ORGANISATIONAL MODULES 2024

MUCKAMORE ABBEY HOSPITAL INQUIRY WITNESS STATEMENT

Statement of Dr Marina Lupari Date: 26th February 2024

I, Dr Marina Lupari, make the following statement for the purpose of the Muckamore Abbey Hospital (MAH) Inquiry.

The statement is made on behalf of Independent Health and Care Providers ("ihcp") in response to a request for evidence by the Inquiry Panel.

This is my first statement to the Inquiry.

I will number any exhibited documents, so my first document will be "Exhibit 1".

Qualifications and positions

- I am a qualified Registered Nurse. I hold a First-Class Hons degree in BSc Community Nursing with Health Visiting. I hold a master's degree in Primary Care & General Practice. I hold a Doctor of Philosophy.
- 2. I have held the following positions. From 2002 to 2004, I was Option Leader for Health Visiting at University of Ulster. From 2004 I was Service Improvement Lead with Homefirst Community Trust. From 2007 I was Assistant Director of Nursing: Research & Development NHSCT. From 2014 to 2015 I was seconded to Professional Lead for Community Nurse and Practice Nurses with Royal College of London, London. I returned to Assistant Director of Nursing: Research & Development NHSCT in late 2015. In 2016 I became owner of Town & Country

Care Homes Ltd – two care homes for people with Learning Disability. In 2021 I became a director at ihcp to represent ihcp members providing care for people with Learning Disability.

Module

- 3. I have been asked to provide a statement for the purpose of M6: Resettlement.
- 4. My evidence relates to paragraph 16 of the Inquiry's Terms of Reference.
- 5. I have been asked to address a number of questions/ issues for the purpose of my statement. I will address those questions/issues in turn.

Q1. Please explain the role of the Independent Health and Care Providers in the process of resettling patients from Muckamore Abbey Hospital (MAH) into the community, and the effectiveness of working arrangements, throughout the time period within the Inquiry's Terms of Reference, that is between 02 December 1999 and 14 June 2021.

- 6. ihcp was established in 1997 as a non-profit making membership organisation representing private, not-for-profit, charity and church-affiliated organisations providing residential and nursing home care, sheltered housing, day care and care in the home. The independent sector provides services to over 50,000 people across Northern Ireland every day and employs over 34,000 people. 15,000 of the 16,000 care home beds in NI and over 70% of the overall homecare support is provided by the independent sector.
- There was no engagement with ihcp within the designated timeframe between 02 December 1999 and 14 June 2021.

Q2. Please explain what, if any, training resources were made available to Independent Health and Care Providers by the Belfast Health and Social Care Trust, or the Department of Health.

 There were no training resources made available to Independent Health and Care Providers by the Belfast Health and Social Care Trust, nor the Department of Health between 02 December 1999 and 14 June 2021.

Q3. Was any analysis undertaken by the Independent Health and Care Providers in respect of failed resettlements of patients from MAH into the community? If so, was there any mechanism to pass on learning into the process to improve future resettlements?

 It would not be the remit of ihcp to undertake an analysis in respect of failed resettlements of patients from MAH into the community. Ihcp were not invited to participate in any analysis being conducted by Belfast Health and Social Care Trust, nor the Department of Health between 02 December 1999 and 14 June 2021.

Q4. Do you wish to draw to the attention of the Panel any other matters that may assist in the Panel's consideration of paragraph 16 of the Terms of Reference?

- 10. In January 2022 I represented ihcp in the commissioned review of Resettlement that was undertaken by Bria Mongan and Ian Sutherland on behalf of the HSCB. I had a preliminary conversation with Bria Mongan and Ian Sutherland, and it was agreed that ihcp would facilitate a focus group to provide a response from ihcp members.
- 11. The focus group was held on 18 February 2022 and three members of ihcp attended.

12. On 30 September 2022 I attended a feedback session with two members of ihcp with Bria Mongan and Ian Sutherland on the findings from the 'Independent Review on Learning Disability Resettlement Programme in Northern Ireland'. Our attendance was to consider the draft version of the Review which has been attached as Exhibit 1. We confirmed during discussions that the findings represent the experience of ihcp members. This was then shared with ihcp members on 01 October 2022 for comments. No comments were received, and I confirmed that the content of the draft PowerPoint confirmed the position of ihcp members. The final report was published which I have included at Exhibit 2.

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 necessary to address the matters on which the Inquiry Panel has requested me to give evidence.

Mhappei

Signed:

Date: 26th February 2024

List of Exhibits (Dr Marina Lupari)

- Exhibit 1: Draft PowerPoint: Independent Review of Learning Disability Resettlement Programme in Northern Ireland. Authors Bria Mongan & Ian Sutherland September 2022.
- Exhibit 2: Department of Health (2022) Independent review of Learning Disability Resettlement. Version saved 260224 ML

MAHI - STM - 209 - 6

Independent Review of Learning Disability Resettlement Programme in Northern Ireland

Bria Mongan & Ian Sutherland

September 2022.

Terms of Reference

- Length of time patient has been in MAH and where they were admitted from
- Ascertain if resettlement has already been trialled
- Identify those individuals where plans are absent or weak in relation to their resettlement
- Summarise the policy and practice evidence base in relation to resettlement programmes.
- Work with leaders in the appropriate Trusts to ensure that suitable resettlement plans are developed.
- Critically evaluate the progress of resettlement plans as devised by the responsible Trust for the identified individuals.
- Business cases which have been completed or are still in process identifying any positive outcomes and any strategic or operational barriers. Make recommendations for actions that would strengthen or accelerate the delivery of proposed pipeline schemes.
- Review to what extent the engagement strategies employed individually by Trusts, and collectively by the system as a whole have been effective in supporting the delivery of the MAH resettlement programme.

Terms of Reference [2] - 209 - 8

• INTER-AGENCY WORKING

- Whether/how the agencies and professionals involved in resettlement of patients, have worked effectively with each other at each and every stage of the process.
- PARENTAL ENGAGEMENT/ADVOCACY
- Whether and to what extent the families of the patients were engaged in decision making around resettlement.
- Whether and to what extent, independent advocacy and support was provided.
- OUTSIDE OF SCOPE
- Issues relating to children and young people with Learning Disability/Autism who may be subject to delayed discharge in other settings

Methodology

- The review team decided to adopt an approach for the review based on 'appreciative inquiry'
- This is a strengths-based positive approach to leadership development and organisational change. This approach seeks to engage stakeholders in self-determined change and incorporates the principle of co-production.
- The review team adopted the following methods to progress the key lines of inquiry:
- Direct observation and participation in key processes
- Direct interviews with a wide range of stakeholders
- Gathering and analysing data relevant to the resettlement process
- Focus groups both face to face and digital engagement.

Key Engagement

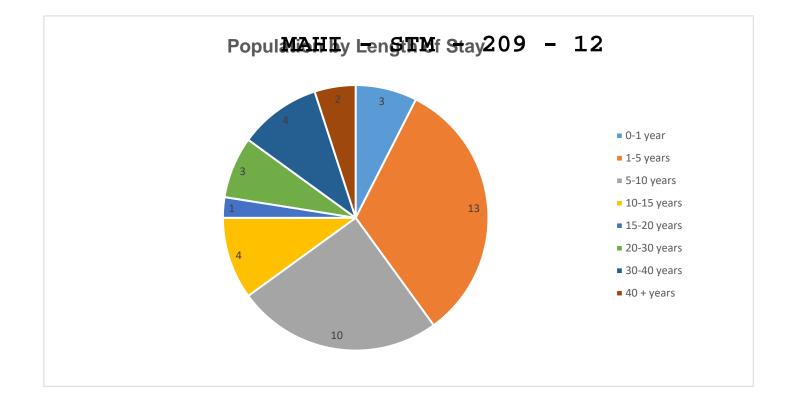
- Mental Health Leadership Forum [Senior leaders HSCB/SPPG & Trust Directors]; RLDOG Regional Learning Disability Operational Group [Trust Assistant Directors and Commissioning/Finance Leads in HSCB/SPPG]
- Senior leaders and policy leads in DoH
- Focus meetings with Trust Leadership Teams for LD to review plans and overall approach to resettlement.
- Meeting and feedback from other key stakeholders including senior leaders in Housing and Supporting People;
- Independent Sector Providers in the Voluntary, Private and Not for Profit Sectors
- Parents & Carers.
- RCPsych in Northern Ireland Intellectual Disability faculty -
- Regulators-RQIA-NISCC
- Meetings with leaders in other system in England and Rol.

Delayed Discharge Population-

• N. I. Total- 62 patients- MAH(46) Dorsey(8) Lakeview(8)

Trust of Residence	Number of In-Patients
NHSCT	21
BHSCT	16
SEHSCT	8
SHSCT	1
WHSCT	0
Total	46

Trust of Residence	Number of In-Patients
NHSCT	14
BHSCT	15
SEHSCT	6
SHSCT	1
WHSCT	0
Total	36





Legislation, Strategic and Bolicy Context

- Review of Legislation and Policy across UK and N.I highlighted common themes and strategic priorities for LD across all UK Nations- Human Rights approach in line with the Bamford Review of Mental Health and Learning Disabilities
- The 2007 Bamford Review of Mental Health and Learning Disabilities represented the key strategic driver to shape delivery of services for individuals with learning disabilities and/or autism in Northern Ireland. Equal Lives(2007) is the second report from the Review and sets out a compelling vision for developing services for men, women and children with a learning disability
- The principles and values underpinning the Bamford Review remain relevant to current policy direction however LD strategic policy needs to be urgently updated for 2020's
- There have been a series of high profile scandals following investigations identifying abuse to residents in HSC facilities over the past decade across the UK
- Delayed Discharge breaches incompatible with obligations pursuant to section 6 of the Human Rights Act 1998 and Art 8 of the European Convention on Human Rights.
- The ethical and legal imperative to complete resettlement is powerful and unassailable and articulated in legislation and policy over the past two decades
- Targets set since 1980's Missed and reset-

Legislation, Strategic and Policy Context

- The review team reviewed the strategic policy for Learning Disability services across England, Scotland, Wales and the Republic of Ireland to identify best practice and the learning from actions taken by other regions in regard to learning disability resettlement and avoidance of hospital admission.
- identified common themes in the strategic direction for Learning Disability
- focus on hospital avoidance through development of intensive care and support in the community.
- Strategic Policy in England- Building the Right Support-Transforming Care England' placed emphasis on the "highly heterogeneous" or diverse characteristics of the population
- Scotland's Keys to Life' 10-year Learning Disability Strategy developed a National framework agreement for procurement for specialist residential based care with a focus on the outcomes
- Welsh 'Improving Lives Programme' focus on need to promote Positive Behavioural Support and Trauma Informed care. Need to focus on soft skills and relationships.
- Ireland-'Time to Move On' Integral to the strategy was the We Moved On' stories of successful transition and promoting the voice

Leadership and Governmane - STM - 209 - 15

- The review considered leadership in three separate contexts-(1)strategic leadership (2)senior
 operational leadership (3) the extent to which people at the centre of resettlement, particularly those
 who were being moved to their new homes and their family members, were engaged and involved in
 the process, and how effectively they could shape and influence leadership
- Many of the findings and recommendations from the "Way to Go "report and the Leadership and Governance review report are still relevant
- System wide inertia with evidence of crisis management in response to legal and demand challenge
- Number of weaknesses in the HSC system including a lack of clarity in regards to Accountability and Decision-Making
- Strategic regional meetings not effectively coordinated and level of representation not consistent or sufficiently senior representation from all Trusts
- Resettlement/ delayed discharge was not on all of the HSC Trusts Corporate Risk Register
- Trust Boards oversight and scrutiny limited. BHSCT Trust Board focus shifted from resettlement to securing safety within MAH. [repeated]
- This review found that the focus was now on managing the wards to the detriment of resettling patients, despite the fact that reducing the population in Muckamore would have provided the most effective measure in mitigating the risks and challenges identified in the Leadership and Governance Review

Leadership and Governmencer - 209 - 16

- Trust Boards oversight and scrutiny limited. BHSCT Trust Board focus shifted from resettlement to securing safety within MAH. [repeated from slide 10]
- Significant instability in the leadership teams for LD ; most significant in BHSCT, but in other Trusts also several AD's new to role ; also some commissioning leads new to role
- No over-arching strategic plan for the resettlement of the remaining patients in MAH and closure or repurposing of MAH. Lack of joint strategic commissioning plan agreed between HSCB/NIHE focussed specifically on providing suitable alternative housing with care and support options for the people awaiting discharge from MAH.
- Limited evidence of effective performance management some evidence of performance monitoring but lack of robust targets in terms of effective delivery of strategic objectives. Needed to establish ' tracker tool' which could be used to support progress of plans for individuals
- There was no evidence of a project management approach being applied to the resettlement
 programme to ensure effective collaboration and shared oversight of delivery by key partners. Limited
 evidence of corporate team working
- Poor communication between key partners within the system, which contributed to the lack of a shared purpose and collective leadership focussed on the delivery of improved outcomes for the cohort of people in MAH awaiting resettlement.
- The voice of carers was not evident within the leadership processes, and there was no evidence of effective co-production with carers being involved at all levels. They did have a role in oversight as carers were represented within MDAG.
- Families reported that Culture needs to change due to their experience of a lack of openness and transparency, and reflect psycho-social approaches to care and support

Strategic Commissionin # Plan Ming and Inter-Agency Working

- The absence of an overall strategic framework and commissioning plan for LD services has meant that delivery can be disjointed and poorly integrated.
- Transforming Care in England has provided an overarching strategic framework and delivery plan
- LGA/TLAP/NHSE have developed a useful guide called 'Integrated Commissioning for Better Outcomes A commissioning framework " which is a helpful guide to best practice in commissioning
- There is a need to distinguish between the process of strategic commissioning, and individual/micro commissioning which is closely aligned to care planning and care management.
- Agencies hold significant data on the range of provision for adults with Learning Disability who have additional complex needs – good example is the NIHE data on supported living accommodation for adults with LD/ASD.
- There is little analysis of the data available, and insufficient consideration to the potential for data to inform strategic commissioning and provide an effective supply map.
- The current provision with both registered nursing & residential care sector and the supported housing sector have significant vacancy levels which indicates available capacity
- The Social Care Procurement Board is going through a refresh process, but needs to consider urgently the need for a new contract for 'specialist nursing and residential placements

Strategic Commissionin % Plasthing and Inter-Agency Working

- HSC Trusts continue to operate as a significant provider both in terms of registered residential care and supported living schemes for adults with LD/ASD. It appeared to the reviewers that this was a historical arrangement, rather than a strategic position. It wasn't clear what criteria were being applied in relation to the type of provision Trusts were responsible for and whether this represented good VFM for the public purse
- Providers felt that resettlement teams had not engaged with them to look at the potential to place in existing homes/schemes even where some re-design or re-purposing might be required.
- Independent sector providers generally indicated that engagement in a strategic discussion with commissioners was poor or inadequate, and that there was an over emphasis on contract review
- The commissioning for the cohort of people who are delayed discharges in MAH is poorly framed. The HSCB/SPPG has had limited impact in ensuring timely progress has been made by HSC Trusts to secure suitable new homes for these people.
- NHSCT and SEHSCT Trusts have made significant progress in developing schemes and bespoke placements for individuals, although the transition plans for these people has been slow.
- BHSCT has allowed significant delay on proposed schemes for a significant number of the remaining individuals in MAH beyond the very preliminary stages. Business cases have not been progressed in a timely fashion, and therefore the assessment of need has changed over time, and undermined the foundation of the business case

Individualised Care Planning

- There is not one overarching resettlement/ discharge policy and pathway that informs the roles and responsibilities of the range of organisations and individuals involved
- It was not evident that discharge planning was consistently led by the Community LD team
- HSC Trusts used NI Single Assessment Tool/ Care Management process however there was variation across HSC Trusts in the utilisation of additional tools such as Essential Lifestyle planning resulting in variation in the quality and consistency of information shared with provider organisations
- Provider organisations were expected to develop their care plans on the basis of information shared by the Hospital, getting to know the patient during in-reach and from the assessment shared by the relevant HSC Trust- They reported significant weaknesses with this approach
- Not all care plans were robust in highlighting the key issues and risks for the individual.
- Limited evidence of Care Planning process highlighting the requirement for Positive Behaviour approach

Individualised Careman armingo - 20

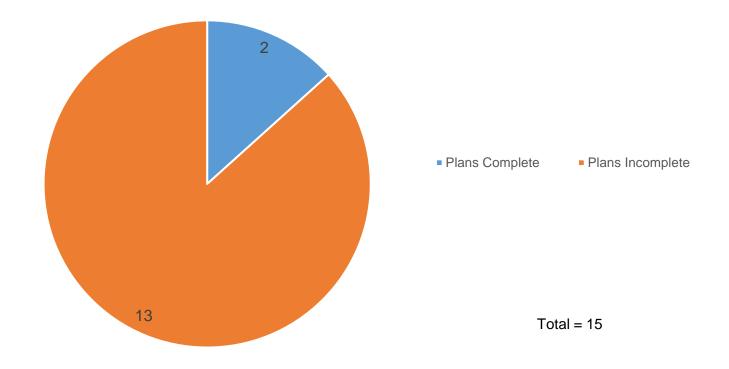
- The discharge process requires sufficient flexibility to ensure agility and prevent the process being risk averse. An overarching pathway that maps out who does what at critical stages of the resettlement process is required across all stakeholders
- Review and standardisation of the regional care planning pathway and assessment tools for people with learning disability/ ASD should be progressed
- Essential Lifestyle Plan should be developed for each patient with all Trusts investing in training staff to develop and utilise essential lifestyle plans
- Families should be seen as integral to the care planning and review process and invited to all meetings
- Advocacy support should be available and strengthened at all stages of care planning
- The process for standing down the resettlement team and transitioning to the community LD team should be clearly mapped out through the resettlement pathway providing indicative timeframes for patients and families
- HSC Trusts should establish system for monitoring the timeliness and effectiveness of the Care planning and Review process

Discharge Planning MAHI - STM - 209 - 21

- The Care Quality Commission- Brief Guide; discharge planning from Learning Disability assessment and treatment units (August 2018) provides a useful checklist of what needs to be in place for effective discharge planning;
- At the point of admission, the care plan should include a section on 'when I leave hospital' and the discharge plan discussed at each meeting
- Ensure family and the individual are involved with clear goals agreed
- Discharge plans need to contain a date, an identified provider and discharge address
- Evidence that the person is being supported to develop skills for independence and living in the community
- Evidence that information is shared appropriately with providers to prepare for discharge with the outcomes of assessment and treatment clearly stated.
- The review team were tasked to review the care plans for all the service users in MAH and critically analyse the actions taken to identify and commission suitable community placements.

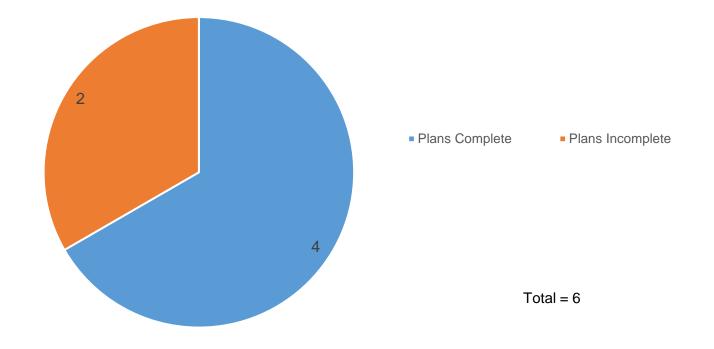
MAHI - STM - 209 - 22 Progress on Discharge Planning- BHSCT

BHSCT: Discharge Plans for MAH Patients at July 2022



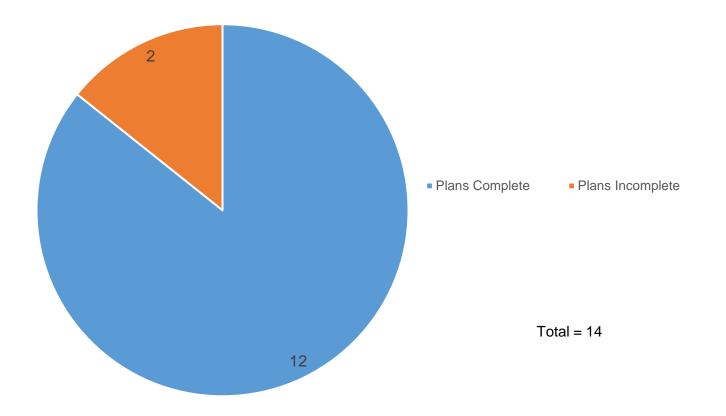
Progress on Discharge Planning-SEHSCT

SEHSCT: Discharge Plans for MAH Patients at July 2022



MAHI - STM - 209 - 24 Progress on Discharge Planning-NHSCT

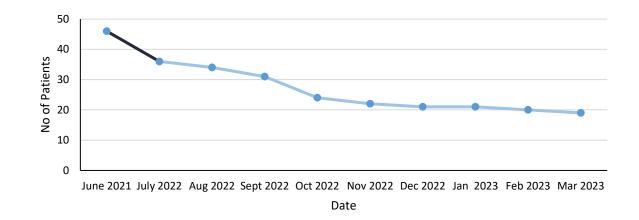
NHSCT: Discharge Plans for MAH Patients at July 2022



Progress and Trajector TATE - STM - 209 - 25

- Whilst progress at the beginning of the review had been slow HSC Trusts have recently reviewed their approach to consider alternative options that have potential for more timely discharge. The review team were pleased to see that this has improved the resettlement trajectory which anticipates that the population will reduce to between 15 and 19 by the end of March, 2023
- Evidenced in the following diagram

Reduction in Number of Patients in MAH between June 2021 and July 2022 and trajectory for Robust planned discharge by end March 2023





Operational Delivery MAHI - STM - 209 - 28

- There is an impressive range of accommodation and support provision for adults with learning disability. Detailed numbers are in the report, and this forms the basis for a 'supply map'.
- The biggest single issue raised by all stakeholders but especially by the provider representatives was in relation to the development of a skilled and stable workforce across the sector. The inability to recruit and retain social care workforce was a massive risk for the sustainability of the existing provision and the most significant barrier for the proposed new developments. This has seriously hampered progress of several of the resettlement schemes.
- There was some evidence that some of the least qualified and experienced social care workers were working with some of the clients with the most complex needs.
- Quality across the sector, given its size and nature, is variable. However there is certainly evidence to suggest that there is a high level of satisfaction with the quality of provision within the registered care and supported living sector from those living within these types of accommodation and their families.
- The reviewers visited a small number of schemes and saw some excellent work being undertaken by independent providers to develop specialist, high quality bespoke provision for individuals with very complex needs. We were impressed by the creativity and commitment of the staff and leaders we met.

Operational Delivery MAHI - STM - 209 - 29

- Several providers commented negatively on the quality and detail provided within assessments and care plans provided by MAH and HSC Trust to support the resettlement of individuals.
- Placements were better where there was effective communication, joint working and support. This was best where there was easy access to specialist Trust services in terms of positive behaviour support, specialist clinical advice, and effective response from specialist crisis teams. Whilst a significant number of families talked about the negative impact of 'failed' placements for their family member, there didn't appear to be any broader lessons learnt approach that could have supported wider systemic improvements. In particular we felt that the lived experience of people engaged in resettlement was not evident or documented and that consequently their voices generally went unheard.
- Several leaders across the system identified the need for better sharing of good practice models, and the need to ensure that the stories about the valued lives of people with learning disability need to be communicated through a positive narrative available to the public and society at large in Northern Ireland

Operational Delivery MAHI - STM - 209 - 30

- There was distinct variation in relation to how effectively the development of new accommodation schemes was executed by individual Trusts
- The NHSCT's discharge planning was based on 2 new build schemes and a number of individual bespoke placements. NHSCT has made significant progress in developing robust discharge plans with progress hindered by challenge with recruitment to the Mallusk scheme and challenges in the building supply chain that slowed building work moving the handover date of the Braefield scheme from end April to end September 2022.
- SEHSCT completed a number of capital business cases some years ago significantly reducing the Trust's long-stay in-patient population to eight patients at commencement of the review and six in- patients at 11th July 2022. It is of note that 1 SEHSCT patient has been on extended home leave from MAH with an extended support package since March 2020 with family taking the patient home at the onset of the Covid pandemic. BHSCT also had 1 patient on extended home leave for similar reasons. An evaluation of how the extended home leave placements have been maintained for this lengthy period without return to MAH should be completed to inform future support models aimed at admission avoidance.
- The Belfast HSC Trust (BHSCT) was an outlier in terms of its ability to successfully progress robust plans to deliver resettlement outcomes for the 15 patients who were their responsibility.
- BHSC Trust's resettlement plans centred on 3 new build schemes in development since 2019 which had not progressed beyond the preliminary stages

Safeguarding

- For families , safeguarding continues to be an abiding concern
- Confidence in HSC system's ability to Safeguard and Protect has been impacted significantly due to findings of abuse at Muckamore Abbey
- Families reported that Culture needs to change due to their experience of a lack of openness and transparency, and reflects psycho-social approaches to care and support.
- Feedback from families generally that CCTV is now a pre-requisite for discharge and is seen as a Safeguarding tool
- Feedback from Provider organisations highlighted dissatisfaction and inconsistency in regards to engagement with HSC Trust Adult Safeguarding teams
- Adult Safeguarding referrals should trigger involvement of an Independent Advocate
- Analysis of trends and patterns should be shared across HSC Trusts and provider organisations
- Routine Audit of Risk Assessment and Safety planning should be in place
- HSC Trusts should ensure that demand and capacity in Safeguarding services is clearly reported within DSF report and actions evidenced to address gaps in staffing of key posts

Advocacy and Carer Englage Filent^{209 - 32}

- Not one voice however common themes, lack of trust, anger- families reported Invisibility of LD services
- Lived Experience Advocacy takes a toll, psychologically and physically on families
- Traumatic impact given the level of trust they had over many years in MAH. Trauma Informed lens needed
- Some families reported a defensive to passive aggressive to hostile approach from HSC Trusts to encourage families to consider/ accept placement proposals
- Some families did not feel listened to as experts by experience
- Families reported a lack of clarity in roles of the Community LD, resettlement team and Muckamore Abbey Hospital MDT when a patient is discharged on trial placement
- Some families reported insufficient effort to maintain community placements
- Families with experience of successful resettlement said "Just get resettlement done"
- The review team did not see evidence of this lived experience being effectively utilised to support current families
- Families reported a fear of losing a placement offered if the HSC Trust was not in agreement with their requests for specific interventions such as CCTV

Advocacy and Carer Engagement 209 - 33

- Current Muckamore families talked about their dissatisfaction about the quality of care at MAH which they feel has been impacted by Covid and staffing shortages.
- Access to wards and the ability to visit unannounced was seen to be an important safeguarding measure for families
- Visiting restrictions were rigidly applied impacting on the quality of visits and the confidence of families during Covid restrictions
- Families also reported concern about restrictions on the range of day opportunities and lack of meaningful skills training for those in transition.
- Families reported a fear of losing a placement offered if the HSC Trust was not in agreement with their requests for specific interventions such as CCTV
- There was variation in the degree of involvement families want to have in the identification of placement options

Recommendations MAHI - STM - 209 - 34

- DOH
- The DoH should produce an overarching strategy for the future of services to people with learning disability/ASD and their families, to include a Learning Disability Service Model.
- The Learning Disability sector should be supported to develop a shared workforce strategy, informed by the consultation being undertaken by the DoH as part of the workforce review, to ensure that there is a competent and stable workforce to sustain and grow both the sector in terms of size and quality, so that it is responsive to significantly changing demand.
- People with a learning disability and their family carers should be respected as experts by experience and co-production built into all levels of participation and engagement across the HSC system.
- There should be an evaluation of the experience of people who have been resettled to understand what has worked well and what needs to change for the better and a regional programme to tell the positive stories of those who have moved on, to include audit of proved clinical and quality of life outcomes.

Recommendations^{MAHI - STM - 209 - 35}

• SPPG

- In the context of the overarching strategy the SPPG should develop a commissioning plan for the development of services going forward. This will include the completion of resettlement for the remaining patients awaiting discharge from MAH, and progress the re-shaping of future specialist LD hospital services.
- SPPG should establish a regional Oversight Board to manage the planned and safe resettlement of those patients not currently under active assessment or treatment or deemed multi-disciplinary fit for discharge across all specialist learning disability inpatient settings in Northern Ireland.
- SPPG needs to continue to strengthen performance management across the HSC system to move from performance monitoring to active performance management, and effectively holding HSC Trusts to account.
- SPPG should develop a more detailed tracker tool to create a master database of discharges, readmissions and trends and establish a clear definition of a discharge plan to provide clear projections about the trajectory for discharge and progress over time.

Recommendations_{MAHI} - STM - 209 - 36

- The Social Care Procurement Board should urgently review the current regional contract for nursing/residential care and develop a separate contract and guidance for specialist learning disability nursing/residential care.
- The SPPG and NIHE/Supporting People should undertake a joint strategic needs assessment for the future accommodation and support needs of people with learning disability/ASD in Northern Ireland.

• SPPG and Trusts

- Strategic commissioners within health, care and housing should convene a summit with NIHE, Trusts, Independent Sector representatives, and user/carer representation to review the current resettlement programmes so that there is an agreed refreshed programme and explicit project plan for regional resettlement.
- SPPG and Trusts should develop a database of people displaying behaviours which may result in placement breakdown to provide enhanced vigilance and service coordination ensuring targeted intervention to prevent hospital admission and support regional bed management.

Trusts

- Trust Boards should strengthen oversight and scrutiny of plans relating to resettlement of people with learning disability/ASD in specialist learning disability hospitals.
- A regional positive behaviour support framework should be developed through provider engagement with the standard of training for all staff working in learning disability services made explicit in service specifications and procurement.
- HSC Trusts should collaborate with all stakeholders to urgently agree a regional pathway to support future resettlement/transition planning for individuals with complex needs.
- HSC Trusts should collaborate to standardise their assessment and discharge planning tools to improve the quality and effectiveness of care plans.
- HSC Trusts should ensure that the lived experience of the person and their family is effectively represented in care planning processes and the role of family carers as advocates for their family member is recognised and respected.

