

**MUCKAMORE ABBEY HOSPITAL INQUIRY
WITNESS STATEMENT**

Statement of Fiona Boyle

Dated this 27th day of April 2023

I, Fiona Boyle, make the following statement for the purpose of the Muckamore Abbey Hospital ("MAH") Inquiry ("the Inquiry").

In exhibiting any documents, I will number each document so my first document will be Exhibit 1.

Section 1: Connection with MAH

1. I have no direct connection to MAH. However, I have information to provide to the Inquiry which I believe is relevant to Terms of Reference. In particular, Number 16 (Resettlement), "*The Inquiry will examine the adequacy and workings of the policy and process of discharge and resettlement of patients of MAH.*"

Section 2: Relevant Time Period

2. The relevant time period that I can speak about is between 2013 and 2017.

Section 3: Information

3. I am Principal Consultant in Fiona Boyle Associates, which has been operating since May 2002, undertaking social research, evaluations and policy work in

the fields of housing, homelessness, learning disability and criminal justice. I attach a copy of my Curriculum Vitae at Exhibit 1.

4. I was commissioned, alongside John Palmer (who is now retired), by the Northern Ireland Housing Executive ("NIHE") to undertake research and produce two reports in relation to the resettlement programme in Northern Ireland. Our first report, co-authored by John Palmer, Alicia Woods, Steve Harris and myself, "The Hospital Resettlement Programme in Northern Ireland after the Bamford Review – Part 1: Statistics, Perceptions and the role of the Supporting People Programme" dated October 2014 (the "2014 Report"), is attached at Exhibit 2. Our second report, co-authored by John Palmer and myself, "The Hospital Resettlement Programme in Northern Ireland after the Bamford Review – Part 2: The Experience of Learning Disabled People Resettled from Long Stay Hospitals" (the "2017 Report") is attached at Exhibit 3.
5. Research for the 2014 Report had three elements; firstly a desk-based review of all relevant literature and policy documents. Secondly, quantitative in nature, analysing all available data, and finally qualitative based consultations with policymakers, programme planners, service commissioners and senior managers involved in the resettlement, and in the delivery of housing and support services to resettled people. Research for the 2017 Report included interviews with resettled people, and in some cases, their families or staff members in the relevant services. Care was taken in the research to not identify individual patients or people who were resettled.

Background

6. By way of background, 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"), by an independent committee led by Professor David Bamford (the "Bamford Review") provided strong evidence of the need for comprehensive reform of services for the learning-disabled people

in Northern Ireland. In line with the Bamford Review recommendations, service developments for learning-disabled people since the 2000s were focussed on the resettlement of people living in a long stay hospital. A key objective of the Bamford Review report was "...to ensure that an extended range of housing options is developed for people with a learning disability", (*Bamford (2005), op. cit., page 8, para1.15*).

7. The NIHE played a significant role in helping to deliver the post Bamford Review resettlement programme. NIHE officers worked alongside the Health and Social Care Board Trusts in commissioning new services for learning-disabled people being resettled. A significant portion of the social housing new build programme, which was planned by the NIHE, was dedicated to the provision of housing people who had additional support needs or who needed to live in supported housing. The support element of these schemes was funded by the Supporting People Programme for which the NIHE has administrative responsibility.

8. The overall aims and objectives of our research are more fully set out in the 2014 Report from page 5. However, in summary, the research was conducted to explore the way in which the resettlement programme in Northern Ireland had been managed, the role of the Supporting People Programme and provide an insight into how, and to what extent, the lives of the learning-disabled who had been resettled from long-stay hospitals, had changed since taking up their new accommodation.

9. In Northern Ireland, there were three long-stay hospitals specialising in the provision for people with moderate to severe learning disabilities and mental health issues; MAH, in Antrim, operated by the Belfast Health and Social Care Trust; Longstone Hospital, in Armagh, operated by the Southern Health and Social Care Trust; and Lakeview Hospital, in Derry/ Londonderry, operated by the Western Health and Social Care Trust. Our research determined that the resettlement of patients from MAH was significantly different to the other two long stay hospitals for reasons I will discuss later in this statement.

10. The main reason for my providing this information to the Inquiry is to draw their attention to the 2014 Report and the 2017 Report. However, I would also like to highlight several areas of the reports.

Progress on resettlement was slow/behind time

11. For context to the 2014 Report, I would draw the Inquiry's attention to page 17 of the 2014 Report, which indicates that around two thirds of learning-disabled people living in a hospital were classed as having a severe or profound learning disability. Page 18 of the 2014 Report indicates a likely increase in the number of people with a learning disability due to an amalgamation of factors which are listed, including, increased life expectancy, leading to a growing population. At page 20 of the 2014 Report, the table shows that in 2012 the hospital with the largest number of people with a learning disability was MAH. Other hospitals had much smaller proportions of people with learning disabilities and were, therefore, able to deal with the issue of discharge and resettlement much faster. Some long stay hospitals had no learning disability patients at all in 2012. The research results showed that by 2012, the average resident in a long stay hospital in Northern Ireland had been in a hospital for over six years and had therefore been living in a hospital for a very long time.
12. MAH had a difficult task to resettle their remaining patients. This was due to two particular lists of patients; those with very complex and acute needs, including nursing care needs, and those with learning disabilities, mental health issues and with a forensic background, demonstrating challenging or difficult behaviours.
13. I would draw the Inquiry's attention to Section 2.2 of the 2014 Report at page 21, which captures the timeline of the resettlement process in Northern Ireland and gives an insight into how resettlement occurred from the late 1970s. Both the Bamford Review and the Northern Ireland Audit Office ("NIAO") reported that progress on resettlement was slow or behind time as compared to that in Great Britain. Citations are provided in the footnote at page 21. This was largely due to a higher proportion of long stay patients with learning disabilities in

Northern Ireland as compared to Great Britain. For example, in Northern Ireland, the proportion of learning-disabled people still living in a hospital setting in Northern Ireland in 2002 was two hundred and twenty-two beds per million people, whereas in England and Wales it was fifteen beds per million people.

The reasons for slow progress on resettlement

14. Page 25 of the 2014 Report shows the progress on resettlement from 2002 to 2011. The report notes that progress was very slow in Northern Ireland. Targets were set throughout the process but were not met. At page 26, we highlight that the target for all long stay in-patients to be resettled into the community by June 2021, was not met. The reasons for the slow progress on resettlement are touched upon on pages 30 and 31 of the 2014 Report and are as follows:
 - a. Lack of co-ordination between DHSSPS and the Department of Social Development;
 - b. A misalignment between health and housing funding streams;
 - c. The absence of an overall resettlement plan;
 - d. The absence of a system to monitor performance against targets;
 - e. The absence of formal procurement arrangement for new community-based services; and
 - f. Weak engagement by Trusts with patients and families, many of whom resisted proposals for resettlement.

15. The Bamford Review notes that developments were uncoordinated and a number of difficulties arose. For example, lack of information for families about where to go for different services, conflicting advice from different specialists, duplication of services and gaps in service provision (page 21 of the 2014 Report). In Northern Ireland, there is no definition of "supported housing" whereas in England and Wales this is defined in law in the Social Housing Rents (Exceptions and Miscellaneous Provisions) Regulations 2016. In England and Wales, housing and social services come under the same administrative umbrella. In Northern Ireland, they do not and it could, therefore, be construed

that this leads to a lack of connection between health, housing and social services.

16. On pages 30 and 31 of the 2014 Report, the tables show the most significant issues affecting the rate of resettlement, the successful delivery of the programme, as well as the factors hindering resettlement. We concluded that many of the people left in hospital from the Priority Target List ("PTL") had acute and complex needs and needed nursing care, while others with challenging forensic behaviours needed highly bespoke housing and care solutions that took time to develop and were expensive. For example, some of those patients required 3:1 staffing. The cost of this care was very high, even for one individual. Other factors including, ongoing negotiations between hospital management and the health sector trade unions about the redeployment of hospital staff were also referred to by those interviewed.

Reasons for the slow rate of development of supported housing in order to enable the resettlement programme

17. I would refer the Inquiry to pages 30-33 (also referred to above) and to page 35 of the 2014 Report. Page 35 deals with the commissioning process for accommodation-based care and support services. The Bamford Review recommended that learning disability patients should not be in a hospital setting but in community or family-based settings. It stated that no-one should be in a scheme of more than five bed spaces. What was produced under the development of social housing (see page 42 of the 2014 Report) was a significant number of services providing larger, congregate-type settings rather than the Bamford Review recommendations. Half of these had more than five bed spaces. Thirty two percent of all services contained eleven or more bed spaces (see page 54 of the 2014 Report). There was a concern from research respondents that the learning-disabled patients were moving from one hospital-based institution to another type of institution. Evidence was obtained (see page 45 of the 2014 Report) to indicate that Belfast Health and Social Care Trust did

not appear to have prioritised the provision of supported accommodation, generally or specifically, for the resettlement programme.

Why resettlement was so slow at MAH

18. Part of the reason for resettlement being so slow at MAH was due to the number of patients involved (referred to at paragraphs 10 and 11 above). However, other factors were a lack of bed spaces being brought into the Belfast Health and Social Care Trust area, compared to the other Trusts. I refer the Inquiry to page 49 of the 2014 Report. The Table on page 49 shows the number of Supporting People Programme funded services, properties, bed spaces and mean number of bed spaces per property by Trust area. I would note that resettlement in the Western Health and Social Care Trust area was complete by 2012 (Lakeview on the Gransha site was closed). Resettlement in the Southern Health and Social Care Trust area was complete for the PTL patients from Longstone Hospital by the end of 2012 having smaller numbers of Delayed Discharge List patients to be discharged.

Effectiveness of the resettlement programme in terms of numbers and structures

19. I would refer the Inquiry to page 51 of the 2014 Report. There was a complex interplay of oversight and regulatory arrangements governing Supported People Programme funded services, but there was no independent regulatory framework for Supported People Programme funded supported housing. The Supported People Programme Department did not have the necessary statutory powers or procedures to conduct formal inspections. These services were subject to contract management oversight by the Supported People Programme team which came close to a monitoring and inspection process but was not governed by statutory powers.
20. I refer the Inquiry to page 53 of the 2014 Report. We found there was a question mark over occupancy levels for some services. It was unclear what this told us.

It was not clear whether the existence of a number of services with occupancy levels below eighty-five per cent reflected a lack of demand or other factors. These included 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 had challenging behaviours.

21. I refer the Inquiry to page 54 of the 2014 Report which details the size of the Supported People Programme schemes. The conclusion reached in the 2014 Report was that people were frequently moving from hospital to congregate (hospital-like) settings.
22. I refer the Inquiry to page 55 of the 2014 Report. Interviews with policymakers, commissioners and service providers suggested that there were still a significant number of services that were institutional in character. There were instances where size criteria had not been fully met and where ethos and delivery had not changed.
23. I refer the Inquiry to page 55 of the 2014 Report, which details the attitudes to resettlement and how this impacted the level and rate of resettlement programme and the process. These issues included attitudes towards learning-disabled people, their personal identity and rights, the perceptions of the policy makers, commissioners and providers who were responsible for delivering resettlement and about the impact of resettlement on the learning-disabled people involved. It was clear that changes in resettlement policy over the years had not always been accompanied by changes in the understanding of learning disability, or the needs and rights of disabled people, whether by health and social care professionals or by the wider community. Almost all of the people interviewed for the research commented on parental and family attitudes, community attitudes and the attitude of professional and nursing staff.

