of work that the social investment report provided.
 - 10.3. The update that the Department of Health has submitted to this review has emphasised the importance of delivering the transformation programme, particularly in the five fast track sites, which will include identifying further capital funding to support the transition.
 - 10.4. It is suggested that the fast track sites will prove fertile ground for exploring how certain funds, such as 'outcomes-based payments' could work 'on the ground.' The reason given is that work needs to be done with local commissioners to enable them to feel confident that this type of financial mechanism can deliver helpful solutions.
 - 10.5. This makes sense. But the lack of commitment to scope social investment options fully must be taken as a failure on the part of the Transforming Care programme to act on the practical questions of implementation. A closure programme requires retraining of staff, the development of community-based facilities, transition programme and alternative investments to underpin the change. Moving forward, it is the job of the partners to link up the work streams that have been taken on in response to *Time for Change* and provide a seamless new model of care for people with learning disabilities and/or autism. Failure to give due attention to any of the pieces will have significant consequences elsewhere.

HOLDING PEOPLE TO ACCOUNT

- 11. Action on the recommendations should be accompanied by improved collection and publication of performance data, and a monitoring framework at central and local level.
 - 11.1. Data on key indicators (such as admission rates, length of stay, and number of beds), need to be collected and published so that local commissioners and national bodies can be held to account on the implementation of these recommendations.
 - 11.2. As discussed above, responsibility for collecting data around the number of people with learning disabilities in inpatient facilities now rests with HSCIC. This Assuring Transformation data is starting to provide a clear, monthly picture. A responsibility to report on where local areas are in terms of transitioning individuals in the community should be an embedded part of any new commissioning framework that is drawn up.

APPENDIX MEMBERSHIP OF THE STEERING GROUP

Sir Stephen Bubb (chair) ACEVO

Jane Cummings NHS England

Andrea Pope-Smith ADASS

Andrea Sutcliffe/Alan Rosenbach CQC

Bob Ricketts NHS England

Dave Williams Salford CCG

Dominic Slowie NHS England

Dr Roger Banks Independent Psychiatrist

Gavin Harding Co-Chair, Department of Health

Transforming Care Assurance

Group

Hazel Watson NHS England

Jan Tregelles Mencap

Juliet Beal NHS England

Karen Flood National Forum of People with

Learning Disabilities

Kate Quail Mencap

Mark Lever/Mark Milton National Autistic Society

Robert Longley-Cook HFT

Sharon Allen/Marie Lovell Skills for Care

Shaun Clee NHS Confederation/2gether NHS

Foundation Trust

Steve James Avenues Group

Vicki Raphael National Valuing Families Forum

Vivien Cooper Challenging Behaviour

Foundation

"This is the opportunity for us, as a nation, to provide the care that people with learning disabilities and/or autism deserve and have been denied for so long."

Sir Stephen Bubb CEO, ACEVO

ACEVO

Regent's Wharf 8 All Saints Street London N1 9RL

ISBN: 1-900685-76-0

From: Valerie McConnell < Valerie. McConnell@hscni.net>

Sent: 18 August 2020 08:51

To: Marie Roulston < <u>Marie.Roulston@hscni.net</u>>; Joyce McKee < <u>Joyce.McKee@hscni.net</u>> **Cc:** Ken Moore < Ken.Moore@hscni.net>; Declan Carvill < Declan.Carvill@hscni.net>

Subject: RE: URGENT / re MAH breach/Ennis Report

Margaret – I am not aware of the "Ennis Report". I think Declan looked for it when the review team first asked.

I am only aware of the an Early Alert BHSCT notified to HSCB some time prior to 06/02/20 for which a SAI incident report was requested by HSCB (me as DRO for the EA), but declined by BHSCT. The verbatim record of correspondence on this (from the HSCB SAI Datix record) is on p104 footnote in the report.

I have no recollection of having seen the Adult Safeguarding investigation report referenced by the review team. HSCB would not normally receive copies of AS Investigation reports.

I will ask SAI Team for a copy of the original early alert.

Valerie

Valerie McConnell

Programme Manager MH & LD HSC Board 442895 363363

Personal Sec: Dorothy Taggart (Mon – Wed am) 442895 362576

Dorothy.taggart@hscni.net

valerie.mcconnell@hscni.net



From: Marie Roulston
Sent: 17 August 2020 16:52
Tax Valoria Ma Cannolly Javes N

To: Valerie McConnell; Joyce McKee

Cc: Ken Moore

Subject: RE: URGENT / re MAH breach/Ennis Report

Importance: High

Valerie/Joyce

Marie has asked me to check with you re Ennis Report – are you aware of this report and was this an HSCB report? Can you please advise urgently as summary data from this report was used re MAH review and has been a data breach and HSCB Governance need to determine if HSCB responsible for breach and this information should assist.

Thank you
Regards
Margaret

serious incidents

From: Irwin, Brian < Brian.Irwin@belfasttrust.hscni.net> on behalf of

SeriousAdverseIncident-SM <SeriousAdverseIncident@belfasttrust.hscni.net>

Sent: 01 September 2015 16:10

To: serious incidents

Cc: Anne Kane; McMullan, Colin; McCaul, Shane; Mooney, Geraldine; Cairns, Claire;

Mitchell, Mairead

Subject: FW: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Attachments: BHSCT_Early Alert Proforma_ 09_11_12.doc

Importance: High

Sensitivity: Confidential

Categories: Work in progress

Sent on behalf of Colin McMullan, Senior Manager Corporate Governance

Dear Colleagues,

Further to the email below the Trust wishes to clarify that this incident will not be reported by the Trust as an SAI. This is because the safeguarding investigation found the allegations were not substantiated and it therefore does not now meet SAI criteria for reporting as such.

If you have any queries or require further assistance please do not hesitate to contact Colin McMullan, Senior Manager Corporate Governance, by email: Colin.McMullan@belfasttrust.hscni.net or Telephone 028 950 43141.

Regards,

Brian

From: Mooney, Geraldine On Behalf Of SeriousAdverseIncident-SM

Sent: 05 August 2015 15:59

To: 'serious incidents'

Cc: Mitchell, Mairead; Minnis, Patricia; McCaul, Shane; McMullan, Colin **Subject:** RE: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Importance: High Sensitivity: Confidential

Sent on behalf of Colin McMullan, Senior Manager Corporate Governance

Dear Colleagues,

Further to your email below regarding the queries in relation to Early Alert Notification EA/BHSCT/09/11/12 HSCB Ref: EA1658, the Directorate has confirmed that this incident was investigated through the PSNI and an extensive safeguarding process. The outcome of both investigations was that there was no evidence of any of the allegations made. The Trust would therefore request that this early alert is closed.

If you have any queries or require further assistance please do not hesitate to contact Colin McMullan, Senior Manager Corporate Governance, by email: Colin.McMullan@belfasttrust.hscni.net or Telephone 028 950 43141.

Regards,

Geraldine

Geraldine Mooney
Risk & Governance Officer
Belfast Health & Social Care Trust

MAHI - STM - 277 - 2538

6th Floor McKinney House Musgrave Park Hospital Stockmans Lane Belfast BT9 7JB

Contact Number: 028 95048098

Email Address: geraldine.mooney@belfasttrust.hscni.net

From: serious incidents [mailto:seriousincidents@hscni.net]

Sent: 23 July 2015 11:33 **To:** SeriousAdverseIncident-SM

Subject: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Sensitivity: Confidential

"This email is covered by the disclaimer found at the end of the message."

Thank you for your email below in response to Lead Officer queries received on 13 May 2015. The Lead Officer responds as follows:

The Procedure for the reporting and follow up of Serious Adverse Incidents April 2010 under which the Trust considered this incident states "All existing local or national reporting arrangements, where there are statutory or mandatory reporting obligations, will continue to operate **in tandem** with this procedure" (page 7 section 3.3). The procedure also states that among its aims are to review of the circumstances and service input to "ensure trends, best practice and learning is identified, disseminated and implemented in a timely manner, in order to prevent recurrence; and provide a mechanism to effectively share learning in a meaningful way across the HSC" (page 5 section 2.0).

There is therefore clearly an expectation that an incident that met the SAI criteria (which in the view of the Lead Officer this one does) would be reported, irrespective of parallel processes such as criminal investigation and adult safeguarding also being initiated. Whilst information and perspectives relevant to an SAI review may well be elicited from these, there aims and objectives differ significantly. Therefore the Lead Officer would once again request that the Trust formally report this incident as an SAI, and review it as such within the terms of reference of the SAI procedure.

Can you please submit a SAI Notification, as requested, to <u>seriousincidents@hscni.net</u> mailbox **as soon as possible**?

Many Thanks

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 95 362064

From: Mooney, Geraldine [mailto:Geraldine.Mooney@belfasttrust.hscni.net] **On Behalf Of** SeriousAdverseIncident-SM

Sent: 13 May 2015 09:10 **To:** serious incidents

Co. Mitaball Mairea de Minnia Datricia e MaCo

Cc: Mitchell, Mairead; Minnis, Patricia; McCaul, Shane; Mooney, Geraldine; McMullan, Colin

Subject: RE: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Importance: High Sensitivity: Confidential

Sent on behalf of Colin McMullan, Senior Manager Corporate Governance

Dear Colleagues,

Please find attached response regarding the queries in relation to Early Alert Notification EA/BHSCT/09/11/12 HSCB Ref: EA1658.

If you have any queries or require further assistance please do not hesitate to contact Colin McMullan, Senior Manager Corporate Governance, by email: Colin.McMullan@belfasttrust.hscni.net or Telephone 028 950 43141.

Regards,

Geraldine

Geraldine Mooney
Risk & Governance Officer
Belfast Health & Social Care Trust
6th Floor McKinney House
Musgrave Park Hospital
Stockmans Lane
Belfast BT9 7JB

Contact Number: 028 95048098

Email Address: geraldine.mooney@belfasttrust.hscni.net

From: serious incidents [mailto:seriousincidents@hscni.net]

Sent: 11 May 2015 11:16 **To:** SeriousAdverseIncident-SM

Subject: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Importance: High Sensitivity: Confidential

"This email is covered by the disclaimer found at the end of the message."

Please see email below, in relation to the above incident. Can you please submit a SAI for the above Early Alert?

Regards

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 95 362064

From: serious incidents **Sent:** 24 April 2015 14:31

To: SeriousAdverseIncident-SM (SeriousAdverseIncident@belfasttrust.hscni.net)

Cc: geraldine.mooney@belfasttrust.hscni.net

Subject: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Importance: High Sensitivity: Confidential

Can you please confirm if the above Early Alert has been submitted as an SAI? If not, can you please submit a SAI as soon as possible as the Lead Officer has stated that this Early Alert meets the criteria for reporting a SAI?

Regards

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 95 362064

From: serious incidents Sent: 06 March 2015 12:10

To: EarlyAlertNotificationMedDir-SM (EarlyAlertNotificationMedDir@belfasttrust.hscni.net)

Cc: geraldine.mooney@belfasttrust.hscni.net

Subject: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Sensitivity: Confidential

Please see email below, in relation to the above Early Alert, where the Lead Officer has requested that a SAI be submitted, to date we have not received a SAI. Can you please submit a SAI as soon as possible?

Regards

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 95 362064

From: serious incidents **Sent:** 03 February 2015 11:54 **To:** 'EarlyAlertNotificationMedDir-SM'

Subject: Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Sensitivity: Confidential

The DRO would draw the Trust's attention to Section 4, Definition and Criteria, within the Procedure for the Reporting and Follow up of Serious Adverse Incidents (October 2013). This incident would appear to meet the criteria set out in 4.2.5 and 4.2.8.

Whilst it is acceptable to delay the SAI review on advice of police carrying out a criminal investigation, the DRO would draw attention to Section 7.3. of the procedure and the expectation that the SAI review will run as a parallel process. The Trust should also note the purpose of an SAI review – to identify learning and prevent where possible any future occurrence of similar incidents. The intention and the scope of the SAI is therefore different from the police criminal investigation and the Adult Safeguarding investigation.

The Trust should therefore formally notify this incident as an SAI and conduct a review of this case in respect to any improvements to care planning, staff supervision, training etc.; or any other cultural or environmental features of the care setting that could be addressed to reduce the likelihood of any future occurrence.

Regards

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 95 362064

From: Irwin, Brian [mailto:Brian.Irwin@belfasttrust.hscni.net] On Behalf Of EarlyAlertNotificationMedDir-SM

Sent: 28 January 2015 11:21

To: serious incidents

Cc: Mitchell, Mairead; Minnis, Patricia; McCaul, Shane; Mooney, Geraldine **Subject:** RE: Early Alert Notification: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Importance: High Sensitivity: Confidential

Sent on behalf of Claire Cairns, Co-Director Risk & Governance - 2542

Dear Colleagues,

Please find attached response regarding the queries in relation to Early Alert Notification BHSCT/EA/09/11/12 HSCB Ref: EA1658.

If you have any queries or require further assistance please do not hesitate to contact Claire Cairns, Co-Director Risk & Governance by email: claire.cairns@belfasttrust.hscni.net or Telephone 028 950 48098 / mob: 078 2514 7249.

Regards,

Brian

From: serious incidents [mailto:seriousincidents@hscni.net]

Sent: 16 January 2015 12:19 **To:** SeriousAdverseIncident-SM

Subject: Early Alert Notification: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Importance: High Sensitivity: Confidential

"This email is covered by the disclaimer found at the end of the message."

Please see email below sent 6 March 2014, in relation to the above incident.

This Early Alert remains open. No subsequent SAI has ever been received and the DRO feels that it should be an SAI.

Can you please let me know the current status of this Early Alert, as it remains open and if an SAI is to be submitted?

Many Thanks

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 3741 4530

From: serious incidents **Sent:** 06 March 2014 15:07

To: SeriousAdverseIncident-SM (SeriousAdverseIncident@belfasttrust.hscni.net)

Cc: Shane.McCaul@belfasttrust.hscni.net

Subject: Early Alert Notification: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Sensitivity: Confidential

Exhibit 67

MAHI - STM - 277 - 2543
The attached Early Alert, which was reported on <u>9 November 2012</u> remains open. No subsequent SAI has ever been received. I had contacted the DRO to see if the Early Alert could now be closed. The DRO has responded saying – 'given the serious nature of this incident and its public interest I am of the opinion that it should be an SAI.'

Can you please let me know the status of the above Early Alert as it hasn't been reported as an SAI?

Regards.

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board **Tower Hill** Armagh

E: Roisin.Hughes2@hscni.net

T: 028 3741 4530

From: McCaul, Shane [mailto:shane.mccaul@belfasttrust.hscni.net]

Sent: 09 November 2012 16:40

To: early alert; 'earlyalert@dhsspsni.gov.uk'; cx office

Cc: brenda.creaney@belfasttrust.hscni.net; Robinson, David; McNicholl, Catherine; Tony Stevens; Champion, June;

Cairns, Claire; EarlyAlertNotificationMedDir

Subject: Early Alert Notification

Importance: High **Sensitivity:** Confidential

Sent on behalf of Claire Cairns Corporate Governance Manager

Dear Colleagues

Please find attached Early Alert Notification for the Belfast Health & Social Care Trust.

If you have any queries or require further assistance please do not hesitate to contact Claire Cairns, Corporate Governance Manager by email: claire.cairns@belfasttrust.hscni.net or Telephone 028 950 48359 mob: 078 2514 7249.

Regards,

Shane

Shane McCaul Risk & Governance **Belfast Health & Social Care Trust 6th Floor McKinney House** Musgrave Park Hospital **Stockmans Lane Belfast BT9 7JB**

Contact Number: 028 95048098

Email Address: earlyalertnotificationmeddir@belfasttrust.hscni.net

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serious incidents

From: serious incidents

Sent: 09 September 2015 11:58

To:SeriousAdverseIncident-SM (SeriousAdverseIncident@belfasttrust.hscni.net)Subject:Closure of Early Alert - Trust Ref: EA/BHSCT/09/11/12 HSCB Ref: EA1658

Attachments: Safeguarding and SAI Processes..pdf

The HSCB are content to close this early alert on the basis Belfast Trust have advised the safeguarding investigation found the allegations were not substantiated. It should however be acknowledged at the time the early alert was reported, a SAI notification should also have been submitted, which could have been subsequently been deferred pending the outcome of the safeguarding investigation (see attached safeguarding flowchart).

Regards

Roisin

Roisin Hughes

Governance Support Officer Corporate Services Department Health & Social Care Board Tower Hill Armagh

E: Roisin.Hughes2@hscni.net

T: 028 95 362064

MUCKAMORE ABBEY HOSPITAL HSC ACTION PLAN

INTRODUCTION

The independent Serious Adverse Incident (SAI) review report into safeguarding at Muckamore made for stark reading. It exposed not only significant failings in the care we provided to people with a learning disability while in hospital and their families, but also gaps in the wider system of support for people with learning disabilities. In short, it told us that, while we have achieved much through Bamford, there is much more we need to do.

This is our response, and sets out exactly what we now must do. It recognises that the events at Muckamore have caused much distress for the patients receiving treatment in the hospital and their families and carers, and has also damaged wider public confidence in how the HSC system provides care, treatment and support to people with a learning disability and their families. The measures set out in this document are intended to address the issues that the SAI report highlighted, but also to provide wider assurance to society that the HSC system is working together in a co-ordinated way to make life better for people with a learning disability.

As the Permanent Secretary made clear when he met with all HSC Chief Executives in January this year, we must effect lasting change, with reference to every single recommendation in the SAI report. It is right that this report acts as our barometer, and the success of our efforts should be measured against it.

This document therefore sets out what we are doing and plan to do in response to its call to action. Specifically, it reiterates the overarching recommendation of the report endorsed by the Permanent Secretary that Muckamore must return to being a hospital not a residential facility. This will require a coordinated programme of action to manage the planned and safe resettlement of those patients not currently under active assessment or treatment into accommodation more appropriate for their needs.

This timeline will be monitored closely by the Muckamore Departmental Assurance Group, which will include representation from the HSCB, PHA, RQIA, the 5 Trusts, professional representatives, specialist accommodation providers, appropriate academic expertise and importantly the families of patients, which will also ensure the team in Muckamore and the wider community services have the necessary support and resources in place to achieve these goals. A first but critical step will be to develop and deliver enhanced services in the community to source, support and sustain people in the places where they live. This will be the key role of the Regional Learning Disability Operational Delivery Group led by the Health and Social Care Board.

However, this document also recognises that more actions will follow as we progress the co-production of a new service model for learning disability as part of our transformation agenda. When developed, this will bring with it a new set of actions to consult on and implement.

We are also conscious that the police investigation into the unacceptable events at Muckamore Abbey Hospital is still ongoing. We await the outcome of that investigation and will be ready to take any additional actions to ensure that lessons are learned and put into practice across the full spectrum of learning disability services in Northern Ireland.

In this context this plan should be considered a live document which will be subject to ongoing review and development to drive further and emerging improvements to current practice.

INDEX

Progress required

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Work in progress		

SECTION A

COMPLETED ACTIONS

Perma	nent Secretary commitme	ents				
PS1		HSCB / PHA	A3	By March 2021, complete an independent review of the current service model / provision for acute care for people with learning disabilities (in patient and community based) and associated clinical pathways in order to recommend a future best practice model for assessment, treatment and care and support for adults with a learning disability, which is regionally consistent and focused on relevant clinical and patient related outcomes.	Acute Care Review	
PS1	Completion of resettlement process commenced in 2011 by the end of 2019, and the issue of delayed discharges addressed.	DOH	A4	By 31 August 2019 , establish a professionally chaired Departmental Assurance Group to assure the Permanent Secretary of the DoH (and any incoming Minister) that the	Governance	

PS1		DoH/DoJ	A9	resettlements commitments and recommendations of the SAI report are met (see full governance structures associated with this plan at Annex A). By 31 December 2019, provide a new statutory framework for Deprivation of Liberty through commencement of relevant provisions in the Mental Capacity Act.	Governance	
PS1		HSCB/HSC Trusts	A10	By 30 December 2020, review current forensic LD services, identify and address service development needs to support people in community settings.	Service Model	
SAI In	l dependent Review Panel r	recommendations				
R1.	Evidence of a renewed commitment (i) to enabling people with learning disabilities to have full lives in their families and communities and (ii) to services which	HSCB/PHA	A11	By December 2020 , deliver a co-produced model for Learning Disability Services in Northern Ireland to ensure that adults with learning disability in Northern Ireland receive the right care, at the right time, in the right place; along with a costed	Service Model	

R.2	understand that ordinary lives require extraordinary supports – which will change over the life course. An updated strategic framework for Northern Ireland's citizens with learning disability and neuro developmental challenges which is coproduced with self-	implementation plan, which will provide the framework for a regionally consistent, whole system approach. This should ensure the delivery of high quality services and support, and also a seamless transition process at age 18. The new model will be subject to public consultation and will be presented to an incoming Minister for decisions on implementation.	
R.2	the life course. An updated strategic framework for Northern Ireland's citizens with learning disability and neuro developmental challenges which is co-	ensure the delivery of high quality services and support, and also a seamless transition process at age 18. The new model will be subject to public consultation and will be presented to an incoming Minister for decisions on	
	accompanied by the development of local services. The Review Team suggests that elements of the latter include purposefully addressing the obstacle		

cited by so many, that is,					
"there are no community					
services". A life course					
vision of "age					
independent pathways,"					
participative planning,					
and training for service					
development, for					
example, remains to be					
described. Elements of					
the contraction and					
closure include individual					
patient relocation, staff					
consultation and					
participation, and					
maintaining quality and					
morale.					
Long term partnerships	HSCB/HSC	A15	By 30 June 2020 review the	Accommodation	
with visionary housing	Trusts		capability of current providers of		
associations, including			supported housing, residential		
those with experience of			and nursing home care to meet		
developing shared			the needs of people with complex needs.		
ownership, for example,			Complex fields.		
is crucial to closing and					
locking the "revolving					
door" which enables					
existing community					

	services to refuse continued support to former patients in group living, residential care or nursing home settings. If a young person or adult has their own home or settled tenancy, there is no question about where their destination will be if they have required Assessment and					
	Treatment.					
		HSCTS	A16	By 31 December 2019 address security of tenure of people with a learning disability living in supported housing.	Accommodation	
		HSCTs	A17	By 31 March 2020 complete working with NIHE develop a robust strategic, intelligence led housing needs assessment to support the planning and development of special needs housing and housing support to inform future funding decisions for adult LD.	Accommodation	
SAI Pa	tients families recommen	dations				

R4.	Families and advocates should be allowed open access to wards and living areas.	Belfast, Southern and Western Trusts.	A19	Co-produce and implement an Open Access policy for MAH (and Lakeview and Dorsey).	Service Model (Assessment & Treatment)	
R5.	There is an urgent need to (i) invest in valued activities for all patients and (ii) to challenge the custom and practice concerning the improper and excessive use seclusion at the Hospital.	Belfast, Southern and Western Trusts.	A20	By 30 June 2020, carry out a review of access and availability of meaningful activity in MAH (and Lakeview and Dorsey), including the range and volume of activities available to patients and monitoring of patient uptake and views to inform a new evidence based model for high intensity therapeutic interventions designed to minimise the need for restrictive practices.	Service Model (Assessment & Treatment)	
R6.	The use of seclusion ceases.	DOH	A22	By March 2021, develop a co- produced and publish regional seclusion and restraint policy/guidance.	Governance (Mental Health Action Plan)	
R8.	People with learning disabilities and their families are acknowledged to have a	Belfast Trust	A24	By 31 December 2019 , review and change needs assessment and care planning culture and processes in MAH to ensure individuals and their families are	Service Model	

	critical and ongoing role in designing individualised support services for their relatives.			fully involved, taking account of lessons emerging from Independent Review into Dunmurry Manor.		
R9.	The Hospital's CCTV recordings are retained for at least 12 months.	Belfast Trust	A25	By 31 October 2019, liaise with provider to explore options for retention of recordings, in compliance with existing regional HSC and national information and record management guidance and legislation.	Governance	
R11.	Families are given detailed information, perhaps in the form of a booklet, about the process of making a complaint on behalf of their relatives.	Belfast Trust	A27	By 31 October 2019 , provide an information booklet to families on the complaints process.	Governance	
R12.	Families receive regular progress updates about what is happening as a result of the review.	Belfast Trust	A28	By 31 October 2019 , a schedule of Trust meetings with families will be produced and circulated to families.	Governance	

R16.	A shared narrative is set out.	HSCB/ PHA/HSC Trusts	A33	By December 2020 , the LD Service Model Transformation project (see Recommendations 1 and 2) will inform the development of a best practice regionally consistent model for community and acute services, which (subject to agreement by an incoming Minister) will set out the road map for regional adult learning disability services in the future.	Service Model	
R17.	Commissioners specify what "collective commissioning" means.	HSCB	A34	By March 2021, HSCB to write to BHSCT outlining the current position and status of commissioning for HSC Services, taking account of learning also emerging from the Independent Review into Dunmurry Manor.	Governance	
R18.	The transformation required in learning disability services must be values driven and well led.	HSCB/ PHA/HSC Trusts	A35	By December 2020, the LD Service Model Transformation project (see Recommendations 1 and 2) will build on the vision set out in the Bamford Review, and adopt an outcomes based approach. It will also be co- produced with people with learning disability, carers, advocates and families. Bespoke governance	Service Model	

R19.	The purpose of all our services is clear.	HSCB/ PHA/HSC Trusts	A36	arrangements have been established and will be kept under review throughout the life of the project. By December 2020 , the LD Service Model Transformation project will inform the development of a regionally consistent model for community and acute services and will provide clarity around purpose.	Service Model	
R23.	Trusts and Commissioners must be knowledgeable about the "user experience" and that of their families.	HSCB/ PHA/HSC Trusts	A42	By December 2020 the LD Service Model Transformation project (see Recommendations 1 and 2) is being co-produced with people with learning disability, carers, and families. The future model for LD services will be designed around their aspirations, and will ensure effective structures are in place on an ongoing basis to fully operationalise this commitment.	Service Model	
R24.	Trusts and Commissioners should set out the steps required in the Department of Health's	DoH/HSCB/ PHA/HSC Trusts	A43	By December 2020 , all parts of the HSC will have been involved in the development of the Learning Disability Service Model which will include a costed implementation plan and provide the framework for a regionally consistent, whole	Service Model	

	post Bamford plan: in the short and medium term.			system approach to delivering high quality services and support to adults with Learning Disabilities. The new model will inform future service developments and investments for LD services.	
LG4	The HSC Board/PHA should ensure that any breach of requirements brought to its attention them has, in the first instance, been brought to the attention of the Trust Board.	HSCB/PHA	A47	This was taken to HSCB/PHA Quality, Safety and Experience meeting on 3/2/21.QSE were asked to discuss potential mechanism to seek Trust assurances. It was agreed that this will be listed for discussion at the quality, safety and experience meeting with Trusts.	
LG5	Pending the review of the Discharge of Statutory Function reporting arrangements, there should be a greater degree of challenge to ensure the degree to which these functions are discharged including	HSCB/PHA	A48	This work has been actioned by HSCB and is progressing and is being led by the Governance Lead in HSCB.	

an identification of any			
areas where there are			
risks of non-compliance.			