Recommendations^{MAHI - STM - 209 - 38}

- HSC organisations need to value different forms of advocacy and promote voice to include independent advocacy, self-advocacy, and family advocacy at all stages of care planning and develop a clear pathway clarifying the role of different advocacy services.
- HSC Trusts should arrange group meetings so that families with loved ones being considered for the same placement can support each other and share experiences and utilise the Lived Experience of families who have supported a family member through successful resettlement to offer peer support to current families.
- The review team recommends a review of the needs and resettlement plans for all forensic patients delayed in discharge from LD Hospitals.
- HSC Trusts should establish a local forum for engagement with LD providers of registered care and supported living to develop shared learning about safeguarding trends and incidents and promote good practice through a collaborative approach to service improvement.

Recommendations - STM - 209 - 39

- Further consultation with individuals, family carers and care providers should be progressed to inform regional policy and practice relating to the use of CCTV in community learning disability accommodation based services.
- HSC Trusts should ensure that capacity in Adult Safeguarding services is maintained to ensure timely investigation and any challenges clearly reported in the Trust Delegated Statutory Function report.
- HSC Trusts should ensure that Contracts or service specifications for services for people with a learning disability have safeguarding requirements adequately highlighted and that arrangements for monitoring are explicit.
- HSC Trusts should review visiting arrangements for family carers to ensure flexibility and a culture of openness so that families access their loved one's living environment rather that a visiting room.

Independent Review of the Learning Disability Resettlement Programme

In

Northern Ireland



Bria Mongan & Ian Sutherland

July 2022

Contents

Acknowledgements	2
1. Executive Summary	3
2. Terms of Reference	8
3. Methodology	10
4. Legislative, Strategic and Policy Context	12
5. Leadership & Governance	22
6. Strategic Commissioning, Planning and Inter-Agency Working	34
7. Individualised Care Planning	56
8. Operational Delivery of Care and Support	74
9. Safeguarding	88
10. Advocacy and Carer Engagement	95
11. Conclusions	107
12. Recommendations	112
Appendices	115
Appendix 1: The Review Team	115
Appendix 2: Biographies	116

Acknowledgements

The review team completed significant engagement and received considerable documentary evidence from a wide range of stakeholders and wish to acknowledge and thank those who so kindly shared their expertise.

The review team would like to thank all those who gave so generously of their time to meet with them and contribute to the review most especially the individuals and family carers who have lived experience of resettlement. The richness of their advice and experience has informed our findings and recommendations.

Learning disability care providers from across the voluntary and independent sectors shared their knowledge as system experts with the review team.

The review team benefited from a site visit to MAH and valued the opportunity to meet with patients and ward staff

The directors in each of the HSC Trusts and their senior management teams actively engaged and supported the work of the review team providing documentary evidence and assisted in the identification of the barriers and challenges that need to be addressed to expedite resettlement.

Staff from DoH, SPPG /HSCB also provided considerable documentary evidence, advice and support.

The HSCB/SPPG provided technical and secretarial support and the review team would particularly wish to thank Patricia Elliott for her technical expertise in the production of the report and Caroline McGonigle for her support throughout the fact finding process of the review.

1. Executive Summary

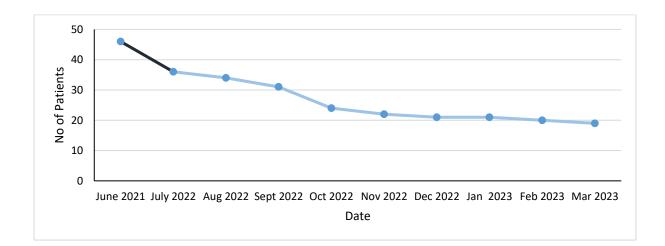
- 1.1 In October 2021 the Health and Social Care Board (HSCB) commissioned two experienced senior leaders in health and social care to undertake an independent review of the learning disability resettlement programme in Northern Ireland, with a particular focus on the resettlement from Muckamore Abbey Hospital (MAH), which is a specialist learning disability hospital managed by the Belfast Health and Social Care Trust (BHSCT) but located outside Antrim.
- 1.2 The purpose of the review built on a stated intention from Department of Health and HSCB to strengthen the existing oversight arrangements for the resettlement of patients from MAH and other learning disability hospitals whose discharge plans have been delayed. The review team were required to work with stakeholders to identify both good practice and overarching vision, as well as barriers, and to develop an action plan to ensure that the needs of the patients are being considered and are met. The review was to include consideration of the effectiveness of planning and delivery for the proposed supported living and alternative accommodation schemes which were in development to support the resettlement plans for these individuals.
- 1.3 There is a strong legislative base and policy framework, although the policy and strategy relating to services for people with learning disabilities/ASD and their families is in urgent need of updating, and this is currently being reviewed. An overarching vision for learning disability services in the 2020's would allow stakeholders to agree a Learning Disability Service Model, which would guide commissioners and providers towards the development of better integrated, community orientated services which will deliver stronger outcomes for people with learning disability and their families. This policy will need to consolidate the outstanding ambition that no-one will live in a specialist learning disability hospital and that hospital will focus on its primary function of offering assessment and treatment only for those people for whom this cannot be made available within a community setting.
- 1.4 Leadership and governance with regard to the resettlement programme in Northern Ireland has been less than adequate. Progress and momentum to deliver homes outside of hospital for the remaining cohort has been slow. There were a number of confounding factors that impacted directly on progress. The global pandemic had a massive impact on the capacity and capability of leadership teams to maintain momentum on 'business as usual' priorities, as a determined focus to tackle ovid was required. Similarly during the same period the impact of MAH being identified at a national level as a hospital where patients had not been well safeguarded meant that the operational day to day logistics of maintaining safe practice in relation to sufficient and stable staffing was a significant challenge in itself. Additionally, there has been an extended period of

significant organisational change as the regional commissioning functions previously undertaken by the Regional HSCB were 'transitioned' back within the DoH under the Strategic Planning and Performance Group, with the new arrangements coming in to effect from the 1.4.22. in order to strengthen the focus on system wide performance management. Whilst these and other factors impacted directly on the progress of resettlement and offers something in way of mitigation for the poor progress of resettlement plans, it does not satisfactorily explain why some Trusts made negligible progress, but for others consistent stepped change was achieved.

- 1.5 The BHSCT which managed MAH, had a significant challenge to balance the dual responsibility of rapidly improving quality and safety within the hospital, whilst maintaining progress on resettlement for those patients. This balance was not achieved, and the focus shifted away from resettlement to crisis management of MAH. The Trust Board were reassured by the executives that there were plans in place to support the resettlement of these individuals, whereas better scrutiny of the assurances provided would have shown this not to be the case, and that the plans were not robust. Arrangements in BHSCT were further hampered by significant changes in the leadership team for LD services. Other Trusts responsible for resettlement of patients from MAH had made more progress in the development of new services, although the delivery had been slower than hoped with delays relating to building over-runs and recruitment difficulties. The HSCB had made efforts to support regional co-ordination of the resettlement programme, but these were not effective in delivery of a well-co-ordinated programme plan. In particular the HSCB was not good enough in terms of performance management of the resettlement programme which amounted to little more than performance monitoring. We saw some strong leadership by individuals both in the statutory and non-statutory sectors, and whilst the rhetoric was of a robust commitment to collaboration there was little evidence of strong partnership working. In terms of leadership around the delivery of schemes in most cases management grip was weak and this contributed significantly to drift and delay. The voices of people who required resettlement and their families were not well heard within this process and they did not feel that they were empowered or engaged in the process at all levels. Opportunities to learn from their expertise by experience were missed.
- 1.6 Strategic commissioning and inter-agency working were supported by a clear and explicit strategic priority being identified around resettlement and workforce development in the 2019/20 commissioning plan. The Northern HSC Trust and South Eastern HSC Trust had response plans that were proactive and generally well progressed, but the BHSCT plans failed to progress beyond the preliminary stages. The lack of either effective programme or project management meant there was no over-arching, costed plan. Trusts were planning in relative isolation and communication of joint arrangements was inadequate. Generally there was

a tendency by Trusts to initiate new developments without fully exploring whether there was some existing provision within the market that could meet some of the identified need, even if this required some re-design or re-purposing of provision. The new build options, whilst being bespoke, were generally costly in terms of capital and revenue, and resulted in long lead in time to delivery. There was limited evidence of senior engagement with the independent social care sector as strategic partners as well as providers, and therefore market shaping was not evident.

- 1.7 The review team looked at the approach being taken to individualised care planning. There was a lack of consistency in the documentation used to support care planning for transition from hospital to community, and nor was there an agreed regional pathway for resettlement, which should map out roles and responsibilities within the process. Families and providers both commented that they felt only involved in a limited way in developing assessments and care plans. Of the remaining patients awaiting discharge almost a quarter had been in MAH for more than 20 years and one person for more than 40 years. About a third of this group had also had one or two previous trials in community placements, although there was little evidence of how lessons were learnt from these unsuccessful moves. However, in the 12 months from June 2021 to June 2022 the population in MAH awaiting resettlement had reduced by 20%, and the trajectory of future resettlements by NHSCT and SEHSCT should mean that between September 2022 and March 2023 the population will reduce by a further approximately 50%, leaving around 19 people in MAH awaiting resettlement.
- 1.8 Whilst progress at the beginning of the review had been slow HSC Trusts have recently reviewed their approach to consider alternative options that have potential for more timely discharge. The review team were pleased to see that this has improved the resettlement trajectory which anticipates that the population will reduce to between 15 and 19 by the end of March, 2023.



- 1.9 A key element of the review was the operational delivery of provision to meet the needs of this cohort and the wider LD population. There is an impressive range of provision across registered care and supported living settings providing approximately 2,500 places for people with LD in the community. There was a tendency of commissioners and resettlement teams to not engage with providers to consider potential existing opportunities, although this has changed in recent months. The overall trend within supported living schemes is to smaller size provision, with the largest number of schemes offering 3 places. The biggest single issue and risk facing the range and guality of the provision was workforce, and the DoH are now sponsoring work regionally to try to address this challenge which will report in 2023. The quality of care within the independent sector is regulated and inspected by RQIA, and the overall quality is good. There is some very innovative practice emerging within the independent sector, with a strong commitment to the use of Positive Behaviour Support (PBS) models, with some examples of transformational care being provided to individuals in their own new homes. Where provision was strongest there was a strong partnership between providers and local HSC Trust commissioning/care management and clinical services, so that individuals had access to a wide range of highly responsive services.
- 1.10 The Trust's commissioning of schemes of registered care provision to meet their respective resettlement cohorts was variable. The NHSCT and SEHSCT demonstrated a more proactive and consistent approach to planning of this provision, and consequently have reached a stage where 2 substantial new care settings, along with some smaller scale provision will over the next 6 months provide new homes to approx. 80% of their remaining MAH residents. The BHSCT have over the last 3 years been scoping 3 potential new schemes, but these have never got beyond the most preliminary stages of planning. The review team are more encouraged that the new leadership group responsible for LD within that Trust are now considering other options, including some existing provision which could have the potential to be rapidly re-purposed. In general, and at variance with statements that the Trusts have a learning culture, there has been little rigorous evaluation of the successes and failures within the resettlement programme. The review team heard a rich tapestry of stories from families about their lived experience, and this should form the basis of some qualitative work, but in addition there should be some review of the clinical and social benefits derived by people who have gone through resettlement.
- 1.11 For families, safeguarding continues to be an abiding concern, which is overshadowed by a loss of trust and confidence in MAH and health and social care systems more generally. The oversight of adult safeguarding will be strengthened when the new adult safeguarding arrangements come in to place, and it is encouraging that an Interim Adult Protection Board (IAPB) was established in 2021. There continue to be issues of concern in relation to the use of physical intervention, and surveillance by CCTV, and for the families the review team met, how these are addressed in community settings is central to the success of placements. There is a need for further consultation with

individuals, families and providers to inform regional policies on these important areas moving forward. Family members were clear with the review team that after community placement they would continue to play a key role in assuring and ensuring the safety of their relative, and therefore wanted to see open and flexible access to care environments. Care providers were clear about safeguarding responsibilities but expressed a concern that they experienced considerable variation in the application of thresholds in relation to investigation of safeguarding concerns, and families expressed concern that in some situations investigations were not progressed in a timely fashion.

1.12 Families were an incredibly rich source of evidence to the review team, and their lived experience tells a tale of both success and failure. The full report includes aspects of these accounts. The review team strongly believe that individual families need to be at the centre of these processes and fully engaged within all aspects of the resettlement, but they also need to be able to influence policy and strategy so that their expertise by experience can inform best practice. The review team were struck by the extent to which trauma and distress featured within the experience that was shared, and that all of the professionals working with these individuals and families need a good understanding of trauma informed practice. Trusts were all considering and developing their advocacy and other supports for individuals and families, and they need to further consider how they can put in place opportunities to ensure better communication and engagement and opportunities to organise carer support events such as group gatherings.

2. Terms of Reference

- 2.1 Terms of Reference: The terms of reference for the review were agreed with the HSCB and DoH, after consultation with senior leaders in learning disability services from the 5 HSC Trusts.
- 2.2 Purpose of Review: The purpose of the review built on a stated intention from DoH and HSCB to strengthen the existing oversight arrangements for the resettlement of patients from MAH (MAH) and other learning disability hospitals whose discharge plans have been delayed. The review team were required to work with stakeholders to identify both good practice and barriers and develop an action plan to ensure that the needs of the patients are being considered and are met. The review was to include consideration of the effectiveness of planning and delivery for the proposed supported living and alternative accommodation schemes which were in development to support the resettlement plans for these individuals.
- 2.3 The review team were to work collaboratively with stakeholders, with the commitment of the Chief Executives and the Directors, engaging appropriately with relevant staff, agencies, families and service users.
- 2.4 Timescale: The timetable for the work was to take place over a 6 month period which began in effect in November 2021.
- 2.5 The Review Team were required to give particular consideration of the current care plans for all the service users in MAH and critically analyse the actions taken to identify and commission suitable community placements. In addition they were asked to look specifically at the following areas:-
 - > Length of time patient has been in MAH and where they were admitted from
 - > Ascertain if resettlement has already been trialled
 - Summarise the policy and practice evidence base in relation to resettlement programmes.
 - Identify those individuals where plans are absent or weak in relation to their resettlement
 - Work with leaders in the appropriate Trusts to ensure that suitable resettlement plans are developed.
 - Critically evaluate the progress of resettlement plans as devised by the responsible Trust for the identified individuals.
 - Business cases which have been completed or are still in process identifying any positive outcomes and any strategic or operational barriers. Make recommendations for actions that would strengthen or accelerate the delivery of proposed pipeline schemes.

- Review to what extent the engagement strategies employed individually by Trusts, and collectively by the system as a whole have been effective in supporting the delivery of the MAH resettlement programme.
- 2.6 Inter-Agency Working : The review team were asked to consider whether/how the agencies and professionals involved in resettlement of patients, have worked effectively with each other at each and every stage of the process.
- 2.7 Parental/Carer Engagement/Advocacy: The review team were also asked to consider as a critical factor whether and to what extent the families of the patients were engaged in decision making around resettlement. In this context the review team were also asked to explore whether and to what extent, independent advocacy and support was provided.
- 2.8 Outside of Scope: Whilst there are Issues relating to children and young people with learning disability/Autism who may be subject to delayed discharge in other settings, this population were not included within the terms of reference for this review.

3. Methodology

- 3.1 The HSCB in appointing the review team intended to ensure that an objective, critical appraisal was undertaken of the existing programme of resettlement for individuals with learning disability/autistic spectrum disorder with a primary focus on the remaining population of people who were awaiting discharge from MAH to new homes.
- 3.2 The review team decided to adopt an approach for the review based on 'appreciative inquiry' (1) this is a strengths-based positive approach to leadership development and organisational change. This approach seeks to engage stakeholders in self-determined change, and incorporates the principle of coproduction.
- 3.3 By adopting this approach the review team were both 'observers' of the system and how it was delivering the required outcomes for people identified for resettlement, but also as 'agents' by helping to seek solutions that would assist key stakeholders to improve the resettlement programme in Northern Ireland.
- 3.4 The review team adopted the following methods to progress the key lines of inquiry:
 - > Direct observation and participation in key processes
 - Direct interviews with a wide range of stakeholders
 - > Gathering and analysing data relevant to the resettlement process
 - Focus groups both face and face and digital engagement.
- 3.5 The initial engagement with the statutory health and social care agencies was through the leadership meetings established by the HSCB to develop and oversee the delivery of effective services for people with a learning disability/ASD. This included the Learning Disability Leadership Group comprising the senior social care leaders from the HSCB, the 5 Trust Directors of Mental Health and Learning Disability Services, along with representation from the DoH and RQIA. Additionally the review team participated in a range of operational and strategic meetings with programme leads for learning disability services within the HSCB and HSC Trusts. Some of these processes were interagency and included NIHE representation.
- 3.6 The review team sought data and documentary evidence from a wide range of organisations including the DoH, HSCB, the 5 HSC Trusts, NIHE, RQIA and other agencies. Information was sought through direct requests and through questionnaire response.

- 3.7 The review team held an extensive range of engagement sessions with a range of external stakeholders. This included the following:
 - > Northern Ireland Housing Executive NIHE
 - Regulation and Quality Improvement Authority RQIA
 - > Northern Ireland Social Care Council NISCC
 - Patient and Client Council PCC
 - Royal College of Psychiatrists NI/Learning Disability Division RCPsych
 - > ARC Northern Ireland
 - ▶ Independent Health Care Providers [NI) IHCP
- 3.8 The review team felt it was of primary importance that the lived experience of individuals with learning disability/ASD and their carers/families who had been engaged in resettlement had to be well represented within the review. They met with individuals and groups of carers who had either been through or were still going through the resettlement process. This provided some of the richest detail of how the system was working, or not working, for people who wanted to have the opportunity to live in a setting outside of hospital with as much independence as possible.

4. Legislative, Strategic and Policy Context.

In this section we will critically evaluate the legislation and strategic policy across England, Scotland, Wales and the Republic of Ireland to identify models of good practice in reducing delayed discharge patients and preventing hospital admission.

- 4.1 MAH opened as a regional learning disability hospital in 1949 and by 1984 the in-patient population had grown to 1,428.
- 4.2 The scale of resettlement between 2007 and 2020 was significant, with reduction in the population at MAH to 46 patients by June 2021. During the period of this review, the Muckamore Abbey population has reduced further to 36 inpatients by July 2022. It is encouraging that further discharges have been achieved however, 10 of the delayed discharge population are from the original Priority Target List (PTL), which relates to patients living in a long stay learning disability hospital for more than a year at 1st of April, 2007, and have been discharge delayed between 16 and 45 years. The impact of institutionalisation for a small number of long-stay patients has been a barrier in transitioning to the community. The complexity of need and range of co-morbidities of recent admissions many of whom have been impacted by previous community placement breakdown, has made discharge particularly challenging. However, the review team visited community resettlement schemes successfully supporting individuals with very complex needs equivalent to the needs of those people delayed in discharge. These examples of good practice highlight that the models of care and support required to build sustainable community placements for individuals with complex needs are already operational in Northern Ireland and the success factors need to be scaled up and embedded in commissioning and procurement processes.
- 4.3 The pace of progress in relation to finding new homes in recent years has been disappointing, with an increasing number of judicial reviews progressed by patients or their family carers in regards to the failure of HSC Trusts to commission an appropriate community placement for people delayed in hospital. Legal judgements have highlighted that delayed discharge breaches are incompatible with obligations pursuant to section 6 of the Human Rights Act 1998. (Ctrl Click) and Article 8 of the European Convention on Human Rights (Ctrl Click) There is therefore an ethical, strategic and legal imperative to complete resettlement.
- 4.4 The policy direction in Northern Ireland and Great Britain changed in the 1980's and from that time there have been a series of targets set to reduce the number of in-patients in Learning Disability hospitals and develop resettlement options.

However, targets and deadlines for achieving this have been missed, ignored and repeatedly reset.

- 4.5 The 1992/97 Department of Health and Social Services (DHSS) Regional Strategy,' Health and Wellbeing into the New Millennium'¹ established a commitment to reduce the number of people admitted to traditional specialist hospitals and a commitment that care should be provided in the community and not in specialist hospital environments. In 1995, a decision was taken by the Department of Health and Social Services to resettle all long-stay patients from the 3 learning disability hospitals in Northern Ireland. The target set by the Regional Strategy for the resettlement of all long-stay patients from learning disability hospitals by 2002 was not met.
- 4.6 The 2002 Bamford Review of Mental Health and Learning Disabilities represents the key strategic driver shaping delivery of services for individuals with learning disabilities and or Autistic Spectrum Disorder (ASD) over the past 25 years.
- 4.7 The second report from the Bamford review 'Equal Lives' published in 2005 sets out a compelling vision for developing services and support for adults and children with a learning disability. Equal Lives 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. This will involve developing responses that are person centred and individually tailored; ensuring that people have greater choice and more control over their life; that services become more focused on the achievement of personal outcomes, i.e., the outcomes that the individuals themselves think are important; increased flexibility in how resources are used; balancing reasonable risk taking and individuals having greater control over their lives with an agency's accountability for health and safety concerns and protection from abuse.
- 4.8 The Bamford review 'Equal Lives' published in 2005 (ctrl click) included a target that all people with a learning disability living in a hospital should be resettled in the community by June 2011. A priority target list (PTL) of those patients living in a long stay learning disability hospital for more than a year at 1st April 2007 was established to enable monitoring of progress on the commitment to resettlement of long-stay patients. In 2005, the Hospital had 318 patients and a target was set to reduce to 87 patients by 2011.

¹ Health and personal social services: a regional strategy for Northern Ireland 1992-1997.

- 4.9 'Transforming Your Care' was published by the Minister for Health in 2011(<u>ctrl click</u>) which further strengthened the commitment to close long stay institutions and complete resettlement by 2015. A draft Strategic Implementation Plan was developed to drive forward the recommendations in terms of learning disabilities with a focus on resettlement, delayed discharge, access to respite for carers, individualised budgets, day opportunities , advocacy and Directly Enhanced Services (DES) Whilst this resulted in the development of additional community services the resettlement target was again missed.
- 4.10 DHSSPS Service Frameworks aimed to set out clear standards of health and social care that service users and their carers can expect. They are evidence based, measurable and are to be used by health and social care organisations to drive performance improvement, through the commissioning process. The Service Framework for Learning Disability was initially launched in 2013 and revised in January 2015 (ctrl click). It sets out 34 standards in relation to the following key thematic areas; safeguarding and communication; involvement in the planning and delivery of services; children and young people; entering adulthood; inclusion in community life; meeting physical and mental health needs; meeting complex physical and mental health needs; a home in the community; ageing well and palliative and end of life care. The standards provide guidance to the sector on how to: improve the health and wellbeing of people with a learning disability, their carers and families, promote social inclusion, reduce inequalities in health and social wellbeing and improve the quality of health and social care services, by supporting those most vulnerable in our society.
- 4.11 RQIA Review of Adult Learning Disability Community Services Phase II October 2016 (ctrl click) reviewed progress made by the 5 Health and Social Care (HSC) Trusts, in the implementation of 34 standards, relating to Adults with a Learning Disability in the Department of Health (DoH) Service Framework. The review found that none of the 5 community learning disability teams in HSC Trusts demonstrated an evidence base for the model of service configuration they have put in place. The RQIA review concluded that community services have developed more as a result of historic custom and practice in each Trust area, with little sharing of practice noted regionally regarding models of care used by each team. It was difficult for the review team, therefore, to effectively compare and contrast the models of service provision across Northern Ireland. The RQIA review found that there is no agreed uniform model for behavioural support services across the 5 Trusts.
- 4.12 This review team noted that these findings still apply. Community services are at different stages of development in each of the 5 HSC Trusts and the terminology used to describe similar services varied across HSC Trusts which makes it

difficult to compare and contrast services. It is still of concern that there is no agreed model for behavioural support services. Each Trust and care provider organisation have adopted differing accredited programmes with training programmes available only on licence which limits the portability of staff working flexibly across HSC Trusts and the independent sectors. It is of note that consideration was given by a HSC Trust to deploy Trust staff to supplement the care provider workforce to expedite a resettlement however, the barrier to this innovation was that the staff in the Trust and staff in the provider organisation had been trained in different therapeutic interventions and could not work in the same team unless re-trained. It is critical that standardisation of positive behaviour approaches and therapeutic intervention methodologies is considered to maximise collaboration and enable mutual aid at times of crisis.

- 4.13 'Systems, Not Structures Changing Health and Social Care' (The Bengoa Report) (DoH, 2016) (ctrl click) Guided by 'The Triple Aim': to improve the patient experience of care (including quality and satisfaction); improve the health of populations and achieve better value by reducing the per capita cost of health care. The report provides a succinct transformation model relevant and useful in the development of the learning disability service model and driving the system towards Accountable Care Systems with the provider sector taking collective responsibility for all health and social care for a given population.
- 4.14 Health and Wellbeing 2026 Delivering Together (DoH, 2017) (<u>ctrl click</u>) is the policy response to the Bengoa Report and aligns to Draft Programme for Government with increasing focus on outcomes.
- 4.15 The emergence in 2017 of allegations of abuse at MAH, resulted in an independent Serious Adverse Incident (SAI) review of safeguarding practices between 2012 and 2017 at MAH. The SAI report exposed not only significant failings in the care provided to people with a learning disability while in hospital and their families, but also gaps in the wider system of support for people with learning disabilities.
- 4.16 The final 'Way to Go' report (ctrl click) was shared with key stakeholders in December 2018 and a summary of the report was published in February 2019. This resulted in a further public commitment to the families of MAH patients by the DoH Permanent Secretary in 2018 that patients delayed in discharge would be resettled by December 2019. This commitment has not been met.
- 4.17 The DoH established a Muckamore Departmental Assurance Group (MDAG) to provide assurance in respect of the effectiveness of the Health and Social Care System's (HSC) actions in response to the 2018 independent Serious Adverse Incident (SAI) review into safeguarding at MAH and the Permanent Secretary's subsequent commitment on resettlement made in December 2018. The DoH

recognised the need for the HSC system to work together in a co-ordinated way to deliver a coordinated programme of action to manage the planned and safe resettlement of those patients not currently under active assessment or treatment into accommodation more appropriate for their needs. Some of the MDAG actions have not yet been achieved.

- 4.18 The 'Review of Leadership and Governance at MAH' (ctrl click) was established to build upon the SAI review and the report published in July 2020 highlighted system-wide issues and a failure in the care provided to some of the most vulnerable members of our society. The findings highlighted the need to provide a clear and coordinated regional learning disability pathway similar to that in place for mental health services. HSC Trusts were remitted to carry out a full reassessment of the needs of their patients in MAH and prepare discharge plans for all those delayed in discharge. The review found that HSC Trusts had not yet completed a full reassessment of all patients.
- 4.19 Many of the findings and recommendations from both the 'Way to Go' report and the 'Review of Leadership and Governance at MAH' (ctrl click) remain relevant and outstanding and will be reiterated in this review. The' Way to Go' report made 2 overarching recommendations; a renewed commitment to enabling people with learning disabilities to have full lives in their families and communities and the development of a Learning Disability strategic framework focused on contraction and closure of the long-stay hospital and a vision for a full lifecycle pathway across children's and adult services. The Leadership and Governance review findings highlight that Discharge of Statutory Function (DSF) reports provided annually by the Trust to the HSC Board, were largely repetitive and did not provide the necessary assurance with insufficient challenge from Trust Board and the HSC Board. This review found that this remains an area of concern and that limited progress has been made in regard to the strengthening of governance to ensure a greater challenge in regard to reporting and accountability arrangements.
- 4.20 The review team reviewed the strategic policy for Learning Disability services across England, Scotland, Wales and the Republic of Ireland to identify best practice and the learning from actions taken by other regions in regard to learning disability resettlement and avoidance of hospital admission. The review team identified common themes in the strategic direction for Learning Disability services across England and Scotland with focus on hospital avoidance through development of intensive care and support in the community. The following sections provide a high level summary of the key policy and practice evidence which should inform the strategic direction for learning disability services and the resettlement programme in Northern Ireland.

- 4.21 Despite the evidence base on concern about safety and quality in institutional settings, there has been a lack of progress in the closure of long-stay beds. This issue has been addressed across all jurisdictions over many years and it is important to learn from these experiences and actions. Our review found a striking alignment across all nations in regards to strategic direction with a focus on a Human Rights and person-centred approach. The 2007 Bamford Review of Mental Health and Learning Disabilities has been the key strategic driver shaping the delivery of services for individuals with learning disabilities and/or autism in Northern Ireland. The principles and values underpinning the Bamford review, remain relevant to current policy direction and are in keeping with the strategic direction of other UK nations. Feedback to the review team from a range of stakeholders however, highlighted the effectiveness of the Mental Health strategy in building upon Bamford and the need for refreshed strategic policy for learning disability services.
- 4.22 The Bamford Review of Mental Health & Learning Disability in 2002 (ctrl click) recommended a comprehensive legislative framework for new mental capacity legislation and reformed mental health legislation for Northern Ireland. The Mental Capacity Act (Northern Ireland) 2016 (ctrl click) has been partially commenced and currently provides a new statutory framework in relation to deprivation of liberty. Part 10 of the MCA will set out the provisions for people in the criminal justice system when enacted. Mental health legislation is complex most especially relating to patients with a forensic history. The review team noted a lack of clarity across the HSC system in regards to patients who have been stepped down from detention in hospital under Art 15 leave. The review team recommends a review of the needs and resettlement plans for all forensic patients.
- 4.23 There have been a series of high profile scandals following investigations identifying abuse to residents in HSC facilities over the past decade. MAH is the largest adult safeguarding investigation across the UK. On 8th September 2020, the Health Minister announced his intention to establish a Public Inquiry into the allegations of abuse at MAH. The MAH Public Inquiry commenced the hearing sessions of the Inquiry in June 2022 which will run until December 2022
- 4.24 The Care Quality Commission report (2011) (ctrl click) after inspection of Winterbourne View found a "systemic failure to protect people" Evidence of maltreatment of patients in specialist hospitals in England continued to emerge and eight years later, The Care Quality Commission report on Whorlton Hall (2019) (ctrl click) found people in learning disability hospital being failed and the Care Quality Commission (2019) found evidence of unsafe patient care and abusive treatment by staff at Eldertree Lodge, an in-patient facility for adults with learning disabilities and autism. These scandals have prompted development in strategic policy and a renewed focus on implementation plans to address the

long-standing issue of over-reliance on admission to hospital resulting in delayed discharge and institutionalisation.