Effectiveness of the resettlement programme in terms of betterment

24. At the end of the interviews, all participants were asked if they thought that the resettlement programme has resulted in 'Betterment' in the lives of resettled people. Betterment is a concept examined in the Bamford Review which talks of betterment in terms of physical, emotional and spiritual wellbeing. From page 59 of the 2014 Report, we explain how betterment was assessed. The methodology was to look at the lives of learning-disabled people before and after resettlement. We found evidence that:
- a. Progress had been slow in establishing mechanisms for assessing betterment in people's lives following resettlement;
 - b. Each Trust developed their own approach. They were not joined up;
 - c. No overall assessment of this critically important aspect of the learning-disabled resettlement programme had taken place at the time our research was carried out. Therefore, I questioned how you could ever know if resettlement was adequate; but
 - d. Good practice developed by the commissioners and providers in England is now being adopted by the Northern Ireland Supporting People Programme team and providers.
25. I refer the Inquiry to page 69 of the 2014 Report and a quote from Doctor Simon Duffy (from England) where he states that it is difficult to bring about change in structures, especially within a bureaucratic system or where there is no vision, leadership or trust.
26. I would refer the Inquiry to the 2017 Report attached at Exhibit 3. I would like to use the 2017 Report to discuss the concept of 'Betterment' further. In most cases, the service users (by which I mean the learning-disabled people who were resettled from a long stay hospital in Northern Ireland) indicated that they were broadly happy with the way resettlement had been carried out. We did not get the sense that the actual move had been traumatic or difficult from those with a good recall of the memory. It is accepted that there were a limited number of service users interviewed and these people were hand selected by scheme managers.

27. We found that betterment had occurred for all twenty-two service users (see pages 19-21 of the 2017 Report). This was in terms of better sleep, better interaction with their families, they were better dressed, they had their own possessions and they had their own rooms, as opposed to just a bed and bedside cabinet. The family members noted that there was an element of choice in the new accommodation and the service users were able to, for example, pick colours for their rooms and curtain materials which they had not previously been able to do. They indicated that they had never had private space before.
28. I would refer the Inquiry to page 19 of the 2017 report where a service user, who had been in MAH for more than thirty years, had lost over five stone in weight since leaving MAH and was now leading a normal life undertaking a range of activities.
29. At page 21 of the 2017 Report, service users noted that they could have a snack or a drink when they wanted, they had their own possessions, a television, their own space and privacy. One service user gave an example from MAH where they said that the tea was made up every day in a jug with milk and sugar already added. They could now make their own tea without sugar and to their own taste and strength.
30. The service users and families noted that there was better interaction with the families after resettlement. For example, they could go out shopping to Tesco or Sainsbury's, go to a café and do things that normal people could do.
31. There was some negative feedback from service managers about service users' readiness for resettlement and I would refer the Inquiry to page 17 of the 2017 Report in this regard. For example, the need for service users to learn personal care and life skills, and the extent to which they understood what was involved in the move.

32. There were some indications of neglect and abuse in our findings. I would refer the Inquiry to page 23 of the 2017 Report. For example, some family members noted that following resettlement, this was the first time they knew that their family member could walk, having previously been confined to a wheelchair in MAH. It was noted by family members that the service users were able to wear their own clothes, as compared to MAH where their clothes became mixed with other patients.
33. Family members noted that, in most cases, good practice had been carried out with regard to the transition to new accommodation and described a gradual transition. Story boards were used to explain what was happening and there were planned visits to the new scheme.
34. We did experience some negativity from family members which was mainly from those service users with severe learning disabilities. Concerns centred around safety, capacity to do things for themselves, uncertainty as to the process and whether they would be accepted in the community.
35. I would refer the Inquiry to page 16 of the 2017 Report which describes the concerns from parents about how the process was handled, for example, that the process had not taken account of those with profound learning disabilities, lack of parental consultation and involvement, a stop/start approach and lack of resettlement options. However, the attitude of these families seemed to change over time and the majority were content with the move to supported living accommodation.
36. I would refer the Inquiry to pages 26-27 of the 2017 report where the service users describe some of the downsides to resettlement. For example, missing the social aspect of MAH, loneliness and feeling physically isolated.
37. Finally, I would refer the Inquiry to page 58 of the 2014 Report regarding the personal identity and rights of learning-disabled people moving out of MAH. I believe that this area is worth significant focus based on our research and findings. One of our findings was that there was a practice of having 'population

wide funds' rather than individual funds within MAH. This was a practice that was carried out for many years prior to our report. For example, patients would have received funds from various sources such as benefits and capital from family members. They appeared to be placed in a 'population wide fund' and therefore, on discharge, it was not easy to identify what monies belonged to a particular patient. Issues were noted with identifying the money belonging to particular patients on discharge into the community and therefore, the patient's money did not always transfer into a personal account.

38. Further, we noted an issue with a lack of personal identification documentation, some patients having been in MAH for many years and never requiring a national insurance number, birth certificate, passport or other personal documentation. This made transferring money to personal accounts difficult.
39. There was an issue with retention of funds for long periods of time, sometimes decades, where the patient could not access it or withdraw funds. There were allegations that the allocation of funds to particular accounts, post resettlement, was actively obstructed by MAH staff.
40. Guidance was issued by the Belfast Health and Social Care Trust in 2012, in relation to patients who were incapable of managing their own financial affairs, that MAH should relinquish their 'Appointeeship', if the patient was resettled on a permanent basis, to the Trust who was responsible for the patient.
41. In summary, I hope that the 2014 and 2017 Reports are of assistance to the Inquiry, with particular reference to (a) the adequacy and workings of the policy and process of discharge and resettlement of patients of MAH and (b) the Inquiry's examination of the nature and extent of abuse of patients at MAH, with specific reference to appropriation of or improper interference with patients' finances or belongings.

Section 4: Giving Evidence

42. I would not like to give oral evidence to the Inquiry.

43. If I am asked to give evidence, I do not require any special arrangements.
44. I do not require a supporter with me.
45. If I am asked to give evidence I am happy to give my name.

Section 5: Declaration of Truth

The contents of this witness statement are true to the best of my knowledge and belief. I have produced all the documents which I have access to and which I believe are relevant to the Inquiry's terms of reference.

Signed: *Fiona M Boyle*

Date: *27/4/2023*

List of Exhibits of Fiona Boyle

- Exhibit 1** Curriculum Vitae of Fiona Boyle
- Exhibit 2** The Hospital Resettlement Programme in Northern Ireland after the Bamford Review. Part 1: Statistics, perceptions and the role of the Supporting People Programme (nihe.gov.uk) Published October 2014.
- Exhibit 3** The Hospital Resettlement Programme in Northern Ireland after the Bamford Review. Part 2: The Experience of Learning Disabled People Resettled from Long Stay Hospitals (nihe.gov.uk) Published June 2017.

CURRICULUM VITAE - FIONA BOYLE, MA**PERSONAL DETAILS**

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RESUMÉ

- Since 2002 Principal consultant with Fiona Boyle Associates.
- Completed more than 75 research and management consultancy commissions for public and voluntary/community sector organisations including: the Northern Ireland Housing Executive, the Housing Rights Service, Simon Community NI, Engage with Age, the NI Assembly, Extern, NIFHA, and various Housing Associations including Oaklee and SHAC.
- Particular expertise in social research, evaluations and Social Return on Investment analyses.
- Previously a Director in a regional homelessness charity, senior manager in a non-departmental public body and Senior Researcher in central government including:
 - Networker for the Foyer Federation (2002 – 2007);
 - Director (Research & Development), Simon Community NI 1995 - 2002;
 - Consumer Affairs Officer, General Consumer Council for NI 1992 – 1995;
 - Senior Research Officer, Scottish Office Central Research Unit 1989 – 1992.
- Number of public appointments including:
 - Member, Postwatch Northern Ireland, and chair of Research sub-committee (2001 – 2008)
 - Board member, Consumer Focus Post (NI) and Consumer Futures Post (NI) (2008 – 2014)
 - Non-executive Board member, NI Prison Service including chair of Audit/Risk Committee (2002 – 2004)
 - Non-Executive member, Ofcom Advisory Committee, NI (2014 onwards)
- Assessor with BBC Children in Need (NI) (2007 – 2016).

EDUCATION

- Sullivan Upper School, Holywood 1978 – 1985
3 A Levels – History (A), Geography (A), Biology (B)
- University of Edinburgh 1985 – 1989
MA (Honours) Social Policy – First Class Honours
- **Academic prizes**
John Craigie Cunningham prize: For best attainment in Social Policy 1
University bursary: Awarded for attainment in First Year and renewed annually for duration of degree 'in recognition of excellent academic performance.'
James Carruthers Memorial prize: Prize for 'outstanding performance' in Final degree exams
- Other qualifications – Certificate of Institute of Supervisory Management, NVQ Level 5 in Management, Scotvec module in typing.

SELECTED EVALUATIONS

- Boyle FM (2006), *Evaluation of Community Service Agreements- for NI Housing Executive*
- Boyle FM (2009), *Evaluation of Safe Moves project - for Simon Community NI*
- Boyle FM (2010), *Evaluation of Adoption Routes service - for Church of Ireland*
- Boyle FM (2007 - 2011), *Evaluation of various projects and programmes - for Extern*
- Boyle FM (2011), *Evaluation of service- for Carrick Child Contact Centre*
- Boyle FM (2012), *Evaluation of Next Steps service - for Church of Ireland*
- Boyle FM (2013), *Evaluation of pilot Tinnitus service - for Action on Hearing Loss*
- Boyle FM (2013), *Evaluation of Kinship Foster Care service - for Extern*
- Boyle FM (2014), *Social Return on Investment Evaluation of 'Hear to Help' service - for Action on Hearing Loss*
- Boyle FM (2015), *Mid-term Evaluation of 'In Touch' befriending service - for Action on Hearing Loss*
- Boyle FM (2015), *Evaluation of AD:EPT2 project for Start 360*
- Palmer JAD & Boyle FM (2016), *Evaluation of Housing First model*
- Pleace N & Boyle FM (2017), *Evaluation of NIHE Homelessness Strategy 2012 – 2017*

RESEARCH PUBLICATIONS

- Boyle FM (2002), *Six papers on the draft Housing Bill - covering the topics of anti-social behaviour, grants, travellers, registered Housing Associations, large-scale voluntary transfers and Houses in Multiple Occupation for NI Assembly, Research & Library Services*
- Boyle FM (2007), *Private Rented Sector – Linking policy to practice, for Simon Community NI*
- Boyle FM (2008), *An analysis of the need and demand for retirement villages in Northern Ireland in their various forms for NIHE, Belfast*
- Boyle FM (2008), *Position Paper on Health and Homelessness, for Simon Community NI*
- Boyle FM (2010), *Assessment of the potential for equity release for older owner-occupiers for NIHE, Belfast*
- Boyle FM (2010), *Gazing at the 4 walls for Engage with Age, Belfast*
- Boyle FM (2012), *The role of sheltered housing in Northern Ireland and future issues for NIHE, Belfast*
- Boyle FM (2013) - Contribution of undertaking key interviews with range of stakeholders and four focus groups with older people (in Belfast, Enniskillen, Dublin and Galway) as part of research led and published by Professor Irene Hardill, University of Northumbria, (2013) *E-government and older people in Ireland, North and South.*

Palmer JAD & Boyle F, with Wood A & Harris S (2014), *Bamford Review: The experience of learning-disabled people resettled from long stay hospitals in Northern Ireland - Interim Report*, North Harbour Consulting for NIHE, Belfast

Boyle FM (2014), *Social Return on Investment (SROI) Evaluation of the Small Pockets of Deprivation (SPOD) Programme* for NIHE, Belfast

Boyle FM (2015), *Calculating the cost of homelessness in Northern Ireland? A desk-based study of the range of direct and indirect costs relating to homelessness*, for Housing Rights Service

Boyle FM (2019), *Homeless Families* (for four voluntary sector providers)

Boyle FM, *Housing and Older people: Housing Issues, Aspirations & Needs* (2019), for NIHE

Boyle FM (Fiona Boyle Associates) with Pleace N (University of York) (2020), *Analysis of Homelessness Presenters and Acceptances, including analysis of regional variation, analysis of Accommodation Not Reasonable (ANR) and comparison to Great Britain*, for NIHE

Boyle FM (2021), *Research study into the acquisition and retention of stable accommodation by individuals released from prison* for Department of Justice (DoJ)

Boyle FM (2021), *Homelessness Service User Journeys*, for NIHE

Boyle FM (Fiona Boyle Associates) with Pleace N (University of York) (2021), *The Impacts of Chronic Homelessness for Women*, for NIHE

Boyle FM (Fiona Boyle Associates) with Pleace N (University of York) (2021), *Experiences of Youth Homelessness*, for NIHE

Boyle FM, *Alternative models of supported housing*, for NIHE – due for publication in 2023.