SECTION B

RESETTLEMENT

Perma	nent Secretary commitmer	its				
PS1	Completion of resettlement process commenced in 2011 by the end of 2019, and the issue of delayed discharges addressed.	HSC Trusts	A1	By 30 November 2019 carry out a full re-assessment of the needs of all patients they have currently placed in MAH, with a view to preparing contingency plans for their patients, including updated discharge plans for each individual assessed as medically fit for discharge, with a target date for the individuals' discharge, a timeline to deliver appropriate high quality placements matching each individual's assessed needs and identifying any barriers to discharge. August 2021 update Assessments updated periodically – all up to date. Working towards estimated target dates however confirmed discharge dates remain	Resettlement	

			outstanding.		
PS1	HSCB/HSC Trusts	A2	By 30 November 2019 develop and oversee a regional resettlement plan and agreed timeline for all individuals who are currently resident in MAH and assessed as medically fit for discharge.	Resettlement	
			Linked to A1.		
			August 2021 update		
			Plans are in place for the resettlement of a number of people currently in MAH, over the next few months. The three Trusts concerned have been asked to produce detailed plans to HSCB via the Delegated Statutory Function process to ensure that all patients have a defined plan.		
			All Trusts continue to actively manage resettlement options for patients in Muckamore		

	<u> </u>	T	Alabara Hannifal and managed to		
			Abbey Hospital and report to		
			RLDODG on a regular basis		
- DO4	D 11/1100D/1100		D 00 0 1 1 0000 :	D	
noPS1	DoH/HSCB/HSC Trusts	A7	By 30 September 2020, in conjunction with DfC/DoF and housing providers, identify barriers to accommodation provision and develop innovative solutions to support individuals' specific needs in their transition to community settings, and inform the development of a long term sustainable accommodation strategy for people with learning disability.	Resettlement	
			August 2021 update In addition to June update, the Chair of the RLDODG is also joint Chair of the HSCB/Housing Executive Disability Thematic Group where the business cases associated with resettlement are reviewed with a view to progressing to the full Business Cases. 1 of the 3 original Business Cases has been		

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SECTION C

WORKFORCE

Permanent Secreta	ry commitments			
PS1	DOH/HSCB/HSC Trusts	A5	By 30 September 2021, develop specialist staff training and a model of support to upskill the current workforce providing care to people with complex needs and challenging behaviours to support current placements and develop capable environments with appropriate philosophy of care e.g. Positive Behaviour Support, and prevent inappropriate re-admissions to hospital, and by June 2022 deliver training to an agreed cohort of staff. August 2021 update	
			Comments have been received and considered regarding the redraft of the Community Based Assessment and Treatment (CAT) for People with a learning disability and Complex Needs approach. The document is currently being revised. Further	

SAI Ho	ospital Staff Recommenda	tions		work is in progress which should inform training needs. Delivering Care funding indicated to each Trust – Trusts considering best use of this resource.	
R13.	An enhanced role for specialist nursing staff is set out.	Belfast Trust	A29	By 30 June 2020, develop a workforce plan for specialist nursing provision in MAH in line with findings from ongoing regional work. August 2021 update Delivering Care funding indicated to each Trust is 1WTE 8B Nurse Consultant, 1WTE 8A Advanced Care Practitioner/Lead Nurse and WTE Band 7 Specialist Nurse roles. BHSCT is considering the best use of this resource in order to develop and agree job roles and facilitate the development of job descriptions.	

		DOH	A30	By September 2021, complete a review of Learning Disability Nursing. August 2021 update No further update.	Workforce	
R20.	All Trusts should invest in people-skills and be cautious about focusing solely on learning disability nursing.	DoH	A37	By September 2021, develop an evidence based plan for recruitment, training and retention of a sufficiently skilled multi-disciplinary workforce, including people skills, to undertake and deliver therapeutic and clinical assessment and intervention across both inpatient and community services. August 2021 update We do not have the resources in-house to take this forward; as a result a proposal has been drafted to enable an appointment to be made and funding is being sought for this. Funding will need to be agreed as part of the 22/23 budget	Workforce	

	process. A Terms of R	eference	
	have been drafted and	will be	
	finalised once an appo	intment	
	has been made.		

SECTION D
TRANSFORMATION: [SERVICE MODEL; ACUTE CARE REVIEW; ASSESSMENT & TREATMENT]

Permanent Secretary co	mmitments			
PS1	HSCB/PHA	A6	By 31 March 2022, commission HSC Trusts to develop robust Crisis and Intensive Support Teams, including local step up and step down services, flexible staff resources and Community Treatment services, to support safe and timely resettlement of in-patients from MAH drawing on findings from the independent review of acute inpatient care. August 2021 update Further comments have been received and incorporated into the latest draft of the Community Based Assessment Rehabilitation and Treatment model (CART) for People with a learning disability and Complex Needs approach. Further work is in progress which should assist the Trusts in developing their community services.	

PS1			HSCB/HSC Trusts	A8	By March 2021, in the context of the Reform of Adult Social Care, establish a regionally agreed framework for higher tariff placements which specifies what staff and service requirements justify a higher tariff. August 2021 Update	Service Model	
SAI P	atients familie	es recommen	dations		HSCB is still scoping this issue with Trusts and plans to use their responses as the basis for a regional approach to consistent decision making.		
R6.	The use of ceases.	of seclusion	Belfast, Southern and Western Trusts.	A21	By 31 January 2021 , complete an urgent review of seclusion policy and practice in MAH (and Lakeview and Dorsey), to inform wider consideration of regional policy, and share outcomes with families.	Service Model (Assessment & Treatment)	Rated moved from Red to Green
					August 2021 update The Belfast Trust Policy, 'Seclusion within Learning		

SAI Senior Trust staff recommen	dotiono		Disability Inpatients Services Procedure – Children and Adults' has now been approved by the Trust's Standards and Guidelines Committee. Suggest amend RAG status from Red to Green		
	HSCB/ PHA/HSC Trusts	A38	By March 2022, deliver community and home treatment services support placements for people with learning disability so that all assessment and treatment options are explored, undertaken and exhausted in the community where possible and only in hospital when indicated/necessary. August 2021 update Further comments have been received and incorporated into the latest redraft of the Community Based Assessment Rehabilitation and Treatment	Service Model (Assessment & Treatment)	

				model (CART) for People with a learning disability and Complex Needs approach. Further work is in progress.		
R21.	The default "Friday afternoon and weekend admissions" to Muckamore Abbey Hospital have to stop.	HSCB/PHA/ HSC Trusts	A39	By 31 December 2019 support HSC Trusts to complete a regional review of admissions criteria and develop a regional bed management protocol for learning disability services	Service Model (Assessment & Treatment)	
R22.	Time limited and timely Assessment and Treatment become the norm.			August 2021 update HSCB is scoping how best to meet this need drawing on existing work and utilising existing resources to make best use of existing bed manager resources. HSCB are planning as a first step to re-issue criteria developed previously for regional sign off. Muckamore Abbey Hospital has not accepted a new admission since December 2019.		

HSCB/HSC Trusts	A40	By 30 November 2019, appoint a regional bed manager for all 3 current in-patient units. August 2021 update Following recent discussions the 8B Mental Health bed manager post job description will be reviewed to include the interface with mental health and learning disability.	Service Model (Assessment & Treatment)	
HSCB/PHA/ HSC Trusts	A41	By March 2022, taking into account the outcome and recommendations of the independent review of acute care for people with learning disabilities support HSC Trusts to develop regional care pathways for inpatient care to ensure that admissions are planned and delivered in the context of an overall formulation. This should include community based assessment and treatment, clear thresholds for hospital admission and timely, supported discharge	Service Model (Assessment & Treatment)	

from hospital. (See Permanent Secretary commitments).	
August 2021 update	
Further comments have been received and incorporated into the latest redraft of the Community Based Assessment Rehabilitation and Treatment model (CART) for People with a learning disability and Complex Needs approach. Further work is in progress.	

SECTION E

CHILDREN AND YOUNG PEOPLE

Hospital Staff Recor		240	Do March 2004 days	Objidence of	
	HSCB/PHA/ HSC Trusts	A12	By March 2021 develop a regionally consistent pathway for children transitioning from Children's to Adult services, including:		
			 People with learning disability and complex health needs. People with Leaning disability and social care needs. People with learning disability and mental health needs (consistent with the CAMHS care Pathway) People with LD who exhibit distressed behaviours. 		
			August 2021 update The issue of transition has been agreed as one of the four priority		
			themes in the Disability Framework developed by the HSCB with the 5 Trusts. This		

paper will be submitted to DoH.	
paper will be easimited to bern.	
A report has been completed on	
transition from CAMHS to AMHS	
as part of the mental health	
strategy.	
The transition of young people	
who have ASD and ADHD is	
complicated when there is no co-	
occurring mental health or	
learning disability diagnosis.	
SEND Act 2016 required a joint	
transition plan for Children with	
Statements of Special	
Educational Need where HSC	
are involved, will leave many	
children who have a statutory	
plan in place under this	
legislation unable to meet the	
criteria for access to services	
post transition in areas such as	
ASDS, ASD, ADD and other	
disabilities where there is no MH	
or LD determination or where a	
range of co-occurring conditions	
occur, requiring a different	
intervention from those provided	

		under current provision.		
HSCB/PHA/ HSC Trusts	A13	By 31 December 2020 finalise and develop a costed implementation plan for the new regional framework for reform of children's autism, ADHD and emotional wellbeing services, including consideration of the services required to support them into adulthood. August 2021 update Implementation costings have been prepared and are part of the three year budget exercise currently in preparation.	Young People	
HSCB/PHA/ HSC Trusts	A14	By 31 December 2020 review the needs of children with learning disability that are currently being admitted to Iveagh Centre and to specialist hospital / placements outside of Northern Ireland with a view to considering if specialist community based service should be developed locally to meet their needs. This should be aligned to the ongoing regional	Young People	

review of children's residential services.
August 2021 update
The issue of placements has been subject to Judicial Reviews;
The Court has outlined a judgement requiring a regional panel comprising Iveagh, HSCB and Trusts to be established to focus on admission and discharge planning with a view to avoiding future delayed discharges as well as keep a focus on existing delayed discharges. This panel has been established and has been meeting on a monthly basis.
The Court also determined that the operational policy of Iveagh to be reviewed to strengthen intake and discharge processes and this is being undertaken by the regional panel.
The Court also clarified the

	duties on Trust in regard to placements and the statutory duties under the Children Order NI 1995 and the option of civil redress in these cases. The Regional Review of Residential has not fully considered the issue of CWD and the HSCB has led on the development of a framework for the reform of CWD services. This framework in line with Children's legislative frameworks is inclusive of all CWD including those with LD. Further work was required on the Framework which is now complete. The Framework will be formally passed to DoH in August.
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SECTION F

GOVERNANCE

R3	Hospital staff at all levels must invest in repairing and establishing relationships and trust	Belfast Trust	A18	Appoint a carers consultant and co-produce a communications strategy with parents and carers. Completed		Rating moved from Amber to Green
	with patients and with their relatives as partners.			August 2021 update The Belfast Trust's newly recruited Carer's Consultant has now taken up post and is being inducted to new role. This post is now called the Carer Involvement and PPI Lead for Adult Learning Disability Services.		
R10.	Families are advised of lawful practices the hospital may undertake with (i) voluntary patients and (ii) detained patients.	Belfast Trust	A26	By 30 November 2019 develop an information paper and share with families and staff. August 2021 update	Governance	

	This work is continuing.	

SECTION G

SAFEGUARDING

SAIP	atients families recomme	ndations				
R7.	The perception that people with learning disabilities are unreliable witnesses has to change. Responses to safeguarding incidents and allegations are proportionate and timely.	Belfast Trust	A23/A31	By 30 June 2020, complete a review of Adult Safeguarding culture and practices at MAH, to inform wider consideration of regional safeguarding policy and procedures taking account of lessons also emerging from the Independent Review into Dunmurry Manor. August 2021 update No further update (BHSCT).	Safeguarding	
		HSCB	A32	By December 2021, carry out a review of regional Adult Safeguarding documentation, to inform wider consideration of regional safeguarding policy and procedures taking account of lessons also emerging from	Safeguarding	

the Independent Review into Dunmurry Manor.
August 2021 update
The interim Adult Protection Board is in the process of establishing and populating a sub-group structure that will support this work, progressing work around the Joint Protocol actions as a first priority.

SECTION H

Leade	Leadership And Governance Review Recommendations					
LG1	The Department of Health should review the structure of the Discharge of Statutory Functions reporting arrangements to ensure that they are fit for purpose.	DOH	A44	By March 2022, complete a review of the accountability arrangements for DSF. The HSCB are developing an outcomes based reporting template which will be the first stage of this process. In preparation for the Social Care Directorate moving into the Department following the closure of the HSCB in 2022, a review of the accountability arrangements for DSF will be undertaken.		
LG2	The Department of Health should consider extending the remit of the RQIA to align with the powers of the Care Quality Commission (CQC) in regulating and	DOH	A45	The Department has carried out a fundamental review of the 2003 Order and the existing regulatory framework and has developed a new draft regulatory policy that includes the principles of regulation, along with the broad scope of services to be regulated and the		

inspecting all hospital	proposal that the regulator
provision.	should have wider powers of
provioien.	enforcement etc. This work has
	been the first phase of the
	process and we intend to
	consult on the draft policy
	before moving on to phase 2,
	which will include the risk
	assessment of each provider
	type and consider the
	appropriate regulatory
	approach, including the range of
	enforcement and
	sanctions. Phase 2 will result in
	a clear regulatory framework
	and legislation and this
	framework will reflect
	Departmental Policy. A
	Departmental Reference group
	was established to enable
	relevant policy areas to be
	involved in the development of
	the draft regulatory policy in
	Phase 1 and to shape the
	regulatory framework in Phase
	2.
	Minister approved the direct
	Minister approved the draft policy for consultation earlier this

	indicators should be developed for inpatient learning disability services and community care environments.			This work is ongoing.	
LG7	The Trust should consider immediate action to implemented disciplinary action where appropriate on suspended staff to protect the public purse.	Belfast Trust	A50	By January 2021, complete disciplinary action in respect of first 7 individuals whose cases have been forwarded by PSNI to PPS. Action against a further 9 individuals will commence when PSNI confirm their cases have been forwarded to PPS. August 2021 update Disciplinary action is continuing in line with employment law regulations.	
LG8	The Trust has instigated a significant number of managerial arrangements at MAH following events of 2017. It is recommended that the Trust considers	Belfast Trust	A51	A Co-Director for Learning Disability services was appointed in June 2020. The dedicated Divisional Nurse post remains and a dedicated Service Manager and two permanent dedicated Assistant	

	sustaining these			Service Managers for the	
	arrangements pending			hospital have been appointed.	
	the wider Departmental			Substantive appointments at	
	review of MAH services.			Band 7 and Band 6 Ward	
				Manager and Deputy Ward	
				Manager level are being	
				progressed. The Interim Director	
				for Learning Disability Services	
				will review the existing	
				managerial arrangements as	
				part of the Chief Executive's	
				overall review of Directorate and	
				Divisional structures which will	
				take place in 2021.	
				August 2021 update	
				The Belfast Trust is establishing	
				a new Directorate for Mental Health, Learning Disability and	
				Psychology Services. The new	
				Director will take up post on 16	
				August 2021.	
		- 15 1 - 1		2 14 1 2224	
LG9	Advocacy services at	Belfast Trust	A52	By March 2021, complete a	
	MAH should be reviewed			review of advocacy services. The Trust is engaging with	
	and developed to ensure			representatives of Families	
	they are capable of			Involved Northern Ireland (FINI)	
	liley are capable or			to develop Terms of Reference	

	providing a robust challenge function for all patients and support for their relatives and/or carers.			for a review of its advocacy arrangements. August 2021 update One independent reviewer has been secured and a second reviewer is currently being sourced via the HSC Leadership Centre.	
LG10	The complaint of Mr. B of 30 th August 2017 should be brought to a conclusion by the Trust's Complaints Department.	Belfast Trust	A53	The Trust have engaged with Mr B and written to him in an attempt to address his outstanding concerns. The resolution of these concerns is ongoing at this time and while every effort will be made to progress the investigation into the outstanding issues of concern, it is not at this stage possible to provide a definitive completion date. August 2021 update As per June update, the Trust continues to engage with Mr B regarding his complaint.	
LG11	In addition to CCTV's	Belfast Trust	A54	CCTV is currently used to	

Trust means that	responsible for holding Trust	
Directors have a	Directors to account for	
aignificant degree of	achievement against their	
significant degree of	objectives, which are set on an	
autonomy; the Trust	annual basis and reviewed	
should hold Directors to	monthly (these are modified as	
	issues arise). Directorate and	
account.	Divisional management	
	priorities, which are set,	
	reviewed and reported on	
	quarterly, are also in place as a	
	framework for accountability.	
	This is being supported by a	
	developing quality management	
	system (QMS) which will provide	
	a comprehensive overview of the	
	performance of the Directorates	
	and Divisions across a range of	
	agreed metrics. The	
	transparency of performance	
	articulated via the quality	
	management system will	
	facilitate the Trust Board to	
	provide ongoing challenge	
	throughout the year, rather than	
	being responsive to issues	
	escalated to it.	
	Codiated to it.	

GLOSSARY OF TERMS

HSC – Health and Social Care

DoH – Department of Health

DfC – Department for Communities

DoF - Department of Finance

HSCB – Health and Social Care Board

PHA - Public Health Agency

RQIA – Regulation and Quality Improvement Authority

BHSCT – Belfast Health and Social care Trust

NHSCT - Northern Health and Social Care Trust

SEHSCT – South-Eastern Health and Social Care Trust

SHSCT - Southern Health and Social Care Trust

WHSCT – Western Health and Social Care Trust

MAH – Muckamore Abbey Hospital

SAI - Serious Adverse Incident

Bamford - the Bamford Review of Mental Health and Learning Disability in Northern Ireland

LD – Learning Disability

- **NIHE** Northern Ireland Housing Executive
- **PBS** Positive Behaviour Support
- RAID Risks, Assumptions, Issues and Dependencies
- **ASG** Adult Safeguarding
- PiPA Purposeful Inpatient Admissions Model
- **MAPA** Management of Actual or Potential Aggression

MUCKAMORE ABBEY HOSPITAL HSC ACTION PLAN

October 2022

INTRODUCTION

The independent Serious Adverse Incident (SAI) review report into safeguarding at Muckamore made for stark reading. It exposed not only significant failings in the care we provided to people with a learning disability while in hospital and their families, but also gaps in the wider system of support for people with learning disabilities. In short, it told us that, while we have achieved much through Bamford, there is much more we need to do.

This is our response, and sets out exactly what we now must do. It recognises that the events at Muckamore have caused much distress for the patients receiving treatment in the hospital and their families and carers, and has also damaged wider public confidence in how the HSC system provides care, treatment and support to people with a learning disability and their families. The measures set out in this document are intended to address the issues that the SAI report highlighted, but also to provide wider assurance to society that the HSC system is working together in a co-ordinated way to make life better for people with a learning disability.

As the Permanent Secretary made clear when he met with all HSC Chief Executives in January this year, we must effect lasting change, with reference to every single recommendation in the SAI report. It is right that this report acts as our barometer, and the success of our efforts should be measured against it.

This document therefore sets out what we are doing and plan to do in response to its call to action. Specifically, it reiterates the overarching recommendation of the report endorsed by the Permanent Secretary that Muckamore must return to being a hospital not a residential facility. This will require a coordinated programme of action to manage the planned and safe resettlement of those patients not currently under active assessment or treatment into accommodation more appropriate for their needs.

This timeline will be monitored closely by the Muckamore Departmental Assurance Group, which will include representation from the HSCB, PHA, RQIA, the 5 Trusts, professional representatives, specialist accommodation providers, appropriate academic expertise and importantly the families of patients, which will also ensure the team in Muckamore and the wider community services have the necessary support and resources in place to achieve these goals. A first but critical step will be to develop and deliver enhanced services in the community to source, support and sustain people in the places where they live. This will be the key role of the Regional Learning Disability Operational Delivery Group led by the Health and Social Care Board.

However, this document also recognises that more actions will follow as we progress the co-production of a new service model for learning disability as part of our transformation agenda. When developed, this will bring with it a new set of actions to consult on and implement.

We are also conscious that the police investigation into the unacceptable events at Muckamore Abbey Hospital is still ongoing. We await the outcome of that investigation and will be ready to take any additional actions to ensure that lessons are learned and put into practice across the full spectrum of learning disability services in Northern Ireland.

In this context this plan should be considered a live document which will be subject to ongoing review and development to drive further and emerging improvements to current practice.