- 4.25 Strategic Policy in England- Building the Right Support: A National Plan NHS England et al (2015) (ctrl click) placed emphasis on the "highly heterogeneous" or diverse characteristics of the population referred to as 'people with a learning disability and/or autism' This challenge has not been sufficiently addressed in learning disability policy in Northern Ireland to date. The majority of people with learning disability live with their families supported if required by a range of community services. The smaller percentage of those with a range of very complex needs requiring coordinated care and support across justice, housing, mental health, and the range of learning disability provider organisations need to be integrated into future strategic policy and commissioning direction.
- 4.26 There have been a range of reports on the issue of delayed discharge however, there has been a lack of robust and independent evaluation of what has worked well. England, Scotland and Wales are further developed than Northern Ireland in refreshing the approach needed. This review has identified a number of key themes across the revised strategic policy in England and Scotland that should inform revised strategic direction and short and medium term actions required for Northern Ireland.
- 4.27 'Transforming Care England' Oct.2015 (ctrl click) Good practice guidance covers strategic, operational and micro- commissioning and describes what 'Good looks like' with nine Golden threads-core principles. Key actions include;
 - Provide enhanced vigilance and service coordination for people displaying behaviours which may result in harm or placement breakdown.
 - Establish a Dynamic Support Database to provide focus on individuals at risk of placement breakdown and development of proactive rather than reactive crisis driven response- Target those escalating in need/ at risk of admissionrisk stratification.
 - Important that experts by experience have been involved in all of the panels. One of the issues has been language – such as database rather than risk register
 - Establish a 'Change Fund' from the centre for development of admission avoidance 24/7 intensive support teams
 - > Positive Behaviour Service framework and provider engagement
 - Housing Needs Assessment
 - Effective Assessment tools/ Discharge planning meetings- Complex care coordinators to focus on transition plans
 - More detailed tracker tool to support analysis and performance management to create a master database-history of discharges, re-admissions and trends.

- Fortnightly meetings on each individual patient with clear projections about the trajectory for discharge and progress over time.
- Specialist LD beds should be increasingly co-located within mainstream hospital settings rather than in isolated stand-alone units.
- The success lies not within systems and processes but within sustainable human relationships and collaboration highlighting the need for system leadership, collaborative working to build a one team approach.
- 4.28 The NHS 10 Year Plan was published in England in January 2019, and made specific commitments to the improvements to be progressed for people with learning disability and ASD. These included:
 - Improve community-based support so that people can lead lives of their choosing in homes not hospitals; further reducing our reliance on specialist hospitals, and strengthening our focus on children and young people
 - Develop a clearer and more widespread focus on the needs of autistic people and their families, starting with autistic children with the most complex needs
 - Make sure that all NHS commissioned services are providing good quality health, care and treatment to people with a learning disability and autistic people and their families. NHS staff will be supported to make the changes needed (reasonable adjustments) to make sure people with a learning disability and autistic people get equal access to, experience of and outcomes from care and treatment
 - Reduce health inequalities, improving uptake of annual health checks, reducing over-medication through the Stopping The Over-Medication of children and young people with a learning disability, autism or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP) programmes and taking action to prevent avoidable deaths through learning from deaths reviews (LeDeR)
 - Continue to champion the insight and strengths of people with lived experience and their families in all of our work and become a model employer of people with a learning disability and of autistic people
 - Make sure that the whole NHS has an awareness of the needs of people with a learning disability and autistic people, working together to improve the way it cares, supports, listens to, works with and improves the health and wellbeing of them and their families.
- 4.29 'Same as You' (2000) (ctrl click) was the catalyst for Scotland's long-stay closure programme. 'Keys to Life' 10-year Learning Disability Strategy (2014) (ctrl click) acknowledged wider system failure in the challenge of expediting discharges and developed a National framework agreement for procurement for specialist residential based care with a focus on the outcomes and rates that will apply. The 'Coming Home' report (2018) commissioned by the Scottish Government (ctrl click) highlighted that a significant number of people remained delayed discharge.

A short life working group was set up to undertake a focused piece of work in relation to complex needs and delayed discharge and published their 'Coming Home Implementation report in February 2022 (Gov.Scot) (ctrl click). The findings and recommendations are broadly similar to the actions arising from Transforming Care England.

- > Engagement with experts by experience and wider stakeholders is critical
- First step is accurate data on Needs Assessment at both population and individual level. Quality of assessments were found to be too generic and quality variable and not sufficiently co-produced with families
- Establish a community living change fund over the next 3 years to be used to design community based solutions running concurrently with disinvestment planning.
- Develop a National Dynamic Support Register to create greater visibility in terms of strategic planning and to allow performance management of admissions to hospital supported by a National panel that can troubleshoot individual cases
- > Develop a Positive Behaviour framework-
- Produce a guide to support commissioning and procurement of complex care packages and establish detailed understanding of revenue costs of different care packages. The report highlighted a lack of effective scrutiny of data.
- 4.30 The Welsh Government published a Learning Disability Action Plan 2022- 2026 in May 2022. The plan builds on and incorporates the Improving Lives Programme (2018) (ctrl click) actions with a focus on reducing admissions through increased community based crisis prevention, access to specialised care and highlights the need to promote Positive Behavioural Support and Trauma Informed care.
- 4.31 The Irish Government published a national policy 'Time to Move On' 2011 (ctrl click) which sets out the way forward for a new model of support in the community The report highlighted that the model is simple in approach but noted significant challenges to delivery. Integral to the strategy was the 'We Moved On' stories of successful transition and promoting the voice to include advocacy, self-advocacy and family advocacy. The review team met with the HSE National lead who advised that bridging funding through a multi-annual investment plan for 5 year period has been established alongside a value for money and policy review of high cost placements to establish the level of funding per person. Robust Needs assessment was also identified as a priority.

The review team found significant learning from engagement with policy leads in England and ROI which have informed this review and findings.

4.32 Tackling the closure of long-stay beds has been a long standing problem for many decades across all UK nations. Recent strategic policy has recognised that the focus should now be on what is achievable rather than being paralysed by the challenges. There has been growing consensus nationally on solutions and next steps. It is critical that a one system approach is developed in Northern Ireland to address the silo working and duplication that remains across the 5 HSC Trusts. Adopting an accountable care approach will drive collaboration between HSC Trusts and the range of organisations involved in supporting individuals who are currently 'stranded' in learning disability hospitals.

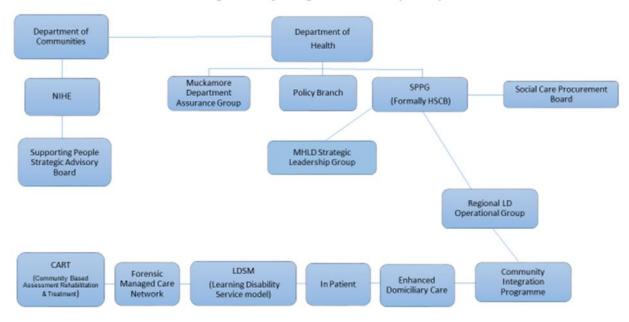
4.4 Recommendations

- DoH should develop the strategic policy for learning disability services, updating the recommendations arising from the Bamford review to reflect the needs of the highly heterogeneous Learning Disability population and inter-connectedness with the Mental Health and Autism strategies.
- There should be an evaluation of the experience of people who have been resettled to understand what has worked well and what needs to change for the better and a regional programme to tell the positive stories of those who have moved on.

5. Leadership & Governance

In the last chapter we consider the policy and strategic context for the delivery of the resettlement programme in Northern Ireland, and in this chapter we want to explore how the leaders within Northern Ireland engaged with this challenge.

- 5.1.1 Within the chapter we will look at how we gathered evidence of leadership and impact, and then go on to consider it under the following areas: strategic leadership and governance; leadership for the operational delivery of resettlement outcomes for individuals awaiting discharge following lengthy periods in hospital; and finally how people who use services and their representatives were engaged in this complex arena.
- 5.1.2 Evidence Gathered: The review team were pleased that in addition to having access to a raft of documentary evidence that we also had direct access to meet with many of the leaders within the system at all levels, and to observe or participate in key meetings within the leadership framework.
- 5.1.3 Amongst the documentary evidence that we accessed included strategic and policy documents, Trust Board minutes and Trust Corporate Risk Registers. We also attended the Muckamore Departmental Assurance Group (MDAG) and had access to their more recent action plans and minutes. We also had sight of material related to the Delegated Statutory Functions Reports including the composite reports and action plans.
- 5.1.4 A very rich area of evidence related to engagement with leaders through direct meetings. This included the Mental Health & Learning Disability Strategic Leadership Group (Directors and other senior officers from HSCB/SPPG & Trust Directors); Regional Learning Disability Operational Group (Trust Assistant Directors and Commissioning & Finance Leads in HSCB/SPPG, along with representation from NIHE and RQIA. We had 'challenge and support sessions with Trust LD Leadership Teams We have tried to represent the statutory leadership framework diagrammatically see below



Learning Disability - Regional Leadership Groups

- 5.1.5 The review team were particularly grateful for the extensive and generous sharing of views and experiences from a broad range of stakeholders. Importantly this included parents and carers of people who had direct experience of the resettlement process along with charities that represent them such as Mencap. We also met with leaders from other agencies including housing, provider organisations in the independent sector, regulators for services and the social care workforce, and clinical leadership through the RCPsych. (NI) Learning Disability Faculty.
- 5.1.6 An important factor needs to be acknowledged from the outset in considering the leadership challenge in relation to the resettlement programme during recent years, and relates to the context from 2019 to 2022. The global pandemic had a massive impact on the capacity and capability of leadership teams to maintain momentum on 'business as usual' priorities, as a determined focus to tackle Covid was required. Similarly during the same period the impact of MAH being identified at a national level as a hospital where patients had not been well safeguarded meant that the operational day to day logistics of maintaining safe practice in relation to sufficient and stable staffing was a significant challenge in itself. Additionally, during this period there has been an extended period of significant organisational change as the regional commissioning functions previously undertaken by the Regional HSCB were 'transitioned' back within the DoH under the Strategic Planning and Performance Group, with the new arrangements coming in to effect from the 1.4.22. Whilst these and other factors impacted directly on the progress of resettlement and offers something in way of mitigation for the poor progress of resettlement plans, it cannot entirely explain leaders' failure to deliver timely alternatives to residence in MAH in the context of the long term planning in this area. The individuals in MAH didn't

'suddenly' need new homes; there had been a lengthy 'gestation' to this situation, and many opportunities for earlier action.

5.1.7 The review considered leadership in three separate contexts. The first was strategic leadership at the most senior level of the organisations involved, including senior leaders in public service, both executive and non-executive. Strategic leadership focuses on establishing the vision and strategic direction, and ensures effective governance, oversight and scrutiny of delivery of strategic objectives. The second is senior operational leadership to ensure that plans for delivery are robust and achieved, and requires effective partnership working between commissioners, providers - both statutory and non-statutory. The third area that we wanted to consider in relation to effective leadership and governance was the extent to which people at the centre of resettlement, particularly those who were being moved to their new homes and their family members, were engaged and involved in the process, and how effectively they could shape and influence leadership. Central to this is the need to understand leadership at all levels, and how this intersects. What the review team were looking for is sometimes referred to as 'the golden thread, that should weave through all the layers of leadership to ensure that there is a seamless route from strategic vision to effective delivery, and that the best outcomes are delivered in the most efficient and cost effective way, with transformational impact on the lived experience of the people who are being resettled from institutional care to new homes within the community.

5.2 Strategic Leadership & Governance

- 5.2.1 Strategic leadership and governance has been central to the successes and failures within delivery of the learning disability resettlement programme in Northern Ireland. The policy context since the Bamford Review and before was clear that long stay specialist learning disability hospitals should never be someone's permanent home. Whilst the ambition was clear, and some progress was made, the goal was slow to achieve and by July 2021 46 people remained living in MAH, and more than 5 of these had been in the hospital for between 30 and 45 years. The emerging picture of extensive institutional abuse in MAH in 2018 re-focused attention on the lives of people living in MAH both in terms of the day to day safety of people who were living there, and the need to push harder to find new homes for those remaining individuals within high quality community settings. Whilst this was a significant challenge, it wasn't a new one, and had been a stated health and social policy objective in Northern Ireland since 2005, so it had to be asked why it hadn't yet been achieved.
- 5.2.2 In order to achieve the significant change required in improving the lives of all people with learning disability and ASD, there was a consistent acknowledgement for the need to update the strategic policy. This was a priority recommendation from the previous Independent Review Panel, which required "an updated strategic framework for Northern Ireland's citizens with learning disability and neuro-developmental challenges which is co-produced with self-

advocates with different kinds of support needs and their families. The transition to community-based services requires the contraction and closure of the hospital and must be accompanied by the development of local services."

- 5.2.3 The response to this recommendation was that there should be a co-produced model for Learning Disability Services in Northern Ireland to ensure that adults with learning disability in Northern Ireland receive the right care, at the right time in the right place; along with a costed implementation plan, which will provide the framework for a regionally consistent, whole system approach. This significant task was to be progressed by the HSCB/PHA, and they commissioned a consultation with a wide range of stakeholders which led to the production of a consultation response entitled "We Matter". The final draft of the "We Matter" Learning Disability Service Model was formally presented by the HSCB to officials at the DoH in early October 2021, but to date this has not resulted in the issuing of the long awaited updated strategic framework. It remains important that this work is brought to completion but equally its delay should not have been a reason for a failure on the part of the HSCB and individual HSC Trusts to expedite the resettlement process.
- 5.2.4 In the next chapter we will explain how in 2019/20, further to a direction from the Permanent Secretary, the regional commissioning framework clearly stated that the resettlement of people from MAH and other LD specialist hospitals remained a strategic priority.
- 5.2.5 In the context of the significant concerns about MAH the DoH established a Muckamore Departmental Assurance Group (MDAG). The Muckamore Departmental Assurance Group was established to monitor the effectiveness of the Health and Social Care System's (HSC) actions in response to the 2018 independent Serious Adverse Incident (SAI) review into safeguarding at MAH following allegations of physical abuse of patients by staff, and the Permanent Secretary's subsequent commitment on resettlement made in December 2018. The Group is jointly chaired by the Chief Social Services Officer and the Chief Nursing Officer, and is made up of representatives from HSC organisations and other key stakeholders, and representatives from families of Muckamore Abbey Hospital patients. It was good to see such a broad constituency, including the families of people living in MAH being brought together. The group undertook considerable work which was organised and monitored through a comprehensive action plan; this was updated and monitored regularly. The plan covered areas such as leadership and governance, safeguarding, resettlement and workforce. In relation to resettlement, after three years of the MDAG operating, all of the actions relating to resettlement continued to be rated as 'red' in relation to delivery. So whilst there was a robust mechanism for holding the system to account and monitoring what had been achieved, in relation to resettlement there was an inertia which represented slow or negligible progress. This led to some considerable frustration across the system, which was evidenced through a number of families launching judicial reviews against health and care organisations to challenge a failure to deliver resettlement

outcomes for their loved ones. Despite a well-articulated call to action there was an absolute lack of urgency and focus in the delivery of the resettlement programme.

- 5.2.6 Within the MDAG action plan the Director of Social Care and Children (DCSC) was the identified lead for all actions in relation to the delivery of the resettlement programme. In order to deliver this the (DCSC) worked with the Trust Directors through a Mental Health and Learning Disability Strategic Leadership Group. The commissioning plan for 2019/20 was clear about the HSCB/PHA strategic priorities and intentions for resettlement and the required Provider Response (set out in Chapter 6; 6.4.6, 6.4.7, 6.4.8). In order to deliver the required action a number of groups were established to progress at pace the resettlement programme, and further explore this under the next section. However, the DSC & C/HSCB also held a responsibility for ensuring that the individual Trusts were held to account in relation to the delivery of their delegated statutory functions (DSF's), and a specific responsibility for performance management in relation to the delivery of the key strategic targets. Whilst there were fully formalised processes for accountability meetings, with remedial action proposed where performance was weak in relation to the delivery of DSF's, this rarely achieved the significant improvement required. In particular in relation to the resettlement programme, the actions taken by senior officers of the HSCB often represented at best performance monitoring, rather than effective performance management.
- 5.2.7 Effective performance management relies on the provision of valid data, analysis of performance measures, responsible challenge in relation to underperformance, and effective support to address broader barriers that stand in the face of objective achievement. The absence of fully effective performance management allowed for significant drift in the delivery of strategic priorities which directly impacted on the broader issues relating to the continued concerns around the safety of MAH. There has been significant organisational change since the Minister announced the closure of the HSCB, and the transfer of many of the strategic commissioning and performance management functions have reverted to the Strategic Planning and Performance Group within the Department of Health. We have seen a change in tone and approach in relation in the execution of performance management responsibilities both immediately prior to the transfer to SPPG on the 1.4.22 and subsequently. A number of additional senior appointments have been made within the social care team which should strengthen capacity. In light of these changes the review team are hopeful that the challenge and support function essential to effective performance management will continue to improve.
- 5.2.8 Belfast Health and Social Care Trust are central to the strategic leadership and governance in relation to the care and treatment of people in MAH, as well as to the resettlement process from the hospital. Their leadership responsibility needs to be set in the context of two important reports commissioned by the

Trust. The first of these was "A Way To Go" (2018) which undertook a review of safeguarding within MAH between 2012 and 2017, which identified extensive evidence of catastrophic failings and found that there was a culture of tolerating harm within MAH. The authors went on to express grave concern that it was "shattering that no-one intervened to halt the harm and take charge". The CCTV evidence which supported the findings within this report also became central to the subsequent PSNI investigation of allegations against significant numbers of staff within the hospital. The second important report was the Review of Leadership and Governance at Muckamore Abbey Hospital completed in July 2020. This report described the leadership team at MAH as dysfunctional, with a lack of clarity about leadership, and a sense of dis-connectedness with the BHSCT as a whole. The report concluded that the changes in senior management resulted in confusion for front line staff; there was little evidence of practice development and quality improvement in MAH; that there was insufficient challenge from the Trust Board and HSCB in relation to the DSF reporting, and that feedback provided to the Trust from the HSCB related to failings in meeting resettlement targets. The report also reported on limited escalation of key events or concerns to the Trust Board, and also that "The resettlement agenda at the hospital meant that focus on the hospital as a whole was lost: - relatives/carers of patients and hospital staff's anxieties about closure were not addressed in a proactive way to reinforce the positives associated with patients' transition to care in the community. There was insufficient focus on the infrastructural supports required to maintain discharged patients safely in the community" In the final section of the report its' final recommendation is that, "The size and scale of the Trust means that Directors have a significant degree of autonomy; the Trust should hold Directors to account."

- 5.2.9 In relation to this recommendation the review team undertook some desk top review of the Trust Board minutes over the preceding year. It was clear that update reports were being brought by the responsible Director in relation to all aspects of the services at MAH. However, we had some concerns about how effective the overview and scrutiny of Trust Board was in relation to certain key elements. In particular there was an acceptance of assurances given that the 16 remaining patients awaiting resettlement from MAH who were the responsibility of the BHSCT had robust plans in place for resettlement. However this was contingent on the proposed service developments which would deliver new homes, and as we will detail in later sections of the report there was no confidence that robust plans were in place for the delivery of such schemes, and that even if in train the earliest date for delivery would have been 2025/2026. In light of this the review team would consider that the Trust Board accepted reassurance from senior leaders, rather than driving for solid assurances which would underpin effective delivery.
- 5.2.10 One year on from the publication of the Leadership and Governance Review, which recommended that BHSCT consider sustaining the significant number of managerial arrangements instigated following events of 2017 pending the

wider Departmental review of MAH services. The current review team looking at the situation through the lens of resettlement find that there appears to have been only limited progress in relation to the changes that were called for. There continues to be some instability in relation to the leadership arrangements, in that during the last 6 months there have been changes of Director, Co-Director, Lead Social Worker and Lead Nurse; and some of these posts are appointed only on an 'interim basis' implying that they may only be temporary appointments, and with none of the incumbents bringing recent senior operational leadership experience in the field of learning disability. Whilst the review team accept the principle of the transferability of skills and that this is particularly important within senior roles, there is also a need to have a sound understanding of the 'business' particularly in the context of risks and opportunities. However the review team also acknowledge the clear commitment that these newly appointed leaders bring to their responsibilities, which could bring significant opportunity to move on at greater speed.

- 5.2.11 The review team could see that within BHSCT there had been a real vigour, both by Trust Board and the Executive Team, to address the issues that had emerged as the full extent of the institutional abuse at MAH became clear. This posed them with the linked challenges of rapidly improving the quality and safety of care for the patients within MAH whilst ensuring that there was progress at pace to achieve more resettlement. The review team could see that to some extent the former was contingent on the latter, i.e. that the more quickly the population reduced in the hospital through resettlement the sooner that the issues related to safe staffing levels could be addressed as assuming the staffing establishment was retained and the patient population reduced then the nurse:patient ratio improved accordingly. The review team felt that this balance wasn't maintained and that the importance of getting the hospital back to a safe and stable position diverted attention away from the importance of steady and consistent progress in relation to moving patients who were deemed medically and multi-disciplinary 'fit for discharge' to new homes. Therefore as will be laid out in subsequent sections the progress of the proposed schemes to be led by BHSCT effectively slowed almost to a standstill, and so other than for a small number of individuals who were able to move to existing provision there were very few people moved. This is in contrast with the NHSCT and SET who have secured new provision which will shortly become fully operational in the next 6 months and consequently a much higher proportion of their clients have plans where there is confidence that they will move in the near future.
- 5.2.12 BHSCT had a wider responsibility than the other Trusts as they were managing MAH, and had responsibility for the dedicated resettlement teams located at the hospital who had a pivotal role in being the link and liaison with the local teams within the MAH resettlement team had a pivotal role with all 3 Trust community teams including for the BHSCT, NHSCT, and SEHSCT who ultimately would assume responsibility for the clients upon transition to their new homes. However all three of these Trusts had a shared responsibility for the overall

delivery of the resettlement programme. Given the high profile concerns about the safety of MAH, and the linked urgency to find alternative homes for the remaining patients as soon as possible, the review team were concerned that not all Trusts had included resettlement of people with LD/ASD on their Corporate Risk Registers, although in some cases they were on Directorate Risk Registers. Again this may have hampered the ability of Trust Boards to assure themselves that all of the appropriate actions were being progressed to ensure swift actions were being delivered to address the significant risks.

5.3 Leadership in Operational Delivery of the Resettlement Programme

- 5.3.1 Within the system delivery relies on having senior executive and operational leaders who can take policy and strategy, and ensure that the linked objectives are delivered in practice, and that the outcomes that follow improve the lives of the people with learning disabilities and their families.
- 5.3.2 Within the HSC system in Northern Ireland this covers a broad range of leaders in senior roles in commissioning, and within statutory and non-statutory provider organisations. We have already mentioned the role of the Mental Health and Learning Disability Leadership Group which comprised Directors across the HSCB and HSC Trusts with input from other key agencies such as PHA and RQIA. It should be noted that some of these Directors had strong clinical and professional backgrounds, and had been well established within an executive role, whilst others were relatively new to role and may have come from other service domains. There was certainly a positive set of working relationships within the group, and whilst there was a well-articulated commitment to work collectively and collaboratively this was not always then evident in the subsequent partnership working. Below this group sat the RLDOG which was chaired by the HSCB, but comprised primarily Assistant Directors/Co-Director from the 5 Trusts. At times it was unclear what role the HSCB held within the RLDOG - whether their role was as convenor and facilitator, or to lead the coordination process and take a performance management role within the group. This contributed to a lack of clarity about leadership within RLDOG, and this meant that the commitment and engagement of senior staff from the HSC Trusts could be variable. More clarity about leadership within the RLDOG, with a clearer focus on achieving progress and delivering improved outcomes would have been more helpful. Whilst RLDOG was expected to work on a broader range of service developments and priorities across the learning disability domain, during the 6 months that the review team were involved it primarily focused on resettlement and access to assessment and treatment services within specialist LD hospitals.
- 5.3.3. The learning disability resettlement programme in Northern Ireland did not have an over-arching programme or project plan. Whilst it was in the commissioning plan as a strategic priority for 2019/20, and Trusts were expected to respond

accordingly, this meant that individual Trusts developed their own approaches to addressing the needs of their cohort of patients within the remaining MAH population. Some Trusts addressed this positively and developed fairly robust plans over time, but overall there was a sense that the programme was fragmented. There was certainly some evidence that HSC Trusts were planning in relative isolation. There were examples of Trusts entering discussions with providers about developing services in other Trust areas, without the 'host' Trust being informed or consulted. The HSCB convened another group called Community Integration Programme (CIP) which had a sole focus on the resettlement but it was unclear how this group's role differed from that of RLDOG, particularly given the significant overlap of membership. The HSCB had developed what they called the MAH template which HSC Trusts were asked to complete in relation to their MAH populations and plans for individuals. The review team supported the social care officer responsible for CIP to make some improvements to this so that it could be used more effectively as a 'tracker tool' and then this could support a performance management approach.

- 5.3.4 In general we found that across significant elements of the HSC system there was poor management grip in relation to the learning disability agenda and this resulted in a lack of momentum and a sense of inertia. The system seemed more pre-occupied with process and there was insufficient focus on solution finding and achieving positive outcomes quickly. The system was also prone to adopting 'crisis-management' approaches linked to pressures escalated from BHSCT in relation to difficulties within staffing or access to admission at MAH. This meant that the system was primarily reactive rather than proactive. We give further examples of how poor leadership hampered progress in delivery in later sections.
- 5.3.5 Overall the review team felt that the learning disability resettlement programme would have benefitted from an effective project managed approach, which we have seen used to good effect in other similar situations. This would have more effectively co-ordinated the efforts of the system as a whole, and ensured less variation in the overall delivery of agreed outcomes. It also would have facilitated more effective opportunities to engage with providers within the social care market in order to streamline the service developments required to support the resettlement process in a timelier way, and would have brought provider-informed solutions forward for consideration.

5.4 Leadership Engagement with People who Use Services and their Carers.

5.4.1 The review team met with the Chief Executive and Patient Client Council (PCC) senior leadership team who are undertaking the role of Advocate to the Public Inquiry and supported families during feedback on the findings of the Leadership and Governance review team. PPC advised that in their engagement, families talked about the invisibility of learning disability and expressed anger and a lack of trust in the HSC system. PCC also found in their

engagement with families that safeguarding was foremost in their concerns. PCC advised the review team that the pain and trauma for families was palpable and that a trauma informed approach would be needed to engage and support families who had been let down so badly.

- 5.4.2 The feedback from PCC concurs with the feedback the review team received in our own engagement with families in the BHSCT, NHSCT and SEHSCT and sets the context for consideration of leadership engagement with people who use services and their carers across the HSC system. The review team will address the issue of carer engagement in more detail in a chapter 10.
- 5.4.3 Families reported that they felt learning disability was invisible at government and policy level and comparison was made by some families to the profile of mental health services resultant from the Mental Health strategy and appointment of a Mental Health Champion. Many families reported their fatigue, the emotional toll of life long caring and battling for resources and services over many years.
- 5.4.4 The Welsh Government 'Improving Lives Programme (2018) placed particular emphasis on communication and effective working relationships at all levels across the system, what they referred to as the softer skills required to drive transformation and improve lives. The importance of and necessity to build trusted relationships was evident at strategic and operational leadership levels but more so in relation to building effective partnership working with individuals and families with lived experience of using services.
- 5.4.5 It is clear that across the HSC system there is recognition of the need for engagement and involvement of people with lived experience in both the planning and delivery of services however this is easier said than done. Two MAH carer representatives are members of MDAG and the review team observed both carers influencing and holding senior leadership to account through constructive challenge. However, the review team did not see evidence of effective engagement of people who use learning disability services or their family carers influencing the numerous other learning disability work streams established by HSCB/SPPG to contribute to and influence the resettlement agenda. The review team acknowledge that HSCB and the 5 Trusts had significant engagement of the draft service model' We Matter'. However this level of contribution was issue specific and has not been sustained.
- 5.4.6 The review team noted some tensions in the relationships between Trust Directors due to the pressures associated with the challenge of accessing an acute learning disability bed when required. The establishment of a regional bed manager as agreed at MDAG would have significantly mitigated the tension however, there was significant delay by HSCB/SPPG in the actions required to establish this post. The review team were pleased to see and wish to

acknowledge that the three Directors co-dependent on MAH have recently committed to working collaboratively with a focus on the mutual aid required to respond to challenges at MAH but also to expedite the remaining resettlement challenge. The Directors have held solution focused workshops establishing time and space for reflection and the development of the trusted relationships that will be required to further enhance a one team approach.

- 5.4.7 Engagement events with family carers highlighted the importance of continuity of key workers in building effective working relationships at case work level but families also referred to a trusted key worker as their go to person when they had to navigate through different parts of the HSC system or when they were facing challenge or difficult decisions. The turnover of staff at both key worker and managerial level was reported by carers to directly impact on their trust in the HSC system. Relationship based HSC practice and continuity of key worker would significantly improve the experience of people at the centre of resettlement and their family members.
- 5.4.8 The impact of the turnover at HSC senior management level was raised by external agencies, both external statutory and independent sector provider organisations that generally have experienced stability in senior leadership teams. NIHE Supporting People leaders advised that there has been a loss of memory for HSC Trusts due to the turnover in senior leadership. Voluntary sector leaders also advised the review team that the turnover in Trust HSC leadership is challenging and highlighted variation across Trusts regarding being respected as valued partners with significant expertise. The voluntary and independent sectors are key stakeholders in the delivery of community-based services and will be central to the accountable care approach needed to meet growing demand and challenge. The review team acknowledged that each Trust has held engagement events with provider organisations but the review team saw it as a missed opportunity not to have collaborated given that many care providers deliver across all 5 Trusts.
- 5.4.9 At operational level, all Trusts have made significant efforts to establish effective engagement strategies as detailed in chapter 10 however, these are at an early stage of development. BHSCT has established a robust infrastructure mapping engagement from Trust Board level with a Non-Executive Director undertaking the role of learning disability lead at Board level, through dedicated forums in MAH and community learning disability services. It is significant that only a very small number of MAH families are in attendance at the MAH Forum meeting. This would suggest a level of disengagement of MAH families. Some MAH families told the review team that they are not willing to attend meetings as they have been led up the hill too many times and only now wish to engage if there is a concrete and viable plan for their loved one's discharge.