**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

**John Palmer, Fiona Boyle and Alicia Wood with Steve Harris
North Harbour Consulting**

October 2014

Research and report by:

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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:

1. 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.

3. 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?

⁵ 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 RoI. 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 RoI;
 - 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.

⁷ 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 led 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 re-provision 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 Rol set out in Part 3 of the report. The evidence from GB and Rol 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 line¹⁷, 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		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

¹⁴ 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 thought 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

¹⁸ 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 20} in 2002 compared with 2001 Census data.

Table 2: Number of patients per originating Trust, 2002

Board	Based on SOS CARE 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 SHSB	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.

¹⁹ 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 fetuses 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’²⁵.** 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.

Table 4: Number and percentage of learning-disabled people in the general population, 2012

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.

²⁵ <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->

²⁶ 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 in-patients. 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.**

²⁷ <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.

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 programme⁴³. 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 2007⁴⁴. 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).

Table 6: Annual resettlement targets and resettlement activity, 1 April 2002 to 31 March 2009

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 spending⁴⁹. 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 – 2015⁵¹ 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.

⁵¹ DHSSPS (2012), *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*

⁵² DHSSPS (2012), *Learning Disability Service Framework*, 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 learning-disabled 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), *Learning Disability Service Framework*, 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

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

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: Learning 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:	
<ul style="list-style-type: none"> • 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:	
<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> • 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 (<i>to commission accommodation-based services – interviewer</i>) 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: <ul style="list-style-type: none"> • 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 over-stretched 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

	<p>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.</p> <p><u>Implementation:</u> 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.</p>
<p>Supporting People</p>	<p>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.</p>

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 ('NIGEA'): 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, 2012*⁵⁸.

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.

⁶⁶ 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 <small>Note</small>	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 <small>Note</small>	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	15	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 Independent 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
<i>Percentage</i>			<i>100.00</i>	<i>73.65</i>		<i>26.35</i>	

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

Trust Area	Number of Providers operating in Trust area	Number of SP-funded services in Trust area	Of which beds in:									
			Unregistered Adult Placements		Residential Care Homes		Shared or Self – contained Supported Housing		Floating Support		TOTAL	
			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		1,304		80		1,560	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	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
<i>Percentages by sector</i>	<i>57%</i>	<i>22%</i>	<i>3%</i>	<i>9%</i>	<i>4%</i>	<i>4%</i>	<i>39%</i>	<i>32%</i>	<i>10%</i>	<i>3%</i>	<i>6%</i>	<i>10%</i>

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 unit 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 ^{Note}	% 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 self-contained 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.

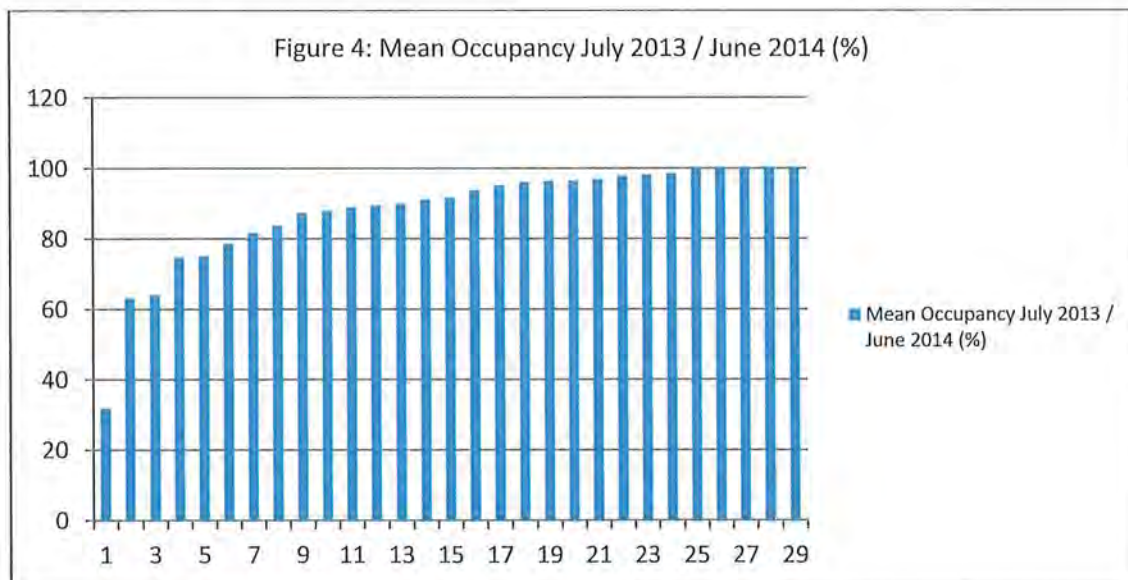
Some interviewees suggested that the SP team’s QAF2 monitoring process is not identifying issues in either accommodation or support because it is partly based on self-monitoring by providers. RQIA was said to be ‘filling the void’ unofficially, reviewing housing support that was provided alongside domiciliary 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.

⁷³ 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 concerns^{77 78} included fears that:

⁷⁵ 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

⁷⁹ 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.

⁸⁰ 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.⁸⁴ 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 practices⁸⁵. Resolving this issue was identified by Bamford as being critical to the success of the *Equal Lives* approach⁸⁶.

“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 achieved⁹⁰ 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.

⁸⁷ 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

⁹⁰ 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%20Resettlement%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 Bromford⁹¹, Reach⁹² and Driving Up Quality Code⁹³ 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."

⁹¹ 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>

⁹² 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."

Selected comments from those who say they do not know whether the programme has been 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."

⁹⁴ 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 community⁹⁶ 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'¹⁰⁰ 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 *Psychological Medicine*, 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*

¹⁰⁰ 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 Agency (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'¹⁰² 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 homes¹⁰³ 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

¹⁰¹ 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.

¹⁰² 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.

¹⁰³ 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 University¹⁰⁴ 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 Group¹⁰⁵. 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.¹⁰⁷ Thus services developed under Supporting People were mainly targeted at these groups¹⁰⁸. As long 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.

¹⁰⁴ 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

¹⁰⁶ 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 services¹⁰⁹. 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.

¹¹⁰ *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."

¹¹¹ *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 accommodation¹¹⁹. 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, **de-institutionalisation 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.

¹²⁵ <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 model^{127 128}."

"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.

¹²⁶ <http://www.sharedlivesplus.org.uk/>

¹²⁷ <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.

¹²⁹ Lundebj, 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

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 Equal Lives 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 learning-disabled 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 re-tender 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.

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 of 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 Interviewee			
Position			
Organisation Name		Type of Organisation	
Location of interview			
Date of Interview		Time of Interview	
Interviewer comments			

1.0 I would like to ask you first about your own role in delivering the resettlement programme						
1.1 In general terms, what is your role?						
1.2 Would you describe yourself as one of the following? SHOW CARD						
Policymaker ?	Planner?	Commissioner?	Funder?	Service Provider?	A combination of these?	None of these
If 'a combination' or 'none of these' please explain:						
1.3 Specifically, what responsibilities for aspects of the resettlement programme do you have?						

2.0 Progress in the resettlement of people with learning disabilities since the publication of <u>Equal Lives – Review of Policy and Services for People with a Learning Disability in Northern Ireland</u> (Bamford 2005)			
First, I'd like to explore your perceptions of the progress that was made in resettling people with learning disabilities from long stay hospitals in the four years immediately following the publication of <u>Equal Lives</u> in 2005 up to the Northern Ireland Audit Office report ' <u>Resettlement of long stay patients from learning disability hospitals</u> ' in 2009. Please say whether you <u>agree</u> or <u>disagree</u> with the following statement.			
2.1 The rate of resettlement was <u>lower</u> , at about the <u>same level</u> as, or <u>higher</u> than expected between 2005 and 2009. SHOW CARD			
Lower	At the same level	Higher	Don't know
Do you have any comments on the rate of resettlement in that period?			
2.2 Does your response relate to the whole of Northern Ireland or a particular geographical area/areas?			
Whole of NI?		Particular area(s)	
If a particular area, say which			
Next, I'd like to explore your perceptions of the progress that has been made in resettling people with learning disabilities from long stay hospitals in the five years since the Northern Ireland Audit Office report on the resettlement programme in 2009. Please say whether you <u>agree</u> or <u>disagree</u> with the following statement.			
2.3 The rate of resettlement has been <u>lower</u> , at about the <u>same level</u> as, or <u>higher</u> than expected between 2009 and 2014. SHOW CARD			
Lower	At the same level	Higher	Don't know
Do you have any comments on the rate of resettlement in this more recent period?			
2.4 Once again, does your response relate to the whole of Northern Ireland or a particular geographical area/areas?			
Whole of NI?		Particular area(s)	
If a particular area, say which			
2.5 Please comment on the influence that each of the following factors has had on the rate of resettlement between 2009 and 2014. SHOW OPTIONS ON CARD			