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Progress required

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Completed		
Work in progress		

SECTION A

COMPLETED ACTIONS

Perma	anent Secretary commitme	ents				
PS1	Completion of resettlement process commenced in 2011 by the end of 2019, and the issue of delayed discharges addressed.	HSC Trusts	A1	By 30 November 2019 carry out a full re-assessment of the needs of all patients they have currently placed in MAH, with a view to preparing contingency plans for their patients, including updated discharge plans for each individual assessed as medically fit for discharge, with a target date for the individuals' discharge, a timeline to deliver appropriate high quality placements matching each individual's assessed needs and identifying any barriers to discharge.	Resettlement	
PS1		SPPG/HSC Trusts	A2	By 30 November 2019 develop and oversee a regional resettlement plan and agreed timeline for all	Resettlement	

PS1		HSCB / PHA	А3	individuals who are currently resident in MAH and assessed as medically fit for discharge. Linked to A1. By March 2021, complete an independent review of the current service model / provision for acute care for people with learning	Acute Care Review	
				disabilities (in patient and community based) and associated clinical pathways in order to recommend a future best practice model for assessment, treatment and care and support for adults with a learning disability, which is regionally consistent and focused on relevant clinical and patient related outcomes.		
PS1	Completion of resettlement process commenced in 2011 by the end of 2019, and the		A4	By 31 August 2019 , establish a professionally chaired Departmental Assurance Group to assure the Permanent Secretary of the DoH (and any incoming	Governance	

	issue of delayed discharges addressed.			Minister) that the resettlements commitments and recommendations of the SAI report are met (see full governance structures associated with this plan at Annex A).		
PS1		DoH/SPPG/HSC Trusts	A7	By 30 September 2020, in conjunction with DfC/DoF and housing providers, identify barriers to accommodation provision and develop innovative solutions to support individuals' specific needs in their transition to community settings, and inform the development of a long term sustainable accommodation strategy for people with learning disability.	Resettlement	
PS1		SPPG/HSC Trusts	A8	By March 2021, in the context of the Reform of Adult Social Care, establish a regionally agreed framework for higher tariff placements which specifies what staff and service requirements justify a higher tariff.	Service Model	

PS1		DoH/DoJ	A9	By 31 December 2019 , provide a new statutory framework for Deprivation of Liberty through commencement of relevant provisions in the Mental Capacity Act.	Governance	
PS1		HSCB/HSC Trusts	A10	By 30 December 2020, review current forensic LD services, identify and address service development needs to support people in community settings.	Service Model	
SAI In	dependent Review Panel	recommendations				
R1.	Evidence of a renewed commitment (i) to enabling people with learning disabilities to have full lives in their families and communities and (ii) to services which understand that ordinary lives require extraordinary supports – which will change over the life course.	HSCB/PHA	A11	By December 2020, deliver a co-produced model for Learning Disability Services in Northern Ireland to ensure that adults with learning disability in Northern Ireland receive the right care, at the right time, in the right place; along with a costed implementation plan, which will provide the framework for a regionally consistent, whole system approach. This should ensure the delivery of high quality services and support, and also a seamless transition process	Service Model	

R.2	An updated strategic	at age 18. The new model will	
	framework for Northern	be subject to public	
	Ireland's citizens with	consultation and will be	
	learning disability and	presented to an incoming Minister for decisions on	
	neuro developmental	Minister for decisions on implementation.	
	challenges which is co-	implementation.	
	produced with self-	Postscript-October 2021	
	advocates with different		
	kinds of support needs	The 'We Matter' final draft	
	and their families. The	Learning Disability Service	
	transition to community-	Model was formally presented to the DoH on 5 October for	
	based services requires	consideration.	
	the contraction and	Consideration.	
	closure of the Hospital		
	and must be		
	accompanied by the		
	development of local		
	services. The Review		
	Team suggests that		
	elements of the latter		
	include purposefully		
	addressing the obstacle		
	cited by so many, that		
	is, "there are no		
	community services". A		
	life course vision of "age		
	independent pathways,"		
	participative planning,		

and training for service development, for example, remains to be described. Elements of the contraction and closure include individual patient relocation, staff consultation and participation, and maintaining quality and morale.	HSCB/PHA/ HSC Trusts	A13	By 31 December 2020 finalise and develop a costed implementation plan for the new regional framework for reform of children's autism, ADHD and emotional wellbeing services, including consideration of the services required to support them into adulthood.	Children and Young People	
Long term partnerships with visionary housing associations, including those with experience of developing shared	HSCB/HSC Trusts	A15	By 30 June 2020 review the capability of current providers of supported housing, residential and nursing home care to meet the needs of people with complex needs.	Accommodation	

SAI P	atients families recomme	ndations		development of special needs housing and housing support to inform future funding decisions for adult LD.		
R3	Hospital staff at all levels must invest in repairing and establishing relationships and trust with patients and with their relatives as partners.	Belfast Trust	A18	Appoint a carers consultant and co-produce a communications strategy with parents and carers. Completed		
R4.	Families and advocates should be allowed open access to wards and living areas.	Belfast, Southern and Western Trusts.	A19	Co-produce and implement an Open Access policy for MAH (and Lakeview and Dorsey).	Service Model (Assessment & Treatment)	
R5.	There is an urgent need to (i) invest in valued activities for all patients and (ii) to challenge the custom and practice concerning the improper and excessive use	Belfast, Southern and Western Trusts.	A20	By 30 June 2020, carry out a review of access and availability of meaningful activity in MAH (and Lakeview and Dorsey), including the range and volume of activities available to patients and monitoring of patient uptake and views to inform a new	Service Model (Assessment & Treatment)	

R6.	seclusion at the Hospital. The use of seclusion ceases.	Belfast, Southern and Western Trusts.	A21	evidence based model for high intensity therapeutic interventions designed to minimise the need for restrictive practices. By 31 January 2021, complete an urgent review of seclusion policy and practice in MAH (and Lakeview and Dorsey), to inform wider consideration of regional policy, and share outcomes with families.	Service Model (Assessment & Treatment)	
R6.	The use of seclusion ceases.	DOH	A22	By March 2021, develop a co- produced and publish regional seclusion and restraint policy/guidance.	Governance (Mental Health Action Plan)	
R8.	People with learning disabilities and their families are acknowledged to have a critical and ongoing role in designing individualised support services for their relatives.	Belfast Trust	A24	By 31 December 2019, review and change needs assessment and care planning culture and processes in MAH to ensure individuals and their families are fully involved, taking account of lessons emerging from Independent Review into Dunmurry Manor.	Service Model	

R9.	The Hospital's CCTV recordings are retained for at least 12 months.	Belfast Trust	A25	By 31 October 2019 , liaise with provider to explore options for retention of recordings, in compliance with existing regional HSC and national information and record management guidance and legislation.	Governance	
R10.	Families are advised of lawful practices the hospital may undertake with (i) voluntary patients and (ii) detained patients.	Belfast Trust	A26	By 30 November 2019 develop an information paper and share with families and staff.	Governance	
R11.	Families are given detailed information, perhaps in the form of a booklet, about the process of making a complaint on behalf of their relatives.	Belfast Trust	A27	By 31 October 2019 , provide an information booklet to families on the complaints process.	Governance	
R12.	Families receive regular progress updates about what is happening as a result of the review.	Belfast Trust	A28	By 31 October 2019, a schedule of Trust meetings with families will be produced and circulated to families.	Governance	

R13.	An enhanced role for specialist nursing staff is set out.	Belfast Trust	A29	By 30 June 2020 , develop a workforce plan for specialist nursing provision in MAH in line with findings from ongoing regional work.	Workforce	
		(Responsible Officer: Director of Disability and Older People)	A30	By September 2021 , complete a review of Learning Disability Nursing.	Workforce	
SAI Se	enior Trust staff recomme	endations				
R16.	A shared narrative is set out.	PHA/HSC Trusts	A33	By December 2020, the LD Service Model Transformation project (see Recommendations 1 and 2) will inform the development of a best practice regionally consistent model for community and acute services, which (subject to agreement by an incoming Minister) will set out the road map for regional adult learning disability services in the future.	Service Model	
R17.	Commissioners specify what "collective commissioning" means.	HSCB	A34	By March 2021, HSCB to write to BHSCT outlining the current position and status of commissioning for HSC	Governance	

				Services, taking account of learning also emerging from the Independent Review into Dunmurry Manor.		
R18.	The transformation required in learning disability services must be values driven and well led.	HSCB/ PHA/HSC Trusts	A35	By December 2020, the LD Service Model Transformation project (see Recommendations 1 and 2) will build on the vision set out in the Bamford Review, and adopt an outcomes based approach. It will also be coproduced with people with learning disability, carers, advocates and families. Bespoke governance arrangements have been established and will be kept under review throughout the life of the project.	Service Model	
R19.	The purpose of all our services is clear.	HSCB/ PHA/HSC Trusts	A36	By December 2020 , the LD Service Model Transformation project will inform the development of a regionally consistent model for community and acute services and will provide clarity around purpose.	Service Model	
R23.	Trusts and Commissioners must be knowledgeable about	HSCB/ PHA/HSC	A42	By December 2020 the LD Service Model Transformation project (see	Service Model	

R24.	Trusts and Commissioners should set out the steps required in the Department of Health's post Bamford plan: in the short and medium term.	DoH/HSCB/ PHA/HSC Trusts	A43	Recommendations 1 and 2) is being co-produced with people with learning disability, carers, and families. The future model for LD services will be designed around their aspirations, and will ensure effective structures are in place on an ongoing basis to fully operationalise this commitment. By December 2020 , all parts of the HSC will have been involved in the development of the Learning Disability Service Model which will include a costed implementation plan and provide the framework for a regionally consistent, whole system approach to delivering high quality services and support to adults with Learning Disabilities. The new model will inform future service developments and investments for LD services.		
LG4	The HSC Board/PHA should ensure that any breach of requirements brought to its attention	HSCB/PHA	A47	This was taken to HSCB/PHA Quality, Safety and Experience meeting on 3/2/21.QSE were asked to discuss potential mechanism to seek Trust	Leadership And Governance Review Recommendations	

	them has, in the first instance, been brought to the attention of the Trust Board.			assurances. It was agreed that this will be listed for discussion at the quality, safety and experience meeting with Trusts.		
LG5	Pending the review of the Discharge of Statutory Function reporting arrangements, there should be a greater degree of challenge to ensure the degree to which these functions are discharged including an identification of any areas where there are risks of non-compliance.	HSCB/PHA	A48	This work has been actioned by HSCB and is progressing and is being led by the Governance Lead in HSCB.	Leadership And Governance Review Recommendations	
LG10	The complaint of Mr. B of 30th August 2017 should be brought to a conclusion by the	Belfast Trust	A53	The Trust have engaged with Mr B and written to him in an attempt to address his outstanding concerns. The resolution of these concerns is	Leadership And Governance Review Recommendations	

	Trust's Complaints Department.			ongoing at this time and while every effort will be made to progress the investigation into the outstanding issues of		
				concern, it is not at this stage possible to provide a definitive completion date.		
				Note: moved to Section A per discussion at August MDAG as single complaint by a family against the BHSCT isn't appropriate to be monitored by MDAG.		
LG12	The size and scale of the Trust means that Directors have a significant degree of autonomy; the Trust should hold Directors to account.	Belfast Trust	A55	The Trust Chief Executive is responsible for holding Trust Directors to account for achievement against their objectives, which are set on an annual basis and reviewed monthly (these are modified as issues arise). Directorate and Divisional management priorities, which are set, reviewed and reported on quarterly, are also in place as a framework for accountability. This is being supported by a developing quality management system (QMS) which will provide	Leadership And Governance Review Recommendations	

comprehensive overview of the performance of the	
Directorates and Divisions	
across a range of agreed	
metrics. The transparency of	
performance articulated via the	
quality management system	
will facilitate the Trust Board to	
provide ongoing challenge	
throughout the year, rather than	
being responsive to issues	
escalated to it.	

SECTION B

RESETTLEMENT

Pe	rmanent Secretary commitm	ients		
	No open recommendations			

SECTION C

WORKFORCE

Perma	anent Secretary commitr	nents				
PS1		DOH/SPPG/HSC Trusts	A5	By 30 September 2021, develop specialist staff training and a model of support to upskill the current workforce providing care to people with complex needs and challenging behaviours to support current placements and develop capable environments with appropriate philosophy of care e.g. Positive Behaviour Support, and prevent inappropriate re-admissions to hospital, and by June 2022 deliver training to an agreed cohort of staff.	Workforce	
SAIH	ospital Staff Recommen	dations				
R20.	All Trusts should invest in people-skills and be cautious about focusing solely on learning disability nursing.	DoH (Responsible Officer: Director of Disability and Older People)	A37	By September 2021 , develop an evidence based plan for recruitment, training and retention of a sufficiently skilled multi-disciplinary workforce, including people skills, to undertake and deliver therapeutic and clinical assessment and intervention across both inpatient and community services.	Workforce	

SECTION D
TRANSFORMATION: [SERVICE MODEL; ACUTE CARE REVIEW; ASSESSMENT & TREATMENT]

PS1		SPPG/PH A	A6	By 31 March 2022 , commission HSC Trusts to develop robust Crisis and Intensive Support Teams, including local step up and step down services, flexible staff resources and Community Treatment services, to support safe and timely resettlement of in-patients from MAH drawing on findings from the independent	Assessment & Treatment	
SAI S	enior Trust staff red	SPPG/ PHA/HSC Trusts	A38	By March 2022, deliver community and home treatment services and support placements for people with learning disability so that all assessment and treatment options are explored, undertaken and exhausted in the community where possible and only in hospital	Service Model (Assessment & Treatment)	

R22.	Abbey Hospital have to stop. Time limited and timely Assessment and Treatment					
	become the norm.	SPPG/ HSC Trusts	A40	By 30 November 2019 , appoint a regional bed manager for all 3 current in-patient units.	Service Model (Assessment & Treatment)	
		SPPG/ PHA/ HSC Trusts	A41	By March 2022, taking into account the outcome and recommendations of the independent review of acute care for people with learning disabilities support HSC Trusts to develop regional care pathways for inpatient care to ensure that admissions are planned and delivered in the context of an overall formulation. This should include community based assessment and treatment, clear thresholds for hospital admission and timely, supported discharge from hospital. (See	Service Model (Assessment & Treatment)	

		Permanent Secretary commitments).	

SECTION E
CHILDREN AND YOUNG PEOPLE

Proposed rating / Comments				
SPPG/PHA/ HSC Trusts	A12	By March 2021 develop a regionally consistent pathway for children transitioning from Children's to Adult services, including: • People with learning disability and complex health needs. • People with Leaning disability and social care needs. • People with learning disability and mental health needs (consistent with the CAMHS care Pathway) • People with LD who exhibit distressed behaviours.	l .	
SPPG/PHA/ HSC Trusts	A14	By 31 December 2020 review the needs of children with learning disability that are currently being admitted to Iveagh Centre and to specialist hospital / placements outside of Northern Ireland with a view to considering if specialist community based service should be developed locally to meet their needs. This should be aligned to the ongoing regional review of children's residential services.	Children and Young People	

SECTION F

GOVERNANCE

SAIP	SAI Patients Families Recommendations							
	NO OPEN RECOMMENDATIONS							

SECTION G

SAFEGUARDING

SAIP	atients families recon	nmendations				
R7.	The perception that people with learning disabilities are unreliable witnesses has to change. Responses to safeguarding incidents and allegations are proportionate and timely.	Belfast Trust	A23/A31	By 30 June 2020, complete a review of Adult Safeguarding culture and practices at MAH, to inform wider consideration of regional safeguarding policy and procedures taking account of lessons also emerging from the Independent Review into Dunmurry Manor.	Safeguarding	
		SPPG	A32	By December 2021, carry out a review of regional Adult Safeguarding documentation, to inform wider consideration of regional safeguarding policy and procedures taking account of lessons also emerging from the Independent Review into Dunmurry	Safeguarding	

		Manor.	

SECTION H

Leadership And Governance Review Recommendations							
LG1	The Department of Health should review the structure of the Discharge of Statutory Functions reporting arrangements to ensure that they are fit for purpose.	DOH (Responsible Officer, Deputy Chief Social Work Officer)	A44	By March 2022, complete a review of the accountability arrangements for DSF. The HSCB are developing an outcomes based reporting template which will be the first stage of this process. In preparation for the Social Care Directorate moving into the Department following the closure of the HSCB in 2022, a review of the accountability arrangements for DSF will be undertaken.			
LG2	The Department of Health should consider extending the remit of the RQIA to align with the powers of the Care Quality Commission (CQC) in regulating and	DOH (Responsible Officer: Director of Quality, Safety and Improvement)	A45	The Department has carried out a fundamental review of the 2003 Order and the existing regulatory framework and has developed a new draft regulatory policy that includes the principles of regulation, along with the broad scope of services to be regulated and the proposal that the regulator should have wider powers of enforcement etc. This work has been the first phase of the process before			

inspecting all	moving on to phase 2, which will	
	include the risk assessment of each	
hospital provision.	provider type and consider the	
	appropriate regulatory approach,	
	including the range of enforcement	
	and sanctions. Phase 2 will result in a	
	clear regulatory framework and	
	legislation and this framework will	
	reflect Departmental Policy.	
	After restoration of the Assembly in	
	January 2020, the Minister approved	
	on 2 July 2020 the Consultation on	
	Phase 1 of the Review of 2003 Order	
	and the current Regulatory	
	Framework, which would involve the	
	proposed policy being launched for	
	public consultation for a period of 16	
	weeks to allow sufficient time to	
	engage with service	
	users/providers/public during the	
	current pandemic and its associated	
	restrictions in terms of social	
	distancing. As part of the	
	Department's continued response to	
	the pandemic the Departmental Top	
	Management Group (TMG) decided to	
	reactivate the Department's Business	
	Todouvato trio Departmento Dusiness	

				Continuity Plan in Autumn 2020. As a result the launch of the consultation was delayed.	
LG3	The Department of Health, in collaboration with patients, relatives, and carers, and the HSC family should give consideration to the service model and the means by which MAH's services can best be delivered in the future. This may require consideration of which Trust is best placed to manage MA	DOH (Responsible Officer: Director of Disability and Older People)	A46	By June 2021, develop in partnership with patients, relatives and carers a plan for the future configuration of services to be delivered on the Muckamore Abbey Hospital site, including appropriate management arrangements.	

	H into the future.				
LG6	Specific care sensitive indicators should be developed for inpatient learning disability services and community care environments.	SPPG/PHA	A49	This action will be taken forward by Nursing and AHP Directorate of PHA in partnership with multi-disciplinary colleagues and SPPG. The Nurse Consultant for Mental Health and Learning Disability has now commenced post in PHA.	
LG7	The Trust should consider immediate action to implemented disciplinary action where appropriate on suspended staff to protect the public purse.	Belfast Trust	A50	By January 2021, complete disciplinary action in respect of first 7 individuals whose cases have been forwarded by PSNI to PPS. Action against a further 9 individuals will commence when PSNI confirm their cases have been forwarded to PPS.	
LG8	The Trust has instigated a significant number of managerial arrangements at	Belfast Trust	A51	A Co-Director for Learning Disability services was appointed in June 2020. The dedicated Divisional Nurse post remains and a dedicated Service Manager and two permanent	

	MAH following events of 2017. It is recommended that the Trust considers sustaining these arrangements pending the wider Departmental review of MAH services.			dedicated Assistant Service Managers for the hospital have been appointed. Substantive appointments at Band 7 and Band 6 Ward Manager and Deputy Ward Manager level are being progressed. The Interim Director for Learning Disability Services will review the existing managerial arrangements as part of the Chief Executive's overall review of Directorate and Divisional structures which will take place in 2021.	
LG9	Advocacy services at MAH should be reviewed and developed to ensure they are capable of providing a robust challenge function for all patients and support for their relatives and/or carers.	Belfast Trust	A52	By March 2021, complete a review of advocacy services. The Trust is engaging with representatives of Families Involved Northern Ireland (FINI) to develop Terms of Reference for a review of its advocacy arrangements.	

LG11	In addition to	Belfast Trust	A54	CCTV is currently used to inform and	
	CCTV's			amend staff practice.	
	safeguarding			Contemporaneous CCTV footage is	
				independently viewed and the	
	function it should be			accounts of this footage, which	
	used proactively to			reflects good practice and highlights	
	inform training and			any areas for concern, are shared with staff.	
	best practice				
	developments.			Questionnaires have been issued to	
	developments.			family members, carers, patient and	
				staff to seek feedback and	
				engagement around the use of CCTV	
				on site. These questionnaires	
				specifically asked for views on the	
				proposed extension of the use of	
				CCTV into areas such as training and	
				practice development. Feedback from	
				the questionnaires will inform next	
				steps.	

GLOSSARY OF TERMS

ASG – Adult Safeguarding

Bamford – the Bamford Review of Mental Health and Learning Disability in Northern Ireland

BHSCT – Belfast Health and Social care Trust

CIP – Community Integration Partnership

DfC – Department for Communities

DoF - Department of Finance

DoH – Department of Health

HSC – Health and Social Care

HSCB – Health and Social Care Board

LD – Learning Disability

MAH – Muckamore Abbey Hospital

MAPA - Management of Actual or Potential Aggression

NHSCT – Northern Health and Social Care Trust

NIHE – Northern Ireland Housing Executive

PBS - Positive Behaviour Support

PHA – Public Health Agency

PiPA - Purposeful Inpatient Admissions *Model*

RAID - Risks, Assumptions, Issues and Dependencies

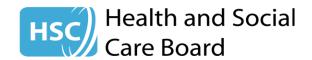
RQIA – Regulation and Quality Improvement Authority

SAI – Serious Adverse Incident

SEHSCT - South-Eastern Health and Social Care Trust

SHSCT – Southern Health and Social Care Trust

WHSCT – Western Health and Social Care Trust



MINUTES OF THE HEALTH AND SOCIAL CARE BOARD HELD AT 10.00AM ON THURSDAY 11 OCTOBER 2018 IN THE BOARDROOM, HSCB, 12/22 LINENHALL STREET, BELFAST BT2 8BS.

PRESENT: Dr Ian Clements, Chair

Mrs Valerie Watts, Chief Executive Mr Paul Cummings, Director of Finance

Ms Marie Roulston, Director of Social Care & Children

Mrs Stephanie Lowry, Non Executive
Mr Robert Gilmore, Non Executive Director
Mr John Mone. Non Executive Director

Mr Brendan McKeever, Non Executive Director

IN

ATTENDANCE: Mrs Lisa McWilliams, Interim Director of Performance

Management & Service Improvement

Mr Sean Donaghy, Regional Director of eHealth &

External Collaboration

Ms L McMahon, Director (Community Planning)
Mr Iain Deboys, Assistant Director of Commissioning

(rep Dr M McCarthy)

Cllr Sorcha McAnespy, Interim Chair, Western Local Commissioning Group (joined the meeting at 10.30am)
Mr Danny Power, Interim Chair, Belfast Local

Commissioning Group

Dr Michael Steele, Interim Chair, South Eastern Local

Commissioning Group

Ms Sarah Johnston, ARIS Manager (for agenda item 8 only)
Ms Mary McElroy, Safety Quality and Patient Client

Experience Lead, PHA, (for agenda item 12 only)

APOLOGIES: Mr Stephen Leach, Non Executive Director

Dr Melissa McCullough, Non Executive Director Dr Miriam McCarthy, Director of Commissioning Dr Sloan Harper, Director of Integrated Care

Dr Adrian Mairs, Acting Director of Public Health, PHA

Dr Carolyn Harper, Executive Medical Director/

Director of Public Health, PHA

Mrs Mary Hinds, Executive Director of Nursing & AHPs, PHA
Mr Miceal McCoy, Interim Chair, Southern Local
Commissioning Group
Mrs Louise Skelly, PCC

83/18 CHAIR'S REMARKS

The Chair welcomed those present to the October meeting.

He pointed out that members would be asked to consider Trust Delivery Plans (TDPs) later in the meeting and Mr Cummings and Mr Deboys would take members through the detail. He thanked those who had attend the TDP workshop on 9 October and said that he had found this helpful.

The Chair advised that National Adoption Week would take place between 15-21 October 2018 and Ms Sara Johnston would join the meeting to show a short video and share plans for the week with members.

Continuing, the Chair advised that the Mid Year Assurance Statement was approved by the Joint Audit & Governance Committees on Tuesday 2 October and was before today's meeting for noting before submission to the DoH tomorrow. The Chair explained that the function of the Mid-Year Assurance Statement (MYAS) was to enable the Chief Executive as Accounting Officer for the HSCB, to attest to the continuing robustness of the organisation's system of internal governance and acknowledged that this continued to be an important aspect of the Board's work, but even more so in a time of organisational change.

The Chair welcomed Mr Iain Deboys who was representing Dr McCarthy.

Before commencing the meeting, the Chair asked members to declare if they had a conflict of interest with any agenda items. There were no declarations.

84/18 PREVIOUS MINUTES

The minutes of the previous meeting on 13 September 2018 were **APPROVED** and signed by the Chair subject to a number of minor amendments, namely:

- Page 1, Chief Executive should be noted as an apology
- Page 13, fourth para should read '... he referred to the roll-out of the Enhanced Care at Home initiative across the South Eastern Trust geography.'

85/18 MATTERS ARISING

There were no Matters Arising.

86/18 STANDING ITEM: CHIEF EXECUTIVE'S REPORT

The Chief Executive commenced her report by providing an update on the neurology recall. She advised that the first phase, which had involved identifying and recalling, for neurological review, patients who had still been under the care of Dr Michael Watt when he ceased clinical practice in July 2017, had now been completed. The Chief Executive advised that these patients had been invited to attend a review appointment during a 12 week period finishing on 29 July 2018.

She explained that the next phase, now underway, involved seeing a small number of patients who had not been seen within the initial 12 week time period (due to patient choice or because they previously didn't attend their scheduled appointment) as well as undertaking reviews of those already seen and seeing previously discharged patients who had been re-referred into the neurology service by their GPs. It was hoped that this phase would be completed at the end of October 2018.

Mrs Watts indicated that consideration was currently being given to the measures that should be put in place in regard to the potential need for patients to be seen, if they were previously under the care of Dr Watt, and had subsequently been discharged back to the care of their GP.

Turning to transformation, the Chief Executive reported that work on transformation continued to make progress and she described a number of recent developments.

The Chief Executive emphasised that Board members had an important role to play in providing leadership and support to staff as we moved through this period of change. She said it would be important to work constructively and proactively if we were to ensure the transition was as straightforward and pragmatic as possible.

The Chief Executive referred to the first meeting of the Implementation and Innovation Board for the Community Development Framework which had been held in September with excellent senior level engagement.

She advised that the recruitment of staff to the new roles in the two initial Multi-Disciplinary Team areas was commencing and added that TIG had discussed progress on pilot elective care centres for cataracts and vascular at their meeting in September with both projects well advanced.

Continuing, the Chief Executive referred to the review by the Children's Commissioner, Koulla Yiasouma, into mental health services for children and young people in Northern Ireland which was published at end of September.

She said that the Board's Director of Social Care and Children, Ms Marie Roulston, had spoken at the event alongside Rodney Morton, Deputy Chief Nursing Officer at the Department, and representatives from primary care, education and the community and voluntary sector.

Mrs Watts said that a number of members of the NICCY youth panel also spoke at the event and their stories, and the stories of hundreds of young people who helped shape the report, had been absolutely vital in helping enhance services in the future.

Mrs Watts believed that NICCY's review provided a timely contribution to the journey of improvement of children's emotional and mental health services. She acknowledged the challenges highlighted in the report that the health and social care system, working very closely with the community and voluntary sectors and wider society, needed to address in the short and longer term.

Mrs Watts indicated that there was no quick or easy fix, and additional investment would be required, as well as continued collective leadership moving forward.

Mrs Watts referred to the importance of maintaining confidence in the services to acknowledge the improvements that had been made in the last decade, stemming from the Bamford Review and other key reforms.

Turning to Muckamore Abbey Hospital, the Chief Executive said members would be aware that the Belfast Trust initiated a Review of Safeguarding at the Hospital in September 2017, following reports of inappropriate behaviour and alleged physical abuse of patients by staff in two wards in Muckamore Abbey Hospital.

She advised that the review had now concluded and Belfast Trust had met with affected families. Mrs Watts said that the Review Team had brought a wide range of experience, perspectives and expertise as advocates, practitioners, clinicians, researchers and managers in service provision for people with learning disabilities and autism. She said their findings highlighted that improvements were required in leadership and management, adult safeguarding approaches, advocacy, access to meaningful activities for patients and physical health care.

Mrs Watts said that the report strongly urged the Trust and the wider health, social care and housing organisations to re-double their efforts to ensure that patients did not have to live in hospital environments. It also recommended patients were enabled to live full lives in the community, with access to the right specialist multi-disciplinary support in the right accommodation.

Mrs Watts said that the Board would now work with the Trust and Department of Health in implementing the recommendations and in delivering a future model of care for learning disability and autism.

Continuing, Mrs Watts advised that, last week, the Department of Health published the response of the health and social care system (HSC) to the recommendations in the Commissioner of Older People NI report 'Home Truths' into Dunmurry Manor Care Home.

She said that, in responding, the DoH Permanent Secretary had made it clear that the system was committed to responding positively to the Commissioner's report and to addressing the crucial issues facing our care system. Mrs Watts indicated that the response set out a package of measures which would now be taken forward by senior leaders across the HSC.