- 5.4.10 Effective engagement requires trust and openness and this has been seriously impacted due to the allegations of abuse at MAH which has made engagement more challenging. Some families have such a level of distrust that they are not willing to engage with the Trust. It is important that Trusts give this matter consideration. The review team saw missed opportunities for Directors to reach out to families who had raised specific concerns relying instead on delegating to other managers.
- 5.4.11 The review team had the opportunity to spend time with individual families actively listening to their experiences with some families advising that this made them feel respected and their experience valued. Families also advised that at case planning level they are not always respected as experts by experience.

5.5 Conclusions and Recommendations.

The voice of people with a learning disability and their family carers was not sufficiently evident within leadership processes addressing resettlement. The review team did not see evidence of effective co-production in strategic or operational service planning and delivery.

- Consideration should be given to the development of a Provider Collaborative to bring together the range of organisations delivering specialist learning disability care with statutory HSC leaders.
- HSC system should establish an effective programme and project managed approach for the learning disability resettlement programme
- People with a learning disability and their family carers should be respected as experts by experience with Trusts building co-production into all levels across the HSC system HSC Trust

6. Strategic Commissioning, Planning and Inter-Agency Working

In this chapter we will consider the models and approaches to commissioning and how this can support effective inter-agency working.

6.1 **Prevalence of Learning Disability.**

- 6.1.1 At the foundation of good commissioning is understanding the target population and their needs both collectively and individually. Whilst the review was primarily focussed on the population of people experiencing delayed discharge within MAH, this group of individuals with very specific needs based on their experience of living with a disability and in addition their experience of living in institutional care for an extended period of time, it is important to consider them in the context of the wider population of people with learning disability or intellectual disability in Northern Ireland.
- 6.1.2 The 2021 Northern Ireland (NI) Census data will include data on health and disability, but this element of the data will not be published before September 2022. However the University of Ulster and others undertook data analysis funded by the ESRC (Economic and Social Research Council), which was supported by health and social care organisations, both statutory and nonstatutory in Northern Ireland. The research focussed on access and analysis of existing administrative data relating to learning disability in Northern Ireland between 2007 and 2011. Their key findings included prevalence data and demonstrated that within the overall Census Population the prevalence of learning disability was 2.2%; the prevalence rate amongst those aged 15 or younger was 3.8%, whilst the prevalence rate amongst those over 16 was 1.7%. Overall prevalence of learning disability ranged from 1.9% in the NHSCT to 2.5% in BHSCT. From the Census data they found that learning disability was also associated with greater deprivation. Within their conclusions the researchers comment that there is burgeoning international research which continues to detail the extreme disadvantages that are disproportionately faced by those in society living with a learning disability. Additionally they comment that learning disability specifically, at a population level, has either remained unrecorded and undetected or has been camouflaged/hidden/buried within general health data, that have referred to limitations in day-to-day activities or inability to work as a result of health problems or disability. Learning Disability Data & Northern Ireland, Ulster University, 'Enhancing the visibility of learning disability in NI via administrative data research' Ctrl Click

- 6.1.3 Mencap is a charity which works across the UK with and for people with learning disabilities and their families. They have published figures calculated using learning disability prevalence rates from Public Health England (2016) and from the Office for National Statistics [2020). They estimate there are approximately 1.5 million people with a learning disability in the UK, indicating that approximately 2.16% of the UK adult population have a learning disability. They indicate that there are 31,000 adults with a learning disability in Northern Ireland, and 11,000 children with a learning disability (0-17).
- 6.1.4 In simple terms what we know about the 31,000 adults is that the vast majority live in their local communities either independently or semi-independently with support from their families, friends, and support services. Less than 10% of them live in registered care or supported accommodation schemes, and in most circumstances, these are still either within or close to their local communities. At the time of writing there were only around 60 people with learning disabilities in specialist hospital in Northern Ireland which equates to approximately 0.2 % of the total LD population, and of this small group about three quarters were awaiting resettlement or discharge to new permanent homes. In considering the needs of this last group of people we have needed to look at how the system works to meet the needs of the larger population, and to look at how those commissioning services and those providing services ensure positive outcomes for this important group of individuals in our society.
- 6.1.5 We have commented in a previous section about the importance of developing a regional strategy and service model for services for people with learning disabilities in Northern Ireland. This strategy will need to describe this community and their diverse and varied needs so that regionally work can be completed to develop a strategic commissioning plan which can support the service delivery for this group of people. You will see later in this section that work was commenced by the HSCB and PHA on the development of a Learning Disability Service Model in 2019/20, which resulted in the co-production of a report called "We Matter " which is currently being considered by the DoH and will contribute to the production of the final strategy.

6.2 Commissioning Models

6.2.1 Whilst there are numerous models of commissioning the one that we have chosen to identify primarily is "Integrated Commissioning for Better Outcomes" which (ctrl click) was developed by NHSE, the LGA and ADASS as a practical tool for local authorities and NHS commissioners to support improving outcomes through integrated commissioning. It was published in 2018 to support health and social care economies to transform their services through a person centred approach to commissioning which is focussed on the needs of the local area. It

emphasises that effective commissioning relies on a strong focus on people, place and population.

The framework identifies what matters most to people:

- > Being the person at the centre, rather than the person being fitted into services.
- Citizens, people who use services, patients and carers are treated as individuals.
- > Empowering choice and control for those people.
- > Setting goals for care and support with people.
- > Having up-to-date, accessible information about services.
- > Emphasising the importance of the relationship between citizens, people who use services, carers, patients, providers and staff.
- > Listening to those people and acting upon what they say.
- A positive approach, highlighting what people can do and might be able to do with appropriate support, not what they cannot do.
- 6.2.2 The framework draws on a definition of commissioning developed by the Cabinet Office and Commissioning Academy in its statement about public sector commissioning.

"We commission in order to achieve outcomes for our citizens, communities and society as a whole; based on knowing their needs, wants, aspirations and experience."

6.2.3 The second example is designed to help the voluntary sector work with the statutory sector and is based on the well-known commissioning cycle model. It describes the 4 stages of commissioning within the commissioning cycle as:

Analysis: this stage aims to define the change that is needed by defining the need – the problem that needs solving – and the desired outcome.

Planning: involves designing a range of options that will work to address the issues identified against the desired outcome.

Securing services: is the process of funding the option or range of options agreed to deliver the defined outcome via an agreed funding method – grant funding, contracting, etc.

Reviewing: entails evaluating the chosen option(s) to see what has worked well and what can be improved further.



Model of Commissioning

Fig 1

6.2.4 It is important to understand that commissioning activity will be essential at all levels within the health and care system. Strategic commissioning needs to support a population based approach underpinned by a strong assessment of needs, which is delivered by senior strategic leaders in partnership with other parts of the system. Locality based commissioning requires HSCT's to ensure that at a local level these strategic ambitions are delivered through the effective purchase and supply of a broad range of directly delivered and commissioned services from providers across the independent providers, both private and charitable/" not for profit". This locality-based commissioning should ensure a sufficient supply of key services including access to registered care in nursing and residential homes, and access to accommodation providing care and support for people with significant needs. Both of the above need to relate closely to 'micro-commissioning' which is where care and support is commissioned in a bespoke way for the needs of an individual through a detailed understanding of their specific needs and requirements, resulting in a personalised care solution. Micro commissioning is directly aligned to the individualised care planning which is described in a later session, and must be underpinned by a commitment to co-production with the individual and as appropriate with the involvement of family.

6.2.5 The review team needed to look at how this broad approach to commissioning had been applied to the needs of the cohort population of people who remained in MAH and who required to be discharged to appropriate community-based accommodation with access to ongoing care and support appropriate to their needs. The approach we took was to review the programme that had been developed in England to address the needs of a similar population; to consider the framework for commissioning both health & care and housing services; and to review how these arrangements had been applied in practice to support the resettlement of the group of people who had been prioritised through direction from the Permanent Secretary.

6.3 Transforming Care in England.

- 6.3.1 "Transforming Care for People with Learning Disabilities Next Steps" was published in January 2015 by NHS England, Local Government Association, and Association of Directors of Adult Social Services (ADASS). The report identified a significant change in direction in the policy and practice in relation to gatekeeping admission to specialist learning disability settings, alongside dedicated strategies for admission avoidance and more effective discharge planning. The report relied heavily on a report commissioned by NHS England from Sir Stephen Bubb which reviewed how to accelerate the transformation of key services that people with learning disabilities and their families were looking for. The catalyst for this reform came after the shocking expose by Panorama/BBC in 2011 of institutional abuse of people with learning disabilities and/or autism at Winterbourne View, an independent private hospital at Hambrook in South Gloucestershire. The key organisations committed to strengthen the Transforming Care delivery programme by creating a new delivery board, bringing together the senior responsible owners from all organisations.
- 6.3.2 Central to the approach within Transforming Care was a commitment to empower people with learning disability and their families, and to strengthen people's rights within the health and care system. A key recommendation from Sir Bubb was for NHS England to introduce a "right to challenge "by providing a Care and Treatment Review (CTR) to any inpatient or inpatient's family which requested one. CTR's were to be embedded as "business as usual". Early evidence showed that the use of CTR's was effective in speeding up and strengthening discharge planning for those individuals in specialist learning disability hospitals.
- 6.3.3 A guiding principle in the approach was to ensure that people get the right care in the right place, and to ensure that people with learning disabilities and/or autism were discharged into a community setting as soon as possible. In

parallel there would be the development of robust admission gateway processes so that where an admission to hospital was considered from someone with a learning disability and/or autism, that a challenge process would be in place to check that there is no suitable alternative. The ambition was to reduce the number of people in inpatient settings, reduce their length of stay, and ensure that there was better quality of care both in hospital and community settings. Critically the process also required that where an individual is identified as requiring admission to a specialist learning disability inpatient facility that they have an agreed discharge plan from the point of admission. Work was undertaken in parallel to ensure that services for people with learning disability and/or autism who also have a mental illness or behaviour that challenges were improved both within inpatient and community support provision.

- 6.3.4 The above approach was supported through strategic commissioning by NHS and local authorities who had a shared responsibility to fund care and support throughout the pathway. This required the health and care system to develop quality standards and outcome metrics which were reflected within the NHS Standard Contract and were then applied with assurance processes undertaken by clinical commissioning groups at a local level to ensure that there were robust arrangements to monitor that individuals were receiving the right care in the right place. To support this strengthened commissioning there was a refocus on the quality of data and information so that those implementing commissioning intentions had access to the right information to ensure effective analysis and decision support.
- 6.3.5 Within Transforming Care there was a renewed commitment to strengthen regulation and inspection. The Care Quality Commission (CQC) were required to further refine its inspection methodology for mental health and learning disability hospital services, and to ensure that regulatory action is taken. Central to this was an explicit commitment that CQC would work with other partners to develop a clear approach for ensuring that unacceptable mental health and learning disability services were closed through use of its enforcement powers.
- 6.3.6 In 2017 NHS England followed up with model service specifications within the Transforming Care Programme in the context of "Building the Right Support National Service Model " as a resource for commissioners, The model service specifications particularly focussed on (1) enhanced and intensive support, (2) community based forensic support, and (3) acute learning disability inpatient services. These 3 aspects of the service model describe the specialist health and social care provision aimed specifically at supporting people with a learning disability who display behaviour that challenges.

- 6.3.7 The review team subsequently met with senior officers from the Kent and Medway Integrated Care System who had been responsible for implementation of Transforming Care within their system as strategic commissioners. Their overall conclusion was that Transforming Care had been effective in ensuring a more targeted approach particularly in relation to admission avoidance through more effective gate keeping, and the provision of the dynamic support framework, which was delivered through an inter-agency forum to ensure effective strategies were in place for individuals identified at risk of admission. Additionally, they had received funding from NHSE to improve access to 24/7 intensive support teams. Transforming Care had also ensured that there were fortnightly reviews of all inpatients with a clear focus on the trajectory and progress over time for the individual.
- 6.3.8 In Kent and Medway there had been a renewed effort in terms of governance with the development of a new governance framework and an oversight board to ensure that partners were accountable for commitments and performance. However even with this strengthened focus 66% of the original population identified still were awaiting resettlement. They reported that there had been some issues in relation to effective working with the Ministry of Justice in relation to those individuals who were within justice domain, and in some situations local authorities had been slow to undertake and progress housing needs assessments. Positives had been the development of a Positive Behaviour Support framework of accredited providers, and a central source of capital funding to support bids for discharge plans for individuals who had specialist accommodation needs. More recently in the early part of 2022 they had found an increase in crisis referrals which they felt could be an acuity surge related to the aftermath of Covid.
- 6.3.9 At a national level organisations such as Mencap and the Challenging Behaviour Foundation monitor the monthly published data from NHSE and provide a commentary on progress. This reflects a view that whilst Transforming Care has provided an effective framework for the delivery of enhanced services to people with learning disabilities and/or autism whose behaviour can challenge the improvement has been slower than originally hoped for within specified targets, and there is a concern nationally about the growing number of young people being treated within inpatient settings.

6.4 Commissioning of Health and Social Care services in Northern Ireland.

- 6.4.1 Up until April of 2022 the responsibility for the commissioning of health and social care services sat with the Regional Health and Social Care Board (HSCB) and the Public Health Agency (PHA) in partnership. These bodies set their key priorities and areas for action within a commissioning plan, in response to a Commissioning Plan Direction issued by the Department of Health.
- 6.4.2 For our purposes we wanted to look particularly at the commissioning plan for 2019/2020, as this identified some actions which were required in light of the exposure of significant abuse of individuals living in MAH which was managed by the BHSCT. The commissioning plan also identifies how resources will be allocated to Health and Social Care Trusts and other providers to maintain existing services and develop new provision.
- 6.4.3 There are a few general points of note in relation to the 2019/20 commissioning plan. There was little reference in the earlier sections of the document to the needs of people with learning disability in terms of emerging issues or key policy and strategy. It did refer to the production of the "Power to People "Report in 2017 looking at the possible solutions to the challenges facing the Adult Social Care and Support System in Northern Ireland. Additionally, it highlighted the continued commitment of strategic commissioners to supporting Personal and Public Involvement to improve patient and client experience. Central to this would be the embedding of co-production within collaborative working of health and social care systems, including the adoption of co-production and co-design models for the development of new and re-configured services.
- 6.4.4 In terms of the financial resources made available to Trusts and other providers to meet the needs of people with learning disabilities and their families this amounted to 6.58% of the total allocation for health and social care in Northern Ireland, which comes to approximately £342 million. It should be noted that these allocations may not meet the full cost of services and there may be additional cost pressures emerging for certain groups.
- 6.4.5 In terms of the specific commissioning commitments in relation to learning disability services made within the 2019/2020 HSCB & PHA Commissioning Plan, these are laid out in a separate short chapter of the overall report. There is a commitment to continue to adopt the Bamford Report principles when developing services for people with learning disabilities, with a particular emphasis on supporting integration, empowerment and 'ordinary lives'. There was also commitment to co-produce with a broad range of stakeholders including people with learning disability and their families, a Learning Disability Service Model (LDSM) based on a regional review of services. Within the population sections of the plan there was no specific reference to the numbers

of people with learning disabilities, although the plan did note that, "the number of people with a learning disability and the levels of accompanying complex physical and mental health needs continues to grow in Northern Ireland."

- 6.4.6 There were 2 strategic priorities identified which are of relevance to the resettlement programme for people with learning disabilities. The first states "Effective arrangements should be in place to address deficits in assessment and treatment in LD inpatient units as highlighted by the Independent Review of MAH (and other incidents affecting NI patients in private LD hospitals). In relation to this priority the Provider Requirement was, "Trusts should demonstrate plans to develop community based assessment and treatment services for people with a learning disability with a view to preventing unnecessary admissions to LD hospital and to facilitate timely discharge. (CPD2.8)"
- 6.4.7 The second of the strategic priorities was, "Effective arrangements should be in place to complete the resettlement and address the discharge of people with complex needs from learning disability hospitals to appropriate places in the community (CPD 5.7). In relation to this priority the Provider Requirement stated, "Trusts should demonstrate plans to work in partnership with service providers and other statutory partners to develop suitable placements for people with complex needs."
- 6.4.8 In addition there was a specific Skills Mix/Workforce area identified within the commissioning plan for action. This highlighted that, "Effective arrangements should be in place to develop multi-disciplinary services in community settings to address the actions required within the Independent Review of MAH." The Provider Response required in relation to this area was that "Trusts should demonstrate plans to recruit multi-disciplinary teams to build the community infrastructure to support people with a learning disability outside of hospital settings. Trusts should demonstrate plans to work with their independent sector partners to build the skills and capacity of their workforces to enable them to support and sustain people with complex needs in their community placements."
- 6.4.9 These elements of the HSCB's commissioning plan clearly laid out the expectations of both the Department through its directive and the HSCB/PHA response to progress actions directly relevant to the delivery of the resettlement programme in Northern Ireland. HSCT's would have been expected to reflect these within their Trust Delivery Plans (TDP's) so that commissioners had an understanding of the actions Trust's proposed which could then be monitored at a regional level for progress.

6.4.10 In subsequent sections we will look at how these clear commissioning intentions were executed and to what extent these requirements were delivered.

6.5 Commissioning of Specialist Housing with Support for People with Learning Disabilities in Northern Ireland.

- 6.5.1 In order to consider how the Trusts were to meet the objectives laid out above it is important to understand the role of the Northern Ireland Housing Executive (NIHE) and housing associations/charities in terms of the provision of specialist housing with support for adults with learning disabilities. The NIHE is the largest social housing landlord in Northern Ireland; it is required to regularly examine housing conditions and housing requirements; it is also required to draw up a wide ranging programme to meet these needs. For individuals with housing needs that have additional support needs this is addressed through the Supporting People Programme. The Supporting People Programme helps people to live independently in the community and is administered by the NIHE in Northern Ireland on behalf of the Department for Communities. The Supporting People Programme grant funds approximately 85 delivery partners that provide over 850 housing support services for to up to 19,000 service users across Northern Ireland, with the total programme operating an annual budget of £72.8m in 2021/22. In relation to schemes for people with learning disability, the current provision has the potential to support 1334 individuals in 149 accommodation-based schemes. With an annual budget of £16.3 million.
- 6.5.2 The 2015 review of Supporting People recommended the introduction of a strategic, intelligence led approach to identify current and future patterns of need. Consequently, the NIHE and partners developed a Strategic Needs Assessment (SNA). This provides a comprehensive picture of housing needs for people who require additional care and support. It highlighted that people who are living with learning disability mostly require accommodation-based support rather than floating support as their disability is lifelong. A time-bound floating support intervention in these cases is not deemed an adequate intervention. Although floating support services offer the opportunity to allow individuals to remain in their own homes, respondents noted that this does not negate the need for accommodation services for those living with a greater complexity of need.
- 6.5.3 In terms of the SNA for people with learning disability they conclude that the analysis of current need suggests that there is an undersupply of 224 units. Research previously commissioned by the NIHE (2016) in reference to the resettlement of individuals living with learning disabilities from long stay

institutions highlighted that for these people there are several elements of supported housing services that are important:

- > location or at least access to public transport network,
- > safety
- Integration into the community.
- 6.5.4 These are important to the individuals to allow for their own independence and the feel of being part of a community. It is apparent from their research that the demand for learning disability services and in particular autism services has increased due to improved diagnosis and treatment services, which in turn will lead to an increased demand on housing support services. As the future calculations show, it is estimated that there will be an undersupply of 479 units for this cohort within a ten-year period.
- 6.5.5 Additionally, the SNA highlights the important issue of access to capital for housing development. Some providers have highlighted that capital investment would allow them to provide the required level of service to meet the growing demand as well as a wider range of housing support services.
- 6.5.6 It also refers to some early joint planning work between the NIHE, HSCB and HSCT's in relation to improving planning for the needs of people with learning disabilities. The information gathered and analysed in 706 person pilot conducted by HSCB with HSCTs for people with learning disability the report identifies could help inform future strategic needs assessment particularly if standardised approach were developed.

6.6 How commissioning operated in practice to deliver the resettlement programme for the people awaiting resettlement from MAH.

- 6.6.1 The commissioning plan from the HSCB/PHA had made an explicit requirement for the resettlement of the remaining people awaiting discharge to be progressed at pace.
- 6.6.2 In order to progress the HSCB convened a number of groups to support this process. There was a Mental Health/Learning Disability Strategic Leadership Group comprising senior leaders from the Directorate of Children and Social Care in the HSCB and the Directors responsible for learning disability services in each of the Trusts. This group had a leadership role across the whole of mental health and learning disability services, and held a collective strategic responsibility for the delivery of resettlement. This group sponsored 2 subgroups which comprised officers of the HSCB and senior operational staff

from the Trusts, including the Assistant Directors/Co-Directors responsible for learning disability services. Initially this only included representation from Belfast, Northern and South Eastern Trusts as the remaining people in MAH awaiting discharge were the responsibility of these organisations by virtue of the individual's original place of residence. These subgroups were (1) the Regional Learning Disability Operational Group (RLDOG) which included some representation from NIHE, and other agencies such as RQIA, and (2) Community Integration Programme (CIP) which looked more specifically at the issues pertaining directly to the resettlement programme.

- 6.6.3 The review team were able to observe and participate in all of the above groups and in addition had specific meetings with each of the Trust's senior leadership teams responsible for learning disability resettlement.
- 6.6.4 It was positive that the HSCB had created a structure of groups and meetings to progress the resettlement programme and address related issues, particularly in relation to access to learning disability hospital beds for assessment and treatment. There was a clear commitment from senior leaders to support the delivery of the resettlement programme and to work jointly to face and address the significant challenges.
- 6.6.5 However we felt that overall the commissioning of services was poorly framed and lacked effective performance management. This meant that the HSCB (and more recently SPPG) has struggled to achieve timely impact in ensuring the Trusts secured new homes for the people awaiting discharge from MAH.
- 6.6.6 There were a number of particular weaknesses which the review team identified. The HSCB were using a basic table to monitor the status of the individuals in the target population, which the review team assisted with redesign. Updates on this revised 'tracker tool' were sometimes only provided after chase up, and often not validated by the respective Trust AD/Co-Director, so may not have been reliable. Attendance at these key meetings was generally poor and inconsistent, contributed to in some instances by the too frequent changes in personnel in significant delivery or planning roles. Hopefully this report will be a catalyst for the SPPG to review with its partners the effectiveness of both CIP and RLDOG.
- 6.6.7 Whilst colleagues from other agencies NIHE and RQIA were involved in RLDOG it was sometimes unclear how they were expected to engage in the activity to progress schemes and proposals at speed. In particular the housing professionals held a wealth of information and data about activity in the existing system and had expertise in both design and delivery of housing schemes which wasn't always drawn on by colleagues from health and social care. Housing colleagues described how they felt the inter-agency working had

become less evident and effective in recent years, partly due to the lack of stable leadership and management arrangements at times in health and social care. They felt that some of the current senior staff lacked the understanding of the housing and Supporting People sector that their predecessors had demonstrated.

6.6.8 Whilst there was a verbalised commitment to working collaboratively, this was sometimes hampered by poor communication between the key partners. This was especially significant where a lead Trust was developing or planning a scheme which had the potential to provide accommodation for individuals from other Trusts. In some instances plans had not been shared with other partners which meant they weren't sighted on proposals for developments to be located in their Trust area, without their involvement in the planning, which had potential to place demand and pressure on local learning disability and other services.

Perhaps the most significant area of concern was the scrutiny of the proposed accommodation schemes and the supporting business cases to develop those schemes by the HSCB and individual Trust Boards. This rarely involved rigorous assurance that the planning for schemes would deliver new accommodation for individuals awaiting resettlement within a reasonable timescale. Subsequently the stated ambition that all people awaiting discharge from MAH would be resettled by the end of 2019 was completely missed, with slow progress verging on inertia beyond that point.

- 6.6.9 Having set out the regional landscape for strategic commissioning of health, social care and housing we will move in the next sections to look at how Trusts have progressed the individualised care planning (Chapter 7) and local commissioning of new provision to progress the resettlement plans developed for individuals.(within Chapter 8)
- 6.6.10 Across the system the review team were concerned that there were significant examples of poor or slow decision making, limited communication to support a fully collaborative approach, and weak management grip to address practical barriers that delayed positive outcomes being achieved – an example of this was transition/discharge plans being delayed for sometimes lengthy periods because required adaptations to property had not been completed, or legal advice in relation to placement matters had not been satisfactorily addressed.
- 6.6.11 There were a few legitimate challenges faced by the HSC system which we acknowledge compromised delivery within agreed timescales. The obvious challenge across the whole system was the global pandemic and the significant impact this had on capacity. This impacted further on workforce issues which all parts of the system described as placing them under real difficulties. Less likely to have been anticipated were the issues in relation to building and

estates , as new providers experienced unprecedented pressures in relation to the escalating cost and reduced supply of building materials which slowed the delivery of some schemes.

- 6.6.12 It is worth noting that all of the Trusts had engaged with some of the well-known providers in the not-for-profit sector, several of whom had a well-tested track record of meeting community demand for care and support to individuals with learning disability and behaviour that can challenge. This had resulted in a small number of resettlements being achieved through the design and delivery of high-quality singleton placements. Some of the families that we had engaged with told us stories of truly transformational and life changing experiences when their relative moved on from hospital to these schemes, and we will return to this in Chapter 8 when we look at the Operational Delivery of Care and Support.
- 6.6.13 However, it should also be noted that generally the review team found that Trusts often initiated planning for proposed new accommodation schemes without fully exploring the opportunities for potential provision within either existing or re-designed provision. If this had been possible then options for resettlement could have been developed in a much more speedy way.

6.7 Shaping the Independent Health and Social Care Market for People with Learning Disability

- 6.7.1 In the last few decades across the UK and more widely we have seen a significant shift away from hospital based long term care for people with learning disability towards community based provision. This shift has been driven by a clearer commitment to respecting the human rights of people with learning disabilities which has been enshrined in health and social policy.
- 6.7.2 Large scale institutional care has been replaced by a mixed economy of alternative care arrangements ranging from large scale group living to individualised specialist housing with dedicated care and support.
- 6.7.3 In England the responsibilities for market shaping are enshrined in the Care Act (2014) which states that each local authority "Must promote the efficient and effective operation of a market in services for meeting care and support needs with a view to ensuring that any person wishing to access services in the market:
 - Has a variety of providers to choose from who (taken together) provide a range of services
 - > Has a variety of high quality services to choose from

- Has sufficient information to make an informed decision about how to meet the needs in question."
- 6.7.4 The Care Act reinforces that commissioning should be at the heart of personalised care and support. This includes commissioning with health and care organisations but goes further to include engagement with community development and working with other agencies, for example the community sector.
- 6.7.5 Whilst a similar statutory responsibility is not placed on HSC Trusts, they do have legal responsibilities to provide services, and should do this not only through direct provision but also by purchasing services from independent sector providers. Implicit within these broader responsibilities is a need to support and shape the market to ensure robust supply and to secure value for the public purse.
- 6.7.6 The review team found that health, social care and housing agencies held significant data on the current market provision relating to services for people with learning disability. RQIA hold information on each registered provider of nursing or residential care and can provide information not just on the capacity of those providers but also can provide quality information through a highly regulated inspection process. In addition, they are responsible for registering the domiciliary care element of supported living schemes which are responsible for providing the support element. We were impressed by the data that the NIHE hold relating to the 149 accommodation based supported living schemes which included both activity and financial data relating to both housing and HSC investment in these schemes, where the balance of the funding for each scheme is based on a functional analysis of the housing support vs care needs of the clients within the scheme.
- 6.7.7 However, the review team found that this data was not routinely shared by partners across the sector and that there was no strategic overview of what the market was providing for adults with learning disability across Northern Ireland, and at what cost. Given the availability of significant data we would expect that both strategic and local commissioners of care and housing would undertake some analysis to develop a 'supply map' of care and specialist housing for people with learning disability in Northern Ireland. This could inform strategic commissioning and market shaping, but it would also be of benefit to care managers, individuals seeking care and their families so that they understood the options available to them which could promote choice. This should be a live and dynamic picture of supply.

6.7.8 The review team gathered information from a range of sources, and undertook some analysis to establish an initial supply map, and identify commissioning trends. We will address within the recommendations. Below is a table which shows the overall range and location of registered care settings and supported living schemes in Northern Ireland. This sector provides accommodation capable of meeting a diverse range of needs, all located within the community. In total there are somewhere in the region of 2,500 places in the community for people with learning disabilities and a significant minority of the schemes have been devised to accommodate individuals who additionally have mental health difficulties or behaviour that can challenge. The cost of care across the sector is highly variable and is linked directly to the level of support and care required. For those individuals who live in the registered care sector all of the care costs are met by health and social care (although there could be a small number of 'self-funders'). HSC Trusts purchase places in registered care setting either through block contract or on a 'spot purchased' basis for individuals.