	Very significant	Significant	Slightly significant	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?					
Prompt: Where do low expectations come from?	Residents	Families	Commissioners	Provider organisations	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 you think had the <u>most significant</u> influence on the rate of resettlement of people with learning disabilities into the community between 2009 and 2014					
	Very significant	Significant	Slightly significant	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?					
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, work and social activities for resettled people?					
The availability of community support services for family carers?					
The difficulty of finding appropriate accommodation placements?					
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					
2.7 Please comment on why you have chosen your five most significant factors?					
2.8 Are there any other factors that you think helped to promote resettlement or which acted as barriers to resettlement?					
<u>Promoted resettlement:</u>					
<u>Barriers to resettlement:</u>					
2.9 What do you think are the most important current issues for policymakers, commissioning and delivery bodies in progressing resettlement?					
2.10 On the assumption that most of the people who are easiest to resettle into the community have now been resettled, what are the main difficulties in resettling people with moderate to severe learning disabilities, challenging behaviours or forensic background (e.g. those detained via the Mental Health Acts and the Criminal Justice system)?					
3.0 Questions about accommodation and support					
I would now like to ask you some questions about post-resettlement accommodation and support.					
3.1 Please describe how new accommodation schemes are commissioned.					
3.2 Have there been any changes in the commissioning process since 2009? (Yes, go to 3.3; No, go to 3.4)					
Yes		No			
3.3 If you answered 'Yes', what were they?					
3.4 What criteria are currently being applied for new schemes in the commissioning process?					
3.5 Do all schemes – new, recent and heritage - now follow the recommendations on size, arrangements and conditions set out in the Bamford Report on LD services? (Yes to 3.5; No to 3.4)					
Yes		No			
3.6 If you answered 'No', in what ways do they differ					
3.7 Do some schemes still offer similar arrangements and conditions to those found in a long stay hospital setting? (If Yes, go to 3.7; if No, go to 3.6)					
Yes		No			
3.8 If you answered 'Yes', when will these schemes be recommissioned?					
3.9 What have been the most successful models of housing, care and support from the perspective of resettlement and full integration into community life?					
3.10 Is there now an extended range of different types of housing options developed to meet different needs as a result of the resettlement programme?.					
Yes		No			
3.11 How effective has the resettlement process itself been?					
Prompt: probe opinion on whether placements have been appropriate, people were fully prepared for the					

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?			
<u>How assessed?</u>			
<u>By whom?</u>			
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?			
<u>Criteria:</u>			
<u>Who makes the assessment:</u>			
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?			
Yes		No	
4.7 Has the resettlement programme been successful in public policy terms?			
Yes		No	
4.8 Has the resettlement programme provided value for money to the public finances?			
Yes		No	
4.9 Do you have any final comments?			

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.

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 ENGLAND¹³³

Type of Service	Description
Supporting People-funded services	
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 housing, 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.
Forms of Family Investment: A family or other relatives may be able to provide housing directly. The main options are set out below, 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: <ul style="list-style-type: none"> - 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.

	<p>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.</p>
Joint Ownership	<p>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</p>
Joint Ownership – Parents and Sons/Daughters	<p>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'.</p>
Company Ownership	<p>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.</p>
Inheritance	<p>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.</p>
Discretionary Trusts	<p>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.</p>
Getting Housing, Care and Support Together (Accommodation Based Services)	
Unregistered shared group homes	<p>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.</p> <p>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.</p> <p>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.</p> <p>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</p>

	<p>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.</p>
Extra Care, Sheltered Housing and Core and Cluster	<p>This option includes three forms of specialist provision</p> <ul style="list-style-type: none"> - sheltered housing, - extra care and - 'core and cluster'. <p>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.</p> <p>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 development.</p>
Residential Care	<p>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.</p>
Intentional Communities	<p>"Intentional communities" is a term used to describe a variety of planned residential 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.</p> <p>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.</p>
Other forms of support	
Shared Lives	<p>Shared Lives (SL) arrangements are distinguished by the following features:</p> <ul style="list-style-type: none"> - 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 <p>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</p>

	<p>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.</p>
Supported Lodgings	<p>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.</p>
Support Tenants	<p>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.</p>
Community Support Networks – Keyring	<p>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.</p> <p>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 applying.</p>

APPENDIX 5**MEMBERS OF THE RESEARCH TEAM****JOHN A D PALMER****ROLE**

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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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 NI; 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*.

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North Harbour Consulting

**THE HOSPITAL RESETTLEMENT PROGRAMME IN NORTHERN IRELAND
AFTER THE BAMFORD REVIEW**

**PART 2: THE EXPERIENCE OF LEARNING DISABLED PEOPLE
RESETTLED FROM LONG STAY HOSPITALS**

A REPORT FOR THE NORTHERN IRELAND HOUSING EXECUTIVE

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KEY FINDINGS AND CONCLUSIONS

Findings

Responses were obtained from twenty two service users with learning disabilities, their family members and the support staff working in housing support schemes where they were housed after resettlement. The service users had all been resettled from long-stay hospitals between April 2012 and March 2016 as part of the post-Bamford Review resettlement programme. Views were sought on whether the resettlement programme had been successful for resettled people and whether betterment in their lives had been achieved in the ways advocated by the Bamford Review.

There was general contentment expressed by service users with the resettlement process, although this may have been influenced by the extent of their memory of the move from long-stay hospital and their capacity to understand the process. Service users' responses indicated that, in most cases, resettlement had been based on a staged approach in which hospital patients had visited a scheme, had stayed there overnight, and had then been given the opportunity to stay for a slightly longer period before finally deciding to move there permanently. It should be noted that most service users had limited recall of whether a range of accommodation and locations had been offered to them, but their responses suggested that the actual move had not been traumatic or difficult.

Feedback from families was generally very positive about the resettlement process. Family members said they thought that the resettlement process had been well managed and that their family member's life had improved considerably as a result. Other positive factors that were highlighted included:

- Well managed procedures for handover of responsibility for resettled people from hospital staff to the supported housing staff;
- A process for matching people to ensure the compatibility of service users moving to the same scheme; and in most cases,
- A comprehensive level of involvement of both service users and family members in the resettlement process.

However, some difficulties were also noted in individual cases. These difficulties tended to be associated with:

- The service user's assessed 'readiness' for resettlement;
- A perceived lack of compatibility between and a poor mix of tenants living together in a small number of schemes; and
- Delays in identifying suitable sites, obtaining planning permission and community consultation which had delayed resettlement after people were judged by their hospital care managers and medical staff to be ready to move on.

Other limitations to betterment included:

- The location of supported housing schemes, especially those in rural areas or in places where public transport was not available;
- Distance from and lack of accessibility to services; and
- The availability and affordability of external activities including day centres.

The impact of these limitations did raise questions about whether the service user was fully living in and integrated into the wider community, or if they were effectively living in a smaller institution, albeit in a community setting.

There was a general view among scheme managers that strategic oversight had been lacking in terms of the identification of the costs associated with the resettlement programme, and the time schedules for implementation.

A small number of family members identified other concerns. These mainly related to service users with a severe learning disability or complex needs. These included:

- The safety of a small number of resettled people outside the hospital they were familiar with and felt safe in;
- The family's uncertainty about whether resettlement was appropriate for their relative;
- The suitability of people to be resettled in terms of their capacity to do things for themselves and to integrate into the community; and
- Whether the individual would be accepted in the community.

Family members also raised concerns about aspects of the resettlement process, including:

- Lack of parental consultation and involvement;
- The timing and stop/start approach taken by Trusts to resettlement; and
- the lack of appropriate accommodation options.

However, there was evidence that the attitude of these more reluctant family members to resettlement had changed over time from reluctance and outward resistance in some cases to acceptance and support.

Loneliness was an issue raised by a small number of service users who missed the wider environment, on-site activities and interaction with a larger number of people provided by the long-stay hospital.

In a small number of cases poor relations between the scheme and its immediate neighbours had a negative impact on peoples' experience of resettlement. Difficulties included differences of opinion about where staff should park their cars, and complaints about the behaviour of service users.

Families and staff said that, for some service users, resettlement in the community and the potential for betterment had come too late in their lives to make a significant difference. This mainly related to service users aged over 60 who had been in long-stay hospitals for lengthy periods of time. Even in these cases, however, there was clear evidence that the individual had benefited from resettlement.

The research team noted a small number of cases in which the service user was effectively locked away from other service users and the outside world, and their activities were very limited. These individuals' needs required them to live in secure accommodation and they required high levels of supervision and intervention. These cases were largely those with forensic background, a severe learning disability and severe autism. The research team questions whether in this very small number of cases a placement in a supported housing environment was appropriate.

In almost all cases, however, and in spite of these limitations, examples of betterment included more privacy, access to food and drink when the individual wanted it, the ability to see visitors at any time, to have personal belongings and personal space, and to do things for themselves. A majority of responses confirmed that service users were engaged in meaningful day-time activities related to their mental capacity and ability.

Resettlement also appears to have resulted in better family relationships for around half the service users. There was increased frequency of contact, better access, more privacy and new opportunities to interact with their family member. In contrast, in a small number of cases family contact had not been re-established either because parents or the wider family were deceased, or because of the length of time that had elapsed since there had been involvement, or there was minimal contact.

Conclusions

Although it was clear that the resettlement process had been painful for a small number of families, the majority of those interviewed were content with the resettlement process and the move to a supported housing scheme. Most family members said that their loved one had adapted very quickly and very well. The evidence from the interviews was that betterment had occurred in the vast majority of cases. There were notable improvements in the lives of all twenty two people who had been resettled.

Whilst it was clear that life for many of the service users now living in the community was not fully comparable to or consistent with that of non-disabled people, it was nonetheless viewed as being better than their previous experience of life in a long-stay hospital.

Improvements were seen as having come about as a result of service users having more choice, better opportunities to do things and to participate in what could be deemed a more normal life in comparison to life in an institution.

The interviews also showed that service users were happier and brighter, and engaged less in self-harm or the challenging behaviours that had been part of their experience in long-stay hospital.

In addition, service managers and staff provided evidence that other forms of 'betterment' had occurred including observation of changes in behaviour, better sleep functions and better interaction with other people. They also talked about quality of life in terms of better family relationships, a better living environment, more privacy and more involvement in activities.

Taken overall, the evidence is that – for those who were interviewed at least - the resettlement programme has resulted in significant betterment compared with life in a long-stay hospital even though the degree of betterment was inevitably influenced by individual levels of disability.

BACKGROUND: THE BAMFORD REVIEW

1. Learning disabled people began to be resettled from long-stay hospitals in Northern Ireland from the late 1970s onwards. In the early 1990s there were more than 880 learning disabled people living in long-stay hospitals. However, progress on resettlement was slow. As a consequence, many people remained in hospital for years after they were assessed as able to be resettled. This remained the case until April 2012 when there were still 250 long-stay hospital patients. On that date a new management system for the learning disability resettlement programme came into effect which speeded up the resettlement process.
2. In 2002, the Department of Health, Social Services and Public Safety commissioned a review of legislation, policy and provision for people with mental health issues and learning disabilities from an independent committee led by Prof David Bamford. Widely known as the Bamford Review, the committee's reports set out a new vision for mental health and learning disability services.
3. Leading a fuller life through active participation in the community and being able to engage in meaningful day-time activities were key themes in the Bamford Review reports, particularly *Equal Lives: Review of Policy and Services for people with a Learning Disability in Northern Ireland*¹. In a chapter focussing on accommodation and support, 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 five core values that the Bamford committee believed should govern how accommodation and support services for learning disabled people should develop. These were:
 - 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;
 - Citizenship – people with a learning disability are individuals and each has a right to be treated as an equal citizen;
 - Empowerment – people with a learning disability must be enabled to actively participate in decisions affecting their lives;
 - 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;
 - Individual Support – people with a learning disability will be supported in ways that take account of their individual needs and helps them to be as independent as possible.
4. A key principle in the Bamford vision was that of 'betterment'. Bamford used the term betterment as shorthand for improvements in the quality of learning disabled peoples' lives following resettlement. The term emerged in the mid-1990s when conflict arose between

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

those charged with delivering the resettlement programme at that time, and families who sometimes felt that their family member would be better off in hospital.² In 1995, the Northern Ireland Minister of Health at the time gave a public assurance to families that a member of their family living in hospital would only be resettled into the community if there was clear evidence of betterment for the patient and provided that it was not against their wishes³. This commitment has been restated by successive Ministers and remained in place during the period of time being examined for this research (April 2012 – March 2016).