She said it had also been recognised that, in the absence of a Minister, there were a number of recommendations the Department would be unable to action. However, she added, the Department had stressed they would give these issues due consideration and provide appropriate advice to any incoming Minister. Mrs Watts said that the Board would work closely with the Department and Trusts in taking these recommendations forward.

She indicated that, in parallel, the Department had also commissioned an independent review into the actions of the HSC around Dunmurry Manor Care Home and added that this review was ongoing.

Concluding her remarks, Mrs Watts referred to Adoption Week which would take place between 15-21 October and said that she was very much looking forward to the presentation later in the meeting morning. Mrs Watts acknowledged the work which had been put in to this campaign led by the Board working in partnership with Health and Social Care Trusts, the regional Adoption and Fostering Network and Adoption UK.

She referred to the current shortage of adoptive parents and emphasised the importance of encouraging more people in Northern Ireland to become adoptive parents. Mrs Watts thanked all those involved in the campaign and said that it would play a key role in helping to safeguard children in care and help provide the opportunity of a loving family.

Mrs Lowry alluded to the Community Development Framework referred to by the Chief Executive in her report and sought further detail.

Mr Power indicated that this work had been led by Ms Mary Black who had recently retired from the PHA.

The Chair suggested that it might be helpful for members to receive a presentation on the Framework and the recommendations emanating from the Framework at a future Board meeting. He referred to the work taken forward by Ms Anne McMurray in relation to the current relationships and potential of local planning through

locality networks and added that Ms McMurray had worked with Ms Black in the development of the Community Development Framework.

Mr Power said that the workshops had brought together individuals from within the HSC system as well as individuals from the community and voluntary sector and Integrated Care Partnerships to define where community development lay within the construct of health planning. He added that focus had also been on building capacity within communities to engage.

Mr Power referred to the Design Groups which had been established and said it would be important for these groups to take cognisance of the convergence and overlap at locality level in terms of working practices across organisations.

Mr Power enquired whether the report produced by the Review Team into Muckamore Abbey Hospital would be made public. Ms Roulston confirmed that she understanding that the initial report had been shared with families and added that the HSCB had not yet received the report. She said that there would be an Executive Summary and an associated action plan and said that it would be important to be mindful of the identity of those patients remaining within Muckamore. Ms Roulston advised that the Review Team planned to meet with families, RQIA, the Trust and the Board and added that a workshop, hosted by RQIA and the Board, would be held on 24 October to examine the recommendations emanating from the review.

The Chair thanked members for their comments and members **NOTED** the Chief Executive's report.

87/18 FINANCE: HSCB FINANCE REPORT ENDING AUGUST 2018 (MONTH 5); TRUSTS' FINANCIAL REPORT ENDING JULY 2018 (MONTH 4)

Mr Cummings reported that the HSCB financial position was showing a surplus of £1.2 million at the end of August 2018 and added that there was a projected break-even position for the year end. He explained that the surplus was mainly made up from surpluses in FHS and the HSCB Administration budgets.

Turning to the General Pharmaceutical Services budget, Mr Cummings advised that the budget showed a slightly improved position on the previous month and that the year-end projected deficit had reduced slightly due to lower than expected medicine prices. He acknowledged the concerns relating to EU Exit and pharmaceutical supply.

Mr Cummings reported that the General Medical Services budget was currently showing a break-even position while the General Dental Services budget was reporting a small surplus. He indicated that there was a changing trend in dentistry as a result of reduced dental activity. Mr Cummings reminded the meeting that, in the financial crisis, dental activity had increased with more people using NHS dentistry and said that there now appeared to be a return to private dentistry.

Continuing, Mr Cummings advised that the General Ophthalmic Services budget was showing a small surplus of £377,000. He referred to pressure within the ECR budget and said that there was an increasing number of people availing of services in the Republic of Ireland, for example, for orthopaedic services in particular.

Mr Cummings advised that the voluntary and community budget was forecast to achieve a break-even position at the year end.

Turning to the HSCB Administration budget, Mr Cummings reported that this budget was showing a surplus of £500,000, mainly caused by vacant posts. He said that the turnover currently being experienced and the number of existing vacant posts had resulted in a surplus in both the HSCB and the PHA. He added that he did not expect a change before the end of the financial year.

Moving to the Trusts' financial report for the period ending July 2018, Mr Cummings advised that, while the Northern, South Eastern, Southern and NIAS Trusts had reported small deficits, they were expecting to achieve a break-even position at year end. However, he said, the Belfast and Western Trusts were projecting year end deficits of £20 million and £21 million respectively and added that the HSC was continuing to examine the consequences of these organisations' deficits.

Mr Cummings referred to the significant financial challenges facing the HSC, for example, in terms of auto-enrolment into the pension scheme, increased costs in relation to Looked After Children, increased costs associated with locums/bank staff and added that pressures were varied across Trusts. However he said that this would be revisited as part of the Trust Delivery Plan process.

The Chief Executive advised that Mr Cummings had agreed to provide advice and assistance to the Western Trust as it attempted to regain control of its finances.

Mrs Lowry referred to the General Dental Services budget and acknowledged that, while this could be vired to cover other overspends, she was concerned at the reducing demand for dental services and the potential health implications.

Mr Cummings indicated that there was no evidence of increased waiting times or difficulties with access to dental services.

Dr Steele expressed concern in relation to unmet need in the elderly community. He pointed out that there was no requirement for the elderly to be registered with a general dental practitioner as there was with a general medical practitioner and added that there was an increasing number of elderly within nursing/care homes who were not registered. He said that in the past, this service had been provided by Trusts.

Mr Cummings undertook to bring this issue to the attention of Mr Donaldson, Head of Dental Services, and suggested that it might be helpful to have a presentation at a future Board meeting in terms of what was currently available in terms of services.

Mr Mone referred to issues around capitation funding and the potential impact on the Southern, South Eastern and Northern Trust, for example, in their attempts to ensure a break-even position. He expressed his concern at the potential to have those Trusts projecting a break-even position to contribute further savings to the overspends in the Western and Belfast Trusts. Mr Mone believed that this could potentially have a significant impact on service delivery coming into the winter period. He suggested that it would be helpful for the Trust to develop a phased approach to achieve a balanced financial position over a number of years.

Agreeing with the points put forward by Mr Mone, Mr Cummings advised that he had in the last few days received correspondence from the Western Trust detailing the steps they would intend to take should it be necessary to break-even in the current financial year.

Mr Cummings said that he would not support such an approach as this could potentially impact on the safety and quality of services in the West. He said that the Board was required to advise the DoH that it was not prepared to approve the Western Trust TDP. Mr Cummings said that he intended to suggest to the DoH that he would support an approach in which the Trust would be given a period of time within which to achieve a break-even position. Mr Cummings reminded the meeting that the Trust had a statutory duty to achieve a break-even position, however the decision lay with the DoH as to how it wished to address this issue.

The Chair noted the reliance placed on the professional advice from HSCB/PHA officers in terms of their assessment of the measures being recommended to reach a break-even position.

Mr Cummings acknowledged the significant challenges in ensuring equity in terms of the need to achieve an equitable position without compromising the quality and safety of services to patients in the West.

The Chair thanked Mr Cummings for his report and members **NOTED** the HSCB Finance Report (month 5) and the Trusts' Finance Report (month 4).

88/18 STANDING ITEM: HSCB PERFORMANCE REPORT ENDING AUGUST 2018 (MONTH 5)

Commencing her report, Mrs McWilliams advised that the primary focus would be on unscheduled care as requested by members at the previous meeting and said that she wished to draw a small number of areas to members' attention.

With regard to the delivery of core, she had reported at the September meeting that the under-delivery had improved upon month 4 and that had continued in month 5. Performance was noted as 11.1% against 13.6% for under-delivery of assessment and 8.1% against 11.4% for treatments compared to the same period last year.

Mrs McWilliams noted that, at the September meeting, Mrs Lowry had expressed concern with regard to the Belfast Trust's projected deterioration in delivery of core. She indicated that the Trust was forecasting a 21% under-delivery with a year to date figure of 8.9%. This positive variation had been raised with the Trust. However

concerns about theatre and theatre nursing restrictions were still expected to have a negative impact on performance.

Turning to mental health performance, in particular CAMHS and psychological therapies, Mrs McWilliams advised that, following discussion with Mrs Roulston, Director of Social Care, the Performance Report to be presented at the November Board meeting would focus on this area.

Mrs McWilliams referred to the 14-day breast cancer performance. She reported that the regional position had reduced from 92% to 79.5% and said that this was largely due to a deterioration in Northern Trust performance. Mrs McWilliams indicated that the Trust's performance had been 59% in July but this had since reduced in August to 19.2% and provisional figures had indicated a further reduction to 15% in September. She explained that the difficulties being experienced by the Trust related to capacity issues in terms of general surgery which had become exacerbated over the summer months by a series of unexpected absences.

Continuing, Mrs McWilliams advised that the Trust had submitted an action plan and said that a number of Trusts had offered support with a view to undertaking 1-2 lists per week. She added that there was an expectation that the Trust would return to 100% performance in the next few months and said that Board officers would closely monitor progress.

Mrs McWilliams then reported on unscheduled care and advised that EDs were continuing to experience significant pressure due to a number of factors including an increase in attendances and the demographic profile of patients with older, sicker patients with more complex needs who are admitted to hospital and the challenges in supporting them to return home once medically fit.

In terms of the 4-hour performance, Mrs McWilliams reported that seven out of ten patients presenting at ED were seen and treated within four hours. However she said performance had started to reduce and added that, in August 2017, performance had been 78%, this has since reduced to 70%. Mrs McWilliams advised that attendance at ED over the last five years had increased by 96,000 (13%) and said, in 2017/18, there had been 823,000 ED attendances. She added that, in the same time period, ie 2017/18, there had been a 78% increase in seriously ill patients attending ED. Mrs McWilliams acknowledged that, once admitted, these

patients tended to have a longer Length of Stay (LOS) and required a more complex care package upon discharge.

Continuing, Mrs McWilliams acknowledged that the 12-hour ED performance was often viewed as a barometer of pressure within the system prevalent during winter months. However she indicated that, in the year to date, numbers had been unprecedented with an additional 1,051 12-hour breaches in August. She emphasised that it was very likely that those patients waiting more than 12 hours were waiting for an appropriate hospital bed to become available.

Mrs McWilliams said that there was strong emphasis on improving timely discharge and she referred to work being taken forward by Mrs Hinds relating to intermediate care incorporating discharge to assess and seven day decision making. She alluded to other initiatives, such as Acute and Enhanced Care at Home and ambulatory pathways, being taken forward through funding made available from the Confidence and Supply monies to avoid people presenting at ED.

In referencing Cat A response times by ambulance services, Mrs McWilliams referred to the Clinical Response Model on which NIAS was commencing consultation and the substantial regional work on ambulance handover. A short-term initiative was a 4-week pilot to increase the number of 'receivers' of patients at the Ulster Hospital in an attempt to free up ambulance crews. She said if this initiative proved successful, it could be rolled out to other Trust areas.

Continuing, Mrs McWilliams alluded to work being taken forward within Integrated Care General Medical Services targeting the period 24 December – 3 January when an enhanced service was being finalised which will include the cessation of half day and lunchtime closing as well as no prior book appointments to protect slots for urgent patients.

Mr McKeever suggested that discussing mental health might provide an opportunity to involve those groups focussing on mental health. He said that it was his understanding that more people had died by suicide than had died in the Troubles.

Mr Cummings said that this issue had been discussed at SMT and it had been suggested that a future Board meeting would focus on the issue of mental health by including it as a Board agenda item.

In Dr McCullough's absence, the Chair said that she had expressed concern in relation to the increase in waiting times for psychological therapies and had asked if there was an action plan to improve the position.

Ms Roulston advised that, as part of the overall Performance Report, she would bring a paper to the November Board meeting focussing on mental health services.

Dr Steele referred to CAMHS services and said it was interesting to note that there were variations in waiting times across Trusts. He pointed out that South Eastern Trust had no-one waiting for these services which were provided by the Belfast Trust. However the Belfast Trust had 26 patients waiting longer than 9 weeks.

Ms Roulston pointed out that the biggest challenges were within the Western Trust and added that the Northern and Southern Trusts had sustained performance for some time.

Mr Mone referred to the increasing waiting times for outpatient/inpatient/daycase procedures and the implications of the increase in those patients waiting four hours in ED. He asked whether figures were available to clarify the situation regarding the monthly increase both for consultant outpatients and the impact on inpatient figures as well as the pattern of increase in relation to attendance at EDs generating the increase in 4- and 12-hour waits. He added that it was likely that demand would continue to increase.

Mrs McWilliams confirmed that data was available relating to monthly referral information at specialty level and added that SBAs would also provide information in terms of the Board's expectation of what Trusts should deliver. She acknowledged that demand would continue to increase and said that work was being taken forward with a view to introducing new ways of working through transformation. Mrs McWilliams said that it would also be important to consider the effective use of resources in terms of procedures being carried out.

Continuing, Mrs McWilliams referred to work recently undertaken by Dr David Stewart into the health needs assessment for emergency and urgent care looking forward to 2020. She said that, in profiling patients, Dr Stewart had forecasted the percentage of attendances at ED by individuals aged over 65 years of age and added that there would be a correlation to increasing length of stay.

Mr Cummings suggested that it would be helpful for Dr Stewart to present on his findings to a Board member workshop.

Mrs Lowry referred to theatre nurses and commented that many of the difficulties being experienced by Trusts related to issues with regard to workforce shortage.

Dr Steele alluded to discharge to assess and commented that there was a direct correlation between the length of time a patient spent in hospital to the care package required at the time of discharge and said that a longer stay in hospital usually required a more complex care package to be put in place for a patient. He referred to the pilot to have additional 'receivers' in place at ED and asked if what training these individuals would have.

Responding, Mrs McWilliams said that it was her understanding that the 'receivers' would be from private and/or voluntary ambulance organisations and that they would have an appropriate level of training.

Responding to concern expressed by the Chair, the Chief Executive said that she had no doubt that the NIAS Trust had examined the initiative in detail before its implementation.

Cllr McAnespy welcomed initiatives which would alleviate pressure and echoed Mrs Lowry's comments in relation to workforce shortages.

The Chair thanked members for their comments.

Members **NOTED** the HSCB Performance Report ending August 2018 (month 5).

89/18 NATIONAL ADOPTION WEEK - 15-21 OCTOBER 2018

The Chair welcomed Ms Sarah Johnston, ARIS Manager, to the meeting.

Ms Johnston described the plans in place to publicise the National Adoption Week NI which would take place between 15-21 October 2018. She also shared with members videos of successful adoptive parents discussing their experiences of the adoption process and

said that these would be disseminated through various social media avenues.

Mr McKeever said that very often the public perception of the adoption process was one fraught with difficulties. He referred to kinship care in the Western Trust and asked whether there was a role for family members.

Responding, Ms Johnston acknowledged that the adoption process could be lengthy and pointed out that severing links between a birth family and a child's adoptive family could not be taken lightly. She explained that, because the process could be lengthy, concurrent care had been introduced to ensure the child was placed in an environment which could ultimately become their home, thereby removing the need for a child to move through the care system.

Ms Johnston continued by emphasising the need to 'bust' a number of myths in Northern Ireland in relation to potential adoptees. She referred in particular to the LGBT community for whom it was now possible to adopt a child and advised that the service had taken a stand at the recent Pride Festival in Belfast to promote adoption. She pointed out that it was also possible for single individuals to adopt a child and referred to one of the videos shown earlier in the meeting which featured a single adoptive parent.

Referring to kinship care, Ms Johnston acknowledged that there were kinship carers who adopted children. She pointed out that if children came into care, every effort was made to place a child with kin and added that, if it was not possible for a child to return to birth parents, the potential for the kinship care arrangement to be made permanent was examined.

Cllr McAnespy welcomed the introduction of Adoption Week NI and sought clarification on the current position with regard to 'out of country' adoptions.

Ms Johnston advised that the process for 'inter-country' adoptions could be very lengthy and very expensive. She added that individuals may choose to follow this route for a number of reasons and said that a lot of countries where inter-country adoption had previously been possible had now ceased the practice.

Ms Roulston pointed out that the number of inter-country adoptions had decreased significantly and that, at its height, there would have been approximately 90 inter-country adoptions per year.

Ms Johnston sought members' assistance in publicising National Adoption Week and encouraged them to share any social media posts with friends and family.

The Chair thanked Ms Johnston for her presentation and wished her well with Adoption Week.

Ms Johnston withdrew from the meeting.

90/18 TRUST DELIVERY PLANS

At the Chair's invitation, Mr Deboys gave a synopsis of the Trust Delivery Plans (TDPs) as a response to the Draft Commissioning Plan 2018/19.

Mr Deboys reminded the meeting that Trusts were required to develop TDPs to respond to both the commissioner priorities contained within the draft HSCB/PHA Commissioning Plan and the Ministerial Objectives set out within the DoH draft Commissioning Plan Direction which was received 24 May 2018.

Mr Deboys advised that the draft Commissioning Plan 2018/19 had been formally submitted to DoH on 26 September 2018 following approval by Board at its meeting on 13 September 2018 and approval by PHA Board on 20 September 2018.

He explained that, in order to ensure consistency of approach, Trusts had been issued with guidance outlining the format and structure of TDPs for 2018/19 and had been asked to prepare TDPs which adequately responded to the Ministerial Targets and the Commissioning Priorities outlined in the draft Commissioning Plan 2018/19.

Mr Deboys described the process followed upon receipt of the draft TDPs and said that assessments included:

 The financial elements of the plan; in particular the forecast financial position at end-of-year, associated financial assumptions and components of savings plans etc. The service elements of the plan; in particular details of key deliverables in response to Ministerial Targets and Commissioning Priorities.

Mr Deboys advised that all Trusts had indicated that, while a small number of targets could not be delivered, they would work to achieve them as far as possible. He pointed out all TDPs were considered to provide a generally acceptable response in relation to the commissioning priorities and demographic pressures identified in 2018/19. However, he said, further clarity was required from all Trusts on the volume of activity expected against investments made in 2018/19.

Continuing, Mr Deboys pointed out that, with the exception of Belfast and Western Trust, the finance element of the TDPs provided an acceptable response to both the Income Assumptions and Savings Proposals, with four Trusts forecasting a breakeven position in-year for 2018/19. He indicated that further work was required by Belfast and Western Trusts to provide a balanced TDP and added that, as a result, the Western and Belfast TDPs could not be recommended for approval by the Board. He added that revised TDPs would be brought forward for consideration by the Board at a later date.

The Chair referred to the recent TDP workshop which had provided an opportunity for members to go through the Plans in detail.

Agreeing with the Chair, Mrs Lowry said that she had found the workshop helpful. She added that, when considering the number of objectives/targets which would not be achieved, it was clear that these had increased across all Trusts. Mrs Lowry sought clarification on the process should the Board approve the TDPs.

Mr Cummings explained that the Board would only refer TDPs to the DoH if it was unable to confirm approval.

The Chair referred to concerns which had been expressed at the workshop in relation to the inability of Trusts to achieve a number of aspirational targets and suggested that the Board had a responsibility to highlight these to the DoH.

Ms Roulston advised that she met with the DoH Chief Social Work Officer on a regular basis and said that he would be very aware of the challenges within children's and adult social care.

Mr Cummings referred to concerns previously expressed by members that the HSC was increasingly funding recurring services with non-recurrent resources and he suggested that it would be helpful to make reference to this in the Chair's letter to the DoH.

Agreeing with Mr Cummings' comments, Mr Mone said that any approval to the TDPs would be on the basis that the Plans provided for a financial break-even position supported by non-recurrent funding. He pointed out that there were issues around safety and quality in respect of inpatient/daycase/outpatient waiting times, in particular 12-hour breaches. Mr Mone said that it would be important to highlight to the DoH that these issues were impacted upon by recruitment difficulties. He emphasised that, while members may give their approval to the TDPs, approval was caveated by a number of issues to be brought to the DoH's attention. Mr Mone suggested that the Chair would share the letter with members when finalised.

Mr McKeever was of the view that the HSC was not being funded sufficiently to guarantee safety and quality. He cited the increasing waiting lists as an example and said that, as patients were unable to access services, safety and quality was not guaranteed. Mr McKeever said that Trusts were already highlighting a number of areas where they would be unable to meet targets and he pointed out that it was likely the position would deterioriate. He said that it was for these reasons that he could not approve the TDPs before the Board today.

Dr Steele expressed concern that slippage on demography funds was being used to achieve a break-even position in the SET. He suggested that such funding might be better spent on care packages, for example.

Responding, Mr Cummings indicated that Mr Turley, Commissioning Lead, had been involved in detailed discussions with the Trust about the impact of this and added that some slippage was occurring naturally as the Trust had been unable to recruit domiciliary care staff.

Mr Gilmore commented that he had found the workshop helpful and said that he would share his colleagues' concerns in relation to the safety and quality aspect of services. He added that these concerns had been expressed at the workshop. Continuing, Mr

Gilmore said that he would agree that a letter should be forwarded to the DoH. He sought clarification on the process to be followed if TDPs were not approved.

Mr Cummings reminded the meeting that the Board had no ability to approve any TDP which did not produce a break-even position and added that Plans which did not produce a break-even position had to be returned to the Trust. He clarified that, where Board officers were firmly of the view that the Trust would not be able to produce a break-even Plan, that Plan would be referred to the DoH for consideration. Mr Cummings indicated that the Belfast Trust had been given further time to explore whether it would be able to achieve a break-even position. However, he said, agreement had been reached between the Board officers and DoH colleagues that this would not be possible in respect of the Western Trust. Therefore, he said, the Western TDP would be forwarded to the DoH for consideration in terms of what steps the Trust should now take to achieve a break-even position.

Mr Power referred to last year's experience whereby Trusts had been required to submit savings plans which would have had significant impact on the provision of services. Additional funding had then been identified at that time which had resulted in the savings plans not being implemented.

The Chair referred to the involvement of LCGs in the consideration of TDPs and said that this was an iterative process. He added that advice from professionals on LCGs in terms of the content of TDPs was important in respect of feedback through Commissioning Leads to the Director of Commissioning/Senior Management Team and ultimately to the Board.

Mr Power acknowledged the input from the LCG professionals at various stages throughout the process. However he pointed out that LCGs were not required to approve TDPs and he felt that there was a gap in the process if LCGs were unable to have sight of Trust savings plans.

Following this discussion, with the exception of Mr McKeever, members **APPROVED** the Trust Delivery Plans from the Southern, South Eastern, Northern and NIAS Trusts as an acceptable response to the draft Commissioning Plan 2018/19.

91/18 ANNUAL REVIEW OF THE HSCB STANDING ORDERS, STANDING FINANCIAL INSTRUCTIONS AND SCHEME OF DELEGATED AUTHORITY

Mr Cummings reminded members that the HSCB Standing Orders and Standing Financial Instructions were reviewed on an annual basis.

He pointed out that a number of minor textual amendments had been made both to the Standing Orders and the Standing Financial Instructions. Mr Cummings referred to the Scheme of Delegated Authority and explained that this had been reviewed and amended to incorporate an alignment to the recently refreshed business case/Investment Proposal Template (IPT) process in line with normal business. He clarified that Directors could approve IPTs up to the value of £1 million. However any above that value would come to SMT for approval.

Mr Gilmore confirmed that the Audit Committee had considered and approved these documents at its meeting on 27 September.

Members **APPROVED** the annual review of the HSCB Standing Orders, Standing Financial Instructions and the Scheme of Delegated Authority.

It was noted that the Standing Orders remain subject to change with any further revisions being submitted to the Board for approval throughout the year.

92/18 MID YEAR ASSURANCE STATEMENT AS AT 30 SEPTEMBER 2018

The Chair reminded the meeting that the Mid Year Assurance Statement (MYAS) enabled the Chief Executive as Accounting Officer for the HSB to attest to the continuing robustness of the organisation's system of internal governance and was based on the same principles as the Board's Governance Statement.

He noted that Mrs Lowry had chaired the Joint meeting of the Audit and Governance Committees on 2 October 2018 at which the draft Mid Year Assurance Statement was considered and invited her to comment.

Mrs Lowry acknowledged that there had been detailed discussion at the meeting with a number of amendments to the draft being suggested by members. She said that she was happy to confirm that the amendments suggested had been incorporated into the MYAS before the Board today.

The Chair commented that, while 85 training places had been made available in 2016/17, only 48 GPs had qualified and he sought clarification as to the possible reasons for this.

Members **NOTED** the Mid Year Assurance Statement as at 30 September 2018 for onward submission to the DoH by 12 October 2018.

93/18 QUALITY IMPROVEMENT PLAN REPORT: APRIL 2016 – MARCH 2018

The Chair welcomed Ms Mary McElroy, Safety Quality and Patient Client Experience Lead, PHA, to the meeting and invited her to highlight the salient points of the report to members.

Ms McElroy explained that Trusts were required to submit to the PHA an annual Quality Improvement Plan which included indicators identified in the HSCB/PHA Commissioning Plan as well as locally identified quality improvement indicators. The data collated was reviewed and analysed by HSCB/PHA staff and used to inform the report before members.

Ms McElroy advised that the key areas covered in the report related to the:

- prevention of pressure ulcers
- reduction of harm from falls
- compliance with accurately completed National Early Warning Scores (NEWS) charts
- Mixed Gender Accommodation

Ms McElroy noted that, while these initiatives were implemented across NI Trusts, there was a lack of standardisation with regard to the current systems being used locally, regionally and nationally to monitor Quality Improvement Plans. She said that this had led to some concerns around the variation in reporting and acknowledged that, whilst there had been significant work from all involved to improve upon this, further work was needed to continue to evaluation and refine the process. This would ensure better quality

data and improved patient experience for the coming year and into the future.

Continuing, Ms McElroy referred to the marked increase in avoidable pressure ulcers in the NHSCT. She said that PHA staff had worked and continued to work closely with NHSCT colleagues to improve the position and she added that there were no new notable patterns or trends emerging.