	Learning Disability	Residential Care Places		Supported Living	
	Disabilty /Nursing Home places	Statutory	Independent	Statutory	Independent
BHSCT	4 N-Homes/103 Places	6 RCH/39 Places	4 RCH/40 Places	7 Schemes	18 Schemes
NHSCT	8 N-Homes/247 Places	2 RCH/15 Places	6 RCH/58 Places	6 Schemes	27 Schemes
SHSCT	6 N-Homes/166 Places	0 RCH/0 Places	6 RCH/57 Places	13 Schemes	11 Schemes
SEHSCT	2 N-Homes' 55 Places	2 RCH/15 Places	11RCH/180 Places	5 Schemes	38 Schemes
WHSCT	1 N- Homes/ 35 Places	5RCH/55 Places	6 RCH/ 88Places	2 Schemes	15 Schemes
Total	21 N- Homes /606 Places	15RCH/123 Places	33 RCH/423 Places	33 Schemes	109 Schemes
				Total of SP = 1420 Suppor	ting People Tenancies/144Scheme

(RCH – Registered Care Home) Fig 2

6.7.9 For those living within the housing with support provision the individual is usually funded through a combination of rental income which is commonly paid through housing benefit, an element for housing support paid from Supporting People funds, and then a care element paid for by the placing HSC Trust. Obviously in the case of supported living, the financial costs are spread more across 2 government departments – communities and health – and then arranged through the NIHE and HSC Trusts. In supported living the individual will have a secured tenancy, which ensures rights as a tenant under the relevant housing legislation. Additionally, the individual will be eligible to apply for

personal benefits and therefore could have more disposable income which can support greater financial choice.

- 6.7.10 The review team undertook a preliminary analysis of the market and in this context there were some interesting features of the market in Northern Ireland which merit some note. There are vacancies across all sectors, although the data on this wasn't readily held or available when we asked for it from Trusts, yet when talking to providers they all reported some level of vacancy across provision. For some providers in the private sector this was a particular issue in terms of sustainability, and they stated a willingness to work with local commissioners to adapt their services to be more appropriate to need and demand both now and in the future. Across the supported living sector there was somewhere in the region of 5% vacancy, which whilst relatively small did provide some opportunities to meet emerging demand, although the SNA completed by the NIHE indicates that they believe there is under provision for people with learning disability at present.
- 6.7.11 HSC Trusts continue to be a major direct provider of services to this client group both in registered care and supported living. Trusts operate 31% of the registered care settings for people with learning disabilities accounting for almost a quarter of the registered care places. In the supported living accommodation schemes 24% of the schemes were operated by the local HSC Trust. There is considerable variability in the extent to which Trusts continue to operate as providers. For instance, the SHSCT operate 55% of the supported living schemes in its area, but the WHSCT operates 11% of the supported living schemes in their area. This raises some interesting questions which the review team haven't fully explored in terms of the delineation of roles for Trusts both as commissioners and providers of care.
- 6.7.12 In relation to the registered nursing home sector these are all private sector operators. There are 21 specialist learning disability nursing homes in Northern Ireland, and the majority are operated by local providers some of whom have entered the market because of a family related interest in learning disability care or are led by professionals who previously worked within statutory services. However, 60% of the specialist nursing homes are located within 2 Trust areas of the NHSCT and SHSCT, with the majority in the NHSCT.
- 6.7.13 Further strategic inquiry is merited in relation to the type of need being met by statutory versus non-statutory as anecdotally this appeared to be based on historical context rather than based on strategic decisions. There could be a rationale for the HSC Trusts continuing to be such a significant provider, especially if this was to meet a category of need that the market for social care had struggled with, but again anecdotally this didn't appear to be the case.

Providers pointed out that as statutory providers were using Agenda for Change terms and conditions in employment arrangements within their direct provision, this placed Trusts at a tactical advantage in terms of recruitment and retention of staff. We will return to this issue in the later section on workforce.

- 6.7.14 Engagement with Private Sector Providers: we engaged with provider sector providers through a number of focus group sessions organised by 2 of the network organisations representing providers across the independent sector. These were ARC (NI) and Independent Health Care Providers (IHCP). The sector engaged very readily in the review and were keen to give their views and share their experiences of working within the wider system. Generally, providers, especially those in the private sector, felt that the resettlement teams and HSC Trusts had not engaged them in a strategic discussion about the sector's potential in meeting the needs of people awaiting discharge from long stay institutions. Several providers described that whilst they may not have been considered in the first instance, there were several occasions where they had been asked to consider and had admitted some individuals who had experienced unsuccessful placements elsewhere. In these cases several of the subsequent placements had gone on to be both successful in terms of client outcomes and stability over time.
- 6.7.15 Generally, providers expressed concern about the lack of effective partnership between commissioners and providers. In particular they felt that HSC Trusts were unwilling to engage in negotiations around 'risk-sharing' in terms of contractual measures that ensure a reasonable level of income to support the borrowing necessary to allow capital development and borrowing. This was more of an issue for smaller providers who were newer to the market. Providers also expressed a general view that whilst there was extensive engagement with HSC Trusts care management staff and contracting teams in relation to contract review, there was little discussion about forward planning or potential for service development. Additionally, several providers worked with a number of commissioning agencies or HSC Trusts and commented on the variability in processes and overall approach. Given the size of Northern Ireland there definitely should be consideration given to the development of a commissioning collaborative operating under a single commissioning framework. Nursing and independent residential care providers commented that they were being expected to operate under out of date nursing/residential care contracts with amendment through letter of variation, and these arrangements were not fit for purpose. This proved unsatisfactory, particularly in the context of the complexity of need of some of the clients.
- 6.7.16 The statutory sector within health and social care have organised their activity through the Social Care Procurement Board (SCPB) which was chaired by the

Director of Children and Social Care at the HSCB/SPPG with representation from each of the 5 Trusts and legal services. The SCPB has been going through a 'refresh' process to review its role and how it operates. Its revised draft terms of reference include:

The Social Care Procurement Board will:

- a) Develop a Social Care Regional Procurement Plan that places all approved procurement projects within the overarching strategic commissioning landscape and includes the rationale for each procurement project being taken forward.
- b) Ensure any request for a regional procurement project is only approved when the project can demonstrate a clear and unambiguous link with the Programme for Government and strategic commissioning plan for a related programme for care.
- c) Establish a Social Care Procurement Project Delivery sub group for the operational management of the Social Care Regional Procurement Plan, with the Chair of the sub group to be a member of the Social Care Procurement Board.
- d) Establish additional specialist sub groups in response to strategic commissioning needs.
- 6.7.17 Whilst it is encouraging to see this renewing of the SCPB it is imperative that they engage effectively in broader strategic engagement with providers so that commissioning strategies are informed and shaped with intelligence from the sector itself. There needs to be a recognition that the commissioned services with independent sector constitute a multi-million pound investment which has a massive impact on the lives of people with disability. Additionally, as elsewhere in the rest of the UK and Europe there is a growing recognition of the demographic shift in the population of adults with learning disability/ASD and behaviour that challenges leading to massive increases in demand which are related to the exponential growth in numbers of people with learning disability.
- 6.7.18 Several Trusts have provided us with information about provider engagement events or have established regular provider forums, to improve their partnership working. This would be best progressed through greater regional collaboration which could be supported by the SCPB's prioritisation of this important area of work.
- 6.7.19 Critical to this work will be developing an understanding of the pricing structure for care, and in particular the significant variation in costs across the sector. It will be important to understand both financial viability and financial sustainability of this relatively small cohort of specialist providers.

6.8 Finance and Value for Money

- 6.8.1 Commissioners, both strategic (regional) and local (within Trusts) have a broad duty to ensure value for money in relation to all expenditure within the public purse. This responsibility is scrutinized by the Northern Ireland Office who can pursue Value for Money Audits in relation to key areas of work.
- 6.8.2 The review team were not required in the context of the terms of reference for this review to undertake a detailed analysis of the costs associated with the resettlement programme, but there are a number of observations that we would make in the context of strategic commissioning.
- 6.8.3 The review team have had discussions with finance officers within the HSCB regarding the commissioning of learning disability services, including the services provided at MAH and the alternatives being proposed through the resettlement schemes.
- 6.8.4 The costs associated with the funding of MAH is linked to the funding of the resettlement costs. In the past a 'dowry' system applied where each individual being resettled from a long stay hospital received an allocated sum to support their resettlement, but there was a broad acceptance that the dowry was often insufficient to cover the costs of the placement. Whilst the dowry was person specific once it was no longer required to support that named individual, then it could be incorporated in to the base funding for future community placements at some point.
- 6.8.5 In more recent years this has been replaced with a requirement that the HSCB would receive costed proposals for the resettlement of an individual, directly linked to the cost of a placement or place within a newly developed scheme, and there is an approval process. This requires the HSC Trust to submit a client specific business case for each individual with complex needs, in which the Trust is required to lay out provisions for capital and on-going revenue costs, and should demonstrate value for money to the public purse. The business case must also demonstrate what elements, if any, are funded through sources of funding outside of health, usually housing/supporting people funds. This include access to personal benefits housing and welfare payments, rental costs, or Supporting People funding towards housing support and some elements of management costs within schemes.
- 6.8.6 In broad terms the costs associated with the funding for MAH is linked to the funding of the resettlement costs. There would have been an assumption that a certain proportion of resettlement costs were linked to an expectation of ward closure and decommissioning of beds as the patient population reduced. In reality there should have been a decommissioning plan agreed between the BHSCT and HSCB linked to the resettlement programme, but this doesn't appear to have been put in place.
- 6.8.7 In recent years the number of patients leaving the hospital has been relatively low. However in addition the number of patients remaining in MAH is substantially lower that the commissioned beds. Costs within MAH have

escalated dramatically as there has been an increased reliance on funding of substantial agency staff to replace staff who have been placed on suspension during the course of the PSNI investigation.

- 6.8.8 This has meant that in the last several years the BHSCT has had to seek additional funds non-recurrently from the HSCB to cover these additional substantial cost pressures.
- 6.8.9 The other factor to consider is the cost of the alternative homes that are being commissioned for people moving on from MAH through resettlement. Through the 'tracker tool' the Trusts have reported on discharge planning for each individual and where there is a scheme either nearing completion or with a costed business case approved they provide indicative costs. Not all Trusts provide this information, but based on the return from the NHSCT the annual costs of the new provision range from £212k to £500k per annum for the majority of clients. It should be noted that there was one client who had costs significantly higher than has been quoted in the range but as this was deemed an exceptional individual with what could be considered the most complex needs that individual hasn't been included in the range.
- 6.8.10 As stated previously the SCPB will need to consider benchmarking the costs of these specialist community placements so that SPPG, HSC Trusts and others can establish what 'value for money' looks like in this domain. Additionally it has to be recognised that the community placements should provide significant quality of life benefits to those individuals who have previously lived in MAH.
- 6.8.11 Whilst the review team did not have access to detailed cost per bed data for MAH, based on our discussions with finance officers it would appear that the cost of hospital bed in MAH per annum currently is significantly higher than even the highest costed placement within the range of placements provided by NHSCT, and substantially higher than the estimated average cost of a community placement. In addition it has to be considered that for placements in specialist supported living schemes, a proportion of the costs will be shared with housing.
- 6.8.12 In the context of the position laid out above there needs to be consideration of the opportunity costs in this situation. A simple definition of 'opportunity cost' is "opportunity cost is the forgone benefit that would have been derived from an option not chosen or pursued". The review team consider that if the resettlement of the target group of patients had been achieved more quickly and within the timescale of the original directive from the Permanent Secretary in 2018, then there were opportunities for cost efficiencies in relation to the cost of community placement relative to the cost of continuing hospital placement for these individuals. This may be open to alternative interpretation and debate, but there is certainly merit in considering this as part of any more formal evaluation of the resettlement programme.

6.9 Recommendations

In summary the conclusions and recommendations from this chapter are:

- The DoH needs to produce an overarching strategy for the future of services to people with learning disability and their families, to include a Learning Disability Service Model.
- In the context of the overarching strategy the SPPG will develop a commissioning plan for the development of services going forward. This should include the completion of resettlement for the remaining patients awaiting discharge from MAH, and progress the re-shaping of future specialist LD hospital services.
- Strategic commissioners within health, care and housing should convene a summit with NIHE, Trusts, Independent Sector representatives, and user/carer representation to review the current resettlement programmes so that there is an agreed refreshed programme and plan for regional resettlement.
- The SPPG and NIHE/Supporting People should undertake a joint strategic needs assessment for the future accommodation and support needs of people with learning disability/ASD in Northern Ireland
- The Social Care Procurement Board should urgently review the current regional contract for nursing/residential care and develop a separate contract for specialist learning disability nursing/residential care.

7. Individualised Care Planning

In this section we will review the policies, and discharge planning guidance in place nationally to identify good practice; critically review the individualised care planning arrangements in place in each of the 5 HSC Trusts and assess their effectiveness.

- 7.1.0 As part of evidence gathering, the review team issued a questionnaire to all 5 HSC Trusts requesting confirmation of the assessment tools and care planning procedures and processes relied on to support discharge planning.
- 7.1.2 Engagement with family carers and provider organisations, provided rich information to the review team in regards to the effectiveness and experience of discharge planning and this feedback highlighted a gap between the perception of statutory HSC Trust teams leading the discharge planning and the experience of other stakeholders.
- 7.1.3 The review team analysed the information returned by HSC Trusts and completed a review of research and available guidelines and best practice relating to individualised care planning. The review of policy and guidelines highlighted the need to plan discharge from the moment of admission. The Care Quality Commission- Brief Guide; discharge planning from Learning Disability assessment and treatment units August 2018, (ctrl click) provides a useful checklist of what needs to be in place for effective discharge planning;
 - At the point of admission, the care plan should include a section on 'when I leave hospital' and the discharge plan discussed at each meeting
 - > Ensure family and the individual are involved with clear goals agreed
 - Discharge plans need to contain a date, an identified provider and discharge address
 - Evidence that the person is being supported to develop skills for independence and living in the community
 - Evidence that information is shared appropriately with providers to prepare for discharge with the outcomes of assessment and treatment clearly stated.
- 7.1.4 There are a range of relevant Guidelines to inform effective assessment and care planning. NICE guidelines- 'Challenging Behaviour and Learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges' (ctrl click) highlights the importance of understanding the cause of behaviour and need for thorough assessments so that steps can be taken to help people change their behaviour The DoH Guidance 'Positive and Proactive Care: reducing the need for restrictive

interventions (2014) (<u>ctrl click</u>) is also based on a positive and proactive care approach The Care Quality Commission, Brief Guide: Positive behaviour support (PBS) for people with behaviours that challenge (2018) (<u>ctrl click</u>) provides the policy position and helpful good practice case examples.

- 7.1.5 Promoting Quality Care' Good Practice Guidance on the Assessment and Management of Risk in Mental Health and Learning Disability services(May 2010) (ctrl click) states that a crisis plan should be included in the care plan and specify triggers and warning signs with explicit proactive and preventative strategies in the care plan. Effective assessment and care planning is central to supporting the transition of individuals from hospital to the community who have highly individual communication and support needs. Guidance and policy highlight that an essential lifestyle plan alongside the positive behaviour support plan should be central to discharge planning in addition to core assessment tools. The Centre for the advancement of PBS-(BILD) (ctrl click) advocate a whole organisational approach to embed PBS with all staff having a basic understanding of PBS and its value base. The learning from resettlement placements that have broken down and feedback from families and care providers highlights that positive support plans have not always been in place and that further work is required to ensure regional standardisation in regards to the quality of assessments and the tools used.
- 7.1.6 Questionnaires returned by HSC Trusts highlighted a lack of consistency regionally in the documentation used to develop care plans supporting a person's transition from Learning Disability hospital to the community. HSC Trusts use a range of assessment templates which are not always collated into one document. All HSC Trusts used the Northern Ireland Single Assessment Tool (NISAT) DoH Procedural Guidance- February 2019 (ctrl click). However, this comprehensive care management assessment tool is generic and not sufficiently person centred. Some Trusts, appropriately supplemented the NISAT with a range of assessment tools, including 'Essential Lifestyle plans 'Promoting Quality Care assessment, Functional assessment, Motivation assessment scale and Behaviour support plan. If a person is displaying challenging behaviours, a functional assessment can help uncover the reasons behind that behaviour. Knowing the function, allows changes to be made that reduce challenging behaviour. It is essential that discharge planning is person centred and that the information is accessible and available to all the stakeholders involved in supporting the person to move on from hospital. This highlights that assessment tools will only be effective if the organisational culture is based on positive behaviour support for people with behaviours that challenge and staff trained to understand and evaluate communication and to implement proactive and preventative strategies in response to triggers and warning signs to avoid escalation and crisis. Review of strategic policy across

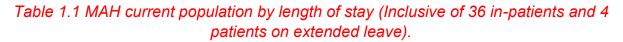
England, Scotland and ROI confirmed that all prioritised the development of a positive behaviour framework.

- 7.1.7 The review team recommend that HSC Trusts collaborate to standardise their assessment and discharge planning tools to improve the quality and effectiveness of care plans. The review team recommend that the learning disability strategy / learning disability service model to be progressed by DoH takes the evidence base for PBS and learning from other UK nations into consideration.
- 7.1.8 The discharge process requires sufficient flexibility to ensure agility and prevent the process being risk averse, however, an overarching pathway that maps out who does what at critical stages of the process is required. The review found that there is no overarching resettlement/ discharge policy that informs the roles and responsibilities of the range of organisations, teams and individuals involved. Indicative timelines for case transfers between teams and organisations is required so that individuals and their families know what to expect at each stage of the transitions pathway. The review team recommend that HSC Trusts collaborate with all stakeholders to develop a resettlement pathway and operational procedure.
- 7.1.9 Most Trusts were clear that it is the community HSC Trust that has the lead role for discharge planning rather than the hospital team however, this was not consistently applied regionally. The review team worked with all HSC Trusts throughout the period of the review with agreement reached that the community HSC Trust held responsibility and accountability to lead resettlement planning once the patient had been identified as ready for discharge. The community HSC Trust will be reliant on the MAH team who have the contemporaneous experience of caring for the patient to provide clinical information and input to the care plan however the community HSC Trust should hold a challenge function in addressing any discharge delay.
- 7.1.10 The MAH resettlement co-ordinator has a central role in facilitating meetings and coordinating the information the hospital team need to share with community Trusts and provider organisations. Provider organisations had to develop their own care plans from information shared by the MAH team and the assessment completed by the relevant HSC Trust, whilst getting to know the patient during in-reach. They reported significant weaknesses with this approach.
- 7.1.11 It was generally recognised that it is a complex task to develop care plans for community living based on behaviours and triggers evident in an institutional setting. This highlighted that the community teams should lead the discharge

care planning processes with active collaboration with families and provider organisations which was not always evident in the review.

- 7.1.12 Learning from failed placements and engagement events with provider organisations and with families, highlighted that not all care plans were robust in highlighting the key issues and risks for the individual. Families shared their experience of resettlement placements breaking down within weeks and months of the trial placement with recurring themes; staff not knowledgeable or trained in Positive Behaviour approach, inexperienced staff relying on physical interventions and care plans that did not reflect the level of support that would be required in the community.
- 7.1.13 Families were confused by the process of handover between teams due to a lack of clarity regarding the roles of the community learning disability team, the dedicated resettlement team and the MAH team when a patient is discharged on trial. Families were unclear of the process for standing down the resettlement team and transitioning to the community learning disability team. Some families who had experienced placement breakdown during trial resettlement felt that the process was too focused on the MAH multi-disciplinary team for advice and support rather than involvement and wraparound services from the community learning disability team. Some families expressed the view that their loved family member was returned to MAH at the first challenge when more should have been done to sustain the community placement. There should be a clear process mapped out through the resettlement pathway providing clarity of roles and mapping out indicative timeframes for transitions between teams for patients and families long the resettlement pathway.
- 7.1.14 Care providers reported a negative experience of care planning due to gaps in the information that should have been provided by HSC Trusts. Assessments were stated to be based on the current behaviours in an institutional setting and not on the hopes and dreams that should be central to strength based person centred planning
- 7.1.15 There was insufficient evidence of the learning from things going wrong being used to improve discharge planning regionally and no evidence provided that the learning is shared with care providers. Care providers also highlighted that the focus tends to be on what has gone wrong rather than on what is going right and that the HSC system should collate the learning from successful placements. The review team recommend that HSC Trusts collaborate with key partners to share the learning when things have gone wrong as well as the success factors when resettlement has worked well and celebrate positive resettlement stories.

7.1.16 The review team were tasked to review the care plans for all the service users in MAH and critically analyse the actions taken to identify and commission suitable community placements. The terms of reference asked the review team to look specifically at the MAH population profile by the length of time the person has been in MAH, where they were admitted from and if resettlement has already been trialled. The analysis of the thirty six current in-patients and 4 patients on extended leave is presented in the following charts.



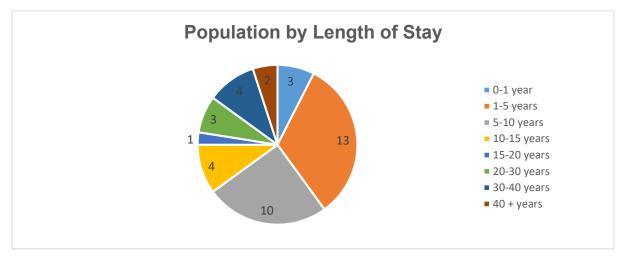


Fig 3

- 7.1.17 The original Patient Target List (PTL) was established to target long-stay patients for resettlement who had been in-patient at MAH for more than one year in 2007. The analysis of length of stay of the current in-patient population identified ten patients from the PTL list who have not been resettled of whom six have been in MAH over thirty years and 2 in MAH over forty years. The range of lengths of stay for the remaining 16 delayed discharge patients not on the PTL list, varies by HSC Trust. SEHSCT range between 2 and 4 years. BHSCT range between 2 and seven years and NHSCT range between 2 and ten years.
- 7.1.18 The hospital has been virtually closed to admissions over the past 2 years however, it is of note that the 3 admissions in the past year were all BHSCT patients. Two of these admissions were from a respite facility managed by BHSCT and one from a facility managed by an independent sector provider. It is clear that HSC Trusts are responding to a higher level of acuity and risk in the community than previously however, further action is needed to embed hospital avoidance measures through community treatment and intensive support to prevent further admissions and adding to the delayed discharge population.

7.1.19 The impact of new admissions on a long stay population is significant due to the challenge of managing very diverse and competing needs. The majority of patients in MAH are NOT on active treatment and should be progressing on a skills development and transitions pathway. Unplanned new admissions have the potential to impact on the opportunities and quality of life for longer stay patients if the focus in the hospital is on managing risk and crisis response. It is critical that community based crisis response and intensive support services are further developed to prevent crisis admissions.

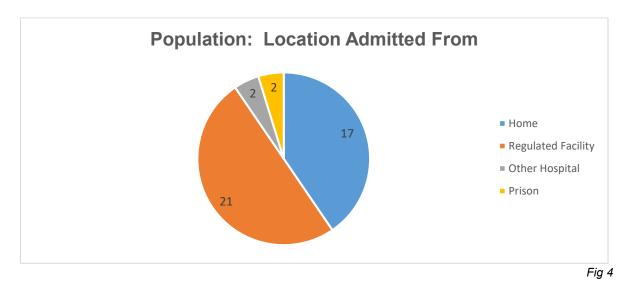


Table1.2 MAH Admitted From

7.1.20 Patients with longer lengths of stay were more likely to have been admitted from home, but those admitted in more recent years were likely to have been admitted from a range of regulated facilities. Two patients transferred from prison and 2 of the MAH patients transitioned from the children's inpatient facility the Iveagh centre. Children & Young People with learning disability were not in scope for this review however, feedback from family carers stressed that a lifecycle approach to planning is essential to effectively project and plan for transitions and that children, young people and their family carers should have a say and input into planning adult services as a key stakeholder. Analysis of the data relating to where patients have been admitted from, highlights that recent admissions have all been from regulated learning disability facilities managed by both statutory and independent sector providers. The review team did not see evidence of the learning from these crisis admissions however, the evidence base and policy/commissioning direction in England and Scotland highlights the need to step up wraparound intensive support services to meet the needs of the individual but also to wraparound the staff teams often struggling to respond.

- 7.1.21The review team had the opportunity to visit people in supported living environments who had previously been transferred to medium secure hospital in the UK and were now successfully returned to their home community. The success factors in sustaining the placement reported by both the Independent sector provider and the Trust was the level of collaboration, responsive and proactive interventions by the Trust Learning disability forensic team. The independent sector care staff talked about the importance of building relationships and trust with statutory colleagues. The Welsh Government's 'Improving Lives Programme (2018) placed particular emphasis on communication and effective working relationships at all levels across the system. The emphasis on these 'softer' skills within the Improving Lives programme of change is significant. The review team received feedback from statutory, independent sector providers and from families highlighting concerns about the lack of openness, trust and respect in relationships. Families reported that lack of continuity of key workers has impacted on developing trusted relationships alongside the fact that their trust in the HSC system has been broken due to the allegations of abuse at MAH. Care Providers and HSC Trusts expressed negative experiences in the contracting and monitoring of services due to a lack of trust.
- 7.1.22 It is critical that community based intensive wraparound services are developed to prevent placement breakdown and prevent hospital admission. However there is also a need to get back to basics and spending time repairing and building relationships which should be informed by the values underpinning the HSC Collective leadership strategy (ctrl click) to ensure effective person centred planning and collaboration with all relevant stakeholders

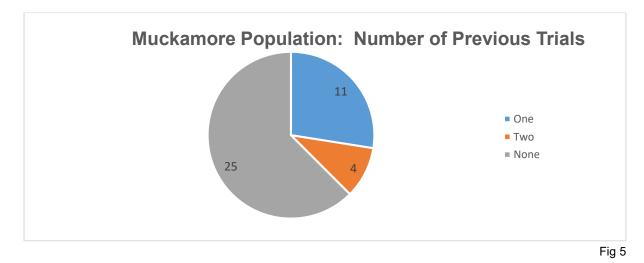


Table 1.3 MAH current population Number of previous trial placements

7.1.23 In regards to previous trial resettlement, the analysis confirmed that all PTL long-stay patients had at least one previous trial placement with one PTL patient

who had been offered 2 placements but would not leave the hospital. A small number of patients who had become institutionalised by having lived most of their adult lives in hospital were distressed by the experience of trial resettlement, which were then unsuccessful. This is a key reminder that whilst we should be ambitious for timely resettlement the primary importance is getting the resettlement right first time in order to prevent further breakdown causing trauma and distress. The majority of patients who have not yet had a previous trial placement are the more recent admissions or the small number of patients subject to a hospital order with restrictions with step down from detention requiring collaboration with the Department of Justice.

- 7.1.24MAH serves 3 HSC Trusts, the BHSCT which manages the hospital, the NHSCT and SEHSCT. The WHSCT has its own Learning Disability in-patient beds at Lakeview Hospital and the SHSCT has its own Learning Disability in-patient beds at Dorsey hospital. There are a few out of area placements. SHSCT has one patient in MAH. NHSCT has one patient in Dorsey and one patient in Lakeview.
- 7.1.25 At commencement of the Review of Resettlement, there was a total of sixty Learning Disability in-patients delayed in discharge regionally; 46 at MAH, 8 in Dorsey Hospital and 8 in Lakeview Hospital.
- 7.1.26 The review team established the baseline MAH Population in June 2021 and updated the population baseline as of 11th July 2022. It is encouraging to note that there have been ten discharges between June 2021 and July 2022 however 3 admissions. The NHSCT had the highest in-patient numbers at commencement of the review however, BHSCT now has the highest number of in-patients.

Trust of Residence	Number of In-Patients
NHSCT	21
BHSCT	16
SEHSCT	8
SHSCT	1
WHSCT	0
Total	46

Table 1.1: Patients by HSC Trust – June 2021

Fig 6

Trust of Residence	Number of In-Patients
NHSCT	14
BHSCT	15
SEHSCT	6
SHSCT	1
WHSCT	0
Total	36

Table 1.2: - Patients by HSC Trust-11th July 2022

- 7.1.27 The review team critically evaluated the progress of resettlement plans as devised by the responsible Trust for each patient in MAH and reviewed all business cases which have been completed or are still in process, to identify any strategic or operational barriers and make recommendations for actions to accelerate the delivery of proposed pipeline schemes. The review team reviewed the data submitted by all 5 Trusts on the monthly tracker to HSCB/SPGG and met with Northern Ireland Housing Executive, Supporting People leads to validate information relating to Supporting People schemes. Through this analysis, the review team identified individuals where plans are absent or weak requiring alternative plans.
- 7.1.28 At the outset, the review team met with the Director and senior management team of each of the 5 HSC Trusts to discuss their approach to discharge planning, to clarify the specific plans in place for each patient and the business cases being progressed directly by the Trust or reliance on schemes being progressed by another HSC Trust. The review team assessed discharge plans against deliverability and timescale for discharge. There were common issues raised by all HSC Trusts with the key challenge to discharge noted as workforce recruitment and capability alongside gaps in the community services infrastructure required to maintain community placements.
- 7.1.29 Tracking resettlement from the 1980's, has seen a clear move over the years from large institutional settings to smaller nursing and residential homes in the community and progression to supported living models based on single tenancy or small number of people sharing
- 7.1.30 The focus currently has moved to new build bespoke schemes that have a minimal design to delivery timeline of between 2 and 5 years which has become a significant delay factor. BHSCT has 3 capital schemes in the pipeline. Minnowburn which was a BHSCT only scheme for 5 patients and the On-Site and Forensic schemes to accommodate patients from all 3 HSC Trusts. The timelines for the new build schemes have drifted and most are still at an early stage of development. The review team view the uncertainty of

Fig 7

projected discharge dates for these capital schemes as unacceptable and highlighted the requirement for alternative options to be pursued.