5. The term was used in the *Equal Lives* report 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. There were three tests of whether betterment had taken place: resettlement of the individual was clinically appropriate; it met the patient's needs; and it had the potential to improve the patient's life.

THE RESEARCH

6. The Northern Ireland Housing Executive (NIHE) has played a significant role in helping to deliver the post-Bamford resettlement programme. Housing Executive officers have 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 is planned by NIHE, is dedicated to the provision of housing for people who have additional support needs or who need to live in supported housing; and the support element in these schemes is funded by the Supporting People Programme for which NIHE has administrative responsibility.
7. This is the second phase of this research; it was commissioned by NIHE in its capacity 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 partners⁴ with an insight into how and to what extent the lives of learning disabled people who have been resettled from long stay hospitals⁵ have changed since taking up their new accommodation.
8. The research has been divided into two phases, each looking at the resettlement programme from a different perspective.

² Northern Ireland Audit Office (2009), *Resettlement of long-stay patients from learning disability hospitals*, page 37, para 4.5; and page 38, para 4.8.

³ Northern Ireland Audit Office (2009), *ibid*, page 2, para 3

⁴ The partners in this programme are: Northern Ireland Government Departments, statutory health and social care organisations, housing, care and support providers from the independent sector, regulatory bodies and others.

⁵ 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.

Phase 1

9. Phase 1 of the research was undertaken by North Harbour Consulting in partnership with Fiona Boyle Associates with advice from the Housing and Support Alliance. The main focus was on the institutional delivery of the resettlement programme including:
- the evolution of the learning disability resettlement programme⁶ since the Bamford Report;
 - the models of housing, care and support provision on which the resettlement programme was based;
 - the characteristics, quality and costs of those 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 had been 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.
10. Phase 1 of the research concluded that:
- Progress had been slow in establishing mechanisms for assessing whether betterment had occurred in peoples' lives following resettlement;
 - Each Health & Social Care Trust was developing its own approach;
 - No overall assessment of this critically important aspect of the learning disability resettlement programme had taken place;
 - However, good practice developed by commissioners and providers in other parts of the UK were being considered for adoption by the Trusts and the NIHE Supporting People team.

Phase 2

11. Phase 2 of the research has been led by Fiona Boyle (Fiona Boyle Associates) with the support of John Palmer (North Harbour Consulting) and Gillian Greer (NIHE Research Team). This second phase of research reports on the experiences of people who have been resettled in the period April 2012 to March 2016 following a major reorganisation of the resettlement programme.
12. The focus of Phase 2 has been to interview service users⁷, their families and the support staff who work with them to establish whether they thought that the resettlement programme had been successful for resettled learning disabled people and whether betterment in their lives had been achieved in the ways advocated by Bamford.

⁶ The description 'learning disability resettlement programme' has been 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.

⁷ Service users who were resettled from long-stay hospitals between 1 April 2012 and up to 31 March 2016. In effect this is service users who were patients in Muckamore Abbey long-stay hospital and Longstone long-stay hospital during this period. All patients from Lakeview Hospital had been resettled prior to 2012.

Identification of the resettled population and sampling

13. There were believed to be around 220 people still living in Muckamore Abbey and Longstone long-stay hospitals in March 2012⁸. The majority of these people had been resettled by March 2016. The research team made a number of approaches to the Health & Social Care Board and the five Health & Social Care Trusts during the period 2014 – 2016, requesting information about the characteristics and location of the people with a learning disability resettled from long-stay hospital from 2012 onwards. This information was not available on the grounds of confidentiality and because Health and Social Care Board stated that the information was covered by the Data Protection Act 1998. An alternative approach was therefore adopted. This involved constructing a sampling framework based on information that was available from NIHE's Supporting People team and from housing associations and housing support providers.
14. NIHE's Supporting People team, which was closely involved in the resettlement programme and had funded housing support services for a substantial number of the people who were resettled, provided the research team with information about supported housing schemes that had played a part in resettlement. This included the service provider's name and landlord, the scheme name where resettled people were thought to be living, and the addresses and number of units for each scheme. This information suggested that the locations of around 80 resettled learning disabled people⁹ living in housing support schemes that were funded from the Supporting People programme were known to the Housing Executive. In discussion with the NIHE research and SP teams it was agreed to use this information as a basis for constructing a sample of 25 resettled people, their family members and their support staff who would be interviewed as part of the research. 22 interviews were completed (27.5% of the identified population of people resettled between 2012 and 2016).
15. A considerable amount of administration was involved in making contact with landlord housing associations and their managing agents who operate these schemes, with briefing managers and then negotiating access to the schemes, and with seeking consent from resettled people and their families to take part. In the process, it became clear that some of those who were identified for interview had moderate to profound learning disabilities, lacked sufficient comprehension to understand the aims and requirements of the research, and had weak communication skills. In these cases, where family members who were the responsible adults for the individuals concerned gave their consent, interviews took place with the family and with members of the staff team.
16. Table 1 (following page) provides information on the number of contracted places in schemes identified by the SP team. In addition, the table shows the number of interviews targeted from each provider and the number of interviews achieved.

⁸ Based on discussions with the Health and Social Care Board in 2015.

⁹ This was for people with learning disability resettled into supported housing schemes being provided by housing associations, with service provision from the housing association (direct service provision) or by another service provider (including Health & Social Care Trusts and independent providers).

Table 1: Number of resettled people by provider, number of interviews requested and number of interviews achieved

Landlord Housing Association	Housing Support Service Provider	Number of resettled people	Number of interviews targeted	Number of interviews achieved	Notes
Triangle Housing Association	Triangle HA – direct service provision	24	7	9	6 interviews directly with service users. Interviews with 3 family members
	Autism Initiatives	4	5	2	Interviews with 2 family members
	Mainstay DRP	3		1	Interview with one family member
	Northern HSC Trust	2		2	2 interviews directly with service users
	Sub-total	33	12	14	
Choice Housing Association	Autism Initiatives	2	7	1	One interview with service user and family.
	Inspire Wellbeing	15		2	Interview with one family member. One interview directly with service user
	Sub-total	17	7	3	
Apex Housing Association	Southern HSC Trust	23	5	3	3 interviews directly with service users
	Subtotal	23	5	3	
Northern Ireland Institute for the Disabled	NIID	7	2	2	2 interviews directly with service users
	Subtotal	7	2	2	
TOTAL		80	26	22	

Research process

17. The research process was undertaken in line with Social Policy Association Guidelines on Research Ethics¹⁰ and the general ethical principles for research with vulnerable groups¹¹ in Northern Ireland. Particular emphasis was placed on the obligations to research participants in terms of protection from harm and in relation to their rights; as well as requirements in terms of informed consent, confidentiality and the sharing of research findings and safe storage of data.
18. Access was obtained in the first place via the housing association and service provider. Depending on the nature of the learning disability exhibited by individuals (ranging from low to moderate to severe) advice was obtained from families (parents/adult siblings) and providers on the best means of obtaining informed consent to take part. Where informed consent was possible, and where the individual gave their consent, interviews were arranged directly with service users with the help of their family member or service provider. However, where there were issues of mental incapacity or lack of communication, the principles of 'best interest'¹² were applied. In cases where informed consent could not be provided an interview was requested via a family member (parent or adult sibling) or a member of the service provider's staff working with the person we wished to interview.
19. All the housing associations and service providers identified in Table 1 were approached to participate in the research and were briefed about the research process. The majority agreed to facilitate access to service users and family members, thus enabling representation across the schemes and geographical locations.
20. A written briefing was given to family members and service users before they were asked whether they wished to take part in the research. The latter was in an easy to understand format including photos. These documents are attached in Appendix 1.
21. A total of 22 interviews were undertaken directly with service users and family members. Additional feedback was provided by service managers and support staff with knowledge of the individual. The interview questions are outlined in Appendix 2. These were primarily for use with service users; but were adapted as appropriate for interviews and discussions with family members and service managers and staff, when responding about service users who could not provide consent and/or did not have communication skills.

¹⁰ www.social-policy.org.uk/downloads/SPA_code_ethics_jan09.pdf

¹¹ *Ethical Principles for Researching Vulnerable Groups (2003)* Paul Connolly, University of Ulster

¹² In carrying out this research we wanted to ensure we included all people with learning disabilities, including those with no verbal communication and those that lack mental capacity. Medical Research Council guidance is clear that adults who are not able to consent for themselves should be included in research, provided that this is done in line with relevant legal frameworks and ethical principles, Therefore we have adopted the principles embodied in the Mental Capacity Act 2005 which apply in England and Wales as if they also apply in Northern Ireland.

RESEARCH FINDINGS

22. The research findings are linked to five themes around which the interviews were structured:
- Experience of the resettlement process;
 - Betterment for the service user;
 - Limitations to betterment;
 - Too little, too late and a forgotten few;
 - Family contact and family contentment.
23. Service user names and some details relating to their cases have been changed to preserve their anonymity.

Theme 1: Experience of the resettlement process

Service users and their families

24. Service users, family members and carers were asked about their experience of the move from a long-stay hospital to their supported accommodation in the community (the resettlement process). In particular they were asked whether and how they chose the location and type of accommodation, who had helped them make the decision, what options they had been given (location and type of housing), what information they had been provided with, how easy they had found the move, and how easy they had found it to settle in their new home.¹³
25. In most cases resettlement had been based on a staged approach¹⁴ in which hospital patients had visited a scheme, had then perhaps stayed there overnight, and had then been given the opportunity to stay for a slightly longer period before finally deciding to move there permanently.

Service User – ‘Doris’

Doris was aged in her mid-50s and had been in Muckamore Abbey long-stay hospital for 30 plus years. She had mild learning difficulties and a good level of verbal communication and understanding. Doris now lives in a two-person bungalow with a co-tenant in a large supported housing scheme. She participates in many activities in her home including cooking and doing the laundry, and has an active life in the community, including different clubs and going on holidays with support in Northern Ireland and England.

¹³ Full interview questions are outlined in Appendix 2.

¹⁴ Depending on the service users' needs, some were moved in one move; this was referred to as a 'direct move'. Others were moved in a gradual, staged or phased move – different terminology was used by different stakeholders.

Doris said she had a range of opportunities to look at the bungalow, to meet the co-tenant and to stay overnight – in advance of resettlement. It was a staged approach.

Doris talked about the process – and remembered how it had happened at Muckamore. She said that [name of doctor] had talked to her about moving – and that she had then come to see the house. She also talked about picking a bed and picking out different things like cushions.

26. Service users who were interviewed were broadly happy with the way resettlement had been carried out, although in most cases this finding was based on their fairly limited memory of the move from a long-stay hospital, and their capacity to understand the process. Their views were expressed simply. For example, they talked about being excited when they first saw the house, and they talked about the phased approach - first going for a visit, then staying for a meal, then staying for one night. In the majority of cases, where service users had good recall, there was no sense that the actual move had been traumatic or difficult. Equally, service users had little recall of whether other accommodation had been offered to them, whether they had looked at it, and how they had been helped to make the move. Each of the service users with recall of the process thought they had settled in comparatively quickly.

They went into Muckamore for the last year (before the service user was resettled) – the staff knew him when he moved here, how to handle him and what the procedures were.