Ms McElroy advised that the Trust had undertaken an in-depth validation exercise to review the reporting and analysis of grade 3 and 4 pressure ulcers. She added that the Trust was currently undertaking an improvement project in conjunction with the PHA and had produced an action plan to have a targeted reduction in hospital acquired avoidable pressure ulcers. Ms McElroy said that the Trust was focussing its efforts on the pressure ulcer risk assessment, the plan of care to promote pressure ulcer prevention and on learning from hospital acquired and avoidable pressure ulcers. She said she was happy to report that the Trust was now starting to see an improvement

Referring to compliance with the National Early Warning Scores (NEWS), Ms McElroy indicated that regional compliance had now reached 90% and added that the focus for the coming year would be on outcomes.

Ms McElroy referred to mixed gender accommodation and believed that this presented its own challenges. She said that, while processes were in place to monitor occurrences of mixed gender accommodation, there were variations in reporting and recording across Trusts.

Mr Cummings advised that SMT had considered the report at a recent meeting and believed that it clearly demonstrated where differences were being made.

The Chair suggested that it would be helpful also to include references to the work carried out by Trusts in the HSCB Annual Report. He sought clarification as to the motivation for Trusts to become engaged in the process. The Chair referred to the fact that Quality Improvement Plans had been introduced in the UK and were subject to financial incentive.

Responding, Ms McElroy explained that Quality Improvement Plans were recognised by Trusts as contributing towards safe and quality care. She pointed out that regional groups had been established to take forward work relating to the four key areas covered in the report and added that these were very much multi-disciplinary based. She said that the groups allowed sharing of good practice and all Trusts had been supportive of this approach.

Ms McElory advised that a learning event for pressure ulcers was being held on 12 October and a recent event on safeguarding and pressure ulcers had proved very successful.

The Chair asked whether the Department identified areas for quality improvement and whether new priorities were identified.

Responding, Ms McElroy explained that HSCB/PHA officers had had an opportunity to contribute to the content of the Commissioning Plan Direction and added that the areas for quality improvement were subsequently identified from the Commissioning Plan Direction. She pointed out that some areas rolled over to subsequent years and cited the example of mixed gender accommodation which had been included in the previous year. Ms McElroy added that it took, on average, 2-4 years for improvement to become evident.

Mrs Lowry said that she had found the report very interesting. She referred to compliance with the National Early Warning Scores and asked whether these were being completed consistently. Mrs Lowry also enquired as to how the scores were used once they had been completed.

Ms McElroy explained that work was being taken forward to examine Serious Adverse Incidents in more detail, in particular looking at how these were escalated. She added that HSCB/PHA officers and the Safety Forum were working to develop an action plan on how this escalation can be improved upon and how it would be best monitored.

The Chair commended all involved in the development of the report and thanked Ms McElroy for her attendance.

Members **NOTED** the Quality Improvement Plan Report: April 2016 – March 2018.

94/18 ITEMS FOR INFORMATION

- (i) Minutes of Local Commissioning Groups:
 - South Eastern 7/618
 - Western 9/5/18
 - Southern 13/6/18
 - Belfast 21/618 & 16/8/18
 - Northern 21/6/18
- (ii) Audit Cttee minutes 7/6/18
- (iii) Governance Cttee minutes 7/6/18

Dr Steele noted that the SELCG continued to engage with ICP colleagues at local level to work in a more collaborative way.

The Chair suggested that it would be helpful to bring the outcome of the recent workshops involving LCG and ICP members to a future meeting of the Board and also to look at how Ms McMurray who facilitated the workshops was reporting to the workstreams.

Cllr McAnespy noted that, at the Western LCG meeting on 10 October, members had commended the MDT pilot but had expressed concern in relation to availability of the workforce.

Referring to the resources which had been made available through the Confidence and Supply funding, Mr Power alluded to the current political position and asked if this funding could now potentially be at risk.

Mr Cummings advised that, while there were significant challenges in spending the funding, it had been guaranteed until 31 March 2019 but not beyond that date

Members **NOTED** the content of the above.

95/18 DATE OF NEXT MEETING

The next meeting of the Health and Social Care Board will take place on Thursday 8 November 2018 in the Youth Suite, The Jethro Centre, 6 Flush Place, Lurgan BT66 7DT

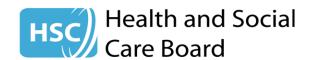
96/18 ANY OTHER BUSINESS

There were no items of Any Other Business.

97/18 RESOLUTION TO GO INTO CONFIDENTIAL SESSION

The Board **APPROVED** a resolution to go into Confidential Session to consider a number of confidential items of business.

SIGNED:	 	
DATE:		



MINUTES OF THE HEALTH AND SOCIAL CARE BOARD HELD AT 10.00AM ON THURSDAY 13 DECEMBER 2018 IN THE BOARDROOM, HSCB, 12/22 LINENHALL STREET, BELFAST BT2 8BS

PRESENT: Dr Ian Clements, Chair

Mrs Valerie Watts, Chief Executive (joined the meeting at

10.20am)

Mr Paul Cummings, Director of Finance

Ms Marie Roulston, Director of Social Care & Children

Mr Stephen Leach, Non Executive Director

Mrs Stephanie Lowry, Non Executive

Mr Robert Gilmore, Non Executive Director Mr John Mone, Non Executive Director

Dr Melissa McCullough, Non Executive Director

Mr Brendan McKeever, Non Executive Director (left the

meeting at 2.30pm)

IN

ATTENDANCE: Dr Sloan Harper, Director of Integrated Care

Mrs Lisa McWilliams, Interim Director of Performance

Management & Service Improvement

Mr Sean Donaghy, Regional Director of eHealth &

External Collaboration

Ms L McMahon, Director (Community Planning)

Mrs Mary Hinds, Executive Director of Nursing & AHPs,

PHA (left the meeting at 11.30am)

Dr Adrian Mairs, Acting Director of Public Health, PHA

(joined the meeting at 1pm)

Mrs Carol Mooney, Corporate Secretariat Manager

Cllr Sorcha McAnespy, Interim Chair, Western Local

Commissioning Group

Mr Miceal McCoy, Interim Chair, Southern Local

Commissioning Group (left the meeting at 12.45pm)

Mr Danny Power, Interim Chair, Belfast Local

Commissioning Group (left the meeting at 1.25pm)

Dr Michael Steele, Interim Chair, South Eastern Local

Commissioning Group

Mr Richard Dixon, Patient Client Council

Ms Valerie McConnell, Programme Manager for Mental Health and Learning Disability (for agenda item 5 only)
Ms Fiona Diamond, Senior Accountant, HSCB (for agenda item 10 only)

Mr Daniel McConville, Principal Statistician, DoH(for

agenda item 10 only)

Mr Joe Brogan, Head of Pharmacy & Medicines

Management (for agenda items 11, 12 & 13 only)

APOLOGIES: Dr Miriam McCarthy, Director of Commissioning

Dr Carolyn Harper, Executive Medical Director/

Director of Public Health, PHA

Mrs Louise Skelly, Patient Client Council

108/18 CHAIR'S REMARKS

The Chair welcomed those present to the December meeting and said that, in view of today's lengthy agenda, he intended to proceed directly to the agenda.

Before commencing the meeting, the Chair asked members to declare if they had a conflict of interest with any agenda items. There were no declarations.

109/18 PREVIOUS MINUTES

The minutes of the previous meeting on 8 November 2018 were **APPROVED** and signed by the Chair.

110/18 MATTERS ARISING

There were no Matters Arising.

111/18 UPDATE ON THE COMMISSIONING OF MENTAL HEALTH SERVICES

At this point in the meeting, the Chair invited the representatives of #123GP to address members. A copy of their address is appended to these minutes.

The Chair thanked the representatives for their address and invited Ms Valerie McConnell, Programme Manager for Mental Health and

Learning Disability, to update members on the commissioning of mental health services.

Ms McConnell acknowledged that Northern Ireland had reported incidence of mental health problems higher than other UK jurisdictions, for example around 25% higher than England and said that this had been attributed to higher rates of trauma exposure; substance misuse; deprivation and inequality.

Continuing, Ms McConnell advised that, in the 2017/18 financial year, the HSC budget for mental health was £270 million, representing around 6% of the overall health budget. An additional £10 million, ring-fenced for mental health services, was subsequently allocated from Confidence and Supply funding. She advised that, of this £10 million, £3.5 million non-recurrent funding had been allocated to innovation projects designed to improve and modernise some services, improve the knowledge and skills of the workforce and to test innovations while the remainder of the funding had been allocated to meeting service pressures and ministerial commitments such as the roll-out of the regional Trauma Network.

Ms McConnell advised that funding had also been allocated for the implementation of Rapid Assessment Interface Discharge (RAID) service in all HSC Trusts. She explained that this service would provide mental health liaison and support in respect of all mental health conditions to emergency departments and general hospital wards, adding that some of the funding had also been allocated to provide mental health practitioners for the multi-disciplinary teams linked to GP practices.

Ms McConnell drew members' attention to the Board paper and highlighted the main points within areas such as performance against Ministerial targets; mental health in primary and secondary care; Child and Adolescent Mental Health Services; Regional Trauma Network; Suicide Prevention and Mental Health Promotion and Drugs & Alcohol Harm Reduction.

Mr Mone believed that the fundamental issue was one of funding and said that it was clear that Northern Ireland was below the average for the rest of the UK. He alluded to the monthly performance reports which had referenced month by month, for example, the increasing waiting lists for psychological therapies; the difficulties associated with the recruitment of psychologists and social workers and the reduction of available post-graduate training. Mr Mone commended the update provided by Ms McConnell, in particular the work being taken forward by Trusts and primary care in relation to mental health services.

Dr McCullough commended counselling services inside GP practices and said that it would be important to ensure patients were aware if such services were available. She referred to the fact that current funding to CAMHS services was 6% compared to the recommended level of 10% and she stressed the importance of reaching the appropriate funding level.

Dr McCullough felt that a waiting time of nine weeks should not be underestimated in terms of the implications for an individual experiencing a mental health crisis.

Commenting, Mr Cummings emphasised that funding was not the sole limiting issue and added that staffing was also a significant challenge. He stressed that increasing funding in one service area would necessitate difficult decisions in terms of having to shift resources.

Responding to a question from Dr McCullough as to the availability of coaching services, Ms McConnell advised that, within the Belfast Hubs, one of the services commissioned through LCG investment was life-coaching. She said that there was a recognition that this would encourage people to engage more in treatment.

Ms Roulston referred to the Commissioner's report into CAMHS services and said that she would be happy to meet with Dr McCullough to take her through the detail.

Mrs Lowry believed that the update provided by Ms McConnell made for 'sobering' reading and said that the difficulties in staffing were reflected across a number of different service areas. She referred in particular to death by suicide and the fact that a significant number of individuals who have died by suicide were previously not known to mental health services. Mrs Lowry enquired as to prevention strategies in place and asked if they were targeted at individuals known to services.

Ms McConnell clarified that the PHA strategy was targeted at all sections of the population.

Mr McKeever suggested that one possible way of addressing staff shortages might be to invest more in the voluntary and community sector.

Mr Power acknowledged the underfunding in mental health services and said that, while he accepted Mr Cummings' point regarding funding, this did not negate the need for an increase in mental health services funding. He said that it would be important to recognise the important role played by mental health in terms of linkages to other conditions and believed that the challenge would be to look across the system and other types of support.

Mr Power referred to the community planning process in Belfast, involving a significant number of government departments, and said that the area of mental health, in particular around drugs and alcohol, had been designated as the first issue to address. He said that there was also a commitment to ensure that it was prioritised in terms of the community planning process. Mr Power believed that the emphasis should be on building capacity at local level but community organisations were also under significant pressure.

Cllr McAnespy said that the Western LCG viewed this as a priority. She referred to the multi-disciplinary teams and talking therapies within the Western LCG area. Cllr McAnespy stressed that the issues under consideration were not the sole responsibility of health and social care and believed that there was a need to build resilience through early intervention at a young age.

Mr Leach said that he very much appreciated the presentation from #123GP. He asked whether the Board had undertaken any work to determine the reasons why not all surgeries provided counselling.

Dr S Harper clarified that GPs were independent contractors and, as such, the HSCB contracted with them to provide certain services. He acknowledged that, while funding was there to provide counselling services, one third of practices had elected not to do so.

Dr Margaret O'Brien, Head of GMS, explained that this was very much a choice at practice level and that there was a range of reasons why some practices chose not to provide this service, for example, insufficient space within practices or chose not to employ counsellor. Dr O'Brien indicated that funding was made available to all practices and the service was promoted on an annual basis through contract roll-over correspondence as well as

communication to all practices to promote uptake across a range of enhanced services.

Dr S Harper commended counselling services but said there were other forms of services. He said that some GPs felt that, while the service was suitable for certain patients, other patients required the services of mental health practitioners and he added that this would be available within the newly formed multi-disciplinary teams. Thereby, he said, having the full range of service embedded in GP practice teams.

The Chair concluded the discussion and thanked the #123GP representatives for their attendance. They withdrew from the meeting.

112/18 STANDING ITEM: CHIEF EXECUTIVE'S REPORT

The Chief Executive commenced her report by updating members on paediatric pathology services in Northern Ireland.

She reminded the meeting that the service was currently provided on a regional basis by the Belfast Health and Social Care Trust and the work undertaken by a consultant paediatric pathologist. However, she said, this would change with effect from January when the paediatric pathologist would leave this post.

The Chief Executive acknowledged the implications this would have for this specialised and important service in Northern Ireland. She advised that, despite significant efforts to address this position, including repeated recruitment drives both nationally and internationally, it had been necessary to make alternative arrangements by securing paediatric pathology services from Alder Hey Children's NHS Foundation Trust in Liverpool. Mrs Watts emphasised that this was very much an interim arrangement and said that the HSC system would continue to work hard exploring all avenues to provide a local service in the longer term.

She advised the meeting that efforts to actively pursue potential cross-border options to paediatric pathology had been ongoing for a number of months as well as contact being made with all centres across the Republic and the UK which currently provided this service to explore the possibility of securing support to retain a local service in Northern Ireland. Mrs Watts reported that this had not proved possible so far.

She said that, in progressing this further, health officials from Northern Ireland and the Republic of Ireland had agreed to consider the feasibility of an all-island approach to the long-term delivery of paediatric pathology services. She added that the issue was discussed by Chief Medical Officers and senior officials from both Health Departments during a recent meeting in Belfast.

However, Mrs Watts said, in the meantime, the HSCB and PHA continued to work very closely with the Belfast Trust, families, staff, charities and other partners to ensure that any baby or child who requires a post-mortem was treated with the utmost respect, dignity and sensitivity throughout their journey and also to ensure that families would have full support when facing these very traumatic circumstances.

Turning to Muckamore Abbey Hospital, the Chief Executive reported that, following receipt of the final report of the expert independent team reviewing safeguarding at Muckamore Abbey Hospital, the Belfast Trust alongside the independent Chair of the Review Team, had this week met individually with the families of those affected to share and discuss the report with them.

She said the Belfast Trust again wholly and unreservedly apologised for the behaviour of some members of staff which was clearly completely unacceptable.

Mrs Watts said the review had been commissioned by Belfast Trust following reports of inappropriate behaviour and alleged physical abuse of patients by staff in two wards in Muckamore Abbey Hospital which led to adult safeguarding investigations begun in September 2017. She added that the PSNI Adult Safeguarding investigation was continuing and the Trust had placed a number of members of staff on precautionary suspension.

Mrs Watts indicated that the findings of the final report highlighted that immediate improvements were required first and foremost in putting family carers and advocacy central within governance structures; in leadership and management; in adult safeguarding approaches; in access to meaningful activities for patients and in physical health care.

She said that the report had also commented on the appropriate use of seclusion, adding that the Trust's seclusion policy in relation

to Muckamore Abbey Hospital was currently under review by a multi-disciplinary team, which would fully engage with patients, carers and staff.

Continuing the Chief Executive advised that the report also strongly urged the Trust and the wider health, social care and housing organisations to re-double their efforts to ensure that patients did not have to live in hospital environments and were enabled to live full lives in the community with access to the right specialist multi-disciplinary support in the right accommodation.

Mrs Watts assured members that the HSCB would continue to work with the Department of Health, Belfast Trust and the wider system to ensure that the recommendations were implemented and that a new model of care for those with learning disabilities and autism could be delivered.

Mrs Watts referred to the review being taken forward within neurology and reminded members that, following the review of 2,500 neurology patients earlier this year, a decision had been taken to recall a further 1,044 people who had been patients seen by Consultant Neurologist Dr Michael Watt and discharged to the care of their GP.

The Chief Executive said that the HSC had provided a commitment at the outset that it would carefully consider anyone who had previously been seen by Dr Watt and discharged, and then recall any key groups of people who, based on the clinical advice of the consultant neurological team, required a review.

She advised that this latest review process was being concentrated on specific groups of patients taking specific, specialised medicines. She said, of the 1044 people invited as part of this phase of the recall, 456 had been seen and 347 had appointments booked. A further 148 people had either declined an appointment or no longer needed to be seen. Mrs Watts said that it was expected that patients in this phase of the recall will have been seen by February 2019. She added that the vast majority of people were being seen in Belfast Trust, including those who saw Dr Watt in the Ulster Independent Clinic, with a small number being seen in Hillsborough Private clinic, where they had previously seen Dr Watt.

The Chief Executive acknowledged the commitment and dedication of staff in the Belfast Trust for progressing this recall in such a well organised yet patient sensitive manner.

Turning to winter planning, the Chief Executive reported that a series of detailed winter resilience initiatives had been planned to mitigate pressures in the weeks and months ahead.

However, she said that, despite these significant efforts, it would still be a difficult period for patients and staff with a similar pattern right across the UK.

Mrs Watts indicated that everyone could assist service at this time and she emphasised the importance of using services appropriately and taking the right steps to keep ourselves well.

The Chief Executive believed that these challenges facing the service again highlighted the need to continue the transformation of HSC services.

She referred to the work being led by David Stewart to consider the population needs for urgent and emergency care and said that this had recently been published, adding that a regional review announced by the Department would also help in our planning for the future.

The review will aim to establish a new regional care model with a particular focus on meeting the needs of the rising proportion of older people in the population.

Referring to the work being taken forward in relation to the future arrangements, the Chief Executive reported that there had been good progress with the Design Groups. She said members would recall that each of the design groups were co-chaired by colleagues from the HSCB and the DoH and had been tasked with bringing forward recommendations for the future operating model when the Board closes and also recommendations to ensure an effective transition for staff.

The Chief Executive referred to the design workshop held in November attended by over 60 people from the impacted organisations. She said that there had been constructive engagement at the workshop and subsequent feedback had been positive.

Mrs Watts mentioned that LCG chairs had also had an opportunity to feed in their views to members of the Commissioning and Planning design group.

The Chief Executive emphasised the importance of concluding this stage of the work to bring reassurance and certainty to staff.

She added that, following discussion at the recent Oversight Board meeting, a way forward for the HR and Staffing workstream had now been agreed. Mrs Watts said that this work will be led by Karen Hargan, Director of HR and Corporate Services, BSO. She added that an approach for defining the governance and accountability models to support the future operational arrangements had also been agreed.

Mrs Watts reminded the meeting of the challenges around the provision of GP services at the Northland Surgery in Dungannon following the resignation of three of its GPs. She advised that there had been a 4-week advertising period for a new contractor to provide General Medical Services at the surgery and confirmed that expressions of interest had been received in relation to the provision of these important services.

Mrs Watts emphasised that there would be no change to the GP services until 31 March 2019 and patients at Northlands should continue to contact the practice as normal.

She indicated that the HSCB would be writing to all patients to inform them of their new GP arrangements when the new contract had been agreed and finalised.

The Chief Executive referred to recent meetings with a number of local political representatives when the HSCB assured them and patients that its priority was to ensure that high quality GP services were available to all.

Turning to pharmacy funding, the Chief Executive advised members that the Permanent Secretary had written to Community Pharmacy NI and community pharmacy contractors to confirm a financial envelope for 2018/19 of at least £104 million.

She said that, in addition to this, transformation funding of £2.1 million and non-recurrent funding of £3 million had also been

committed. The Chief Executive added that, in addition to these funding streams, respective funding of £4 million and £1 million had been provided to community pharmacies for pre-registration funding and public health services.

The Chief Executive added that commitment of £3 million had also been given to support clients who were in receipt of domiciliary care and required medicines compliance aids.

Continuing her report, the Chief Executive advised that, on 3 December, International Day of People with Disabilities, the Board and the DoH, in partnership with Disability Action, hosted an event to recognise work arising from the Regional Physical and Sensory Disability Strategy and Action Plan.

She advised that Ms Kellie Armstrong MLA had sponsored the event at Stormont on behalf of the All Party Groups on Disability and Visual Impairment and that the event celebrated the essential contribution service users made throughout the implementation of the Strategy.

Mrs Watts said that Trust and voluntary sector partners attended to showcase initiatives realised from investment made available through the Strategy and Action Plan. Initiatives included Social Networking and Community Access, the Eye Care Liaison Service, Hearing Aid User Support Service, Tinnitus Service, Augmentive and Alternative Communication Equipment and Services, the consolidation of Brain Injury Services at Spruce House and Musgrave Park Hospital outreach to Thompson House in Lisburn.

Mrs Watts said that the Board very much looked forward to working with DoH colleagues, through a multi-agency approach, to establish a Regional Disability Forum which would continue the co-design and co-production of services for people with physical or sensory disabilities.

The Chief Executive reported three successes for the Board's Pharmacy & Medicines Management Team and the Northern LCG at the recent Northern Trust Chairman's Awards ceremony.

The first, she said, related to the Regional Prescribing Support Pharmacy Team who won the 'Partnership Award' which provides a prize of £2,000 towards investment in the team.

The second award related to a drug outreach project, the Benzo Z, which was nominated for a Special Award in recognition of its excellent outcomes in supporting patients and the final award was given to the IMPACTAgewell initiative which was an integrated community development approach to health and wellbeing and which was shortlisted for the 'Integrated Services Award'.

The Chief Executive congratulated all involved in these projects.

Concluding her report, the Chief Executive advised that this was Mr Donaghy's last Board meeting before his retirement. She acknowledged the significant contribution made by Mr Donaghy over his 35 year career in health and social care and wished him well in his retirement.

The Chair said that he would like to take this opportunity, on behalf of Board members, to wish Mr Donaghy every happiness in his retirement.

Dr Steele referred to the Awards achieved by the Pharmacy & Medicines Management Team. He said that the LCG had recently received a presentation on the Benzo and Z drug reduction programme run by a pharmacist and mental health nurse (working in GP practices) and added that the LCG hoped to develop a similar service within the its geography.

Mr Leach sought clarification in relation to the paediatric pathology service and enquired whether contact had been made with the state pathology service to explore whether they had capacity to offer any assistance.

Responding, Mr Cummings said that it was his understanding that the state pathology service was also experiencing capacity challenges as was the service in the Republic of Ireland.

Dr McCullough referred to the patients being recalled as part of the neurology review. She asked how much the review had cost to date and how this was being funded.

The Chief Executive acknowledged that she was unable to answer Dr McCullough's question at this point and said that the focus to date had been on ensuring patients were recalled and reviewed appropriately. She believed that reference to the cost of the review would be included in the final report.

The Chair thanked members for their comments and the Chief Executive's report was **NOTED** by members.

113/18 FINANCE: HSCB FINANCE REPORT ENDING OCTOBER 2018 (MONTH 7); TRUSTS' FINANCIAL REPORT ENDING SEPTEMBER 2018 (MONTH 6)

Commencing with the Trusts' finance reports, Mr Cummings reminded members that the Board had not yet approved the Belfast or Western Trusts' Trust Delivery Plans (TDP)and said that officers were working with both organisations to clarify their respective financial positions. He advised that, due to a range of issues, largely slippage and difficulties in recruitment, the Belfast Trust believed that it could produce a balanced financial position, thereby allowing the HSCB to consider its balanced TDP.

With regard to the Western Trust, Mr Cummings said that he had attended several meetings with the Permanent Secretary and Trust Chief Executive when it had been confirmed that the Western Trust's TDP would report an unbalanced financial position with a deficit of £24.5 million. Mr Cummings said that this would be set as the Trust's control total and it would be necessary for the rest of the HSC system to identify surpluses to cover this Trust's deficit. He added that discussions were ongoing as to how the Trust would return to a balanced financial position. Mr Cummings believed that this could result in the Trust being placed in a formal recovery process which could take 2-3 years.

Turning to the HSCB financial report for the seven months ending October 2018, Mr Cummings reported that there was a small surplus of £1.1 million which mainly related to a surplus on FHS and administration budgets, offset by an overspend in ECRs. He added that a small surplus was currently forecast for the full year.

Mr Cummings advised that the HSCB's assumption would be any surpluses would be recouped by the DoH.

Mr Cummings reported that a mid-year review had taken place of the General Pharmaceutical Services budget The Chair thanked Mr Cummings for his report and members **NOTED** the HSCB Finance Report (month 7) and the Trusts' Finance Report (month 6).

114/18 STANDING ITEM: HSCB PERFORMANCE REPORT ENDING OCTOBER 2018 (MONTH 7)

Commencing, Mrs McWilliams reported that, with regard to elective care, including diagnostics, 26% of patients waiting for a first outpatient appointment were waiting less than nine weeks. She said that this had been a slight improvement, ie a reduction of 2,000 patients, on the September figure when 25% of patients had been waiting. However, she said, the number of patients waiting longer than 52 weeks had increased by 748 patients to 94,970 patients at the end of October 2018. Mrs McWilliams reported that there had been a slight improvement in the number of patients waiting less than 13 weeks for inpatient or daycase treatment.