- 7.1.31 The review team were concerned that robust needs assessments had not been completed for patients identified for the On-Site and Forensic schemes resulting in a lack of clarity about the appropriate service model and whether registration of the On-Site scheme should be for a nursing home or residential facility. Robust Needs assessment should be the basis for any procurement or service development. It was a recurring issue throughout the review that insufficient attention has been given to needs assessment at individual case and population level.
- 7.1.32 The review team obtained information from Supporting People and data from RQIA in regards to regulated nursing and residential schemes which highlighted vacancies in current schemes. Feedback from provider organisations suggests that Trusts have not worked sufficiently with provider organisations to explore how current capacity could be customised to meet need with view to speed of implementation. This requires fresh thinking and imagination based on robust needs assessment. It would appear that the HSC system has become risk averse and focused on bespoke new build schemes.
- 7.1.33 HSC Trusts need to be clear about risk appetite based on robust Assessment of Need/Risk and analysis of what is working for similar needs in the community. Delivering this challenging agenda also requires a corporate and regional approach to ensure the relevant skill set promotes fresh thinking and delivery.
- 7.1.34 HSC Trusts narrative and reporting in relation to resettlement plans was repetitive, providing reassurance rather than assurance based on evidence. Trust Boards should have challenged the timelines presented for resettlement and queried contingency arrangements for expediting earlier discharges. At the commencement of the review, all HSC Trusts reported that discharge plans were in place for the majority of their patients however the review team's analysis identified that most plans were still at scoping stage and therefore lacked the robustness and detail required to establish a reliable trajectory for tracking performance. Delegated Statutory Function reports for all HSC Trusts focused on the lack of community living options, rather than on breach of Human Rights and did not provide the assurance required. There was insufficient challenge by Trust Boards and the HSCB/SPGG.
- 7.1.35 Four discharge placements had already been commissioned and had been available from commencement of the review including 3 planned discharges to Cherryhill (BHSCT Supported living). One of the Cherryhill discharges was delayed due to the wait for minor adaptation work. This matter should have

been escalated for urgent approval through senior management rather than rely on routine processes. Three of the Cherryhill discharges were delayed due to staffing shortfall and requirement to recruit additional staff. In light of the fact that discharge placements for 3 patients were available, there should have been a more strategic approach taken in regards to deployment of the workforce with view to reducing the MAH in-patient population. BHSCT had a strategic focus on the stability of the MAH workforce with daily monitoring and reporting given the reliance on agency staff. This appeared to impact on decision making about using agency staff to transition with the patient until sufficient staff could be recruited and trained. The bigger picture of reducing the population through more flexible utilisation of the workforce to expedite the discharges was raised by the Co-Director but not progressed. The complexity of the logistics associated with workforce allocation cannot be underestimated however, the delay and drift in discharging 3 patients added to the staffing pressures in MAH. Prioritising a consultation with legal services in relation to the fourth patient who had a placement already commissioned by community LD services was agreed but not actioned, resulting in drift. In this specific case, the community HSC Trust and the BHSCT should have been working more collaboratively to an agreed action plan. It was concerning to note the drift in these specific cases despite the opportunities being highlighted to the involved HSC Trusts by the review team. Whilst there are recognised delays associated with new build schemes there should have been more focus on those discharges that could have been expedited more speedily.

- 7.1.36 The review team completed an analysis of resettlement plans, revised the performance tracker tool and provided advice to HSC Trusts on the immediate actions required to accelerate resettlement and strengthen reporting and accountability arrangements.
 - Advice to Trusts to rethink the deliverables to focus on speed of implementation given the unacceptable timelines for new build schemes still at initial development stage
 - Advice to BHSCT to extend the TOR for the On-Site project chaired by Director to include the Forensic scheme given the inter-dependencies for the NHSCT and SEHSCT on both schemes
 - Advice to NHSCT to engage the care provider for the new build scheme Braefields, to agree concurrent admissions rather than the eighteen month phased implementation as planned.
 - Advice to Trusts to review available capacity in the nursing home and residential/ supported living schemes and agree how placements could be tailored to meet need
 - Advice to Trusts to urgently re-assess patients identified for the Forensic scheme and bring forward individual discharge solutions.

- Advice to all Trusts to prioritise the focus on individual cases with an increased potential for early discharge rather than focus on new build schemes.
- 7.1.37 The landscape changed throughout the period of the review, with HSC Trusts revising their plans in recognition of the long lead in time for new build schemes. The review team welcome the fresh thinking and renewed collaboration between the Belfast, South Eastern and Northern Trusts evident from April 2022 resulting in solution focused workshops to address the long standing challenges associated with delayed discharge. Consideration was given to the development of an interim model on the MAH so that patients pending discharge to community placements would be cared for in a social care model as part of transition planning. However, due to the continuing pressure on workforce availability and capability which is evident in MAH, the thinking is rapidly changing with re-focus on building individual placement discharge options rather than on an interim on-site social care solution. The review team completed a stocktake of all plans at commencement and end of the review fieldwork and will present the analysis on progress on a Trust by Trust basis and summarise the projected discharges by end March 2023.
- 7.1.38 The SEHSCT was reliant on the BHSCT and NHSCT new build schemes for 5 of their patients and are now pursuing alternative plans to replace reliance on the forensic and on-site schemes. Discharge plans in development for 4 patients appear to be realistic and deliverable. The Trust plans to discharge 2 patients in August 2022 and a further patient in September 2022. The Trust does not yet have plans in place for their 2 forensic patients but have plans in development for the other patients. The profile of the SEHSCT remaining delayed discharge population highlights very diverse needs ranging from 1 patient who has lived in MAH for 45 years, 1 patient on a Hospital Order with restrictions and 1 young person who transferred from a children's facility.
- 7.1.39 The NHSCT's discharge planning was based on 2 new build schemes and a number of individual bespoke placements. The NHSCT was reliant on the BHSCT delivering the On-Site scheme for 1 patient and the forensic scheme for 1 patient. The NHSCT has robust plans in place for six NHSCT patients to transfer to the Braefields scheme from August 2022 and for 4 patients to transfer to Mallusk new build scheme between August 2022 and March 2023. Two patients have commissioned placements at named schemes with discharge dates agreed by end July 2022. The NHSCT has progressed planning for their patients delayed in discharge across all 3 learning disability hospitals in Northern Ireland and have definite dates agreed for discharge of patients from Dorsey and Lakeview In summary the NHSCT has made

significant progress in developing robust discharge plans with progress hindered by challenge with recruitment to the Mallusk scheme and challenges in the building supply chain that slowed building work moving the handover date of the Braefield scheme from end April to end August 2022.

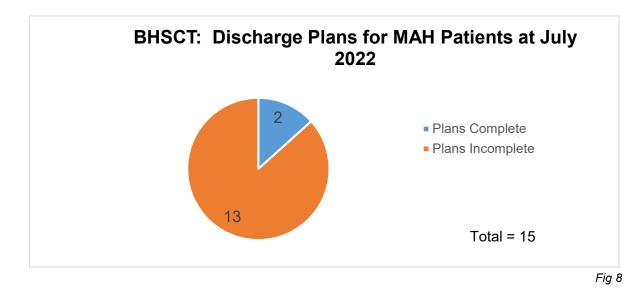
7.2 BHSCT – Regional Role as the Trust Responsible for MAH

- 7.2.1 Reducing the MAH population is a strategic priority and should be a significant measure in providing assurance about safe and effective care in MAH. Reducing the population would defacto reduce workforce challenges and support the remodelling of the hospital site with view to re-establishing patient flow and acute admissions. The Leadership and Governance report (2020) highlighted that the Trust focus on resettlement came at the cost of scrutiny of the Safety and Quality of care of those in-patient. Given that BHSCT has the lead role for the management of MAH as well as the delivery of 2 schemes that other HSC Trusts were co-dependent on, namely the Forensic and On-Site schemes, a review of BHSCT Board agenda and minutes for 1 year, 2020/21 was completed by the review team to identify the level of scrutiny and challenge to address the delayed discharges from MAH.
- 7.2.2 The analysis of Trust Board minutes confirmed that MAH is a substantive standing agenda item at each Trust Board with update report and papers on safety metrics and workforce presented by the MH/LD Director. Updates on the number of patients in MAH are provided however, there was limited scrutiny in regards to the resettlement plans for BHSCT patients or the capital business cases in development.
- 7.2.3 The review team found that the pendulum appears to have swung to a primary focus at Belfast HSC Trust Board on the development of safety metrics and workforce stability with limited challenge to the timelines proposed for resettlement of BHSCT in-patients.
- 7.2.4 The following updates on the MAH population and resettlement plans were provided to Belfast Trust Board by the Director of Mental Health and Learning Disability services.
 - Oct 2020 Director reported 43 patients, 2 on trial and 1 on home leave. Further 5 BHSCT discharges expected to proceed.
 - Dec 2020 Director reported- 47 patients 3 on trial. NHSCT-20, BHSCT-17, SEHCT-8, SHSCT-1, WHSCT-1
 - April 2021- Number of patients noted as 43 2 on trial resettlement and 1 on extended home leave. Expect another 5 discharges of BHSCT patients in the next 6-months by September 2021.

The Executive Director of Social Work reported satisfactory compliance with requirements specified in the Delegated Statutory Functions Scheme of delegation. The DSF report- noted 6 successful discharges and further 5 on trial resettlement with plans in place for a further 16 resettlements. The report noted a lack of community placements for LD impact on delayed discharge.

- Nov 2021- Director for strategic development updated on planning for On-Site business case.4 patients meet criteria. Outline specification drawn up and shared with capital panning team. Design team secured to complete feasibility study of the MAH site. Steering group has held 4 meetings.
- January 2022- Director update- 39 patient- 4 on trial and 1 on extended leave only 2 on active treatment. Chairman sought clarification on timeframe for the On-Site resettlement business case. Director reported that the timeframe for the On-Site scheme was 2024/2025. Further business case to be developed for forensic scheme- Requires identification of appropriate site.
- BHSCT's Delegated Statutory Functions report 2021/22 lacked scrutiny from Trust Board. It is of note that BHSCT reported that resettlement plans were in place for 15 patients and no plan in place for 1 patient.
- 7.2.5 Analysis of the regular updates to Belfast HSC Board and through the Delegated Statutory Function reports in regards to progress on resettlement, highlight the repetitive narrative based on plans in the early stages of development which were not robust enough to provide assurance in regards to projected discharge dates.
- 7.2.6 Whilst the Chairman of the BHSCT sought clarification on timeframe for the On-Site resettlement business case on 1 occasion and Director advised that the timeframe for scheme completion was 2024/2025, this appears to have been accepted rather than discussed or challenged.
- 7.2.7 BHSCT's dedicated resettlement team was funded for 2 community integration co-ordinators and a Social Worker to develop Essential Lifestyle plans. The Social Work post and 1 of the coordinator posts are vacant. A senior manager post established to review SEA's and develop an action plan on the lessons learned is also vacant.
- 7.2.8 BHSC Trust had 16 patients in MAH at commencement of the independent review and still has 15 patients in MAH at 11th July 2022. Our analysis of the current position for BHSCT in regards to revised planning is that BHSCT has robust discharge plans in place for 2 patients to transition to current nursing home and supported living vacancies by September 2022. However, the plans for the remaining 13 patients have not been confirmed in regards to named scheme or estimated discharge date and remain plans in development. There are 3 major challenges for revised plans, Workforce recruitment, re-registration

of schemes and most significantly the time required to engage and gain agreement from family carers. This is a dynamic environment and the summary and trajectory provided by the review team reflects the position at 11th July 2022.

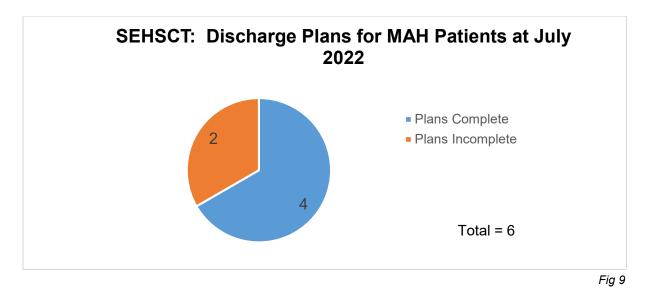


7.2.9 The review team considered in detail how the Trusts developed plans, proposals and accommodation services to meet the aggregated needs of this group as identified through their individual care plans in Chapter 8.

7.3 SEHSCT - Resettlement plans

- 7.3.1 SEHSCT completed a number of capital business cases some years ago significantly reducing the Trust's long-stay in-patient population to eight patients at commencement of the review and 6 in- patients at 11th July 2022.
 - The Trust was reliant on the BHSCT and NHSCT new build schemes for 5 of their patients and The Trust is now pursuing alternative plans to replace reliance on the forensic and on-site schemes. Discharge plans in development for four patients appear to be realistic and deliverable. The Trust plans to discharge two patients in August 2022 and a further patient in September 2022. The Trust does not yet have plans in place for their 2 forensic patients but have plans in development for the other patients. The profile of the SEHSCT remaining delayed discharge population highlights very diverse needs ranging from one patient who has lived in MAH for 45 years, 1 patient on a Hospital Order with restrictions and one young person who transferred from a children's facility.

- SEHSCT has a new build scheme in development in partnership with a care provider but recognised that this will not be a viable option for MAH discharges given the long lead in time
- It is of note that one SEHSCT patient has been on extended home leave with an extended support package from March 2020 with family taking the patient home at the onset of the Covid pandemic. BHSCT also had one patient on extended home leave for similar reasons. An evaluation of how the extended home leave placements have been maintained for this lengthy period without return to MAH should be completed to inform future support models aimed at admission avoidance.
- 7.3.2 The review team have used the Care Quality Commission Brief Guide; definition that a discharge plan needs to have an identified care provider, an address and a discharge date to be agreed as a discharge plan. The review team used this definition to assess the robustness of the SEHSCT updated discharge plans. SEHSCT has a confirmed placement at Mallusk scheme for one patient with discharge expected in August 2022. The Trust has commissioned a nursing home placement for one patient with discharge date in August 2022. SEHSCT expect an additional patient to transfer to a specialist facility in the Republic of Ireland with discharge expected by September 2022. Three of the SEHSCT 6 patients have robust discharge plans and imminent discharge dates. A plan is in development for one patient and 2 patients do not have a robust plan.



7.4 Northern HSC Trust – Resettlement plans

7.4.1 Historically the NHSCT has been reliant on hospital admission resulting in the highest number of patients to resettle regionally. At the outset of the independent review, the NHSCT had nineteen delayed discharge patients in

Muckamore Abbey Hospital, 1 patient delayed in Lakeview Hospital and 1 patient delayed in Dorsey Hospital

7.4.2 The Northern HSC Trust's discharge planning was based on two new build schemes and a number of individual bespoke placements. The Northern HSC Trust was reliant on the Belfast HSC Trust delivering the On-Site scheme for one patient and the forensic scheme for one patient. The NHSCT has robust plans in place for 6 NHSCT patients to transfer to the Braefields scheme from August 2022 and for 4 patients to transfer to Mallusk new build scheme between August 2022 and March 2023. Two patients have commissioned placements at named schemes with discharge dates agreed by end July 2022. The NHSCT has progressed planning for their patients delayed in discharge across all three Learning disability hospitals in Northern Ireland and have definite dates agreed for discharge of their patients from Dorsey and Lakeview Hospitals. In summary the Northern HSC Trust has made significant progress in developing robust discharge plans with progress hindered by challenge with recruitment to the Mallusk scheme and challenges in the building supply chain that slowed building work for the Braefields scheme moving the handover date from end April to end August 2022.

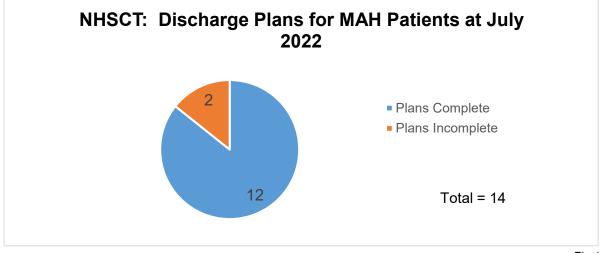


Fig 10

Key findings; the analysis of the review of Individualised care planning has highlighted a number of concerns and themes

- HSC Trusts were not responsive to data requests with responses missing deadlines and monthly performance monitoring templates not being robustly completed with key data missing or not updated.
- The narrative from HSC Trusts was repetitive and had not been sufficiently challenged by HSC Trust Executive teams, Trust Boards or the HSCB/ SPPG resulting in significant delay in identifying and challenging the lack of progress.

- Proposed discharge plans were not assessed against an agreed definition for a discharge plan, namely that a plan requires a confirmed care provider, confirmed scheme address and confirmed estimated discharge date to be agreed as a robust discharge plan.
- HSC Trusts were asked by the review team to validate the data supplied by RQIA and Supporting People and provide additional data on housing with support placements not captured in the NIHE and RQIA data sets. A questionnaire was developed by the review team to collate data from HSC Trusts to establish a regional supply map. The response from HSC Trusts was poor and not reliable. The HSCB/SPGG completed an exercise in 2020 to complete Needs assessment for Housing with Support. The variation regionally in demand reflected the poor quality of the information returned by HSC Trusts based on a range of interpretations of the questions.
- There is a need to get back to basics to ensure effective person centred planning and collaboration with all relevant stakeholders in the development of discharge plans. There appeared to be a lack of dialogue between HSC Trusts and providers to share the lessons learned from failed placements. The learning from trial placement breakdowns should inform discharge planning and will only be achieved through an integrated care approach based on partnership and collaboration.

Recommendations

- SPPG needs to strengthen performance management across the HSC system to move from performance monitoring to active performance management holding HSC Trusts to account.
- SPPG should establish a regional Oversight Board to manage the planned and safe resettlement of those patients not currently under active assessment or treatment
- Consideration needs to be given to building highly specialist community based crisis response support teams to promote admission avoidance.
- A regional positive behaviour framework should be developed with the standard of training for all staff working in learning disability services made explicit in service specifications and procurement.
- Learning disability strategy / service model to be progressed by DoH should incorporate the evidence base for PBS and learning from other UK nations
- HSC Trusts should collaborate with all stakeholders to develop a resettlement pathway and operational procedure.
- HSC Trusts should ensure that the lived experience of the person and their family is effectively represented in care planning processes and the role of

family carers as advocates for their family member is recognised and respected.

HSC Trusts should collaborate to standardise their assessment and discharge planning tools to improve the quality and effectiveness of care plans

8. Operational Delivery of Care and Support

In the previous chapters we have talked about the strategic and commissioning framework for services, and also have considered the importance of good individualised care planning. In this chapter we need to consider the delivery of care and support and the experience of the individuals who have gone through resettlement and their families.

It is worth briefly revisiting what the current mapping of accommodation, care and support services looks like. There are 21 specialist LD nursing homes in NI offering a total of 606 places; there are a total of 48 residential care homes (15 statutory and 33 independent) offering a total of 546 places (123 statutory residential care places and 423 independent residential care places); and there are 149 accommodation based supported living schemes for people with learning disabilities offering a total of 1334 places across Northern Ireland.

8.1 Range of provision available:

8.1.1 There is a really impressive array of different types of homes for people with learning disabilities, and this diversity reflects the heterogeneous nature of the learning disability who will have a wide range of needs and wishes that need to be considered for each individual. This diverse picture also reflects significant variation in the cost of care, again dependent on a range of factors but primarily the needs of the individual and the staffing associated with those needs to ensure a safe and stable quality of care can be routinely delivered. In this context schemes which are designed and very bespoke to the particular needs of an individual will be higher than for those living in group living environments, where there may be 'economy of scale' factors to reduce the care costs. There has to be a recognition that for some individuals living with other people poses too significant a challenge and their needs can only be met in living alone situations, although there is always a need to ensure that these individuals have access to social relationships and community interaction as appropriate. Some providers have moved to try some innovation through congregated settings, but with separate living accommodation.

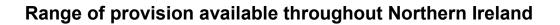




Fig 11

8.1.2 The broad thrust within the Bamford Review had been towards smaller group living options, and away from large congregated community settings. The bar chart below shows the spread of size within accommodation-based supported living schemes funded through Supporting People and HSC funding agreements, and the general trend is in favour of smaller schemes. Whilst this is a welcome change of direction the emerging policy and strategic positions in relation to both learning disability and adult social care within Northern Ireland will need to address the sustainability of funding as demand increases linked to the demographic changes that we can expect for this population.

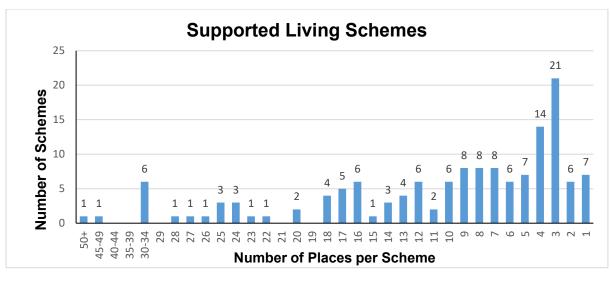


Fig 12

8.1.3 It is also important to recognise that within the independent sector it is highly probable that in the current population of residents and tenants within their settings that there will be individuals with similar needs profiles to those individuals who are awaiting resettlement from hospital. The sector has already demonstrated a readiness to meet the needs of individuals with complex needs often relating to co-morbidity of learning disability and mental health issues along with behaviour that can challenge. We heard several success stories which should be a strong foundation for understanding what works well for this group of especially vulnerable individuals.

8.2 Workforce

- 8.2.1 It is fair to say that across all stakeholders workforce was the single biggest concern, both in terms of the existing and future provision. Providers and NISCC as the regulator of the social care workforce expressed concern about the continuing need to develop a skilled and stable workforce across the sector. The inability to both recruit and retain a social care workforce was a massive risk for the sustainability of the existing provision and the most significant barrier for the proposed new developments. This has seriously hampered progress of several of the resettlement schemes which it is hoped will provide new homes for existing people living in MAH.
- 8.2.2 The models supporting the development of many of the new schemes are psycho-social rather than medical. Therefore the workforce will need to have skills in the delivery of psychological and social interventions, along with an understanding of the need to re-refer to specialist clinical services as and when appropriate. Most providers were now adopting Positive Behaviour Support as central to their service offer, although we heard concerns expressed by the

Royal College of Psychiatrists about the 'fidelity' of this approach which was often variable in both delivery and positive outcomes. There was certainly some anecdotal evidence to suggest that in some settings some of the least qualified and experienced staff were working with some of the clients with most complex needs. This sometimes resulted in poor continuity linked to high turnover of staff.

- 8.2.3 However the workforce issue was also a mixed picture. Some of the more established providers with a longer track record of service provision had better ability to recruit and retain staff, and some of the not for profit organisations had also recruited specialists in psychology or positive behaviour support to provide consultancy and support to their own provision. We also heard some providers describe how they had expanded the skill base within their teams by recruiting professionals from other disciplines such as teaching or youth and community work. Similarly we were impressed that some of the private providers described very stable teams, who were generally recruited from the local community with high rates of retention.
- 8.2.4 We have commented in an earlier section about the issues related to differential rates of pay, and particularly the disparity between statutory and non-statutory services in terms of Agenda for Change profiled pay in services provided by HSC Trusts. Whilst rates of pay are going to vary across the sector there needs to be some discussion within the sector to ensure that this isn't operated in a way that becomes a barrier to stability within the workforce. An integrated workforce strategy that looked at staffing across the whole landscape of learning disability services should be linked to the Learning Disability Strategy and Service Model, and should provide better learning and developmental opportunities as well as supporting greater mobility across sectors and roles. The review team are encouraged that MDAG has oversight of a regional workforce review across adult learning disability teams and services. This review has a wide scope of the learning disability workforce across statutory, private and independent sectors. A multi-disciplinary team has been put in place to undertake this important piece of work which is expected to complete in 2023; a survey has been undertaken to establish the baseline of the current workforce as of 31st March 2022.

8.3 Quality of Care within Services

8.3.1 Given the size and nature of the sector it has to be recognised that quality could be variable. However, there was certainly encouraging signs that would suggest that services were of good quality in many settings. RQIA have a responsibility to inspect registered care settings and in doing so seek the views of residents and staff. Generally in most registered care settings these are positive, with positive comments about compassionate and caring staff in many settings. Whilst it could be argued that these may be more subjective than objective observations, RQIA are working with ARC and PCC through projects like "Tell It Like It Is" to ensure that there are a range of ways of accessing the views of people living within these settings and their families.

8.3.2 The review team were able to visit one particularly innovative example of a bespoke placement for a young man who was living with learning disability and ASD, and who was being supported to live on his own with 24/7 on-site support. He had successfully been transitioned back from a long term specialist placement in another part of the UK. The staff team supporting him were especially attuned to designing support appropriate to his needs and tolerances, as well as addressing the significant risks both within his home setting and when accessing the community.

8.4 **Resettlement Process and Outcomes:**

- 8.4.1 Broadly speaking the resettlement process could be split in to 3 phases (1) pre-placement which included assessment and consultation to identify suitable placement opportunity; (2) transition phase which focuses on the planned move and immediate monitoring and support intensively immediately after placement; and (3) ongoing post placement support, including contingency plan to manage 'crisis'.
- 8.4.2 One area of concern was that the region didn't appear to have developed a regionally agreed resettlement/transitions pathway for people who were transitioning from hospital settings. Several stakeholders raised this as a concern. Families felt that they were insufficiently involved in developing these plans at times of a critical move. We asked the BHSCT as the lead Trust in terms of resettlement to provide us with the resettlement pathway, and after a gap of several weeks they issued us with a 'draft resettlement pathway' which we believe was produced without consultation with other Trusts, families or providers. Whilst it was good to see a willingness to develop an agreed pathway, we would have expected it to have previously been in place and to have gone through a co-production process. Consequently there was a great deal of variability to the quality of pre-placement arrangements and transition plans.
- 8.4.3 There were key issues which an agreed pathway and protocol could have resolved. Central within this would be where the primary responsibility for resettlement lay especially what role the hospital multi-disciplinary team had in relation to the process relative to the role and responsibilities of the receiving/home Trust who would have on-going responsibility for supporting the

placement. We certainly were told of a concern that the hospital teams held an overly prominent level of sway in terms of choice of placement and the parameters of moves, including the extent to which 'leave' was extended for lengthy periods beyond the point where the individual had left the hospital. Several providers commented that the assessment of the client's needs provided by the hospital was sometimes not fit for purpose in terms of how they would devise a plan of care and support appropriate to the new care setting. Often the hospital had limited experience or understanding of how the client might be in other community-based settings. There was a general view that hospital perspectives could be overly risk averse, and rarely acknowledged the significant experience of the more established providers. The review team drew a conclusion that it was imperative that Community Learning Disability Teams/Services of the receiving/home Trust needed to take the lead during the transition phase and to act as an effective bridge between the hospital at the point leading up to discharge and the provider as they accepted the client.

- 8.4.4 Sadly several of the families that were willing to share their experience had gone through a process of placement break down, and we heard some harrowing accounts of how placement disruption was handled. However it is important to note that for many of these individuals and their families the system continued to support them and ultimately they found suitable new homes.
- 8.4.5 In terms of the third phase of post-placement support, again we heard of a very mixed picture from providers. Some providers talked about a lack of clarity between the roles of different teams.
- 8.4.6 Where systems described placements going well there were a number of key features which are worthy of note. The extent to which the 'new' staff supporting the client had an opportunity to begin to establish a working relationship and understand the individual and how best to meet their needs was an important foundation stone. Plans that had considered contingency if things started to go wrong were more robust, and in particular access to additional dedicated support from local Trust services at times when a crisis was emerging was particularly important. There is some variability between HSC Trusts in relation to the extent that they have been able to develop these specialist levels of support, although all are making moves in that direction. One provider described that their ability to support some individuals with very high levels of challenge and potential risk because of the responsiveness of the Trust services when they 'put up the flag'. In this scenario it was the strong and established partnership between the provider and the Trust services – clinical and commissioning – that gave them the resilience to support a number of individuals with the highest levels of need. In this situation there was clear evidence of effective communication, joint working and mutual respect and

support, all of which was focused on keeping the client at the centre of the process.

8.4.7 Whilst in all areas we heard about providers and local commissioners having engagement through contract review processes, there didn't appear to be well established broader engagement across the sector to support more effective partnership working. We felt that at a time when the health and social care system is committed to further development of integrated care systems, that there could be some work done here to support an integrated care pathway for these individuals with significant complexity of need.

8.5 Local Commissioning by HSC Trusts of Accommodation Schemes to address the needs of Individual Resettlement Plans

- 8.5.1 In chapter 7 the review team laid out what we found in relation to the evidence for good individualised care planning and the current level of practice. In order to find accommodation solutions for the individuals awaiting resettlement the Trusts needed at a local level to commission, either singly or jointly, new schemes that could meet the requirements for this clearly identified population.
- 8.5.2 There was distinct variation in relation to how effectively the development of new accommodation schemes was executed by individual Trusts.
- 8.5.3 Positively the NHSCT had worked well with a small number of trusted providers to develop several schemes which then had the potential to accommodate most of their remaining patients from MAH. At the time of the review this had ensured that business cases had been approved for social care and housing funding as appropriate, and the development of these schemes had reached completion of the buildings and were now moving to transition planning contingent on successful recruitment and staffing of the schemes.
- 8.5.4 Historically the NHSCT had historically been reliant on hospital admission resulting in them having the highest number of patients to resettle regionally. At the outset of the independent review, the NHSCT had 19 delayed discharge patients in MAH, 1 patient delayed in Lakeview Hospital and 1 patient delayed in Dorsey Hospital
- 8.5.5 The NHSCT's discharge planning was based on 2 new build schemes and a number of individual bespoke placements. The NHSCT was reliant on the BHSCT delivering the On-Site scheme for 1 patient and the forensic scheme for 1 patient. The NHSCT has robust plans in place for six NHSCT patients to transfer to the Braefields scheme from August 2022 and for 4 patients to transfer to Mallusk new build scheme between August 2022 and March 2023. Two patients have commissioned placements at named schemes with

discharge dates agreed by end July 2022. The NHSCT has progressed planning for their patients delayed in discharge across all 3 learning disability hospitals in Northern Ireland and have definite dates agreed for discharge of patients from Dorsey and Lakeview In summary the NHSCT has made significant progress in developing robust discharge plans with progress hindered by challenge with recruitment to the Mallusk scheme and challenges in the building supply chain that slowed building work moving the handover date of the Braefield scheme from end April to end August 2022.