Family member

27. Feedback from families was generally very positive about the resettlement process, except for a small number of parents and family members (mainly of service users with severe learning disability or complex needs). In these cases, whilst some parents acknowledged that they had not been happy with their child or sibling being committed to a long-stay hospital, when it came to the proposed resettlement to the community, these families had concerns. These included concerns about safety, the suitability of all the patients being resettled (in terms of their capacity to do things for themselves and to integrate into the community), the uncertainty of the process and whether the resettled placement would work and the individual would be accepted in the community.
28. Safety was a concern for all the families during the resettlement process. This ranged from fear of them being attacked (physical safety), fear of abuse (including by staff who at that point they were only getting to know), fear of fraud (in relation to their finances) and concerns about them being accepted by the community.

29. In addition, a small number of family members suggested that the resettlement process had not adequately taken into account those with profound learning disabilities and other disabilities. Others thought that their family member was better off in a hospital where they were familiar with and trusted the staff.

People were moving into this ward from other wards; people were coming in from the community...the situation changed within the ward and safety then became paramount.

Family member

We knew it wasn't right for him... everyone thrown in together... we felt it would be better for him to have a place on his own – so he could listen to music and have his own bedroom and sitting room... we couldn't wait for him to leave – he was in a bad ward for the last year.

Family member

30. Some family members raised concerns about how certain things had been handled during the resettlement process. These included lack of parental consultation and involvement, particularly at the outset, the timing and stop/start approach and the lack of appropriate accommodation options. However, the attitude of these more reluctant family members appeared to change over time – from reluctance and even resistance in some cases to acknowledgement and acceptance.
31. Although it was clear that the resettlement process had been a painful process for a small number of family members, the majority of family members interviewed were content with the resettlement process and the move to a supported living scheme. Most family members noted that a staged move-in and smooth transition had been provided and that their loved one had adapted very quickly and very well.
32. In addition, in most cases family members felt that there had been a good handover of responsibility, with staff in the supported housing scheme visiting the service user for a period of time in advance of resettlement, and getting to know them and relevant routines.

It was staggered, first a short visit, then a visit for tea and then an overnight – she loved it.

Family member

The whole process was very well phased over a period of a year. Staff came up to Muckamore – they shadowed staff – then they worked with him. This covered getting up, dressing, the whole routine – how staff approach him. Then there was the reverse role and shadowing where the staff from the scheme worked with him whilst the Muckamore staff supervised.

Family member

33. In a number of cases the fact that service users were moving with other service users they had known in hospital was noted as helping with the settling in process and familiarisation. This was more likely to occur in resettlement to one of the larger housing support schemes.

Service managers and front line staff

34. Service Managers and staff felt the process of resettlement had been well handled by the housing support provider, the housing association that acted as the landlord, the HSC Trust and the hospital. However they noted some difficulties.
35. Firstly, the resettlement process and timetable were subject to an assessment of the compatibility of different service users in order to ensure that the right mix of people could be accommodated together. This was viewed as being an important issue in relation to the success of resettlement, but it caused delays for individuals.
36. The need for compatibility of co-tenants was very apparent from the interviews. In one case a service user gave mixed feedback in terms of whether he liked living with his co-tenant or not. At first he said “*unfortunately I live with him*” but later said “*he’s alright but he doesn’t talk to me*”. In this case staff noted that the co-tenant had severe autism and did not communicate with other people. However, in another case two co-tenants had been matched prior to resettlement, with one tenant moving from a community placement and the other from a long-stay hospital. This match was said to have worked very well.
37. Secondly, difficulties had arisen in terms of people’s ‘readiness’ for resettlement, including the need for them to learn personal care and life skills, and the extent to which they understood what was involved in the move.
38. In other cases there had been delays in identifying suitable sites, obtaining planning permission and community consultation. They acknowledged that these difficulties had been exacerbated in cases where the disability of the service user was severe or complex.

It didn’t always end up being a scheme for the people identified at the outset....There was never actually a set timescale from scheme identification through to being open.
Staff member

39. Service Managers and staff also highlighted difficulties arising from public consultation, suggesting that this had not been helpful in some instances.
40. Overall Service Managers felt resettlement had been a relatively smooth transition with comprehensive involvement of service users and family members.

My experience of the resettlement team at Muckamore was very positive – from the social worker with the HSC Trust, to the nurse on the hospital staff – I can’t fault them. There was so much to share – everything was on the table – the men’s needs and risks.
Staff member

41. Staff said that they thought service users had been comprehensively involved in the resettlement process. In many cases customer journey maps¹⁵ had been developed by housing associations and service providers in conjunction with the hospital resettlement team, and service users were shown photos of possible locations and schemes, were then driven past the scheme, and then taken to it for progressively longer periods of time.

Service User – ‘Sheila’

Sheila’s family said that resettlement had taken four years from when it was first mentioned until she was resettled. They gave a number of reasons for this – different locations were offered: some were considered too far away, some were considered unsuitable. The family felt the process was unsettling, too long and drawn out. Once a place was identified, however, the resettlement process was relatively smooth. The only issues had been in relation to the financial and legal aspects of resettlement – getting financial controllership in place and signing a tenancy agreement for someone with limited capacity.

42. In terms of the overall strategic oversight of the resettlement programme, service managers (and some family members) felt there had been a lack of foresight in terms of cost calculations and time schedules for implementation.

Theme 2: Betterment for service users

43. Service users, family members and carers were asked about whether they felt that their lives had benefitted from the move out of hospital into a community setting. In particular they were asked if they were happy where they live now, if they felt happier in comparison to where they used to live and to provide reasons for their answer. In addition, they were asked what things they liked and disliked about where they currently live and where they used to live. An assessment of *life now for the resettled person* was made by the service users themselves, family members and staff. The ability to reflect on this varied across the various respondents.

¹⁵ Customer journey maps were a photographic and paper based journal, developed for and with service users as part of their ‘journey’ from a long-stay hospital to a supported housing scheme. This included details of their meetings, photos of trips, planning the various rooms – bedrooms, living room, bathroom, kitchen and outdoor space.

Service users and their families

44. Service users were asked about how they felt in terms of their accommodation and life in comparison to their life in long-stay hospital. Responses were provided by service users, and where appropriate, by family members and carers speaking on behalf of service users who were unable to speak for themselves. In all 22 cases life was seen as better, and 'betterment' was deemed to have taken place. Whilst it was clear that life for many of the service users now living in the community was not fully comparable to or consistent with that of able-bodied people, it was nonetheless viewed as being better than their previous experience of life in a long-stay hospital.

Service User – Tony

Tony was aged 69 and had been in Muckamore Abbey long-stay hospital for more than 30 years. He had mild learning difficulties and a good level of verbal communication and understanding. Tony now lives in a two-person bungalow with a co-tenant in a large supported housing scheme.

This service user said that he liked living here – *all the staff are nice, I have lovely views from the bedroom – it's the best room of all.* It was clear from the service user and staff feedback that this individual's life has changed and developed immeasurably. He is involved in going to a wide range of clubs and activities – on Tuesdays he goes to the Memory Café and on Thursday he goes to a club where he makes things and does colouring in. He also likes to go on trips. On the day we saw him the service user and his key worker were going to the Ulster Museum in Belfast.

There were other clear advantages to the move. Tony has lost over 5 stone in weight – through Slimming World in the community - and is now able to walk around the site and get out and about. Staff commented that the service user, like other tenants, is now able to *lead his life as normal. They are not institutionalised, they don't have to fit into a routine; we make the service to suit their needs.*

45. In some cases, particularly those service users with mild learning disabilities, their own comments indicated that life was considerably better. Improvements were seen as having come about as a result of them having more choice, better opportunities to do things and to participate, and the provision of and access to what could be deemed a more normal life in comparison to life in an institution.

They are in their own home, treated as an individual. After 40 years of going to the Day Room and asking which nurse is on... These were grown men – but where they came from – they couldn't have buttered their toast, or made a cup of tea, or even put the washing on – they couldn't even identify a potato.

Staff member

46. Examples were given of 'betterment' experienced by service users in terms of the living environment and physical accommodation, and the type of activities service users were now supported to take part in, in their own homes and in the community. These were deemed to be normal everyday activities as well as rights and opportunities available to everyone else – privacy, access to food and drink when wanted, the ability to see visitors at any time, to have personal belongings and personal space. In particular, when asked about what type of support they needed and received, and what type of things they could do themselves or needed support with¹⁶, responses indicated that service users were now engaged in meaningful day-time activities, related to their mental capacity and ability. Being able to engage in meaningful day-time activities was available to all service users. Participation emerged as a large part of what service users (and their families) viewed as contributing to betterment. Reference was made by those with mild to medium learning disability to the type and range of housework and domestic activities they now participated in.
47. Service users were largely satisfied with their accommodation and the scheme; in particular interviewees mentioning their own bedroom, shared living space, the local neighbourhood and amenities, and the range of things they could do, as a result of living in the community.

Service Users – 'Harry', 'Jim' and 'Nick'

Three male service users in one Supported Living Scheme provided feedback on their experiences. They were aged between 50 and 65 and had been in Muckamore Abbey long-stay hospital for more than 20 years. These service users had mild to medium learning disabilities, all with varying levels of communication and mobility, and some additional needs. They live in a four-bedroom house in a residential setting.

They ... (CONTINUED)

¹⁶ Section 4 of Interview schedule – see Appendix 1.

They talked about the positive side of living in the house. For two of them, there were no restrictions in terms of visitors (when they came) – in both cases visitors were family coming to take them out. They liked the fact that they could have a snack or drink when they wanted and that all of the items in the house were their own personal belongings. They said they had been part of the process of choosing them; they talked about having their own TV in their bedroom and having DVDs. They also liked the fact they had their own space, could put their things around them, and had privacy in their bedroom. Two of the service users offered to show us their bedrooms and seemed very proud of their furniture and belongings.

One simple example was given by service users of the new-found life they now experienced. In Muckamore the tea was poured from a large jug with sugar and milk already added so there was no personal choice and the person did not make it for themselves. In the house, service users were able to make their own hot drink and to make it to their own taste and strength - a simple but important every day task. They also helped to prepare food and plan meals.

They also talked about being more independent and doing things for themselves. One example given was that they have responsibility for cleaning their rooms one day each week, using the Hoover and changing the sheets on their bed. They compared this to their previous situation in the long-stay hospital – *a person in Muckamore would have come and done it for me*. They talked about shopping in Tesco and Sainsbury's – *there's a smashing café there* - and making a shopping list of things that they liked.

48. Whilst acknowledging their initial reluctance and fears about the resettlement process, the majority of family members pointed to both a sense of betterment and actual examples of better quality of life for their family member. They said that service users were happier and brighter, and engaged less in self-harm or challenging behaviours that had been part of their experience in long-stay hospital.

He's happier here, he smiles more...the self-injuries are not a fraction of what they were...we never see a mark on him.

Family member

49. The family of one service user with a severe learning disability and severe autism noted that life had improved immeasurably for him: ... *he's much better – before he was depressed and had lost weight. It's more normal here – not like a hospital – it's more natural. He can go out for walks with staff or out in the car.*
50. It was noted that challenging and disruptive behaviours were less frequent – *the behaviours were through the roof – but there are less incidents and he isn't displaying poor behaviour. His sleeping patterns and eating patterns are much better.* Staff at this scheme noted that in comparison to the long-stay hospital the resident now had choice: ... *before he would sit down – dinner was set in front of him with no choice – and if he was not quick someone else would eat it.*

You couldn't get any better – this is different altogether – they were all institutionalised while they were there. People took the attitude 'out of sight, out of mind' and there was no stimulation.