Mrs McWilliams referred to the additional non-recurrent £30 million available as a result of the Confidence and Supply Transformation Fund and reported that 28,000 patients had either been assessed or treated; 19,000 patients from the AHP backlog, ie those patients waiting longer than 13 weeks for AHP treatment at the end of March 2018, had been reviewed and 9,000 patients from the diagnostic backlog, ie patients waiting longer than 26 weeks for a diagnostic test at the end of March 2018.

Mrs McWilliams advised that the elective care centres for cataracts and varicose veins commenced treating patients this month and added that the DoH had commenced work on the next cohort of services for phase two which included orthopaedics and urology. She said that the DoH was also considering the possibility of including scopes and general surgery.

Mrs McWilliams drew members' attention to page 6 of the report which provided detail on the Trusts' Performance Improvement Trajectories (PITs) for delivery of core. She said that nearly all Trusts were forecasting an improvement on last year's position with the exception of the Northern Trust which showed a -7.9% for assessment and -16.5% for treatment. Mrs McWilliams said that,

while the Trust was showing small improvements on a monthly basis, it was unlikely to finish the year in an improved position than 2017 and that one of the contributing factors was the reduced general surgery capacity over the summer months which has previously been discussed.

Turning to AHP services, Mrs McWilliams reported that, with the use of the Transformation Fund monies, 19,000 patients had been seen from the AHP backlog thus resulting in a material reduction in AHP waiting lists. However she said 19,783 patients were waiting longer than 13 weeks and added that this had reduced by 3,673. Mrs McWilliams explained that a significant number of those patients waiting were waiting for physiotherapy treatment.

Mrs McWilliams said that the Chief Executive had alluded in her remarks to the winter resilience arrangements and the challenges facing the health and social care system. She reported that the 12-hour performance clearly demonstrated a system under considerable pressure. Mrs McWilliams said that, in October 2018, 1,628 patients waited longer than 12 hours in ED, with the Southern Trust in particular having 643 patients waiting longer than 12 hours. She advised that the pressures in the Trust ED could be attributed to delayed discharges, difficulties in securing community care package and staffing issues. Mrs McWilliams said that Board staff had been working with Trust colleagues, in particular the Community Teams, to examine the Trust discharge assessment profile.

With regard to the 4-hour ED performance, Mrs McWilliams reported that 72% of patients had been treated and discharged or admitted within four hours. She said that, while this had been a slight increase on the previous month, ie 71%, the figure had reduced compared to the same month last year, ie 74%.

Turning to cancer services, in particular the 14-day target, Mrs McWilliams advised that 87.8% of urgent breast cancer referrals were seen within 14 days and added that this was an improved position from the previous month. She pointed out that the Northern Trust's performance had improved from 11.9% in September to 57.5% in October and said that Board officers continued to work with Trust colleagues to improve upon this position. Mrs McWilliams commented that provisional figures for November were positive and said that the Trust hoped to achieve 100% performance by January as a result of support from other Trusts.

Mrs Mc Williams said that the 31-day target, 95% of cancer patients commenced treatment within 31 days against a standard of 98%. She added that all Trusts, with the exception of the Northern Trust, were performing in line with their respective PITs.

In relation to the 62-day target, Mrs McWilliams reported that 59% of patients urgently referred with a suspected cancer began their first definitive treatment compared to the standard of 95%. She said that there had been an increase in activity and that the year to-date figure was 65%. Mrs McWilliams advised that referrals had increased by 15% and she explained that, in the context of activity, in the seven month period there had been an increase of 43,000 suspected red flag referrals across the system and 140,000 urgent referrals. She believed that this clearly demonstrated the pressure within the system and assured members that every effort was being made to meet the 62-day target.

Alluding to CAMHS Step 2 services, ie early intervention, Dr McCullough asked whether there were thresholds to access this service.

Responding, Ms Roulston advised that there were thresholds in place and added that the Northern Trust was the only Trust reporting on the current position of its waiting list in respect of this service. She undertook to discuss further with Mrs McWilliams and Trust colleagues.

Mr Mone referred to the increase in 12-hour breaches and asked if the position was deteriorating as a result of Trusts being unable to ensure appropriate care packages to enable discharges to take place.

Responding, Mrs McWilliams explained that the majority of those patients waiting longer than 12-hours in ED were waiting for hospital admission. She acknowledged that the increase in waits could not be explained by the number of patients presenting and the number of patients brought to ED by NIAS. With this in mind, she said that the conclusion would be that the waits were caused by the inability to access appropriate care packages to allow the discharges to take place or allow access to nursing homes which releases beds for admissions. Mrs McWilliams referred to the discharge workstream work being led by Mrs Hinds. She acknowledged that Trusts

struggled with discharges at weekends but added that discharges on Fridays were not at the anticipated level.

Mr Mone suggested that the issue was rather the availability of staff at weekends to facilitate patient discharges and he asked if any work had been done to explore this further. He referred also to the work being progressed by the DoH in relation to a review of urgent and emergency care across Northern Ireland. Mr Mone was of the view that unless patient discharges took place on a 7-day basis, the current difficulties would only continue.

Mrs McWilliams advised that 7-day working had been rolled out to Trusts and she referred, in particular to the intermediate care discharge to assess process which focussed around ensuring assessment took place in a home setting which frees up hospital beds and ensures that the appropriate level of package was delivered to the patient.

Mr Leach referred to the transformation monies which had been used to address waiting list backlogs in diagnostic and AHP services and asked how confident Board officers were that the funding would be spent by the end of March.

Mrs McWilliams confirmed that the transformation resources had been allocated to Trusts and associated robust monitoring arrangements were in place. She added that, while assurances had been given by Trusts to the DoH that the total allocation would be spent, Board officers had some concern.

Mr Mone referred to the target that 15% of patients with a confirmed stroke would receive thrombolysis treatment, where clinically appropriate. He said that this target meant that 85% of those patients not designated as clinically appropriate would not receive the treatment. Mr Mone said that he would find it helpful to receive an update in relation to the 15% target as to how Trusts intended to achieve this and noted that this target had been in existence for some time. He added that he very much recognised that this intervention could be significant for patients in terms of reducing further disability or a further stroke.

Mrs McWilliams undertook to highlight this to Commissioning Leads.

Members **NOTED** the HSCB Performance Report (month 7) ending October 2018.

115/18 VOLUNTARY/COMMUNITY SECTOR FUNDING IN 2018/19

Mr Cummings reminded the meeting that the Board oversaw a range of contracts with voluntary and community sector providers. He advised that, going into 2018/19, there were 54 contracts in place totalling approx £18 million per annum.

In terms of the proposed approach for 2018/19, Mr Cummings advised that the Board's assessment would be to apply an uplift to those community and voluntary contracts for residential and non-residential services which did not have agreed contract values already in place for 2018/19. For HSC organisations, it was proposed that an uplift of 2.00% could be applied to the respective closing 2017/18 contract values. Mr Cummings said that, on this basis, the cost for an inflationary uplift to voluntary and community contracts would be £0.168 million in 2018/19.

Members **APPROVED** an uplift of 2% to those community and voluntary contracts for residential and non-residential providers in 2018/19, backdated to 1 April 2018 (excluding procured contracts with already agreed contract values). The meeting **NOTED** that an uplift would not be applied to those contracts which had an agreed procured contract value and/or where a fixed uplift already applied for 2018/19.

116/18 PROPOSED CHANGES TO THE NI WEIGHTED CAPITATION FORMULA – REVIEW OF FAMILY & CHILDCARE

The Chair welcomed Ms Fiona Diamond, Senior Accountant, HSCB, and Mr Daniel McConville, Principal Statistician, DoH, to the meeting.

Ms Diamond said that the HSCB must ensure its funding was targeted upon health needs and indicated that, since 1994, a complex statistical tool known as the 'Capitation Formula' had been used to assist them in this process

Ms Diamond explained that the Board was responsible for the maintenance and update of the Regional Capitation Formula which measures the relative need of local populations for available HSC resources. She advised that individual formulae or models, based on the nine Programmes of Care that are used in the management of Health and Social Care services, are developed and then

consolidated. Two cost adjustments are then made to reflect the unavoidable cost of delivering services in rural/urban areas (rurality) and the effect hospital and community infrastructure size has on costs (economies of scale). The overall formula provides the fair share of available resources across localities.

Ms Diamond explained that the Capitation Formula did not determine the level of investment required for a Programme of Care but provided the equitable distribution of that Programme's funding by LCG based on the weighted population.

Ms Diamond pointed out that an equity review was carried out on an annual basis comparing expenditure with capitation fair shares and added that a periodic assessment of variances in quality and performance was also undertaken. The formula provides a direction of travel for strategic investment decisions.

Ms Diamond and Mr McConville then described the process and the statistical work involved in reviewing the F&CC model in detail.

Mr Cummings commented on the complexity of this work and reminded the meeting that the capitation formula was the benchmark on how resources were allocated and potentially could change the equity position of Trusts. He pointed out that 0.1% of a movement equated to approximately £4 million.

He explained that the potential changes to financial allocations to LCG fair shares had not been shown in the report as this could have a material impact on the acceptability of the review.

Ms Diamond referred to the new Family & Childcare model and said that it used the same modelling principles as previous models with updated data and costs. As a result of this work, Ms Diamond said, a number of new models had been developed with a preferred option being recommended. The work was also informed by an expert Peer Reviewer and the Family & Childcare Advisory Group.

She said that the Board's approval was being sought to undertake a 8-week targeted consultation and that the formula could be incorporated into the 2019/20 Capitation Formula.

Mr McCoy emphasised the importance of a fair and reasonable Formula. He alluded to the increase in numbers of young people and the elderly in the Southern LCG area.

Mr Cummings indicated that the HSCB, and prior to that the legacy HSSBs, had always allocated resources using a capitation methodology. He acknowledged that a major difficulty in its application was the movement of populations. Mr Cummings accepted that immigration to the Southern geography had been significant but services had been based around the acute hospitals in Belfast.

Mr McKeever referred to the draft consultation document and questioned the practice of wording questions 'Do you agree....'.

Dr McCullough suggested that there could be a further tick box for respondents, ie 'Strongly Disagree'.

Responding, Ms Diamond accepted that the question could be reworded to start with a statement and then seek the respondent's view and undertook to revisit this.

Dr S Harper commented that an emerging view from the Bengoa report had been that the wider determinants of health, eg lifestyle and lifestyle behaviours, engagement, communities had been losing out based on this method of funding. He pointed out that the Bengoa report suggested that a budget should be given to a population of providers. Dr S Harper suggested that, in order to encourage change, there had to be incentive for providers.

The Chair commented that the challenge would be to ensure how best such a collaborative and aligned approach would work and ensure the most appropriate allocation of resources.

Ms McMahon suggested that it would be helpful for Community Planning Partnerships to have sight of the consultation document.

Mr Power referred to the earlier discussion on mental health and related challenges and questioned how the legacy and the impact of conflict was built into the Formula as there was very minimal statistical data available other than the numbers of deaths. He felt that the impact on society over a sustained period of time was often not considered as a contributing factor.

Mr Cummings believed that this was more relevant to the Mental Health rather than the Family & Child Care component of the Formula.

Mr McConville advised that, during the last review of the Mental Health specific Programme of Care formula, cognisance was taken of various Troubles-related issues, for example, distance to peace walls, Troubles-related deaths in geographical areas to determine if there had been a pattern. However, he said no Troubles-related variable was specifically represented in the top 5-6 explanatory variables for the formula. Mr McConville confirmed that, while drivers relating to the troubles had been tested, there was a need to include the most statistically significant drivers such as unemployment rates and benefit uptake.

Mr Power contended that these issues related to the legacy of the troubles and believed that one difficulty was that the quality of the information in relation to the impact was not there. He said that, when one took into account the geographical location services, the majority of services were located in inner city areas in Belfast for example where there were higher levels of deprivation. He said that it was almost an anomaly that, while services were based in areas of high deprivation, they did not appear to be having a long-term impact.

Members **APPROVED** that a 8-week targeted consultation be undertaken on the update to the Family & Childcare formula and that the updated Family & Childcare formula should be incorporated into the 2019/20 Capitation Formula.

Before withdrawing from the meeting, the Chair thanked Ms Diamond and Mr McConville for their attendance and their work on such a complex issue.

117/18 CONFIRMATION OF COMMUNITY PHARMACY FINANCIAL ENVELOPE

The Chair welcomed Mr Joe Brogan, Head of Pharmacy & Medicines Management, to the meeting.

Before commencing his presentation, Mr Brogan advised members of the 'Pharmacy First' scheme which, he said, was a reconfiguration of the previous 'Minor Ailments Scheme'. He indicated that HSCB had notified community pharmacists in mid-November that it had £2.1 million to commission the scheme which commenced on 1 December 2018. Mr Brogan added that there had been positive support from community pharmacists for the Scheme.

Turning to the financial envelope for community pharmacy services, Mr Brogan reminded members that, since 2005/06, the DoH and the representative group of pharmaceutical contractors (CPNI) had been in dispute regarding the overall financial package available to community pharmacy and linked to the development of a new community pharmacy contract.

He indicated that this dispute had culminated in three judicial reviews taken by CPNI against the DoH and the HSCB with respect to elements of reimbursement and linked to the statutory duty of the DoH and HSCB to provide fair and reasonable remuneration. Mr Brogan advised that the DoH had confirmed an interim funding position for the years 2018/19 and 2019/20.

Mr Brogan described in detail to members the interim financial position, taking into account recurrent and non-recurrent investments. He advised that the financial envelope for community pharmacy, including retained profit of £26.5 million, was £104 million.

He said that an additional recurrent investment of up to £3 million had been identified for the provision of medicines management to domiciliary care. Mr Brogan said that, while this would be included in the financial envelope for 2018/19 and 2019/20, it would create an additional pressure. A further investment of approximately £5 million had been identified for issues such as pre-registration training and PHA-led services.

In terms of non-recurrent investments, Mr Brogan advised that a one-off payment had been made in November 2018 in respect of additional support for pharmacies in rural isolated communities. He pointed out that this investment also included a payment on account for 2018/19 to address the impact of discount particularly on branded medicines in advance of a review. Mr Brogan added that bids totalling £2.1 million under transformation funding had also been approved for 2018/19 and said that further bids were being considered for 2018/19 and 2019/20.

Mr Brogan advised that the PwC Cost of Service Investigation (COSI) had identified a financial envelope of £125 million was required. He added that the HSCB had advised Community Pharmacy NI (CPNI) that it was not affordable and that the COSI

had been used to inform discussions around a reasonable financial envelope.

Continuing, Mr Brogan pointed out that CPNI had argued that community pharmacists were providing a number of service areas which were not commissioned by the HSCB. However he confirmed that the proposed financial envelope of £104 million covered those services clearly commissioned by the HSCB.

Mr Brogan cited the example of the provision of medicines management to domiciliary care services and said that a number of agencies relied on community pharmacists to provide medication in blister packs for patients. He acknowledged that the decision to do so had come about as a result of discussions between domiciliary care agencies and community pharmacies. Mr Brogan acknowledged that, while the provision of blister packs greatly assisted domiciliary care workers in terms of ensuring the safe administration of medicines, he had some concerns around governance.

Mr Brogan said that, following discussion with DoH colleagues, the HSCB had bid for and had been successful in receiving funding of £3 million for this service which would be commissioned from 1 April 2019 onwards. Mr Brogan added that between 7,000-8,000 patients would benefit.

Mr Leach referred to EU Exit and the fact that most drugs were imported. He asked whether it was possible that the figure of £26.5 million of retained profit would increase and if so, did the HSCB have an option to renegotiate the financial envelope.

Mr Brogan acknowledged that there was fluctuation in the supply chain and said that this would likely continue over the next 6-9 months. He advised that, while the £26.5 million was the funding required by community pharmacists and formed part of their income stream, the overall pharmacy budget was approximately £400 million.

Referring to the cost of drugs, Mr Brogan indicated that, on average, an additional £650,000 was added each month to the drugs bill. He said that in order to mitigate against this, the HSCB had allowed a special advance of £2,000 per contractor to allow for the vagaries of the supply chain.

Members **NOTED** the paper presented by Mr Brogan.

118/18 CONSULTATION ON COMMUNITY PHARMACY FEES FOR 2019/20

Mr Brogan acknowledged that this agenda item was directly linked to the preceding item. He said that he was seeking the Board's approval to go out to consultation with community pharmacy contracts in respect of the multiple dispensing element of their remuneration package.

Mr Brogan reminded members that pharmacy global sum fees consisted of three elements, ie ordinary dispensing, multiple dispensing and practice allowance and he outlined to members how this investment had increased since 2012/13.

He described in detail the various options available to members, namely:

- Option 1 at 0% growth, fees will be reduced as activity was increasing, thus leaving a balance of £0.5 million uncommitted given that £56.1 million global sum has been budgeted. This would provide an opportunity to invest £0.5 million in other elements of the pharmacy envelope;
- Option 2 maintain the current fee levels at 2018/19 levels. This will require an increase of 0.7% for the global sum element or £0.4 million into the pharmacy financial envelope.
- Option 3 allow for an increase of 3% for the global sum element or £1.7 million. This budgetary uplift has been proposed in light of other economic and financial issues. However, there is some uncertainty in relation to such an increase given the wider political and economic concerns in the short and medium term. Given this uncertainty, it is proposed that fee levels remain the same and the additional £1.3 million, if it is made available, should be negotiated as part of pharmacy contract discussions.

Members **APPROVED** the Option 2, ie to maintain current fees with any additional uplifts being made available to be negotiated as part

of the pharmacy contract discussions. Members also **APPROVED** a targeted consultation in line with the options as set out.

119/18 PHARMACY NEEDS ASSESSMENT – DEFERRAL OF DECISIONS BY PHARMACY PRACTICES COMMITTEE

Mr Brogan advised that an action arising from the second community pharmacy related Judicial Review in 2011 was to consider taking forward a pharmacy needs assessment. He explained that this assessment would consider whether the provision of pharmaceutical services was sufficient to meet the needs of the population and specifically consider whether there was over- or under-provision.

Mr Brogan indicated that, from 2012 to 2017, work had been carried out to establish the range of data/information required to assess service provision. He said that, in March 2018, the DoH asked the Board to conclude this work.

Continuing, Mr Brogan explained that the 'Statutory Framework' for considering applications to join the pharmaceutical list is the Pharmaceutical Services Regulations (NI) 1997. He said that, under these regulations, the HSCB was required to consider applications to join the pharmaceutical list through a statutory committee of the HSCB, the Pharmaceutical Practices Committee (PPC).

Mr Brogan said that this legislation required the HSCB to process applications to go on the Pharmaceutical List and which were either minor relocations or a change to the ownership as set out in Regulation 6.

Mr Brogan said that it would be important that the Pharmacy Needs Assessment Project, established to take forward the work over the next 12 months, could do so without the challenges of a changing pharmacy network through new applications and non-minor relocations.

He said that, to this end, it was proposed that a targeted consultation should be undertaken with Community Pharmacy NI (CPNI), General Practitioners Council NI (GPCNI) and Patient Client Council (PCC) to seek their views for the potential to suspend

consideration of such applications by the Pharmacy Practices Committee (PPC) for the period 1 April 2019 – 31 March 2020.

Mr Brogan explained that, as pharmacy services were accessible in Northern Ireland in comparison with other parts of the UK, and there had been a relatively low number of new applications to join the pharmaceutical list in recent years, it was expected that there would be general support to suspend decision making for a time-limited period of time.

Mr Brogan also believed that this would also signal to community pharmacy contractors that the HSCB was considering the commissioning and delivery of pharmaceutical services providing an appropriate context for consolidation within businesses in localities. He said that, as part of the consultation, it was proposed that HSCB would seek views on the potential for consolidation and the potential for impact on the provision of services.

He added that the Pharmacy Needs Assessment Project Board had indicated its support for this proposal.

Mr Mone expressed his support for the proposals in his capacity as PPC Chair and agreed that the impact would be negligible in terms of new applications.

Mrs Lowry, Vice-Chair of the PPC, referred to those applications focussing on a change in hours and asked if the PPC would continue to meet to consider these applications.

Responding, Mr Brogan confirmed that these applications would continue to be considered. He added that the needs assessment work would also take into account pharmacy opening hours, including contracted hours and contractual hours.

Members **APPROVED** the initiation of a targeted consultation to suspend decisions on applications by the Pharmacy Practices Committee for a period of 12 months.

The Chair thanked Mr Brogan for his attendance and he withdrew from the meeting.

120/18 COMMISSIONING OF AN EHEALTH & CARE BLUEPRINT

Given the complexity of this agenda item, members agreed that it would be helpful to convene a workshop to discuss in the first instance. The Chief Executive undertook to make the necessary arrangements.

121/18 ITEMS FOR INFORMATION

- (i) Minutes of Local Commissioning Groups:
 - South Eastern 4/10/18
 - Western 10/10/18
 - Southern 18/10/18
 - Belfast 18/10/18
 - Northern 18/10/18

Members **NOTED** the content of the above.

122/18 DATE OF NEXT MEETING

The next meeting of the Health and Social Care Board will take place on Thursday 14 February 2019 at 10.00am in the Boardroom, HSCB, 12/22 Linenhall Street, Belfast BT2 8BS.

123/18 ANY OTHER BUSINESS

There were no items of Any Other Business.

124/18 RESOLUTION TO GO INTO CONFIDENTIAL SESSION

The Board **APPROVED** a resolution to go into Confidential Session to consider a number of confidential items of business.

This being all the business, the Chair closed the meeting at 11.40am.

#123GP Speaking Notes for presentation to HSCB 13 December 2018

Kirsty – 5 minutes

We welcome the invitation to engage with you today as there is a real urgency to addressing the changes being called for by the #123GP campaign, the main one being that every GP practice is equipped with an in-house counsellor.

We are here representing people who are bearing the terrible cost of the mental health crisis and the ongoing failure to equip GPs with appropriate mental health expertise. A mental health crisis in which 305 people lost their lives to suicide in 2017; more people have now died by suicide since the peace agreement in 1998 than died as a result of the conflict.

Our campaign is made up of people experiencing mental health problems, their carers and families who have lost loved ones to suicide – in other words, people who sadly know only too well what's not working and what needs to be improved.

We all know that GPs are the first port of call for over 90% of people concerned about their mental health.

It is vital that they have the tools to be able to treat people effectively for anxiety, depression and other common mental health problems.

We know that counselling works and is a cost effective treatment option. It is an essential part of mental health management by GPs.

This is one woman's positive experience of getting counselling through her GP practice illustrates just how valuable it is:

"I have sadly lost two family members to suicide in the past year. I went to my GP because I knew I was struggling with the impact of these bereavements, as well as the death of my brother. My GP offered to refer me to counselling, an offer I took up. I was given an appointment within two weeks of being referred. There was no limit on the number of sessions provided – it was just as long as it took. I think every GP should have a counsellor based in the practice. I think it is more intimate if it is provided in this familiar setting,

through your own GP. It also means that people who don't have transport or money to pay for transport can access it"

My own experience of accessing counselling through my GP, but also through Lighthouse.

We also know that Northern Ireland has one of the world's highest prescription rates for anti-depressants. People tell us they want to be offered counselling as a first option or in conjunctions with medication, rather than the GP always reaching for the prescription pad. In fact, GPs also want to be able to offer counselling as a first option.

But we know that at the moment, only two thirds of GPs have an in-house counsellor, and the number of practices offering in-house counselling has gone down since last year. We know that there are also huge inequalities in access to GP practice based counselling depending on what Trust area you live in. We know that there are long waiting lists for getting counselling through the Hubs. So something is not working.

#123GP campaigners have already engaged with the Board on these issues.

In June this year we presented a petition of over 2000 signatures, calling on you to ensure that every GP practice is equipped with a counsellor.

In August we met with your senior officials and highlighted the fact that the Board's LES funding for in-house counselling works out at an average of £2.29, the price of an ice-cream, if everybody who would potentially benefit from counselling through their GP practice tried to access it.

In response Dr. Harper acknowledged that only two thirds of GP practices provide in-house counselling, but stated that counselling was available through the Primary Care Talking Therapy Hubs to people whose practice does not provide in-house counselling. Dr. Harper also pointed to the roll out of new Multi-Disciplinary Teams across NI. These teams are a model we support, but their roll out does not in any way do away with the need for GPs to have access to in-house counselling. It's not one or the other that's needed, it's all of it, and more!

Following that meeting and the Board's response, we were left with a feeling that the scale of the mental health crisis facing this society is not being recognised and that the urgency and commitment we bring as campaigners is not being reciprocated by the Board.

Everything we have learnt since only serves to confirm that belief.

Barry – 5 minutes

Everything we read around the treatment of mental health and suicide in the North tells us that mental health, despite all the publicity and talk, is still the poor relation of human illnesses. It is still a secret illness. It is still considered shameful. It is still not properly recognised as a "genuine" illness. Sadly that is reflected in the statistics we see and the budget allocation from the Health Authorities.

The budget of £1.6m allocated by this Board to GPs for the provision of in-house practice based counselling in 2016/17 is totally inadequate. Now we see that the number of GP's providing access to in-house counselling has actually fallen within the past year. GPs accessing the funding provided for in-house counselling has actually fallen by 2% between 2016/17 and 2017/18; from 69% to 67%.

Then we have big disparities in access of funding by GP's across the various health trusts. Its as low as 48% in the Southern Trust and up to 89% in practices in the Northern Trust. We would ask the obvious question.....why is this? Why is it not 100% access to funding by all GP services in all Health Trusts? Are the health board members, present here today, aware of this 'post code lottery' in regards to mental health treatment? And if so what do they propose to do about it; allowing that this is not just a recent phenomenon?