- 8.5.6 The Mallusk new build scheme was completed 2021 with 2 admissions to date with significant and unacceptable delay in the care provider recruiting sufficient staff to support further admissions to the remaining six places. This scheme will accommodate another 4 NHSCT patients and 1 SEHSCT patient.
- 8.5.7 The Braefields new build scheme for seven places has been developed to accommodate six patients from Muckamore and 1 NHSCT patient in Lakeview hospital. The NHSCT patient in Dorsey. Hospital is in the process of transitioning to a vacancy in a community scheme by end July 2022.
- 8.5.8 The NHSCT plans to discharge twelve MAH patients prior to end March 2023 to named and commissioned placements. These plans are viewed as robust 6 to Braefields, 4 to Mallusk and the other 2 patients to named supported living and nursing home vacancies. The plans for the remaining 2 MAH patients are in development and not yet robust. The review team remain confident that the Mallusk and Braefields schemes will come to completion within the coming 6 9 months, and that this would allow the majority of the NHSCT clients to transition to their new homes. Whilst there had been some slippage in the time scale, their robust plans had supported effective review and senior leaders within the Trust engaged effectively with providers to challenge poor progress against agreed timescales.
- 8.5.9 SEHSCT completed a number of capital business cases some years ago significantly reducing the Trust's long-stay in-patient population to eight patients at commencement of the review and six in- patients at 11th July 2022.
- 8.5.10 The SEHSCT, by working effectively in tandem with the NHSCT had been able to support the delivery of a number of schemes that would offer new homes to their remaining patients/clients. SEHSCT had the smallest number of clients remaining and relied on a mix of engagement with the collaborative inter-Trust schemes, and singleton or bespoke solutions. This allowed them to demonstrate that they had robust plans with a realistic potential of positive outcomes, although again recruitment difficulties for providers tended to be the limiting or constraining factor which delayed delivery.

- 8.5.11 The SEHSCT was reliant on the BHSCT and NHSCT new build schemes for 5 of their patients and are now pursuing alternative plans to replace reliance on the forensic and on-site schemes. Discharge plans in development for 4 patients appear to be realistic and deliverable. The Trust plans to discharge 2 patients in August 2022 and a further patient in September 2022. The Trust does not yet have plans in place for their 2 forensic patients but have plans in development for the other patients. The profile of the SEHSCT remaining delayed discharge population highlights very diverse needs ranging from 1 patient who has lived in MAH for 45 years, 1 patient on a Hospital Order with restrictions and 1 young person who transferred from a children's facility.
- 8.5.12 SEHSCT has a new build scheme in development in partnership with a care provider but recognised that this will not be a viable option for MAH given the long lead in time, and therefore will be likely to meet future emerging need.
- 8.5.13 It is of note that 1 SEHSCT patient has been on extended home leave from MAH with an extended support package since March 2020 with family taking the patient home at the onset of the Covid pandemic. BHSCT also had 1 patient on extended home leave for similar reasons. An evaluation of how the extended home leave placements have been maintained for this lengthy period without return to MAH should be completed to inform future support models aimed at admission avoidance.
- 8.5.14 The Belfast HSC Trust (BHSCT) was an outlier in terms of its ability to successfully progress robust plans to deliver resettlement outcomes for the 15 patients who were their responsibility. However, it is worth making a few contextual comments in relation to the Belfast Trust's system wide responsibility. BHSCT had management responsibility for the provision of the hospital services provided at MAH, which dated back over an extended period of time. This meant that the Director and Co-Director in BHSCT responsible for learning disability services were balancing the ongoing delivery of the MAH hospital services, which faced significant safeguarding and staffing issues following the allegations of abuse, alongside the responsibility to support the resettlement not only of their own clients, but also of the patients in MAH who originated from other Trust areas. It should be noted that the HSCB had funded some additional dedicated staff posts within BHSCT to support the regional resettlement programme(detailed in chapter 7), and that the HSCB had provided substantial additional non-recurrent funding in light of the financial pressures associated with the heavy reliance on agency staffing within MAH staffing levels. The review team acknowledge that this placed the leadership team in BHSCT under considerable pressure, and it is to be regretted that this appears to have hampered their commitment to delivering the overarching resettlement requirements.

- 8.5.15 The BHSCT had through its planning processes proposed that the majority of its clients could be resettled through a number of dedicated new schemes. The primary focus of the new schemes was around 3 groups of patients. The first of these was patients who had been described as having a 'forensic' profile and required specialist provision specific to their needs. The second group was a small number of patients, most of whom had lived in MAH for several decades, and for whom it now appeared there should be a dedicated 'on-site 'provision' that would allow them to remain in situ but within a new or re-purposed accommodation on the hospital site. The third group were 5 patients, all from the BHSCT area, who had been identified for a new provision within the Belfast.
- 8.5.16 To meet the needs of these 3 distinct group of patients within MAH BHSC Trust's resettlement plans centred on 3 new build schemes in development since 2019. The 3 capital build schemes were planned to accommodate ten of the BHSCT patients. One patient for the On-Site scheme, 4 patients for the forensic scheme and 5 patients for the Minnowburn scheme which was a proposed development but not projected to be ready until at least 2025. The review team met with Northern Ireland Housing Executive's Supporting People leads in regards to the planning process for the Belfast Trust's Supporting People schemes in development and the strategic outline case (SOC) submitted for the forensic scheme and the process and timelines for full business case and delivery. Supporting People also provided update on discussions with BHSC Trust in regards to their plans for the Minnowburn proposal. The review team analysed the SOC submitted by the Trust and minutes of the Strategic Advisory Board meetings chaired by NIHE Supporting People Director. The review team noted confusion and drift in the range of schemes submitted by BHSCT as strategic outline cases. The SOC was drafted and submitted by a senior planning manager with extensive experience of previous resettlement schemes. When this manager retired it would appear that both organisational memory and experience were lost when he left, resulting in drift with SOC not progressing to full business cases as agreed.
- 8.5.17 At commencement of the review, the plan for the forensic scheme was a 12 place extension to an existing scheme, Knockcairn/Rusyhill. The original plan was for a twelve placement scheme to accommodate both MAH patients and BHSCT community clients and a strategic outline case (SOC) was submitted to Supporting People. Further analysis concluded that this design would not meet the needs of the remaining forensic population. Supporting People advised the review team that the full business case for the forensic scheme was anticipated in October 2019 but not received- Supporting People also highlighted that no funding from Supporting People has been ring-fenced therefore BHSCT will require to fund both capital and revenue funding.

- 8.5.18 BHSCT then asked a Housing Association to identify a suitable site for a new build scheme. Seven sites were identified however, location of the majority of sites were unsuitable for a forensic scheme due to proximity to high density areas. Preferred sites were identified in both the NHSC Trust and SEHSCT areas with the second confirmed as the most suitable. Given the inter-dependencies of the NHSCT and SEHSCT on this scheme all 3 HSC Trusts should have been collaborating on decision making but this was not the case, and the other Trusts were unaware of these proposals. Given the delays in progressing the business case, the NHSCT and SEHSCT are now scoping alternative individual placements with view to agreeing more timely discharge dates for their forensic patients.
- 8.5.19 The Belfast Trust Co-Director has now advised the Housing Association to take no further action to purchase a site pending further discussion in relation to needs assessment and current demand for a forensic new build scheme. The forensic scheme has been in development since 2019. Priorities have changed over the 3 years the outline case has been in development undermining the planning assumptions underpinning the proposed scheme. The process highlights confusion and drift and illustrates poor planning and delivery.
- 8.5.20 Minnowburn scheme for 5 BHSCT patients. The Minnowburn scheme requires disposal of a current BHSCT property/ site through Public sector trawl with an eight stage process and earliest delivery timeframe 2024/25 Whilst this scheme is in development it will not be ready until at least 2025. Alternative individualised discharge plans are now required given the long lead in time for project delivery.
- 8.5.21 MAH On-Site Provision: The picture in relation to the 'on-site' provision was particularly confused. The DoH had made it clear to Trusts that there should be consideration given to an on-site re-provision for those individuals for whom MAH had effectively been the only home they had known as adults. Whilst the letter from the DoH refers to a small number anticipated to be less than 10, at the point where the review team were considering the revised plans for individuals, only 4 patients had been identified as potentially requiring the onsite facility. The letter was clear that this provision should be separate from the assessment and treatment provision within the hospital. Four long-stay patients met the criteria identified; 1 BHSCT client, 1 NHSCT client and 2 SEHSCT clients. A project team was established chaired by the BHSCT Director and membership included SEHSCT and NHSCT representatives along with other key stakeholders. A design team was appointed to compete a feasibility study. In our meetings with senior staff responsible for learning disability services at the time in BHSCT there was a lack of clarity as to what type of provision was required, in terms of models of nursing provision, or social care and housing.

There seemed to be lengthy delays in establishing the feasibility of re-purposing some of the existing hospital estate and the associated indicative costs. In recent months due to the escalating concerns about the delay in the progression of plans for this provision by BHSCT the 2 other Trusts responsible for 3 of the 4 targeted clients have decided that the proposed on-site provision no longer represents the best option for their individuals and are pursuing other potential solutions. In light of this the BHSCT will need to consider how best to meet the needs of the 1 remaining patient who was in the cohort of 4.

- 8.5.22 Whilst all of these schemes had been in development since 2019 or earlier, at the point of the review in early 2022 none of these schemes had progressed beyond the most preliminary stages and given the dynamic position in terms of changes in the needs of the broader population the rationale underpinning the original cases for the schemes became unsustainable. In reality there were not credible plans in place for delivery of these schemes, and both capital and revenue funding had not been secured.
- 8.5.23 We have previously referenced the significant changes in leadership and planning roles, which was particularly apparent within BHSCT. This meant that there never seemed to be a maintained momentum for delivery of these proposed schemes through a rigorous project management approach. Given these difficulties and delays the projects failed to progress beyond the drawing board stage, and in the most recent discussions the other Trusts have indicated that they are pursuing alternatives to the proposed joint venture for a forensic scheme and on-site provision; they now want to consider separate provision on a smaller scale for their own clients. This has effectively meant that the considerable time and effort expended in the original proposals have not delivered and were ineffective. Additionally, it means that the assurances provided to the BHSC Trust Board regarding the robust plans being in place for the individuals concerned was not underpinned by realistic and deliverable planned schemes.
- 8.5.24However, the recent 'refresh' of the senior operational leadership within the Learning Disability Team at BHSCT has brought some encouraging signs of a new approach. They are urgently reviewing all their plans, in the context of the rapidly changing picture as other Trusts review and accelerate plans for individuals. The additional catalyst for this revised approach and more rapid progress relates to the significant supply and financial pressures that the staffing situation in MAH is creating. In this context the BHSCT has shown a real willingness to look at re-purpose and re-design of some existing provision as an alternative to new build options. This could significantly improve the speed of the resettlement for the BHSCT residents who are patients in MAH, although these proposals are at a very early stage of consideration and have

yet to be tested fully in terms of feasibility, and acceptability to the individuals who will be offered these accommodation options, and their families.

- 8.5.25 Recent contingency planning due to staffing pressures at MAH and request to HSC Trusts to bring forward alternative plans to replace the capital schemes with lengthy and unpredictable delivery dates, has changed the discharge planning position for the 3 HSC Trusts with patients in MAH. BHSCT are responding positively to this new challenge and are scoping discharge options. The Trust has identified supported living schemes in the BHSCT area with under occupancy which may provide viable discharge options. These plans are in an early stage of development but show promise. The Care Quality Commission- Brief Guide; discharge planning from Learning Disability assessment and treatment units (August 2018), highlights that a discharge plan needs to have an identified care provider, an address and a discharge options proposed by all HSC Trusts are robust enough to provide confidence and predictability in regards to timeline for discharge.
- 8.5.26 BHSC Trust had 16 patients in MAH at commencement of the independent review and still has 15 patients in MAH at 11th July 2022. Our analysis of the current position for BHSCT in regards to revised planning is that BHSCT has robust discharge plans in place for 2 patients to transition to current nursing home and supported living vacancies by September 2022. However, the plans for the remaining 13 patients have not been confirmed in regards to named scheme or estimated discharge date and remain plans in development. There are 3 major challenges for revised plans, Workforce recruitment, re-registration of schemes and most significantly the time required to engage and gain agreement from family carers. This is a dynamic environment and the summary and trajectory provided by the review team reflects the position at 11th July 2022.

8.6 Lessons Learnt and Evaluation:

8.6.1 We know that many stakeholders within the overall system are committed to supporting a learning culture, which adopts a 'lessons learnt approach'. Organisations like RQIA have supported the adoption of Quality Improvement [QI] methodologies in supporting providers to promote continuous improvement within their services, and as previously identified the work that RQIA, ARC and the Patient and Client Council are doing within the 'Tell It Like It Is' Project are encouraging. However, we were disappointed that there didn't appear to have been any systematic evaluation of the experience of individuals who had been resettled, both successfully and unsuccessfully. It felt that there were opportunities to undertake some audit activity and also to consider whether

there is scope for pre and post placement Quality of Life measures to be applied so that there is some empirical evidence of the improvement in individual's lives. Although many people told us stories, both good and bad, of the experience of people during the resettlement process we didn't come across any evidence of this being properly documented, and consequently the voices of the people at the centre of this process often went unheard. There is undoubtedly potential for a more formal evaluation of the experience of those who have been resettled contributing to a better understanding of what works well and what doesn't.

8.6.2 On a positive note leaders and citizens across the system talked passionately about the need for better sharing of good practice models, and the need to ensure that the stories about the valued lives of people with learning disability must be communicated through a positive narrative available to the public and society at large in Northern Ireland. This laudable ambition is one that we believe everyone involved in this process would willingly support.

8.7 Recommendations

- The sector should be supported to develop a shared workforce strategy, informed by the consultation being undertaken by the DoH as part of the workforce review, to ensure that it there is a competent and stable workforce to sustain and grow both the sector in terms of size and quality, so that it is responsive to significantly changing demand.
- HSC Trusts should urgently agree a regional pathway to support future resettlement/transition planning for individuals with complex needs.
- HSC Trusts should establish a local forum for engagement with LD providers of registered care and supported living to develop shared learning and promote good practice through a collaborative approach to service improvement.
- There should be an evaluation of the experience of people who have been resettled to understand what has worked well and what needs to change for the better.

9. Safeguarding

In this chapter we will consider the legislation and policy relating to Adult Safeguarding in Northern Ireland, the learning from RQIA inspections, the findings from previous independent investigations of failures in the care provided to vulnerable adults and the views and concerns of family carers and their lived experience relating to safeguarding.

- 9.1 We have talked in previous chapters about the fact that the confidence of family carers in the HSC system's ability to Safeguard and protect people with a learning disability has been impacted significantly due to findings of abuse at MAH. We gathered evidence through our direct engagement with family carers which included family carers whose loved one has already been resettled and living in the community, as well as MAH family carers. All raised safeguarding as a significant concern with the review team. Family carers provided feedback to the review team about the actions they wish to see addressed in regards to their concerns about adult safeguarding and protection and their views and experiences will be explored later in this chapter.
- 9.2 It is important to set the concerns and expectations of family carers and the findings of this review in the context of Adult Safeguarding legislation, policy and practice in Northern Ireland.
- 9.3 A review of Safeguarding policy and practice was not within the scope of this review however, the review team analysed the findings from previous independent investigations of failures in the quality of care provided to vulnerable adults in Northern Ireland to inform our recommendations about individualised care planning and the commissioning and procurement of services to support discharges from Northern Ireland's Learning Disability Hospitals.
- 9.4 The recommendations arising from the 'Home Truths' report on the Commissioner for Older People's investigation into Dunmurry Manor care home (2018) and the CPEA Independent whole systems review into safeguarding at Dunmurry Care Home (2020) have resulted in a draft 'Adult Protection Bill' (July 2021) which will introduce additional protections to strengthen and underpin the adult protection process; provide a legal definition of an 'adult at risk' and in need of protection and define the duties and powers on all statutory, voluntary and independent sector organisations. An Interim Adult Protection Board (IAPB) was established in February 2021. It is clear to the review team that significant steps have been taken by the Department of Health to update legislation and policy in regards to adult safeguarding.in Northern Ireland in response to the learning from failures in care.

- 9.5 The Muckamore Departmental Assurance Group (MDAG) was established to monitor the effectiveness of the HSC system's response to the 2018 independent Serious Adverse Incident (SAI) review into safeguarding at MAH following allegations of physical abuse of patients by staff. The action plan monitored by MDAG, includes an action to complete a review of Adult Safeguarding culture and practices at MAH to inform wider consideration of regional safeguarding policy and procedures taking account of lessons also emerging from the Independent Review into Dunmurry Manor. This action is focused on safeguarding culture at MAH however, our engagement with the wider HSC and care providers highlighted variation both in practice and attitudes cross the Trusts. RQIA inspections of other learning disability hospitals in Northern Ireland also highlight ongoing concern about standards of safeguarding practice.
- 9.6 Current Safeguarding policy and practice is guided by; 'Prevention and Protection in Partnership Policy' (DHSSPS) 2015 and the adult Safeguarding Operational Procedures 'Adults at Risk of Harm and Adults in Need of Protection' (HSCB) 2016. The policy highlights that adult safeguarding arrangements should prevent harm from happening and protect adults at risk. Safeguarding is a continuum from taking steps to prevent harm through to protection highlighting that safeguarding is everyone's business and not just the business of statutory safeguarding teams. The stories shared by family carers later in this chapter and in chapter 10, put the spotlight on psychological and emotional harm and fact that more could have and should have been done to prevent harm.
- 9.7 RQIA carried out a review of safeguarding in Mental Health and Learning Disability hospitals (2013) looking specifically at the effectiveness of safeguarding arrangements. A recommendation from the RQIA review was that the DHSSPS should prioritise the publication of the Adult Safeguarding Policy framework. RQIA published a follow up report, Safeguarding of Children and Vulnerable Adults in MH/LD Hospitals in NI (2015) following inspection in the Southern HSC Trust.
- 9.8 The Bamford Review of Mental Health & Learning Disability recommended a new comprehensive legislative framework for mental capacity legislation and reformed mental health legislation for Northern Ireland. This has been taken forward by the implementation of the Mental Capacity Act (NI) 2016 which has a Rights based approach and brings new safeguards in regards to deprivation of liberty and consent. The Mental Capacity Act (NI) 2016 provides a statutory framework for people who lack capacity to make a decision for themselves and provides a substitute decision making framework. The Act is being implemented in phases. Phase one implemented from December 2019 included provision of Deprivation of Liberty Safeguards (DOLS') and a DOLS Code of Practice. DOH (April 2019) The Mental Capacity Act (NI) 2016 is intended to protect the human rights and interests of the most vulnerable people in society who may be unable to make decisions for themselves and offer enhanced protections to people

lacking capacity. The Act is principles-based and sets out in statute that it must be established that a person lacks capacity before a decision can be taken on their behalf. It emphasises the need to support people to exercise their capacity to make decisions where they can. This legislation will change and shape practice across learning disability services with a focus on Best Interests. Decision making in complex areas such as the use of CCTV will be addressed in more detail later in this chapter.

- 9.9 Whilst progress has been made in regards to legal safeguards for decision making in respect of individuals who lack capacity and in regards to placing adult safeguarding on a statutory footing, incidents highlighting concerns about safeguarding and restrictive practices remain current in practice.
- 9.10 This is evidenced in an RQIA inspection report following an unannounced inspection at Lakeview Learning Disability Hospital between August and September 2021 which identified a number of matters of significant concern in relation to adult safeguarding and incident management. A further inspection was completed in February 2022 which found that progress had been made in a number of areas however, there had been limited progress with regards to adult safeguarding and incident management. The RQIA inspection report noted areas for improvement relating to adult safeguarding including a review of the use of CCTV to support adult safeguarding.
- 9.11 The 'Way to Go' report made a recommendation that In addition to CCTV's safeguarding function as a tool to prevent harm rather than as a means to ensure safe and compassionate care, CCTV should be used proactively to inform training and best practice developments at MAH CCTV needs to be considered This recommendation is included in the MDAG action plan and the BHSCT CCTV policy group continue to engage with stakeholders to reach agreement, on best practice in MAH .The review team were advised that Questionnaires have been issued to family members, carers, patient and staff to seek feedback and engagement around the use of CCTV on site
- 9.12 CCTV was a central issue of concern for MAH families in the context of discharge planning. Some of the MAH family carers stressed the importance of CCTV in providing them with assurance. Families stressed that CCTV has been central to establishing abuse at MAH and that they hold significant concerns about CCTV not being in place in community settings. The review team were advised about one case where this issue created delay in progressing plans for discharge due to the Trust and the family holding differing views of what could be put in place. During engagement events with families, the review team were advised that some families see the need for CCTV as a consequence of their loved one being the subject of abuse at MAH and that maintaining similar monitoring in the community setting is an important bridge for these families. The debate on the use of CCTV between the family and the Trust in one case could be a barrier to discharge with potential to cause delay. CCTV played an important role in

recording potentially abusive behaviour by staff in Dunmurry Manor Care Home, Winterbourne View as well as MAH. The initial concerns were not initiated by CCTV but rather used to explore concerns raised by family which led to the identification of concerns. Given the importance family carers placed on CCTV, the review team reviewed the actions taken by RQIA to address this issue.

- 9.13 RQIA issued Guidance on the use of overt closed circuit televisions (CCTV) for the purpose of surveillance in regulated establishments and agencies (May 2016) The guidance was aimed at assisting registered providers in meeting the best interests of service users when considering the use of overt CCTV systems and reminds them of the requirements of the Data Protection Act 1998 and Article 8 of the European Convention on Human Rights-Right to respect for private and family life. The guidance states that CCTV should not be used in rooms where service users normally receive personal care and that a policy must be in place which outlines the provider's position on the use of CCTV. The RQIA also commissioned Queen's University Belfast to carry out a review of the effectiveness of the use of CCTV in care home settings (January 2020) which was commissioned in response to concerns regarding the quality of care and the potential for abuse in care home settings. The research highlighted that this is a complex ethical matter in the context of existing law and guidance. Expectations on the use of CCTV creates tensions between the needs of residents, family members and those providing care. The review completed on behalf of RQIA concluded that there was insufficient research evidence to support the proposed use of CCTV in care home settings.
- 9.14 Given the importance placed on this issue by some MAH families, the review team recommend further consultation with individuals, family carers and care providers to inform regional policy and practice relating to the use of CCTV in community learning disability accommodation based services.
- 9.15 The review team considered how the feedback provided by families in regards to their concerns about safeguarding should contribute to the discharge planning process and in supporting an individual through the transition process to a home in the community. Family carers were clear in their feedback to the review team that they have an active role in safeguarding by staying observant and alert to concerns and any change in their loved one's presentation. Families advised that they view flexible visiting and having access to the living environment of their loved one as central to building confidence in safeguarding for the family. MAH family carers expressed concern and frustration due to the visiting restrictions required at MAH in response to the Covid pandemic.
- 9.16 The following patient story highlights a family's concern about the care arrangements and impact of the living environment on their son. The family highlighted to the review team that the focus at MAH has been on physical abuse of patients by staff but that in their case their concern is about psychological and emotional abuse.

'Family shared the story of their son who returned to MAH following a traumatic breakdown in trial resettlement placement after six months. His parents advised that they have not been advised to date that their son has been the subject of physical abuse, however, they highlighted that their son has suffered emotional and psychological abuse associated with both his in-patient stay in MAH and in regards to a trial resettlement placement. The family expressed concern about the quality of care in both the community placement and in MAH. Their experience of the community placement which had been a new build resettlement scheme was that it operated as a mini institution rather than to the vision of supported living that they had expected. The family were advised after the decision to end the placement was made by the care provider who did not think their son was compatible with other residents. The family experience of discharge planning and trial resettlement has not been positive and they reflected that the discharge planning was not effective and caused harm to their son due to the care provider not being in a position to meet his needs.

The family advised that since his return to MAH their son has regressed. The family expressed further concern about the impact of the Covid restrictions on visiting and in the reduction of the range of activities available which the family believe is detrimental to preparation for their son leaving MAH. The family talked about their experience of MAH being poor and their confidence in the HSC system significantly impacted.'

9.17 This story about the lived experience of a patient, highlights that transitions between services should be handled smoothly and systematically with attention given to ensuring the person's individual needs are well communicated between services. It also highlights that family carers should be seen as important partners in the care planning approach. The chapter on individualised care planning provides further case examples when communication between services was not as effective as it should have been. For individuals with behaviour that may challenge, it is critical that discharge planning is progressed in line with 'Promoting Quality Care Good Practice Guidance on the Assessment and Management of Risk in Mental Health and Learning Disability services' (2010) with a clear Safety Plan agreed and the family consulted about what is needed to safeguard and protect. The written care plan needs to detail any risks as well as what should happen in a crisis. We give further consideration to good discharge planning in the chapter on individualised care planning, highlighting the need for regional standardisation on the range of assessment and care planning tools used to ensure that individuals are safeguarded. A Person centred safety management plan should be central alongside a functional assessment and essential lifestyle plan and the family fully consulted and engaged in the resettlement planning process. We also highlighted that the risk assessment should be shared with relevant agencies and that the specialist knowledge and communication skills required to care for the individual should be defined and embedded in commissioning specifications and contracts.

- 9.18 Independent sector providers provided feedback to the review team on their experience of the adult safeguarding policy and procedures in practice which highlighted variation across trust areas. Care providers reflected variation in regards to thresholding of safeguarding referrals and variation in the attitude and support from different safeguarding teams. The review team recommend the review of Adult Safeguarding culture MAH is extended across community settings to address the experiences of key stakeholders including families and care providers.
- 9.19 Care providers also raised the use of restraint and the need to ensure appropriate focus on management strategies that enable preparation for discharge to the community. There has been growing recognition of the importance of reducing the need for restraint and restrictive intervention. DoH launched a public consultation on a draft regional policy on the use of restrictive practices in HSC settings in July 2021. It is critical that further review and analysis of incidents across all care providers in learning disability services is progressed to ensure learning and to inform the DoH review. The review team did not see evidence of effective sharing of learning from the analysis of incidents and SAI's with independent sector providers.
- 9.20 Feedback from family carers about safeguarding policy and procedures highlighted concerns that investigations were not progressed in a timely way which causes anxiety for the family. Trusts have highlighted workforce capacity issues. Given the impact of the ongoing PSNI investigation of alleged abuse at MAH and the evidence being provided to the Public Inquiry, more needs to be done to address the impact of delay in safeguarding investigations for families. Engagement with family carers highlighted that their concerns about safeguarding relate to current experience as well as the historic allegations of abuse which are the subject of ongoing police investigation and the focus of the Public Inquiry. It is critical that the experience of individuals and their family carers is heard and addressed.

Recommendations

In summary the conclusions and recommendations from this chapter are

- Further consultation with individuals, family carers and care providers to inform regional policy and practice relating to the use of CCTV in community learning disability accommodation based services.
- Contracts or service specifications for services for people with a learning disability should ensure that safeguarding requirements are adequately highlighted and that arrangements for monitoring are explicit.
- HSC should ensure that capacity in Adult Safeguarding services is maintained to ensure timely investigation and any challenges clearly reported in the Trust Delegated Statutory Function report.

- HSC Trusts should review visiting arrangements for family carers to ensure flexibility and a culture of openness so that families access their loved one's living environment rather that a visiting room.
- HSC Trusts should have arrangements in place to share learning about safeguarding trends and incidents with care providers.

10. Advocacy and Carer Engagement

This section will address the extent to which engagement strategies employed by HSC Trusts and collectively by the HSC system as a whole have been effective in supporting the delivery of the MAH resettlement programme; the extent to which families and patients were engaged in decision- making around resettlement and to what extent Advocacy support was provided.

Sincere thanks are owed to the family carers who engaged with the review team and so generously shared their personal experiences and stories. The families provided the review team with rich information about their lived experience which has shaped the findings for this review.