Family member

Service managers and frontline staff

51. Service managers and staff were in agreement that 'betterment' had occurred and evidenced this from observation of changes in behaviour, better sleep functions and better interaction with other people. They also talked about quality of life in terms of better family relationships, a better living environment, more privacy and more involvement in activities.

What you observe, changes in behaviour, sleep functions...you can see their enjoyment of certain things and responses to you...it's basically a better environment. They have more privacy, more dignity and there are much greater opportunities to be involved. They have choices now – in the past they didn't have choices about what they ate – their food was just delivered to them. It's their quality of life and control over what they can do.

Staff member

52. Service providers qualified their judgement of betterment by noting that not everything in long-stay hospitals had been negative; and equally, not everything about living in the community was positive. It was acknowledged that these factors had an impact on betterment, and that various aspects of life in the community negatively - and often unintentionally – impacted on the concept and reality of betterment. This was particularly true for service users with severe, complex and additional needs¹⁷.

¹⁷ Additional needs including recorded criminal background and/or inappropriate sexual behaviour – for these service users resettled into the community it was noted that their day to day experience is closely managed by staff.

53. Staff gave examples of specific changes that had taken place for particular people after they had been resettled. In one case, a female service user had been given an enema on a weekly basis whilst in Muckamore over a period of some years. They noted that: ... *when she came out this stopped because her diet had changed...and more 1:1 attention could be provided to her in terms of her medical and health needs.*

It's been very encouraging – the involvement, inclusion and family input. You could see them (the service users) growing, nurturing, making choices, going places, doing things, being treated as a normal citizen. It was all about taking risks and managing these appropriately.

Staff member

54. In another case the sister of a service user, who had visited him over a number of decades in Muckamore, was amazed to find that, when he was resettled, he could walk. His sister did not know he could walk. When she visited Muckamore he had always been brought to her, in the lounge or visiting room, in a wheelchair.
55. Another example cited by staff and family members was what people were wearing. They noted that following resettlement there was a wider availability of different clothing, the fact that clothes were not mixed up with other people's in the laundry and the fact that service users could now make an active choice about what they wanted to wear.

Service User – 'Christine'

Christine was aged 36 and had been in Muckamore Abbey long-stay hospital for 17 years. She had mild learning difficulties and a good level of verbal communication and understanding. Christine now lives in a three-person house with two co-tenants.

She said that she much prefers living in the community in this scheme to living in Muckamore. She described that the ward she lived on – *there were 17 of us – the whole lot of us – that there was always people shouting or sick. You didn't have the space you have here. You couldn't choose things at Muckamore. I'm happy here.*

Christine is able to walk to a range of shops, cafes and other services e.g. GP, hairdresser, by herself. It was very clear from the discussion that the range of opportunities she enjoys and her aspirations have greatly increased. The scheme service manager said that when Christine first moved out of Muckamore she needed 1-1 staff support even at the Adult Learning Centre but that now she was able to cope on her own during the day provided that there was staff support in the house overnight. CONTINUED

Christine attends the Adult Learning Centre 5 days per week and is involved in a range of activities including arts, craft, cookery, watching videos and DVDs. Christine said that she felt happy and settled where she is living now. She talked about her sense of freedom.

Theme 3: Limitations to betterment

56. Respondents were asked to say what they thought limited the resettled person's experience of betterment, quality of life and how they feel about themselves. In particular they were asked to speak about what the resettled person disliked about where they now live, and how that compared to the long-stay hospital setting.
57. A number of limitations to betterment were noted by service users themselves and their families. Whilst betterment was the end objective of resettlement for service users, a number of barriers to active participation in the community, ability to and opportunities for engagement in meaningful day-time activities, and actual social inclusion in the community were highlighted. Some of these were based on service users' needs, abilities and capacity, but others were in relation to structural and financial aspects of services in the community, as well as factors such as the location of supported housing scheme the service user was living in.
58. Family members and staff suggested that the physical location of some supported housing schemes had an adverse impact on betterment for service users. This included distance from and lack of accessibility to other services, and appeared to be more of an issue in rural settings. It was also an issue noted in some residential urban settings where, for example, a bus stop was at some distance from the scheme, and access to public transport was therefore impossible for service users. The location of schemes in relation to proximity to family was also noted as a limitation in one case where the family indicated that they would prefer to have their daughter closer to them. This scheme is 10 – 11 miles away from their family home and the family has to make a specific journey to go and see their daughter. The family would prefer if she could live nearer to them, as they feel this would allow more natural family interaction and a better bond to develop between siblings.
59. Transportation was highlighted as a problem in some schemes. The location of some schemes and distance from services, combined with a lack of access to public transport (which was not always suitable for service users) compromised opportunities for service users to have easy access to the wider community. Whilst significant numbers of those who were interviewed owned or had access to a Motability car, other issues were noted about their use. In a number of cases difficulties were noted in the availability of staff able to drive the cars (the minimum age for drivers is 25); reliance on staff availability for driving and supervision of service users; and difficulties ensuring service users could be transported safely. In a number of interviews it was clear that the service user did not have a mobility car, but a co-tenant did. In these cases staff said that they are required to obtain permission for the service user to travel in the car with their co-tenant.

Service User – ‘Michael’

Michael was aged 27 and had been in Muckamore Abbey long-stay hospital for one year because previous placements had broken down. He had severe learning difficulties and severe autism, and does not interact well with others. Michael lives in a flat in a supported housing scheme but does not have any interaction with other service users.

Michael does not take part in activities outside the scheme involving other people mainly because he does not mix well. There had been initial discussion of him attending a day centre but this had not emerged as an option.

However, it was also acknowledged that Michael now has opportunities to be part of the wider community – *he likes walking, the cinema and getting a carry out...but he doesn't have the ability to communicate with people.*

Transport was another barrier to doing things in the community. It was noted that the service user now has a mobility car; however, there have been difficulties with this because drivers have to be over 25 and many of the staff are under this age. Also he prefers to sit in the front but regulations require him to sit in the back and this has caused problems. In addition, the service user's behaviour means that it is too unpredictable for him to go on public transport.

In spite of these limitations his family was satisfied that the move from hospital had resulted in improvements in his life and that betterment had occurred for Michael.

60. Service users living in rural settings had limited services or amenities near at hand. Their ability to take part in activities away from where they lived depended on travel by car or taxi, and in most cases required support from staff.
61. Other limitations to betterment included the availability of services. This included a lack of day centre places and suitable, affordable and accessible external activities. It was also noted that, in a number of cases, day centres would not accommodate service users unless they brought staff support with them and this was not always possible.
62. In a number of other cases respondents noted the lack of external opportunities and external interaction for them or their family member. This raised questions of whether the person was fully living in and integrated into the wider community, or was effectively living in a smaller institution, albeit in a community setting.

63. There was acknowledgement that service users were able to do much more for themselves in a supported housing scheme compared with their previous life in a long stay hospital, but there was an underlying suggestion that they were not living the fully independent lives that their disabilities made them capable of in the community.
64. Families of service users with severe learning disability highlighted the limited opportunity for day care or other activities in the community, whereas everything had been on one site in for example, Muckamore Abbey long-stay hospital. In one larger supported housing scheme, the three service users we spoke to had minimal activity or interaction outside of the walls of their scheme.

Service Users – ‘Tom’, ‘Bill’ and ‘Rosemary’

Tom, Bill and Rosemary were aged between 40 and 49, and had been in Longstone long-stay hospital for more than 25 years. They had mild to severe learning disabilities, all with varying levels of communication and mobility, and some additional needs. They live in six-bedroom houses in a supported housing scheme with 24 SP-funded contracted units.

This scheme is located in a small residential area in a largely rural setting. Whilst there is a small shop nearby, for other amenities service users need to travel by car or taxi. From the interviews with service users and staff it was clear that these service users do not participate in activities outside of the scheme. One service user talked about going to day care when he was in hospital – this was Clover Day Care which was part of Longstone Hospital. This individual now mainly watches TV and listens to the radio, and enjoys going out for a run in the car. Staff said that he does not engage in the structured activities onsite.

For all three service users whilst betterment has occurred in some respects, they appear to spend most of their time in the scheme because there are no day centre opportunities. They have very limited integration into the wider community.

65. There was concern that some of the bigger supported housing schemes (for example, one with more than 15 contracted units) could effectively become mini-institutions and whilst people were resettled in the community, this was not the same as living in the community. Even in the smaller schemes (5 units and less), whilst considerably smaller than the hospital wards in Longstone and Muckamore, there was a feeling that these still could become institutionalised.

A 3-bed house could be as institutionalised as the hospital – but we work very hard to ensure this is not the case.

Staff member

66. A small number of service users, who had the mental capacity to make comparisons with their previous life in hospital talked about missing Muckamore or Longstone. They appeared to miss the wider environment and interaction with a larger number of people, they missed certain members of staff, and they missed activities such as the Cosy Café at Muckamore Abbey and the day centre at Longstone. Loneliness was another issue raised by interviewees. Staff noted that for some service users life in long-stay hospital had provided a level of security and comfort that has not been achievable in their new locations and settings.

A lot of resettled people are lonely. They knew the staff in Muckamore – in many cases for more than 20 years – and they had friends and connections there. It was their home and it was normal to them – it was their life.

Staff member

67. A small number of service users said that they missed the company and environment of the long-stay hospital. One service user talked favourably about his time in Muckamore because he felt he had friends there. When asked if he had friends where he now lives he said: *I had a lot of friends in Muckamore – I do have friends here but not as many here.*
68. Families recognised that some of their hopes for life in the community had not been fully realised, and they had concerns about lack of day-time activities, access to medical facilities and attention, and what would happen to their family member if resettlement broke down. In addition, for those whose family members had been more recently resettled, family members felt that staff did not fully understand the needs of the service user, and were in some cases ‘pushing’ them to do things beyond their ability and capacity.

She’s not in good health at the moment – and yet they’re trying to push her to go out to ... restaurants and cafes....I would prefer they wait until she is better....she has a fear of strange places – I think it should be more gradual. There are certain triggers and signs and the staff haven’t picked up on these.

Family member

69. Staff and managers comments on betterment can be summed up as follows. They said that not everything in the long-stay hospital had been negative, and equally, not everything about living in the community was positive. Some aspects of life in the community had a negative - and often unintentional – impacted on the reality of betterment.

70. They said that, whilst things were better for the majority of resettled people: *life isn't just totally wonderful for all now. You need to balance it out – it (resettlement from hospital) was right for some people and in some situations. But overall it does appear to be better to be resettled out of hospital.*
71. In a small number of cases another factor limiting the experience of betterment was relationships with neighbours. In one supported housing scheme, staff said that they had encountered a number of quite significant and difficult problems with the immediate neighbours. The difficulties had been experienced in relation to where staff park, complaints about the service users smoking and talking in the back garden, one service user allegedly looking through the fence, and one service user creating disturbance by 'coughing' in the back garden. Some of the neighbour response has been significant with tyres slashed on staff cars the involvement of police, and as a result the installation of CCTV. In this scheme, staff feedback indicated that whilst the service users were living 'in the community' in their opinion was that they are not 'integrated' into the community because of neighbour hostility towards them.
72. In a different scheme service users noted that they had experienced problems from the adjacent house. On one side there were noisy parties, and on the other side there was a derelict house which had problems with mice. Elsewhere, family members and staff talked about schemes where neighbours did not speak to either service users or staff, and indeed ignored them.
73. Some family members of service users with a severe learning disability suggested that a further limiting factor in terms of betterment was the number and type of staffing in supported housing schemes. They noted concerns that staff lack medical information and nursing knowledge in respect of the service user. In two cases family members felt staff had insufficient training in dealing with a learning disabled person who also has autism. In a second case, a mother said she had concerns about staff leaving the service provider organisation that the service user had got close to and the impact of this on her daughter's routine.