Passing the buck to the Primary Care Talking Therapy and Well Being Hubs is clearly not cutting the mustard. Why? Well....for a start the waiting times are totally unacceptable for patients who clearly need help and are in distress. The figures show this. In the Western health Trust it is a six months wait for assessment and then another 3-4 weeks to actually begin your therapy. Six months and then another 3 to 4 weeks? Imagine if you were told it would be six months before you can be assessed for your broken leg or your severe heart attack.....and then another 3-4 weeks before you can be treated. In the Belfast trust the waiting time is 40 plus days ...a long 40 days AND nights for someone who is mentally ill. But

(1) why are there such unacceptably long waiting times and (2) why such disparity between Health Trust areas?

But there's more....through a freedom of information request.....neither the Eastern Trust or the Northern trust could provide us with information as to what the actual waiting times were. So that would indicate that there is no attempt even being made to monitor and ultimately improve waiting times. Or worse there was a decision made at some level not to record this vital information. The Board needs to clarify whether a target waiting time exists, if so what that target is and how the Board is monitoring Trusts' compliance with any such target.

Then... when all those 'hoops have been jumped through' by a patient, we find...again via FOI..... that there **is** a de-facto cap on the number of sessions a patient can access. Which averages 5-8 sessions. Despite the Board stating through FOI that no such cap exists. And then what happens if a patient genuinely needs 6 months or a years therapy? The still ill patient is cut loose and that's it. Is that it? So much for the much vaunted Hubs. Is it any wonder that we have rising levels of mental ill health and deaths by suicide here in the North.

The #123GP campaign will be seeking urgent answers from the Board to the following questions

- 1. Why has the uptake of funding for in-house counselling provision by GP practices decreased in the past year and how does it intend to address this?
- 2. Why are there significant disparities across Trusts in the uptake of the funding for inhouse counselling and how does the Board intend to address this?
- 3. How does the Board intend to address the unacceptable waiting times for accessing counselling via the Hubs?
- 4. Is there a target waiting time for accessing counselling through the Hubs and how is the Board monitoring Trusts' compliance with any such target?
- 5. Will the Board commit to at least doubling funding for in-house counselling as a first step to addressing gaps in provision?
- 6. How will the Board monitor and evaluate the use of this funding to ensure quality provision of counselling?

We call on the board to answer these questions on or before the 30th of January next year.

And I might end by saying: If I was making a presentation here today on the access to proper and timely mental health treatment for those who can afford to pay for their therapy...for as long as it was necessary and as soon as it was necessary....would I be outlining the same level of inadequacies in the administration of mental health. I doubt it very, very much.

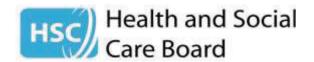
And that is borne out by the fact that in the North the number of suicides amongst the most deprived ten percent was over five times greater than in the most affluent ten percent.

(NISRA report - Suicide Deaths 2016 table 12)

It is a shame on the Health Authorities in the North here that such damning statistics exist for their handling of the mental health crises and suicides ravaging our communities.

But it will be an even bigger shame if we...the ordinary people allow those in power, at whatever level, to continue to condemn those who suffer mental illness to a life of misery or worse.

Finally we would like to invite the board to come to the public launch of our report Equipping GP's with Mental Health Expertise' on Wednesday 30th January 2019 at 11am in the Long Gallery at Stormont. You will receive a formal invitation shortly. Thanks for listening.



MINUTES OF THE HEALTH AND SOCIAL CARE BOARD HELD AT 10.00AM ON THURSDAY 12 SEPTEMBER 2019 AT 10AM IN THE MAIN HALL, ST COLUMB'S PARK HOUSE, 4 LIMAVADY ROAD, LONDONDERRY BT47 6JY

PRESENT: Dr Ian Clements, Chair

Mr Paul Cummings, Director of Finance/Deputy Chief

Executive

Mr Stephen Leach, Non Executive Director Mrs Stephanie Lowry, Non Executive Director Mr Robert Gilmore, Non Executive Director Mr John Mone, Non Executive Director

Mr Brendan McKeever, Non Executive Director

Mrs Lisa McWilliams, Interim Director of Performance

Management & Service Improvement

Ms Marie Roulston, Director of Social Care & Children

IN

ATTENDANCE: Dr Sloan Harper, Director of Integrated Care

Ms L McMahon, Director (Community Planning)

Mrs Mary Hinds, Executive Director of Nursing & AHPs,

PHA

Mr Paul Cavanagh, Assistant Director of

Commissioning (rep Dr McCarthy)

Mr Martin Quinn, Regional Safeguarding Officer (for

agenda item 8 only)

Mrs Jenny Irvine, Interim Chair, Western Local

Commissioning Group

Mr Miceal McCoy, Interim Chair, Southern Local

Commissioning Group

Mr Danny Power, Interim Chair, Belfast Local

Commissioning Group

APOLOGIES: Mrs Valerie Watts, Chief Executive

Dr Miriam McCarthy, Director of Commissioning Dr Melissa McCullough, Non Executive Director

Dr Adrian Mairs, Acting Director of Public Health, PHA

84/19 CHAIR'S REMARKS

Welcoming those present to the September meeting, the Chair reported that, in early September, he had attended an educational conference organised by Hope 4 ME & Fibro Northern Ireland who had been working with the Patient & Client Council, the HSCB and the PHA in a collaborative effort since 2013 to provide specialist NHS services for this large patient population in NI in terms of the development of the new regional specialist Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) service.

The Chair said that conference attendees heard from expert speakers who provided a unique opportunity to learn about the latest cutting edge scientific research trying to provide answers of why ME patients experience an abnormal response to exercise/activity, when compared to healthy controls, or patients with other fatiguing illnesses.

The Chair reported that he had also attended the ICP Leadership Group with Dr Harper and had been struck by the breadth of work being undertaken. He referred to the Northern Trust prototype for an integrated care system being taken forward by Dr Tony Stevens, Chief Executive, NHSCT, and said that this model could potentially be rolled out across the five health economies.

Agreeing with the Chair's comments, Dr Harper commented that TIG had endorsed the approach of the Northern Trust prototype. He acknowledged that the success of the prototype would require new leadership skills, the ability to develop positive relationships and understand differing cultures as well as establishing a learning system. Dr Harper believed that the health and social care system was complex, one which by necessity included hierarchies to ensure accountability but which, in terms of transformation, required more of a network approach. The Northern prototype would help to deliver this.

At the Chair's invitation, Mr Power commented that the discussion had been positive in terms of the principles and ground rules required for working at locality level. However, he said what would be important was the translation from regional to locality planning

and what that would mean in practice. He agreed with the Chair's belief that, although a Northern Trust prototype, there was potential for it to be rolled out across other areas.

The Chair said that HSCB/PHA officers would continue to clarify their roles in the new prototype and bring knowledge and expertise to discussions in moving forward. He added that he intended to have further discussions with the Chief Executive on how the HSCB could influence this work.

Moving to today's agenda, the Chair pointed out that members' approval was being sought to the Delegated Statutory Functions report. He reminded members of the importance of this report which provided an overview of the issues emerging from the delegated statutory functions reports provided by each Trust for the period 1 April 2018 – 31 March 2019. He indicated that Mrs Roulston and Mr Martin Quinn would take members through the detail.

Continuing, the Chair advised that Mr Brogan would join the meeting later to outline the efficiencies to be made through prescribing.

The Chair said that members would recall approving a number of LCG appointments at the August Board meeting. He added that the recruitment exercise had continued and approval was being sought to a further four appointments. If approved, these would then be submitted to the DoH for further consideration.

The Chair said that he wished to use his remarks to pay tribute to Mrs Mary Hinds at what was her last HSCB Board meeting before she retired at the end of the September. He referred to the significant contribution made by Mrs Hinds throughout her career and said that her continuing advocacy for the nursing profession had always been at the forefront of that.

On behalf of the HSCB, the Chair thanked Mrs Hinds for her counsel over the years and wished her every health and happiness for a long and happy retirement.

Finally, concluding his remarks, he asked members to declare if they had a conflict of interest with any agenda items. There were no declarations.

85/19 PREVIOUS MINUTES

The minutes of the previous meeting on 8 August 2019 were **APPROVED** and signed by the Chair.

86/19 MATTERS ARISING

There were no Matters Arising.

87/19 STANDING ITEM: CHIEF EXECUTIVE'S REPORT

In Mrs Watts' absence, the Chair invited Mr Cummings to provide the Chief Executive's report.

Commencing, Mr Cummings said that members would be aware that EU Exit was rarely off the headlines and was changing on a continual basis. He added that health planning in relation to a range of scenarios was also continuing.

Mr Cummings referred to the forum of health and social care organisations convened by the DoH on a fortnightly basis to discuss matters relevant to EU Exit and said that, while preparations for EU Exit had been undertaken previously in anticipation of the exit date of 31 March 2019, arrangements were now being refreshed in the context of the current deadline of 31 October and the possibility of leaving without a deal.

Mr Cummings advised that Board representatives were also involved in other working arrangements with the DoH, including emergency planning, pharmacy, workforce and communications.

He indicated that the 'Operational Readiness Guidance' had been updated to reflect the revised date for departure and said that members had received a copy of this for their information. Mr Cummings added that the guidance was now available on the DoH website and the Board, at the DoH's request, was asked to issue the guidance to the 'Family Practitioner Services' – that is GPs, GDPs, Community Pharmacists and General Ophthalmic Service Contractors. He confirmed that this had been completed and said that, as well as FPS practitioners, the guidance was also issued to independent sector providers of health and social care.

Mr Cummings reported that the main strands of preparation continued to focus on:

- Healthcare supply chain including:
- Supply of medicines and vaccines
- Supply of medical devices and clinical consumables
- Supply of non-clinical consumables, goods and services
- · Cross Border movement and/or free movement of people; and
- Data transfer risks.

He undertook to keep members updated on the key health impacts over the coming weeks.

Turning to Muckamore Abbey Hospital, Mr Cummings believed that it was appropriate to provide a short update in relation to safeguarding at the Hospital. He reported that the PSNI investigation into abuse allegations at the hospital was ongoing and added that there had been 28 suspensions of staff to date.

He indicated that the RQIA had issued improvement notices to the Belfast Trust across three areas staffing, safeguarding and finance.

Mr Cummings indicated that the Belfast Trust had provided assurances that progress had been made over the last 12 months, and had stressed that the care currently provided in Muckamore was safe and compassionate.

Mr Cummings said that the HSCB would continue to work closely with the Trust to monitor the situation, provide support as appropriate, and help to develop a model of care which was receptive to the changing needs of patients.

He added that there was also a dedicated member of staff working alongside the Belfast Trust to drive forward the resettlement and discharge work which was very complex and sensitive. Mr Cummings referred to a recent feature by the BBC last week which had followed a patient journey and believed that the feature had demonstrated very clearly the complexity of the work.

He said that, of the 13 patients identified as being suitable for discharge into the community this year, three had been resettled, a further four would discharged before Christmas, leaving six still to be resettled.

He said that, in addition to this work, the DoH and the HSCB were currently in discussion in relation to the commissioning of an independent review into leadership and governance issues at Muckamore. He advised that Mrs Roulston would provide a further update on this very important issue in the confidential session.

Continuing, Mr Cummings reminded members of the update he had provided at the August Board meeting in relation to the Level 3 Serious Adverse Incident Review carried out by an Independent Panel into the circumstances resulting in the deaths of Michael and Marjorie Cawdery on 26 May 2017.

He reported that Mrs Watts, alongside the Chief Executives of the Southern, Belfast and Western Trusts, met with the Cawdery family on 19 August to offer a formal apology and to discuss how the HSC could address the gaps in mental health provision and improve engagement with families in these very difficult circumstances.

He said it was his understanding that the meeting was very constructive and a number of actions were agreed. Mr Cummings indicated that this important work would be treated as a key priority, and, in moving forward, the HSCB would ensure that there was ongoing engagement with the Cawdery family and other families in similar circumstances.

Referring to the work of the Design Groups, Mr Cummings advised that this had largely been completed and the information issued in early July sets out their proposals and outcomes. He said that the feedback from staff on the communication had been positive but, as expected, there remained some uncertainty over next steps given the broader political context.

Mr Cummings indicated that the drafting of legislation was well underway and continued to make good progress. He said that members would be aware of the complexity of the statutory framework for health and social care which had been amended over the years and believed that there was now an opportunity to simplify it.

Mr Cummings reported that the HR Memorandum of Understanding for the Digital Health and Care teams was now nearing final agreement and should be put in place this month. He advised that the Oversight Board would meet again in September to consider options and set direction for the next phase of the Project, in light of the continued absence of an Assembly.

Mr Cummings also advised that, in order to support staff more widely, a Health and Wellbeing Group had been established and would hold its first meeting on 25 September.

Referring to the public consultation on reshaping stroke and breast assessment care, Mr Cummings said that members would be aware that the DoH had recently led a series of public engagement events across Northern Ireland.

He said that the consultations had closed at the end of August and the DoH would now examine the evidence submitted and decide on the way forward. In addition, he said, the DoH had advised that it was planning further public consultations in the months ahead on the future of day-case surgery services and urgent and emergency care.

Mr Cummings reported that the Board was leading on a project to create a new Regional Model for Adult Learning Disability Services.

He advised that the HSCB was working closely with the five Trusts which provide health and social care services to people across Northern Ireland in hospitals, health centres, residential homes, day centres and other social care facilities. He said that there had also been wide-scale engagement with service users, carers, health and care staff and voluntary and community organisations, seeking individuals' views on what was working well, what could be improved and what was needed to start doing better in order to improve the lives of adults with learning disabilities in Northern Ireland.

Mr Cummings advised that the co-production principles were being used to develop the new model and it was hoped that a report on this work would be produced in early 2020.

Mr Cummings reminded members of the presentation given by Ms Hamilton at the June Board meeting when members had approved the consultation on enhanced trauma services for Northern Ireland and said that the consultation response date had now been extended by a week to 24 September.

He said that members would be aware from the presentation that the HSCB was proposing to improve access to the highest quality trauma services by creating a specialised local trauma team in each of the five HSC Trusts. He explained that the teams would work closely with other statutory HSC services and the community and voluntary sector to deliver nationally and internationally recommended evidence-based trauma treatments across the region with the new services being introduced on a phased approach.

Mr Cummings said that he would encourage victims and survivors of the Troubles/Conflict, as well as anyone impacted by trauma, to take the opportunity to provide their views on the proposals and added that further information was available on the HSCB's website.

Concluding his report, Mr Cummings echoed the Chair's earlier comments in relation to Mrs Hinds' impending retirement and said that he wished to place on record the very significant contribution made by Mrs Hinds to the Board, the Public Health Agency and the wider health service throughout her career and wished her well in her retirement.

The Chair thanked Mr Cummings for his report and invited questions/comments from members.

Mr Leach referred to EU Exit planning and sought further detail on a number of points, including treatment of patients from other jurisdictions; the provision of medicines and how additional costs would be covered.

Responding, Mr Cummings explained that, to date, the only real cost incurred appeared to be staff time and it was envisaged that additional costs would not be significant. He advised that it was his understanding that the DoH had received an additional £300,000 for EU Exit preparation. Mr Cummings explained that HSC was not charged for actual goods until they were used, ie costs did not appear on the Income & Expenditure account and said that this was why a spike in costs was not evident when arrangements were put in place for the previous date of 31 March 2019. He suggested that additional costs might be incurred once the EU Exit had been implemented and added that it would also be necessary to take into currency fluctuations into account.

Mr Leach enquired whether further assistance would be available from the DoH in this regard.

Responding, Mr Cummings advised that this would be an issue for Treasury consideration.

Ms McMahon emphasised that the arrangements were very much being led by the central UK Government with all workstreams being led from London.

Mr Leach referred to those patients who would travel to Dublin for treatment and those patients who would travel from Donegal to access services at the North West Cancer Centre and asked if this would continue.

Ms McMahon confirmed that it was anticipated that such arrangements would continue and she pointed out that they were not EU dependent.

Mr Cavanagh explained that he managed the HSCB patient travel team and had also been involved in the North West Cancer Centre and discussions with CAWT prior to its establishment. He added that EU Exit was very much on the agenda and said that, while there was a need to take a conscious look at the arrangements which needed to be put in place, there was a Memorandum of Understanding between the two organisations, ie the HSE and the Western Trust, and this took precedence. Mr Cavanagh also acknowledged the increase in numbers of people applying to travel outside the UK for services and said that there was the potential for reciprocal arrangements to be put in place with other European countries.

Mrs Lowry said that a recent radio programme had featured some members of a support group who were asking for clarity around the situation. She said that, while she very much appreciated the work being taken forward, perhaps progress was not being effectively communicated to support groups.

Mr Cavanagh acknowledged that, over the last number of months, patients from Donegal had expressed concern as the date for EU Exit drew closer. He advised that patients were speaking directly to their clinicians who offered reassurance but accepted that there probably needed to be more communication with support groups.

Ms McMahon undertook to raise this issue at the ALB EU Exit meeting later that afternoon and suggested that perhaps wider communication needed to be undertaken.

Responding to a comment from the Chair in relation to care homes, Mrs Roulston advised that she had recent met with Trust Directors with responsibility for Older People's Services. She said that, given the volatility previously reported around Four Seasons, Ms Joyce McKee, Regional Adult Safeguarding Officer, had been leading on contingency planning.

With regard to communication, Mr Moore reminded the meeting that the DOH was leading on the communications aspect of EU Exit planning in line with the Department of Health in England and wide Government. He added that the DoH had issued information through NI Direct, a leaflet drop and wider information campaign was planned for October and said that there was a plan to brief MLAs in the coming week.

Dr Harper said that he wished to use the Chief Executive's report to advise members of the move of the Bayview Medical Practice in Londonderry to new premises in the Rath Mor Centre, Creggan, in November. He explained that the current premises were substandard and the practice had felt that it could not wait until the establishment of the new health and care hub planned for the Cityside but had taken the decision to move to new premises now. Dr Harper said that the appropriate consultations had been undertaken.

Mr McKeever declared his Board membership of the Rath Mor Business & Community Enterprise Centre and said that there was a sense of excitement at the new location for the practice. He believed that there would be great potential for the Creggan and its surrounding environs.

The Chair thanked Mr Cummings for his report which was **NOTED** by members.

88/19 STANDING ITEM: FINANCE: HSCB FINANCIAL REPORT ENDING 31 JULY 2019 (MONTH 4); TRUSTS' FINANCIAL REPORT ENDING 30 JUNE 2019 (MONTH 3)

At the Chair's request, Mr Cummings reported on the HSCB Financial position ending 31 July 2019. He advised that, for the four

month period, the Board was reporting a deficit of £0.7 million and added that this related primarily to expenditure ahead of profile on ringfenced budgets combined with a shortfall on the pharmacy efficiency savings, both of which were partially offset by surpluses in other areas, including HSCB Administration.

Mr Cummings reported that small surpluses had been reported on the General Medical, General Dental and General Ophthalmic Services budgets whilst pressures were being experienced within the ECR budget despite significant investment in the budget. Mr Cummings advised that funding would be retracted from this budget and allocated to the Belfast Trust on a recurrent basis for Robotic Prostatectomies in 2019/20.

Mr Cummings reported a surplus of £0.2 million for the year to date on the HSCB Administration budget and said that this was largely caused by vacant posts. He explained that the implementation of Confidence & Supply monies had resulted in temporary posts and said that this would give him cause for concern.

Moving to the Trusts' Finance report for the period ending 30 June 2019, Mr Cummings reported that the overall financial position showed a cumulative deficit of £27.6 million to the end of June with an overall provisional projected deficit position of £95 million.

He indicated that the main issues lay with the Belfast Trust which had a deficit of approximately £30 million and the Western Trust with a deficit of approximately £35 million. Mr Cummings said that HSCB Finance staff continued working with DoH colleagues to finalise the figures to be included in Trust Delivery Plans. He added that, in order to address the magnitude of savings to be achieved by Trusts, it might be necessary to consider high impact savings at future Board meetings.

Mr Leach referred to the savings to be achieve in-year, in addition to the savings rolled forward from the previous year, and questioned whether there was a case for acknowledging the impossibility of achieving such significant savings and introducing a flat baseline.

Responding, Mr Cummings agreed with Mr Leach's comments and said that there was no prospect of Trusts making such significant savings without having to consider high impact savings. He said that, while the HSC system continued to operate on one-year budgets, similar scenarios would arise year after year and he

believed that the current financial position was as a result of continued undelivered savings.

Mr Cummings said that the system was repeatedly having to find slippage to fund savings and inequalities existed as a result.

Mr Leach referred to the 'turnaround programme' to be put in place in the Western Trust and asked if this had commenced.

Mr Cummings confirmed that a turnaround manager had been in post for some time and the current position was that the Trust was on plan to save £6 million in-year and had a significant turnaround programme in place.

The Chair said that the challenges facing Trust Boards when considering their respective Trust Delivery Plans and the potential for high impact savings should not be underestimated. Likewise, he said, when Trust Delivery Plans came to the Board for consideration and he added that the workshop scheduled for 1 October 2019 would prove helpful in this regard.

Mr Mone referred to announcements at Westminster of increases in health service spending and asked if NI would benefit from such announcements.

Responding, Mr Cummings said that there had been an overstatement of how much was real growth. He reminded members that any investment from Westminster was put into a NI block and it was then the Department of Finance, in the absence of a Minister or a NI Executive, which would take decisions as to how best to allocate funding. Mr Cummings referred to a HFMA paper which suggested that, over the period of the NI Assembly, health had not received its fair share of funding.

The Chair thanked Mr Cummings for his report and members **NOTED** the HSCB Finance Report ending 31 July 2019 (Month 4) and the Trusts' Finance Report ending 30 June 2019 (Month 3).

89/19 STANDING ITEM: HSCB PERFORMANCE REPORT ENDING JULY 2019 (MONTH 4)

Introducing this agenda item, Mrs McWilliams advised that, while the Performance Report before members was in its normal format, she had prepared a report for consideration at the DoH Top Management Group (TMG) and she undertook to share this with members. She explained that the report for TMG provided further detail on the key challenges and issues facing the health and social care system and suggested that members might find this more helpful than the current report.

Turning to elective and diagnostic services, Mrs McWilliams reported that waiting lists continued to increase with 226,000 patients waiting longer than 9 weeks for an outpatient appointment and 100,000 patients waiting longer than 52 weeks. She added that, in relation to inpatient/daycase appointments, 59,000 patients were waiting longer than 13 weeks and 24,000 patients longer than 52 weeks.

Mrs McWilliams advised that £14 million had been allocated from Confidence & Supply monies and added that the spend to-date was on track with £4.1 million allowing an additional 19,500 interactions/interventions.

She said that TMG had approved an allocation of £2 million from slippage to direct at AHP waiting lists which would allow further progress on last year's performance. Mrs McWilliams said that, while the numbers waiting for AHP services were steady, the rate of increase had been lower than in other specialties, ie an increase of 1,000 patients at the end of March.

Mrs McWilliams said that, at a previous meeting, she had referred to a pilot being undertaken in terms of waiting list validation with funding having been provided to Trusts for a small administrative resource to undertake a validation exercise at the start of August over a four-week period. She indicated that 1,380 patients had been removed from the waiting list as a result which, when extrapolated, represented 6% of the total number of patients waiting.

Continuing, Mrs McWilliams reported that there had been a deterioration in terms of delivery of core and said that this had been impacted upon by issues relating to workforce and taxation. She pointed out that, while the South Eastern, Southern and Western Trusts had performed ahead of their performance trajectories in the period April – July in terms of assessment and treatment, all Trusts had forecast a deterioration at the year end as a result of issues relating to workforce and capacity.

Mrs McWilliams reported that, during July 2019, 2,564 patients had waiting longer than 12 hours in ED. She acknowledged that, while this was a reduction from the previous month (2,835), the figure was significantly higher than the same month last year (1,868). She advised that regional transfer of care work was now being transferred to the remit of the CMO and CNO and added that a meeting was being held in the coming days to discuss this work further.

Mrs McWilliams referred in particular to the four-hour standard and reported that regionally 67% of patients were treated and discharged, or admitted within four hours. She added that this was a marked reduction on the same month last year when the figure had been 72%.

Mrs McWilliams reported that there had been a 2% increase, ie 5,818 attendees, in ED attendances during the first four months of this year compared to the same period in 2018/19 and added that there had been a 16% increase over the last five years.

She indicated that winter plans were to be submitted by 17 September for consideration by HSCB/PHA staff. She referred to a learning event which had been attended by over 70 Trust staff at which issues including GP out-of-hours services; increases in the numbers of Early Alerts; work/life balance and pension being discussed.

Turning to cancer services, Mrs McWilliams reported that, regionally during July 2019, 81% of urgent breast cancer referrals were seen within 14 days and she noted that 100% of urgent referrals had been seen in the Belfast, South Eastern, Southern and Western Trusts. However, she pointed out the Northern Trust had only 25% of urgent referrals being seen within 14 days. She added that, where patients had not been seen within 14 days, the longest wait had been 27 days. Mrs McWilliams indicated that figures for August would now 47 breaches with the longest wait 19 days. She advised that funding had been provided for an additional surgeon but it was likely to be February 2020 before the individual would take up post.

Mrs McWilliams further reported that, in relation to the 62-day standard, regionally 53% of patients had commenced their first definitive treatment.

Moving to mental health services, Mrs McWillliams indicated that the deteriorating trend was expected to continue in mental health services.

She referred specifically to CAMHS services and reported that 671 patients were waiting longer than 9 weeks at the end of July compared to 487 patients waiting at the end of March. She added that there had been a 22% increase in referrals and said that the demand/capacity gap and recruitment and retention of staff had impacted upon these services.

Mrs McWilliams alluded to adult mental health services and said that there had been a continued reduction in the number of people waiting longer than nine weeks to access adult mental health services with, 1,214 people waiting at the end of July compared to 1,267 at the end of June. However, Trusts predicted an increase in those waiting by the year end. Mrs McWilliams advised that work was being taken forward by the Mental Health and Learning Disability Improvement Board to scope delayed discharges and staff vacancies. She acknowledged that, while some transformation funding had been allocated to this service area, the Board's assessment was that it would not have a material impact on the numbers waiting.