Theme 4: Too little, too late and a forgotten few

74. In a number of cases family members and staff indicated that resettlement (and the betterment that has been achieved) had come too late in the service user's life for them to get full opportunity and benefit from resettlement. Three service users in one supported housing scheme were now aged in their 60s and 70s. They had been resident in Muckamore Abbey Hospital for between 15 and 40 years respectively.
75. Whilst these individuals had been resettled in the period 2012 – 2016, and resettlement was deemed by staff to have involved a very smooth period of transition, they felt regret that this had not occurred more than twenty years previously. They said that, for these service users, resettlement has almost come too late in their life although they did consider that their quality of life in the supported living scheme is considerably better than at Muckamore Abbey long-stay hospital.

It's been very encouraging – the involvement, inclusion and family input. You could see them (the 3 service users) growing, nurturing, making choices, going places, doing things, being treated as a normal citizen. It was all about taking risks and managing these appropriately.

Staff member

76. In a small number of cases, it was clear that the service user was still effectively locked away and restricted, and because of their mental capacity and for other reasons was unable to live without high levels of supervision and intervention. These cases were largely those with forensic background, those with a very severe learning disability and those with severe autism. In the majority of these cases family members and staff did feel betterment had occurred, albeit to a lesser degree than those with mild and moderate learning disability.

Service User – 'Patrick'

Patrick was aged 33 and had been in Muckamore Abbey long-stay hospital for 16 years. He had severe learning difficulties and severe autism, and does not like any noise. Patrick lives in 4-person supported housing scheme but does not interact with other service users. Patrick has his own bedroom and living room and 2-1 support at all times.

Patrick's parents had a vision for their son to live in the community from his teenage years, and have actively lobbied for this. They were content with resettlement in terms of the overall process. However, the main concern for them was the timing and the stop/start approach of resettlement (having initially been told he would be resettled in 2010).

Patrick's parents said that he had adapted to his new home quickly and very well. They had been offered a staged approach to the move but their judgement was that it would be better for their son just to move in one process and this is what was done. *He just took to it...it was as if he knew.*

Despite being isolated in his own quarters and with limited interaction with other service users Patrick's parents talked about how they felt he is now *part of the community*. Overall they felt this was a better place for their son, and that his quality of life was considerably better.

Patrick's parents reflected on how things could be improved further. They felt the Bamford vision had been good but did not go far enough – *Bamford didn't really see beyond getting them out of Muckamore*. The parents felt there was a significant need for more activities in the community for learning disabled people like their son with high needs. They acknowledged that there were day centres but that these were targeted at learning disabled people who were higher functioning.

Theme 5: Family contact and family contentment

77. Responses from around half of respondents (12 out of 22 service users or family members) showed that there was good family contact following resettlement, and that better family contact had been established compared with the situation in hospital. The frequency of contact was said to have increased, the service user was able to phone as well as see their family and the type and range of activities they participate in within the scheme and in the community has increased. Family members referred to better ease of access, more privacy and new opportunities to interact with their family member.

One service user now has regular fortnightly visits from his sister and they go out together occasionally. He said – *she did visit at Muckamore – but not as much – it was too far.*
Service User

78. However, in a small number of cases family contact had not been re-established, either because parents and members of the wider family were no longer alive, or because of the length of time that had elapsed since there had been any involvement. In a few cases there was limited involvement from family both during and after resettlement. This lack of family contact was historical, possibly linked to the services user's background and the nature of their disabilities; in other cases because of old age, infirmity and the distance to travel.

Service User – 'Phelim'

Phelim spoke about the resettlement process and where he now lives. He was in his late 40s and had been in Longstone long-stay hospital for a long time (he could not recall the length of time). He had mild to moderate learning difficulties and reasonable verbal communication. He lives in a 6-person bungalow in a larger supported housing scheme.

Phelim talked very positively about his life since resettlement – *I like it the best.* His key worker said that one significant improvement for him has been more family involvement. A brother and his wife visit. When Phelim was in Longstone this was once every two years; since moving to the scheme this is now once per quarter. They see him in his room or take him out.

79. In the majority of cases family members indicated that resettlement had resulted in some degree of peace of mind for them, in particular in regard to future provision for their family member. Three family members said they had concerns about future, in particular referring to what would happen to their family member when they passed away or when the service user's longer term needs changed or they needed nursing care.

Appendix 1: Written communication with service users, parents and members of staff in supported housing schemes

Research into the experiences of learning disabled people resettled from long stay hospitals in Northern Ireland BRIEFING FOR FAMILIES, CARERS AND SERVICE PROVIDERS

The Northern Ireland Housing Executive has commissioned research into the way in which the lives of learning disabled people who have been resettled from long-stay hospitals (Muckamore Abbey Hospital, Antrim; Longstone Hospital, Armagh; and Lakeview Hospital, Derry/Londonderry), have changed since they took up their new accommodation.

The objectives of the research are to:

- describe the types of accommodation, care and support provided to people who have been resettled, and the ways in which these services are supporting people to experience a more independent way of life;
- provide a socio-economic profile of the people who have been resettled; and
- describe the impact of resettlement on the quality of their lives compared with the lives they lived in their previous hospital settings;

As part of the research, we have been asked to interview 25 learning disabled people who have been resettled from one of the long-stay hospitals; a parent, member of their family or carer; and a service manager who is responsible for providing them with the care and support services they receive.

The interviews will give resettled people and those who are close to them the opportunity to say:

- how resettlement has affected them;
- what they like and what they do not like about the services they are now receiving in comparison with their life in hospital; and
- what difference resettlement has made to their lives.

The research is being carried out by Fiona Boyle (Fiona Boyle Associates) and John Palmer (North Harbour Consulting). Fiona and John have a lot of experience of working with learning disabled people. The interviews will be led by Fiona Boyle. Gillian Greer (Research Officer, NIHE Research Unit) will also support the research process.

We will write to or meet with each of the people that we would like to interview to tell them about the research, to invite them to take part (their written informed consent is required), and to tell them about what will be involved in their interview.

If you would like to find out more about the research, or tell us whether you would like to be involved, please contact:

Mrs Fiona Boyle,
[Address]

Telephone: []

Mobile: []

Email: []

LETTER FOR SERVICE USERS

HOW DO I FEEL ABOUT WHERE I LIVE?

My name is Fiona. This is my picture.



I am interested in the experiences of people who used to live in hospital and who are now living in the community.

I would like to know what it was like moving into your new home, and how you feel about where you live now.



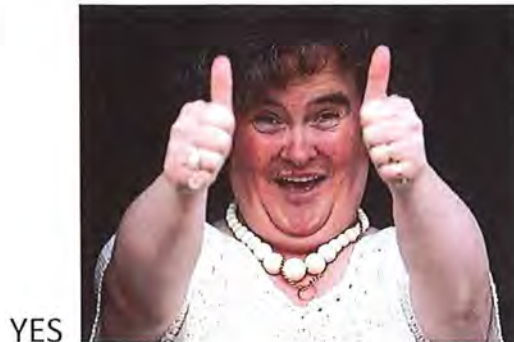
You can have someone with you like a member of your family or someone who looks after you.



It will not take longer than 15 minutes.



You can say yes or no. It is up to you whether you want to take part.



If you do want to take part, please ask someone to explain what will happen if you say yes.



If you would like me to come to talk to you, please ask someone to help you sign the attached form and return it to me.

Thank you for reading this.

Yours sincerely

Fiona Boyle

Mrs Fiona Boyle

HOW DO I FEEL ABOUT WHERE I LIVE?

If I talk to Fiona about her project "How do I feel about where I live?"

I understand that Fiona will write down some of the things I say.



I understand that what I say will be private.



I understand that I can stop the interview at any time.



If you understand the statements above, you now need to decide whether you would like to take part in the project.

I have decided that I would like to talk to Fiona about her project "How do I feel about where I live?"

Please put a tick in the No or Yes box.

No

Yes

Please sign your name here:

Please print your name here:

Appendix 2: Semi-structured interview schedule

QUESTIONS FOR SERVICE USERS

Section 1 - Who you live with?

Do you live alone?

Do you want to live alone?

Would you like to live with others?

Do you want to live alone, but be near others? For example, have your own flat or apartment – but in the same block as other people like you.

Would you prefer to live with family members?

Section 2 - The type of accommodation you live in?

Do you like the place (city, town or village) where you live?

How would you compare this to where you lived before – same, better or worse?

How do you want to pay for your housing – rent, buy or other?

What type of accommodation did you live in before – shared house, individual house/bungalow on site, dormitory or shared bedroom with other facilities?

What type of accommodation are they now in? (Researcher to both note this and ask this)

What do you like about this place?

What did you like about the place you used to live (give name)?

Which would you say is better?

Section 3 - The type of area you live in

Do you like the place (city, town or village) where you live?

Are you content with all the things that are close by – LIST – which ones do you have nearby and which ones would you like?

- Open spaces/park
- Shops/supermarket
- High Street or town
- Pub
- Church or place of worship
- Transport – bus or train
- Community facilities – leisure centre, community centre
- College or work places
- Close to people you care about?

Section 4 - The type of support you need and receive?

Tell me what type of support or help do you get to live here?

Do you need help with any of the following:

- Making drinks and snacks
- Making a hot drink
- Preparing food
- Planning a meal
- Cooking
- Eating
- Going shopping
- Managing money

- *Going to the bank*
- *Going to the post office*
- *Reading and writing*
- *Paying bills*
- *Road safety*
- *Using public transport*
- *Using the telephone*
- *Keeping time*
- *Housework*
- *Doing the laundry*
- *Doing the ironing*
- *Personal care*
- *Getting dressed*
- *Choosing clothes*

Who provides this help and support?

(Check if it's someone that's paid or unpaid – such as family member or friend?)

Section 5 - Making the move to this new accommodation (the resettlement process)

How did you choose to move here (location?) and to this type of accommodation?

Who helped you to make this decision?

Were you given a number of options – both location and type of housing?

Were you able to understand this information?

Who helped you to move?

How was the move – did you find it easy or difficult?

Did you settle within the first few days or weeks?

Section 6 - How you feel now?

Comparison of the before and now – in terms of the accommodation and also their quality of life/how they feel about themselves

Are you happy where you live now?

Do you feel happier here than where you used to live?

Can you tell me why you feel this way?

Is life better now HERE than it was when you lived at INSERT NAME OF PLACE?

Can you tell me why?

What things did you not like about where you used to live?

What things do you not like about where you live now?

Probe:

- *Not able to have visitors when you wanted*
- *Didn't feel like your place or your space*
- *Not being able to have meals/snacks when you wanted them*
- *Not being able to have the pictures on the wall you wanted*
- *Having to share some things – TV room*
- *Being told to do things by staff.*