Mrs McWilliams reported that 331 patients were waiting longer than nine weeks for dementia services compared to 343 at the end of June. She pointed out that three quarters of the total number of patients waiting were within the South Eastern and Western Trust areas and she added both Trusts were forecasting an increase in waits in the coming months.

Turning to psychological therapies, Mrs McWilliams reported that there had been an increased demand from adult mental health and adult health psychology and added that the complexity of cases had also increased.

Thanking Mrs McWilliams for her report, the Chair invited comments/questions from members.

Mrs Lowry commented that the report was not an encouraging read. She referred in particular to CAMHS services and the fact that the numbers of patients waiting to access Step 3 were very high. She sought clarification on the longest wait experienced by patients. Mr

Lowry also commended the waiting list validation exercise undertaken by Trusts.

Mrs McWilliams undertook to clarify the position and advise Mrs Lowry accordingly. In relation to the validation exercise, she explained that all Trusts had received additional funding to undertake this work. She advised that correspondence had been forwarded to patients to verify personal details but also enquiring whether they continued to wait for assessment/treatment and whether their condition still required investigation/treatment. As a result, 1,380 patients had been removed from waiting lists.

Mrs McWilliams said that when one extrapolated the results, it meant 6%, ie approx 14,000-15,000, patients being removed from current waiting lists. She stressed that it was important to make every effort to maximise current capacity where there were acknowledged demand/capacity gaps. She believed that Trusts should be routinely undertaking waiting list validation exercises and commented that it did not involve significant resources.

Mr Leach referred to the ongoing issue of taxation and asked whether Mrs McWilliams believed this acted as a disincentive to medical/nursing staff to undertake additional work. He further enquired whether the issue was being addressed by the DoH. Mr Leach also referred to diagnostic performance and the fact that the Western Trust had achieved 78% performance against a standard of 75%. He asked if there was any potential for the Trust to assist other Trusts in addressing some of their pressures in this area, for example the Northern Trust where performance was 39%.

Mrs McWilliams acknowledged that there had been ongoing discussion between the Western and Northern Trusts in relation to the possibility of the Western Trust taking on some of the Northern Trust diagnostic work and said that this point had been made by the Permanent Secretary in a recent meeting with Trusts. She said that the Board's focus had been on equality of service and said that it was not acceptable to have patients potentially coming to harm because they lived in a different Trust geography. Mrs McWilliams referred to work being taken forward by a DoH HR workforce planning group to assess core services and assess how many PAs were being downturned as a result of the taxation issues.

The Chair reminded members that, following discussion of this issue at a previous Board meeting, correspondence had been forwarded

to the Chancellor of HM Treasury highlighting the impact on health and social care services in Northern Ireland. He said that, while an element could be resolved locally through superannuation, it also required HMRC to revise existing regulations.

Mr Cummings, agreeing with the Chair's comments, indicated that there was potential for individuals to opt in/out of the scheme if a more flexible scheme existed. However, he said, it was not likely that such a scheme would be introduced in the near future.

Mr Mone commented that the numbers of patients waiting longer than 52 weeks for daycase treatment had remained unchanged. He referred to the fact that, over the last number of months, Mrs McWilliams had reported on the continuing deterioration of waiting lists. However he said it was interesting to note the current position in Northern Ireland compared to Scotland, for example, where it appeared that regionally 80% of the target for inpatient/daycase treatment was being met compared to 25-30% in Northern Ireland. Mr Mone suggested that Scotland was more comparable to Northern Ireland in terms of population profile and rurality and asked if there was an unfair distribution of investment in Northern Ireland compared to other countries in the UK.

Responding, Mrs McWilliams said that services in Northern Ireland had been benchmarked against those in England and Scotland. She indicated that, apart from the funding, one significant difference was the recurrent investment in services in other countries and she said that Scotland had recurrent investment in elective services. Mrs McWilliams acknowledged that the current funding model and the lack of recurrent investment had had a material impact on the significant backlog.

Mr Cummings pointed out that Scotland had a higher funding per head of population than Northern Ireland but England/Wales did not. He indicated that Northern Ireland had also been impacted upon by staffing difficulties more so than its counterparts. Mr Cummings reminded the meeting that Northern Ireland health and social care did not have a long-term financial plan but operated on an annual financial and planning cycle. He believed there was a need to be more focussed on the need for a long-term financial plan and said that the issue was not receiving the attention it required.

Mrs Irvine commented that, very often, the first area earmarked for savings was the Trust administration budget and she suggested that these individuals may have previously undertaken some validation work.

Responding, Mrs McWilliams explained that every consultant post had an element of administrative support included. However she acknowledged that Trusts very often targeted administrative budgets for savings and accepted that nursing/clinical staff were now undertaking administrative tasks because they did not necessarily have access to the relevant staff on a daily basis.

The Chair thanked members for their comments and Mrs McWilliams for her report which was **NOTED** by members.

90/19 DELEGATED STATUTORY FUNCTIONS REPORT: 1 APRIL 2018 – 31 MARCH 2019

The Chair welcomed Mr Martin Quinn, Children's Programme Manager, to the meeting.

At the Chair's invitation, Mrs Roulston acknowledged the work of the team in the Social Care Directorate and the ongoing work within Trusts in this important area. She indicated that the report very much reflected the challenges and pressures within the HSCB Performance Report.

Mrs Roulston explained that the report provided an overview of the issues emerging from the Delegated Statutory Functions (DSF) reports provided by each Trust for the period 1 April 2018 to 31 March 2019. She reminded the meeting that Trusts reported annually in a specified format on the full range of Delegated Statutory Functions, and every six months on any emerging issues, risks developing or issues identified in oversight meetings. Mrs Roulston added that these updates incorporated reporting on corporate parenting responsibilities as set out in the DoH Circular CC3/02. She added that Circular CC3/02 had been reviewed and the new Circular OSS 01/18 had been introduced and reported on from 1 April 2019 onwards.

Referring to the reporting structure, Mrs Roulston said that the Board continued to work collaboratively with the Trusts through a Governance Forum to address quality and consistency in DSF reporting and to take forward actions to strengthen social care governance at a Trust and regional level. She advised that the Board had agreed an action plan with each Trust to support areas

for improvement and progress on these was being monitored through local meetings between Board and Trust staff.

She indicated that there were a number of issues highlighted in individual Trust reports and said these would be reflected in Trust Action Plans and progress monitored on a regular basis.

Mrs Roulston said that, in addition to these, challenges and pressures were highlighted by each Trust including:

- Domestic Violence linking with the DoH work on the implementation of the regional strategy;
- Children with complex needs, including placement options and domiciliary care;
- Placement availability for LAC issues exist across fostering, residential, 16 plus and children with a disability;
- Lack of investment in CAMHS & Children's Disability Services;
- Transitions to adult services for children with SEN;
- Unallocated cases rise in number across the region;
- Workforce pressures across a spectrum of children's and adult's services - Transformation monies may create further challenges to core services;
- Domiciliary care significant challenges in accessing timely and appropriate care packages for adults;
- Care Homes challenges in securing placements within care homes, issues around the regional rate and the impact of planned as well as unforeseen closures;
- Mental Capacity Act /Deprivation of Liberty issue around Trusts being required to develop the infrastructure to support Trust Panels for Deprivation of Liberty in line with the requirements of the Mental Capacity Act (to be enacted October 2019).

Mrs Roulston indicated that Trusts had reported increased pressures due to rising demand and complexity of need across all Programmes of Care. She said that the issue of workforce, recruitment and retention had been raised by every Trust and would inform the Departmental led workforce review.

Mrs Roulston pointed out that each Trust had included a range of innovative projects to improve the delivery of statutory functions and the outcomes for service users and cares. She said that work was ongoing with the aim of sharing the learning across Trusts.

The Chair referred to the significant amount of information within the DSF report and conveyed his appreciation to all involved.

Mr Quinn said that he would echo the comments made by Mrs Roulston. He referred to the pressures within workforce and said that these had been exacerbated with the allocation of Confidence & Supply monies resulting in staff moving to new posts and leaving gaps in staffing structures.

As well as the pressures and challenges already highlighted by Mrs Roulston, Mr Quinn pointed out that there had been an increase in the number of children defined as being 'in need'. He referred to the plethora of procurement contracts within the Board and Trusts and said that further work was required to ensure there was a more fully integrated strategic direction. Mr Quinn said that particular pressures within long-term and respite care had been highlighted and added that work would be taken forward by the Social Care Directorate in this regard. He also alluded to the transition from children's to adult services and said that further work was needed to ensure as smooth a transition as possible. He suggested that not all transitions should take place at 18 years and that the individual's needs should be paramount.

Continuing, Mr Quinn referred to CAMHS and said that the number and complexities of referrals were increasing. He pointed out that the NICCY report had responded to these pressures and the Board was working alongside the DoH and partner agencies to address a number of the recommendations. Mr Quinn said that, while not all recommendations were resource dependent, it was dependent on having the appropriate workforce.

Mr Quinn said that the team was working hard to introduce and roll out signs of safety training using a more inclusive approach and engaging in partnership with parents and families to do so. He commented that work was being taken forward in relation to the recruitment and retention of foster carers, in particular specialist foster parents. He said that there was a need to look at the structure of children's services across the five Trusts and added that this had been identified by the DoH as a priority in moving forward.

The Chair referred to social prescribing and, while he very much appreciated the statutory function aspect of the work undertaken,

asked if there was a move to use of social prescribing and the assets available to communities.

Responding Mr Quinn emphasised the importance of engagement and said that discussions were ongoing through the NICCY action plan with a view to strengthening engagement with young people and parents.

Mr McKeever referred to his work with families of children with a disability and said that it was only through engagement that one gained an understanding of their needs. He asked whether there was a mechanism in place which would allow children remain within children's services until such times they were comfortable with adult service provision. Mr McKeever suggested that these issues had been ongoing for some time and said that effective engagement might have highlighted some of these issues. He further suggested that if issues were addressed in a legalistic manner, transition tended not to work.

Responding, Mr Quinn said that, from a children's service perspective, the focus was on the assessment of need and was not condition specific. He said that when a young person transitioned to adult services, the transition was vitally important and said that it was also important to understand the family's experience.

Mrs Roulston cited autism services within the Southern Trust and said that these were provided for individuals up to 30 years old. She referred to the request from the DoH to review children's services structures within Trusts and suggested that this work would highlight good practice which could potentially be rolled out to other Trusts.

Mrs Lowry welcomed the report and commended the wealth of information contained therein. She said that, over the years, the complexity of the challenges and pressures faced by the service had increased significantly. She referred to the Deprivation of Liberty and sought further detail on this.

Responding, Mrs Roulston said that the Mental Capacity Act had been introduced for some time and explained that, because the legislation had not yet been implemented, individuals' liberty had been deemed as being restrained. She said that the DoH had made it clear that it had to be introduced by 1 October 2019. Mrs Roulston referred to the significant training that would be required

and said that the DoH was leading on training which would be rolled out across Trusts. She said that she was making arrangements for SMT to receive some awareness training at a future meeting in relation to the Mental Capacity Act. Mrs Roulston said that implementation of the Act would have implications for Emergency Department, nursing and residential homes for example and clarified that it was not specific to children's services.

Mrs Lowry referred to the fact that a number of children who had been designated as 'Looked After Children' were in fact looked after in their own home.

Mr Quinn acknowledged the challenges faced by the service in this area and said that many children were looked after at home as a result of a Care Order. He said that a recent exercise had looked at children cared for at home as a result of a Care Order and a number of recommendations had been made.

Mrs Roulston further clarified that, on occasions, children may have been looked after in foster care and now resided at home because the Care Order had not yet been revoked by the court. She added that there could also be capacity issues within the social care team which had prevented an application being made to the court to revoke the Order.

Mr Mone welcomed the report and described it as comprehensive and informative. Alluding to the HRPTS system in use for recruitment, he referred to the criticism from Trusts around the time involved in recruiting posts and asked if any progress had been made in this area. Mr Mone also pointed to vacancy control impacting on staffing levels, leading to the employment of agency staff which resulted in higher costs being incurred.

Mrs Roulston advised that she had recently attended a meeting which had provided an update on the various workstreams being taken forward to resolve these issues. She acknowledged that challenges existed in the recruitment of temporary staff and said that on occasions it was quicker to recruit through an agency.

Mr Leach believed that the report provided a very comprehensive picture of not only Looked After Children but the associated wider issues. He referred to the closure of the Board and asked what arrangements were being put in place and whether the Trusts would report directly to the DoH on DSF.

The Chair clarified that such a change in reporting relationships would require the introduction of a new Act. He said that, in his view, the functionality that currently existed under the 2009 Act could not be subsumed without the introduction of a new Act. The Chair said that, while transfers could take place through hosting arrangement in terms of employment, the legalistic statutory function would require primary legislation making the PHA the organisation incorporating the DSF function.

Responding to a further question from Mr Leach, Mr Cummings advised that the writing of the required legislation had commenced and said that Mrs Roulston had met with DoH colleagues to discuss in detail. He pointed out that the legislative process could take up to 18 months from the time the NI Assembly was reinstated.

Mrs Roulston, agreeing with the comments made by Mr Cummings, confirmed that DoH barristers were looking at the legislation with particular reference to DoH and said that one should not underestimate the complexities of such work.

Following this discussion, members **APPROVED** the Delegated Statutory Functions report for the period 1 April 2018 – 31 March 2019.

The Chair thanked Mr Quinn for his attendance and he withdrew from the meeting.

91/19 VOLUNTARY AND COMMUNITY SECTOR FUNDING IN 2019/20

Introducing this agenda item, Mr Cummings reminded the meeting that the Board oversaw a range of contracts with voluntary and community sector providers. He said that, entering into 2019/20, there were 54 contracts in place with a total value of approx £18 million per annum and added that these contracts were for both residential services and non-residential services of which there were seven and 47 respectively.

Mr Cummings indicated that, each year, voluntary and community contracts for residential and non-residential services had been analysed between those that had, through the procurement process, agreed contractual values, including provision for any uplift, and those that were a roll forward of current contract values and which may be considered for an uplift.

Referring to the proposed approach for 2019/20, Mr Cummings explained that the Board's assessment would be to apply an uplift to those community and voluntary contracts for residential and non-residential services which did not have agreed contract values already in place for 2019/20.

He advised that residential service providers included the four hospice providers which had highlighted that the recent 2018/19 Agenda for Change(AfC) pay award may create workforce challenges for them as they would need to match the uplift to try to ensure they could retain/recruit staff.

Mr Cummings said that, in addition to this, the increased employer contribution (16.3% to 22.5%) on the HSC Pension scheme for 2019/20 had also been highlighted as an additional cost. He indicated that this was a HSC wide pressure and the DoH was currently working with the Department of Finance to secure further funding to meet this additional cost for the HSC.

Consequently, he explained, in establishing an uplift for hospices for 2019/20, the HSC Pensions issue was not being considered at this point until further clarity on the funding to HSC for this pressure was advised.

Mr Cummings pointed out that, on the basis that approximately 75% of hospice costs were pay related and that the AfC uplift would apply to these, and applying 2% uplift to non pay costs, then the weighted uplift to contract values would be approximately 3.0%

He indicated that, in respect of remaining contracts, the current CPI rate at June 2019 was 2.0% and it was proposed that an uplift of 2.00% could be applied to the respective closing 2018/19 contract values and noted that the uplift for these contracts was to be reviewed on an individual basis.

Mr Cummings concluded that, on the basis of these proposed uplifts, the cost for an inflationary uplift to voluntary and community contracts would be £0.237 million in 2019/20.

Members indicated their agreement with this and **APPROVED** the following:

- An uplift of 3.00% for 2019/20 to apply to hospice providers, backdated to 1 April 2019;
- An uplift of 2.00%, to apply, subject to individual review, to voluntary/community residential and non-residential providers in 2019/20, backdated to 1 April 2019, excluding procured contracts with already agreed contract values;
- An uplift is not to be applied to those contracts that have an agreed procured contract value and/or where a fixed uplift already applies for 2019/20.

92/19 APPOINTMENTS TO LOCAL COMMISSIONING GROUPS

Mr Cummings sought members' approval to the following appointments to the South Eastern, Northern and Southern LCGs:

South Eastern LCG

- Dr Michael Johnson GP representative
- Dr Jonathan Howe GP representative

Northern LCG

• Dr Samuel Hamilton - GP representative

Southern LCG

Dr Maeve Kelly – Dental representative

Members **APPROVED** the appointments and noted that the Chief Executive would now write to the DoH seeking approval to these appointments.

93/19 25 YEAR SERVICE AWARD

Introducing this agenda item, Mr Cummings said that, within the HSCB, staff were recognised, both informally and formally, for their vital contribution to the provision of services. However he said it was important to continually review and build on this culture of recognition.

Mr Cummings said it had been suggested that one way of recognising staff contribution would be through the introduction of a 25 years' service award to acknowledge those staff who had

demonstrated a commitment to HSC, by remaining in service for this period of time. He clarified that the additional leave would be awarded to staff who had completed 25 years' service with HSC/NHS and added that service did not have to be continuous.

Mr Cummings added that it had also been suggested that a working group should be set up within each organisation to explore further ways of meaningfully acknowledging staff and said that it was envisaged that this could become part of the remit of the HSCB Health & Wellbeing group.

Mr Cummings pointed out that, if approved, those staff who had reached 25 years' service would receive an additional week's annual leave on a one-off basis. He added that this award reflected existing arrangements in some of the Trusts. He indicated that it was acknowledged that there would already be a number of staff with more than 25 years' service and who would not previously have had their service marked by receiving this additional weeks' leave.

Therefore, he said, it would be intended that these staff were included in the scope of this award. Furthermore, Mr Cummings advised, it was proposed that, as a transition arrangement in order to operationally manage the larger number of staff receiving this additional leave, staff with over 25 years' service at date of implementation could take the additional leave over a two year period, ie before March 2021.

Members welcomed this initiative and **APPROVED** the introduction of a 25 years' service award.

94/19 HSC EFFICIENCIES – PRESCRIBING IN PRIMARY CARE

The Chair welcomed Mr Joe Brogan, Head of Pharmacy and Medicines Management, and Dr Brenda Bradley, Pharmacy Lead – Medicines Governance and Public Health, to the meeting.

Drawing members' attention to the paper, Mr Brogan set out the context of prescribing efficiencies and said that, since the DoH had devolved responsibility for the primary care drugs budget on 1 July 2010, the Board had delivered significant levels of prescribing efficiencies.

He referred to the Medicines Optimisation Regional Efficiency (MORE) Programme Board chaired by the Chief Pharmaceutical

Officer (CPO) and consisting of senior pharmacy and finance officers from Trusts and HSCB and said that this group provided the governance oversight. Mr Brogan added that BSO PaLS was also represented on the Programme Board given the focus in secondary care on medicines procurement efficiencies.

Mr Brogan indicated that the delivery of such an ambitious efficiency plan has been challenging and required a greater degree of clinical engagement, particularly from HSC Trusts.

Referring to the efficiencies achieved in 2018/19, Mr Brogan reminded the meeting that the overall pharmacy efficiency target for the Board was £32 million and added that this figure had included a £4.5 million shortfall from the previous financial year.

He explained that a plan, encompassing some 58 projects, had been drawn up to deliver £8 million of efficiencies in primary care drug costs. He said that other efficiencies had been required to be delivered in order to address the overall pharmacy efficiency target for 2018/19.

Continuing, Mr Brogan advised that £26.2 million of efficiencies were achieved in 2018/19, with shortfall of £5.8 million. However he clarified that the shortfall in efficiencies of £5.8 million only applied in-year and said that the recurrent savings delivered in 2018/19 were estimated at £32 million, with no recurrent shortfall therefore having to be considered for 2019/20.

Mr Brogan went on to outline the plan and saving target for 2019/20 and advised that the DoH had indicated that £20 million of efficiencies must be delivered in 2019/20, split between primary and secondary care as £12 million and £8 million respectively.

Mr Brogan believed that, in relation to the target for primary care, and given the delivery of efficiencies in previous years, the potential for efficiencies and the capacity for changes to be made was considered extremely challenging.

He advised that the PERT Plan (Pharmaceutical Efficiencies Review Team) had been developed with targeted efficiencies of £5 million. However he said this was significantly short of the £12 million required by approximately £7 million.

Continuing, Mr Brogan advised that the delivery of the plan was dependent on a number of issues and he described these as being:

- HSCB Pharmacy Advisers, Practice Support Pharmacists (PSPs) and the Medicines Management Dietician Team (MMDT) progressing activity as outlined in the PERT plan.
- GP Federation Practice Based Pharmacists' (PBPs) implementation of actions to support delivery of primary care drug efficiencies.
- GPs engaging with HSCB Pharmacy Advisers during GP practice visits and subsequent actions agreed for practice staff e.g. PBPs, nurses and GPs. These visits provide an opportunity for the advisers to discuss opportunities for efficiencies with GPs, practice pharmacists and other practice staff.
- Actions by Trusts to support delivery of efficiencies with a key focus on areas identified under the 'Boost' work-streams where Trusts agreed to support activity in respect of cost-effective choices and a number of identified low volume, high cost items.
- There have been a number of areas that have been suggested for reconfiguration which would require policy change. One significant issue is the handling of pricing of certain generic medicines which would obviate the need for GPs to initiate cost effective changes to alternative branded medicines. One example of this could yield approx. £1 million efficiencies. It is proposed that this is further explored with DoH and CPNI.

Mr Brogan described the pressures impacting on the above in terms of delivering the planned efficiencies. These included pressures within GP practices; HSCB staff shortages; delays in recruitment of the MMDT resulting in efficiencies associated with nutrition workstream not being realised; transfer of HSCB practice support staff to the NHSCT and difficulties recruiting PSPs to this team (currently at 20% capacity) along with uncertainty over the closure of the HSCB had made it difficult to resource work.

Mr Brogan said that Board officers continued to try to ensure adequate staffing resources within HSCB; that the NHSCT team was delivering against their targets and that GP Federations and HSC Trusts fully understood and supported the efficiency programme.

Concluding his presentation, Mr Brogan said that it was clear that there was a greater degree of engagement by GP Federations and HSC Trusts in relation to the efficiency requirement which he believed would be a pre-requisite to accelerating the efficiency programme, thus building upon it in the coming year.

The Chair thanked Mr Brogan for his presentation and invited comment/questions from members.

Mr Gilmore said that Mr Brogan had referred to the need for policy changes on a number of occasions and he asked if there had been any progress on this.

Responding, Mr Brogan acknowledged that there had not been as much progress as he had hoped for. He said that he had continued to raise the need for change in a number of policy areas through the MORE programme.

Mrs Irvine referred to a report published by Public Health England which linked drug dependency and areas of deprivation and asked if there was anything specific in relation to Northern Ireland.

Mr Brogan said that there were similar issues in Northern Ireland. However he said that one of the most significant challenges related to access through the internet to prescription drugs. He advised that a publicity campaign had been undertaken in relation to the importance of taking prescribed medicines only and said that this work would be progressed through local communities and a community development approach. Mr Brogan said that work was being taken forward in conjunction with Healthy Living Alliance in pilot form.

Mrs Lowry said that she had found Mr Brogan's presentation to be helpful and asked if the impact of the work of Practice Based Pharmacists (PBP) was yet evident.

Responding, Dr Bradley advised that Wave 5 of recruitment had now been completed with Wave 6 to commence in the 2020/21 year. She reminded the meeting that all practices have access to PBPs at some level. She acknowledged the difficulty in trying to evidence their impact and said that the Steering Group, chaired by Dr Harper, had the evaluation of PBPs as a standing agenda item on its agenda.

Continuing, Dr Bradley acknowledged that PBPs had certainly contributed significantly to safety and efficiency within practices, for example by undertaking medicine reviews of those at risk, eg the elderly and those on multiple medicines, patients being discharged from hospital. This, she said, had enabled a significant amount of GPs' time to be freed up from tasks now undertaken by PBPs. Dr Bradley said that PBPs had also been successful in contributing to reduction of antibiotic prescribing and said that this had reduced by 8% over the last year. She undertook to share with members an interim review and agreed to keep members updated.

Mr Leach commended the initiative and said that, since the introduction of PBPs in 2010, impressive achievements had been made. He pointed to the fact that, despite the HSCB highlighting it would be able to achieve savings of £5-8 million, the DoH had advised that its target was £12 million and he asked how DoH officials had arrived at such a target. Mr Leach also suggested that if DoH officials were involved in the various groups looking at potential areas of savings, they must be aware of how feasible such a savings target would be.

Mr Cummings pointed out that the focus was to ensure the health and social care system achieved a balanced position at the year end.

The Chair thanked Mr Brogan and Dr Bradley for their attendance and they withdrew from the meeting.

95/19 ITEMS FOR INFORMATION

- (i) Minutes of Local Commissioning Group
 - Western 12/6/19

Members **NOTED** the content of the above minutes.

96/19 DATE OF NEXT MEETING

The next meeting of the Health and Social Care Board will take place on Thursday 10 October 2019 at 10.00am in the Boardroom, HSCB, 12/22 Linenhall Street, Belfast BT2 8BS.

97/19 ANY OTHER BUSINESS

(i) Mrs Hinds' retirement

Thanking the Chair for his kind words earlier in the meeting, Mrs Hinds said that Non Executive Directors had been respectful in their challenge and generous in their support throughout the years. She conveyed her thanks in particular to Director colleagues, both past and present, for their continuing support and wished everyone well into the future.

98/19 RESOLUTION TO GO INTO CONFIDENTIAL SESSION

The Board **APPROVED** a resolution to go into Confidential Session to consider a number of confidential items of business.

This being all the business, the Chair closed the meeting at 12.50pm.

SIGNED:			
DATE:			