- 10.1 Participation and engagement with a wide range of stakeholders was central to the review however, the priority for the review team was to hear the voice of people with a learning disability and their family carers who have lived experience of delayed discharge and the resettlement journey. This was achieved in a number of ways;
 - The review team issued a letter to every family with a loved one in MAH extending an invitation to contribute to the review of resettlement. Meetings were held at a neutral venue in the NHSCT, SEHSCT and BHSCT areas to bring families in each HSC Trust area together to hear their individual stories and common experiences.
 - Some families did not wish to attend a public meeting but wished to meet with the review team. This was facilitated by home visits and zoom calls.
 - The review team met with the 2 family carer representatives on the Muckamore Departmental Assurance group.
 - The review team met with families of people who have already been resettled from MAH and whose placements have been successful
 - The review team visited individuals with learning disability resettled in their community placement.
 - > The review team met patients and staff at MAH.
 - The review team met with the Patient Client Council in regards to their role in providing Advocacy and supporting families involved in the MAH Public Inquiry.
 - Meetings were arranged with Voluntary and Independent Care provider organisations who facilitated meetings with families.
 - > Engagement with RQIA to learn about user experience from Inspections

10.2 Engagement strategies employed across the HSC

- 10.2.1 The Health and Personal Social Services (Quality, Improvement and Regulation) Order 2003 (<u>ctrl click</u>) applied a statutory duty of quality on the HSC Boards and Trusts. The 5 key quality themes which remain relevant to this review are:
 - Corporate leadership and accountability of organisations
 - Safe and effective care
 - > Accessible, flexible and responsive services
 - > Promoting, protecting and improving health and social well being
 - Effective communication and information
- 10.2.2 The quality standards launched in 2006 (ctrl click) includes a standard for effective communication and information. HSC organisations are expected to have active participation of service users and carers and the wider public based on openness and honesty and effective listening.
- 10.2.3 The Bamford review recommended independent advocacy highlighting the need to support individuals to express and have their views heard. The principle of involving people in decisions about their care has been embedded in policy for many years. In 2012, the Department for Health and Personal Social Services (DHSSPS) launched a 'Guide for Commissioners- Developing Advocacy services' (ctrl click) introducing principles and standards. The DoH 'Co-Production Guide for Northern Ireland (2018) (ctrl click) recognised that co-production takes time and is a developmental process based on building relationships to support effective partnership working with service users and carers.
- 10.2.4 In the BHSCT's Serious Adverse Incident investigation report, 'A Way to Go', advocacy in MAH was described as 'not as uncomfortably powerful as it should be' and stated 'it is possible that the long association that advocacy services have had with the hospital and the impact of protracted delayed discharges have blunted its core purpose'. The report also acknowledges that 'episodic contact is unhelpful' however, did not address the question of how family members, where they exist, are supported to act as the primary advocate for their loved ones as active partners in their care.
- 10.2.5 There is significant learning from the Scottish Government's approach to citizenship and involvement. 'A stronger Voice' Independent Advocacy for people with Learning Disability 2018 (Scottish Commission for LD) (ctrl click) states that Independent Advocacy can empower people
 - ➤ To be listened to
 - > Understand what is happening and why decisions are made

- > Be involved in decision making processes
- Become more confident and able to self-advocate
- 10.2.6 The review team sought to establish the engagement strategies in place across the HSC system at a population and individual case level. It was evident that all HSC Trusts have a formal infrastructure in place at organisational level to meet their patient and public engagement duty through established committees. This review however, was primarily focused on the experience of individuals and families and the extent to which their voice was heard at individual case level and in influencing the policy and practice in learning disability services.
- 10.2.7 The Muckamore Abbey Assurance Group (MDAG) has 2 family carers as members representing the views of families with lived experience. At Departmental and HSCB/SPPG level there is limited evidence of engagement and involvement of service users and carers in the development of policy, however, ensuring that this is effective and that the experience of individuals is one of being respected and valued is challenging. The Covid pandemic significantly impacted on business as usual, however, there is limited evidence of meaningful engagement with individuals and carers prior to the pandemic or currently in the range of learning disability work streams led by HSCB/SPPG.
- 10.2.8 There is variation in the engagement strategies within learning disability services in each of the HSC Trusts however, all HSC Trusts are continuing to review and improve the arrangements in place.
- 10.2.9 This was evident in BHSCT who have an action plan in place to address the recommendations arising from the 'Review of Leadership and Governance at MAH' (2020) (ctrl click) which includes a 'Communication and Engagement plan' the appointment of an engagement lead for learning disability and a non-Executive Director undertaking a lead for learning disability at Board level and being a visible champion for people with a learning disability and carers. The terms of reference for a range of engagement Forums were shared with the review team. There is a separate forum for MAH families with regular newsletters. The forum for community learning disability has a number of subgroups to engage carers about transitions and accommodation. The BHSCT was the first Trust to establish a Carers Lead post to represent the views of people with lived experience of learning disability however, this post is now vacant. Whilst this is a positive step, further work and time is required to improve the number of families involved and engaged in the learning disability forums. There are only a small number of the MAH families actively involved in the MAH forum which reflects a significant level of disengagement due to

the breach of trust experienced by families following disclosure of abuse at MAH. The review team completed home visits with MAH families who have lost trust in the BHSCT and whose level of anger, pain and ongoing concerns about Safeguarding and Quality of service at MAH, highlight that a trauma informed and reconciliation approach is needed. The review team observed a number of occasions when engagement about a specific issue may have had a better outcome if the engagement and direct discussion with the family had been escalated to Director Level. Two discharge coordinator posts based at MAH had been funded to coordinate discharges across all patients. One of the discharge coordinator posts is now vacant. The resettlement team at MAH has reduced in size over the past year with an additional post-holder who had completed person-centred planning not filled. The NHSCT and SEHSCT lead the discharge planning for their own patients however, central coordination is required to arrange discharge meetings and to ensure that the range of information required from the MAH teams is available. The review team recommend that BHSCT considers the demand and capacity in the MAH resettlement team.

- 10.2.10 The NHSCT have also revised their approach to engagement and invited the review team to a public meeting organised by the Trust to engage their MAH families. A key learning point from this engagement event was the recognition that all of the families who attended in person on the evening had a shared experience of being involved in discharge planning for the new Braefields scheme. The families expressed the view that it is their perception that families have deliberately been kept apart and that the principle of stronger together should be embedded so that families can offer each other mutual support and identify common concerns and themes. This raises the need for the HSC system to recognise and value different forms of advocacy and promote voice to include independent advocacy, self-advocacy, and family advocacy.
- 10.2.11 The NHSCT strengthened their resettlement team recently, appointing a senior manager with oversight responsibility for monitoring progress against resettlement plans. The NHSCT is also in the process of appointing a lead Carers post to work in partnership with the senior management team to influence learning disability policy and service development. The review team met with NHSCT families who had a poor experience of communication however, there was positive feedback from a number of families about the relationship with the Trust's resettlement co-ordinator who has been in post for a lengthy period. The continuity of the relationship was valued by the families and highlights the importance of a key worker role, described to by families as the go to person for families trying to navigate across complex services.

- 10.2.12 SEHSCT has a long established Carers Forum for Learning disability who engage with the Trust in regards to policy and service development but also provide advocacy and representation of the views of people with learning disability and carers. The SEHSCT's in-patient population has reduced to just six patients whose age and range of needs are very diverse. A young person who transitioned a few years ago from a children's in-patient facility, a patient on detention though a Hospital Order with restrictions and an individual in his late 70's who has lived most of his adult life in MAH. The Trust's engagement with the remaining families is though the key worker, as the discharge solutions needed for the remaining patients are bespoke and highly personalised. The Trust had a dedicated post ensuring Essential Lifestyle discharge planning for all SEHSCT MAH patients transitioning to the community over the past years. This post is now vacant. There is evidence that using the tools of essential lifestyle planning is effective in developing a meaningful person-centred discharge plan. The review team recommend that all HSC Trusts embed essential lifestyle planning in the discharge pathway.
- 10.2.13 In summary, it is encouraging to see that the engagement strategies in all of the HSC Trusts have developed, but further time and effort is required to address the hurt and harm experienced by MAH families and to build the relationships and bridges needed to facilitate honest and mature dialogue and co-production. Overall across the HSC system, the voice of carers was not sufficiently evident within the leadership processes and there was limited evidence at all levels of effective co-production with carers.

10.3 The Voice of People in MAH - extent to which families and patients were engaged in decision- making around resettlement

- 10.3.1 Most of the families who attended the engagement meetings had previous experience of a trial resettlement that had broken down and were keen to share their experience of discharge planning and what went wrong.
- 10.3.2 There was not one voice but there were recurring themes from the review team's engagement with MAH families.
 - Lack of trust, anger and families reporting invisibility of LD services
 - Significant Safeguarding concerns
 - Traumatic impact of abuse disclosures given the blind trust families had over many years seeing MAH as safety net
 - > not being involved or respected as expert by experience
 - not being involved in relevant care planning meetings
 - Experience of at least one trial placement breakdown

10.3.3 Some families talked about the culture and attitudes they had experienced over the years with HSC staff trying to 'persuade' them to accept a placement with a number of families referring to passive aggressive through to hostile approaches. Families referred to not being valued or acknowledged as experts by experience.

The following story of a mother's experience highlights the impact of culture and unhelpful communication styles;

10.4 A Mother's Story

- 10.4.1 Shared the story of a trial placement for her son which broke down within months. The family felt that the environment was appropriate however staff were not adequately trained or competent. Mother did not feel listened to or respected as an expert by experience who knew the triggers and warning signs that staff should have been attentive to. Family expressed the view that MAH did not provide enough information about relevant incidents on the care plan
- 10.4.2 When asked what needed to improve, the review team were advised by the family that resettlement needed to be accelerated and the following areas addressed;
 - > Better training for staff and assessment of competencies in key areas.
 - An understanding of trauma and recognition of the experience and impact on families as well as their loved ones.
 - Family carers valued as experts by experience and fully included in all decisions and meetings
 - Better communication Improvement needed to ensure communication is respectful and effective.
 - Possibly some tools like a carers charter; an explicit statement of expectations and principles
- 10.4.4 The review team were advised that the family have experienced a breach of trust and confidence in the Trust and wider HSC system. The feedback provided to the review team confirmed that further work is required to ensure that all families feel effectively engaged in decision-making around resettlement and the monitoring of trial placements.
- 10.4.5 A number of families spoke to the review team about the importance of getting the culture, leadership and model of care right. The stories shared by families demonstrate the need for a tiered advocacy framework so that issues of complexity or dissension can be supported and facilitated more effectively

through independent advocacy. Families also told the review team that they have increasingly escalated to legal advocacy through the courts when the issues are systemic about failure to commission a service rather than about individual care planning.

10.5 Patient Story

- 10.5.1 The family confirmed that significant discharge planning had been progressed prior to the trial resettlement placement and expressed their disappointment and anger that the placement broke down within weeks resulting in their family member being returned to MAH without the family being advised in advance. The family had visited the trial placement daily and witnessed that the care staff were not competent to provide the care required. The family highlighted that the focus should not be on the number of staff required but on the culture, leadership and support the staff receive in addition to training and skills development. The family hold the HSC Trust accountable for commissioning the service and feel that HSC Trusts need to seek assurance that care staff have the appropriate competences.
- 10.5.2 The family believe that timely resettlement is in the best interests of their loved one and are actively involved in the planning for another trial discharge. The learning from the failed trial resettlement for the family was that they should be seen as a member of the multi-disciplinary team and involved in all meetings and decisions about care.

10.6 The Voice of People who have been successfully resettled

10.6.1 The review team met with a number of families whose family member has been resettled for some time. The narrative and experience of discharge planning and transition arrangements between MAH and the community are in stark contrast to the experiences shared by current families. It is of note that resettlement in the 1990's was strategically led and was progressed at scale with families reporting clarity about the process. This is best summarised through the story of a father who was very resistant to resettlement when the process commenced.

10.7 Lessons from what has gone well- A Father's story

10.7.1 The family of this young man were not keen on resettlement as they believed that their son was settled at MAH and that he was safe and secure. They were fearful of the unknown and had no experience or understanding of supported living services. The family advised that discharge was well planned and that

they had been able to consider a number of options. What has worked is that the care provider is open with the family who are made aware if their son's behaviour is changing. The staff identify the triggers that may result in deterioration and discuss with the family. The family advised the review team that their main concern prior to transition was safeguarding in the community. The family view the ability to visit their son flexibly and unannounced in his own home as providing then with real time assurance about his care rather than the formality of appointments. The family advised that the outcomes that demonstrate that resettlement has improved the quality of life for their son are numerous including the level of engagement he enjoys in activities in his own community, the fact that the parent/ child relationship has changed with their son supported to make adult decisions and personal choices about how he wishes to celebrate birthdays and Christmas. The family compared their son's life now to when he was in MAH and advised that he is living a fulfilling life and is central to his care planning. The family's advice in regards to what can be done to expedite or improve resettlement planning was quite simply 'Get it Done'.

10.8 Story of a young man with very complex behavioural needs living in Supported Living

- 10.8.1 The review team met with a young man now supported in a specialist supported living placement in the community having previously experienced admissions to MAH and other specialist in-patient facilities. The sustainability of this placement for a young man with very complex needs and challenging behaviour was stated by the care provider to be down to the partnership working between the care provider and the statutory learning disability team. The care provider uses a Positive behaviour approach with staff trained and competent in the methodology. The care provider highlighted that the responsiveness and wraparound support from the statutory team at times of increased challenge, actively reduces the potential for placement breakdown. The review team spoke to the young man and his care staff directly who described the full and active life the young man experiences and the support he receives to make personal choices. Additional positive outcome has been improvement in the young person's physical health with weight loss through a fun focused activity schedule. It was helpful for the review team to see an example of positive behaviour approach in action. The care staff reported that the model provides them with the support they need and they feel part of a wider specialist team.
- 10.8.2 This young man has needs equivalent too many of the patients in MAH who have been discharge delayed many years and this story is a helpful reminder that supported living models rather than new build bespoke are effective for

individuals whose behaviour can challenge. Voluntary sector care provider organisations stressed to the review team that the primary focus should be on a Positive behaviour approach and a skilled and competent workforce not just on the built environment.

10.9 Extent Advocacy support was provided regarding resettlement

- 10.9.1 The Review of Leadership and Governance at MAH recommended that the BHSCT should review and develop advocacy arrangements at MAH to ensure they are capable of providing a robust challenge function for all patients and support for their relatives and/or carers.
- 10.9.2 BHSCT has recently commissioned an independent review of advocacy services which is due to report by September 2022.
- 10.9.3 There are a number of Advocacy service providers engaging with MAH families. NHSCT commission independent advocacy services from Mencap for their families. SHSCT commission independent advocacy services from Disability Action for their families and Bryson House provides the independent advocacy service for both Belfast and SEHSCT. Families reported confusion about the roles of the various advocates involved, which is heightened when there is more than one advocate involved with the family.
- 10.9.4 The landscape has become more confusing for families with the Patient Client Council (PCC) providing direct advocacy support to MAH families. The review team met with the PCC Chief Executive and senior management team, who advised that PPC had been asked to provide support during the Leadership and Governance review feedback to families. In addition, the PPC provided a report on the engagement with current and former patients, families and carers regarding the terms of reference of the Public Inquiry. The PCC are now acting as the Independent Advocate for the Public Inquiry into MAH. As a result, the PPC has appointed a dedicated worker to build relationships with MAH families. The review team did not see evidence that the impact of the extended role for PCC on the long-standing commissioned independent advocacy services was considered or discussed between the various advocacy providers. Families reported that current arrangements are confusing and reported a lack of clarity about definition of advocacy, lack of clarity about roles and provided examples when an advocate from PCC and Bryson house were working at cross purposes. The situation was resolved but further review is required. The review of advocacy services commissioned by the BHSCT should bring forward recommendations to address the concerns raised by families.

- 10.9.5 Some families welcomed the relationship with the advocate involved with the family but struggled to provide examples when the advocate had made a difference in the resettlement outcome. There was confusion between a befriending and advocacy role with families stressing that it was the relationship they appreciated rather than the challenge function.
- 10.9.6 The following patient and carer story highlight the key issues raised by families in regards to advocacy. The strongest message was that family carers should be the first and primary step in advocating for their loved one.

10.10 Story of Long-Stay patient and experience of Advocacy

- 10.10.1 A mother met with the review team to share the story of her son who has been in-patient at MAH for some time. The story tells of a family who have maintained close contact with their son. The family have dreams for their son to experience community living with enhanced personal choices and less bound by hospital routines. However, a trial resettlement went badly wrong with the police being called by the care provider and their son being traumatically returned to MAH. The family believe the placement broke down because the care staff did not have the competencies to cope with behaviour that challenges. The family did not feel they were involved in care planning and expressed the view that they were advised by professionals rather than consulted.
- 10.10.2 The family talked about their experience with advocacy and felt strongly that the family are the strongest advocates in speaking up for their son. The family expressed confusion as there have been 2 advocates involved with the family and they are unclear about their respective roles. Family did not know why advocates became involved and state their view was not sought on the matter. The family advised that their experience of advocacy has not been positive and referred to the fact that the advocates turn up at meetings but the family were not able to identify when the advocate had made a difference. The family expressed the view that advocates had agreed on occasion to do something but did not follow up. The family felt that they are the only ones in their son's life for the long haul and will continue to speak up for their son. The family do not call themselves advocates but felt they provide a strong voice for their son.
- 10.10.3 The review team have reviewed the Terms of Reference for the comprehensive review of advocacy commissioned by BHSCT. The issues raised by families should be addressed by that review.
- 10.10.4 Other family carers reflected on current concerns about Safeguarding and the Quality of care in MAH. The families acknowledged that the Covid pandemic impacted on routine business but expressed concern that patient activities

being curtailed directly impacted on quality of life and preparing for transition to the community. Families also reported that the visiting restrictions implemented in response to the Covid pandemic raised anxiety about safeguarding arrangements due to visits being electronic or having to prebook visiting with no access to their loved ones ward or living environments. Family carers feel they have an active role in Safeguarding by staying observant and alert to concerns and any change in presentation. Families advised that they view flexible visiting and having access to the living environment of their loved one as central to building confidence in safeguarding for the family

10.10.5 Whilst there is relationship complexity across the wide range of stakeholders involved in the resettlement pathway, there is an urgent need to repair relationships and build trust. Families stressed to the review team that professionals talk about services but for the families it is their lives. The change that families want to see in the culture and attitudes across HSC services does not require radical reorganisation. The HSC Collective Leadership strategy (2017) (ctrl click) describes the values needed to promote shared leadership across boundaries and partnership working between those who work in HSC and the people they serve. Families stressed the need for a return to basics to achieve effective person centred planning and involvement of families in all meetings about care and decisions based on openness and respect. A regional one system approach and effective engagement and partnership working with family carers will be required to ensure the effective delivery of the final stage of the MAH resettlement programme

Recommendations

- HSC organisations need to value different forms of advocacy and promote voice to include independent advocacy, self-advocacy, and family advocacy.
- Family members should be listened to and receive a timely response when they advise things are deteriorating
- Advocacy support should be available and strengthened at all stages of care planning-HSC Trusts must ensure that there is a clear pathway and clarification to explain the role of different advocacy services.
- HSC Trusts should utilise the Lived Experience of families who have supported a family member through successful resettlement to offer peer support to current families
- HSC Trusts should arrange group meetings so that families with loved ones being considered for the same placement can support each other and share experiences
- HSC Trusts should improve communication and engagement with families when placements are at risk of breakdown

- Families should be seen as integral to the care planning and review process and invited to all meetings
- A regional policy on the use of CCTV in learning disability community placements should be co-produced with relevant stakeholders.

11. Conclusions

Conclusions

- 11.1 The review team were determined from the outset of the review to ensure that the experience and voice of those with lived experience and their family carers informed the solutions and actions required to expedite resettlement .The review draws on the experience of people with learning disability who have been successfully resettled and those who have experienced breakdown and returned to MAH. The stories shared with the review team by family carers, brings into stark reality the impact that the allegations of abuse at MAH has had on family carers. In contrast, the stories shared by family members who have experienced successful resettlement, provide evidence of the positive outcomes and improved quality of life their loved ones are now experiencing.
- 11.2 It is important not to underestimate the challenge of planning for the resettlement of the remaining population whose needs are complex. The review team considered the learning from the policy and practice evidence base in relation to resettlement programmes across the UK and Republic of Ireland and a detailed analysis is contained in Chapter 4. Transforming Care for People with Learning Disabilities Next Steps" was published in January 2015 The report identified a significant change in direction in the policy and practice in relation to gatekeeping admission to specialist learning disability settings, alongside dedicated strategies for admission avoidance and more effective discharge planning. Actions that should be considered for Northern Ireland include;
 - providing enhanced vigilance and service coordination for people displaying behaviours which may result in harm or placement breakdown;
 - Establish a Dynamic Support Database to provide focus on individuals at risk of placement breakdown and development of proactive rather than reactive crisis driven response-
 - Implementation of a Positive Behaviour Service framework and provider engagement
 - Effective Assessment tools/ Discharge planning meetings- Complex care co-ordinators to focus on transition plans
 - More detailed tracker tool to support analysis and performance management to create a master database-history of discharges, readmissions and trends.
- 11.3 Feedback from a wide range of stakeholders highlighted the need to refresh the strategic policy and service model for Learning Disability in Northern Ireland.

The above actions should be central to policy development but will require system leadership at all levels across the HSC.

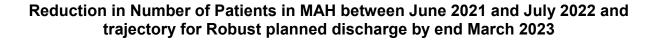
- 11.4 The Learning Disability resettlement programme in the 1990s was successful overall, achieving a significant reduction in the long-stay population. The success factors appear to be that the resettlement programme was strategically and regionally led with ring fenced funding agreed across Department for Communities and the DOH with robust project management monitoring progress against targets. The current resettlement programme would benefit from a similar approach as it is currently a bottom up approach and lacks cohesion and direction. The data provided by the Trusts on progress on resettlement plans was not adequately scrutinised internally in the Trusts or externally by the HSCB/SPPG. The review team advised the HSCB/SPPG officers on actions to establish a more effective tracker tool to improve performance management.
- 11.5 In general we found that across significant elements of the HSC system there was poor management grip in relation to the learning disability agenda and this resulted in a lack of momentum and a sense of inertia and drift. It is critical that a one system approach is developed in Northern Ireland to address the silo working and duplication that remains across the 5 HSC Trusts involved in supporting individuals who are awaiting discharge from learning disability hospitals. The review team were pleased to see improved collaborative working led by the three directors within the past few months to seek solutions to the delayed discharge challenge and agree mutual aid in response to supporting MAH
- 11.6 The importance of and necessity to build trusted relationships was evident at strategic and operational leadership levels but more so in relation to building effective partnership working with individuals and families with lived experience of using services. The review team did not see evidence of effective engagement of people who use learning disability services or their family carers influencing the numerous learning disability work streams established by HSCB/SPPG to contribute to and influence the resettlement agenda. Whilst the review team did see evidence of new initiatives in the BHSCT and NHSCT to build an infrastructure to support engagement with family carers, they do not yet reach the MAH families who have disengaged due to the breach of trust they have experienced. People with a learning disability and their family carers should be respected as experts by experience with Trusts building co-production into all levels across the HSC system.
- 11.7 Family carers raised safeguarding as a significant concern and the review team recommend further engagement with care providers, family carers and Trusts to discuss their expectations and concerns about CCTV.

- 11.8 The area of strategic commissioning also requires a refreshed approach. Strategic commissioning needs to be underpinned by a strong assessment of needs. It was a recurring finding at strategic and operational levels that needs assessment was not robust. The review team identified models of commissioning which could inform improvements in Northern Ireland. "Integrated Commissioning for Better Outcomes" was published in 2018 to support health and social care economies to transform their services through a person centred approach to commissioning which is focussed on the needs of the local area. In Kent and Medway a new governance framework and an oversight board has been established to ensure that partners were accountable for commitments and performance. Accountability needs to be strengthened across HSC in Northern Ireland in regards to performance management against resettlement.
- 11.9 Engagement with independent sector care providers and Supporting People leads highlighted to the review team that knowledge and memory has been lost due to the turn-over in senior leaders most especially in BHSCT. Further work is required to build effective working relationships with key strategic partners to address barriers to resettlement.
- 11.10 The review team sourced data from RQIA and Supporting People in regards to the number of placements and schemes for learning disability and sought additional information from Trusts to form the basis of a supply map as seen in chapter 6. There does not appear to have been any analysis or strategic oversight to inform market shaping and this should be addressed by HSCB/SPPG and Trusts to inform strategic and micro commissioning.
- 11.11 Further development of social care procurement is urgently required and the review team recommends the development of a commissioning collaborative. Training and skills development on commissioning and procurement is required across the system.
- 11.12 The review team reviewed the care planning tools used by Trusts to support discharge planning. There is variation across the Trusts and the review team recommends that work is progressed to develop an over-arching resettlement pathway and standardise assessment tools to ensure that the needs of patients are considered as outlined in chapter 7. The learning from placement breakdowns highlights that discharge plans on occasion have not been sufficiently robust.
- 11.13 The review team scrutinised the current care plans for all the service users in MAH and critically analysed the actions taken by the responsible Trust to identify and commission suitable community placements. The analysis of length

of stay, the location the patient was admitted from and number of previous trial placements is presented in chapter 7.

- 11.14 The review team have assessed the robustness of discharge plans using the Care Quality Commission definition of a plan .Namely there has to be a named provider, address and confirmed discharge date. If this detail is not available the plan is incomplete. It is critical going forward that there is clarity and consistency in Trusts reporting on progress against discharge plans. The review team recognise that there are plans in development for some patients that show promise but in establishing a trajectory the system should only rely on plans that meet the definition outlined.
- 11.15 The South Eastern and Northern Trusts had taken steps some years ago to plan capital schemes that have already delivered or due to be operational in the next months. The BHSCT is an outlier in this regard with three capital business cases still in the early stage of development with the earliest date for completion 2025/26. The NHSCT and SEHST had been co-dependent on two of the three BHSCT schemes namely the forensic and on-site for a small number of their patients but are now pursuing other placements options.
- 11.16 As a result SEHSCT in-patient population at MAH has reduced to 6 patients. Robust plans are in place for 4 patients with no plan yet in place for two forensic patients. Two of the SEHSCT patients will be discharged by end August 2022 and an additional placement by end September 2022.
- 11.17 NHSCT has made good progress in delivering 2 new build schemes. Mallusk and Braefields which is due to complete end August 2022. NHSCT has taken additional steps to commission a number of individual placements in current schemes and plans to discharge 14 NHSCT patients by March 2023 This includes 12 MAH patients and the two NHSCT in out of area placements in Dorsey and Lakeview hospitals. NHSCT has 2 patients in MAH with plans not yet complete. the NHSCT has made significant progress in developing robust discharge plans with progress hindered by challenge with recruitment to the Mallusk scheme and challenges in the building supply chain that slowed building work moving the handover date of the Braefields scheme from end April to end August 2022.
- 11.18 BHSCT has been reliant on the 3 capital business cases providing for 10 BHSCT patients. This includes the Minnowburn scheme for 5 BHSCT patients and the Forensic and On-Site schemes. Given the long lead in time BHSCT is

now seeking alternative options to facilitate a more timely discharge. Whilst the BHSCT has adopted a refreshed approach with view to utilising available voids the plans are not yet complete. As a consequence only 2 of the 15 BHSCT patients have robust plans in place and 13 have plans that are not complete.



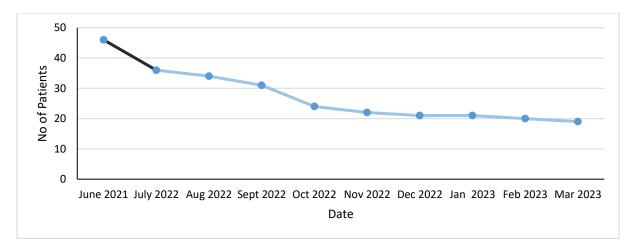


Fig 13

11.19 Fig 13 illustrates the discharge trajectory based on robust plans and robust timeframes. This is a conservative trajectory and the review team have confidence that further individual discharges will be progressed. It is encouraging to note that Trusts have responded to the recent challenge to develop contingency plans and that schemes in planning for some time now have confirmed discharge dates. The MAH population at 11th July 2022 was 36 in-patients, Fig 13 shows that the projected in-patient position by end March 2023 based on completed discharge plans is expected to reduce to 19 patients with potential for further individual discharges. Based on the analysis of the Trusts discharge plans against the Care Quality Commission definition of a discharge plan it is reasonable to assume that a further 17 patients will be discharged by end March 2023.

12. Recommendations

DOH

- The DoH should produce an overarching strategy for the future of services to people with learning disability/ASD and their families, to include a Learning Disability Service Model.
- The Learning Disability sector should be supported to develop a shared workforce strategy, informed by the consultation being undertaken by the DoH as part of the workforce review, to ensure that there is a competent and stable workforce to sustain and grow both the sector in terms of size and quality, so that it is responsive to significantly changing demand.
- People with a learning disability and their family carers should be respected as experts by experience and co-production built into all levels of participation and engagement across the HSC system.
- There should be an evaluation of the experience of people who have been resettled to understand what has worked well and what needs to change for the better and a regional programme to tell the positive stories of those who have moved on, to include audit of proved clinical and quality of life outcomes.

SPPG

- In the context of the overarching strategy the SPPG should develop a commissioning plan for the development of services going forward. This will include the completion of resettlement for the remaining patients awaiting discharge from MAH, and progress the re-shaping of future specialist LD hospital services.
- SPPG should establish a regional Oversight Board to manage the planned and safe resettlement of those patients not currently under active assessment or treatment or deemed multi-disciplinary fit for discharge across all specialist learning disability inpatient settings in Northern Ireland.
- SPPG needs to continue to strengthen performance management across the HSC system to move from performance monitoring to active performance management, and effectively holding HSC Trusts to account.
- SPPG should develop a more detailed tracker tool to create a master database of discharges, readmissions and trends and establish a clear definition of a discharge plan to provide clear projections about the trajectory for discharge and progress over time.

- The Social Care Procurement Board should urgently review the current regional contract for nursing/residential care and develop a separate contract and guidance for specialist learning disability nursing/residential care.
- The SPPG and NIHE/Supporting People should undertake a joint strategic needs assessment for the future accommodation and support needs of people with learning disability/ASD in Northern Ireland.

SPPG and Trusts

- Strategic commissioners within health, care and housing should convene a summit with NIHE, Trusts, Independent Sector representatives, and user/carer representation to review the current resettlement programmes so that there is an agreed refreshed programme and explicit project plan for regional resettlement.
- SPPG and Trusts should develop a database of people displaying behaviours which may result in placement breakdown to provide enhanced vigilance and service coordination ensuring targeted intervention to prevent hospital admission and support regional bed management.

Trusts

- Trust Boards should strengthen oversight and scrutiny of plans relating to resettlement of people with learning disability/ASD in specialist learning disability hospitals.
- A regional positive behaviour support framework should be developed through provider engagement with the standard of training for all staff working in learning disability services made explicit in service specifications and procurement.
- HSC Trusts should collaborate with all stakeholders to urgently agree a regional pathway to support future resettlement/transition planning for individuals with complex needs.
- HSC Trusts should collaborate to standardise their assessment and discharge planning tools to improve the quality and effectiveness of care plans.
- HSC Trusts should ensure that the lived experience of the person and their family is effectively represented in care planning processes and the role of family carers as advocates for their family member is recognised and respected.
- HSC organisations need to value different forms of advocacy and promote voice to include independent advocacy, self-advocacy, and family advocacy at all stages of care planning and develop a clear pathway clarifying the role of different advocacy services.

- HSC Trusts should arrange group meetings so that families with loved ones being considered for the same placement can support each other and share experiences and utilise the Lived Experience of families who have supported a family member through successful resettlement to offer peer support to current families.
- The review team recommends a review of the needs and resettlement plans for all forensic patients delayed in discharge from LD Hospitals.
- HSC Trusts should establish a local forum for engagement with LD providers of registered care and supported living to develop shared learning about safeguarding trends and incidents and promote good practice through a collaborative approach to service improvement.
- Further consultation with individuals, family carers and care providers should be progressed to inform regional policy and practice relating to the use of CCTV in community learning disability accommodation based services.
- HSC Trusts should ensure that capacity in Adult Safeguarding services is maintained to ensure timely investigation and any challenges clearly reported in the Trust Delegated Statutory Function report.
- HSC Trusts should ensure that Contracts or service specifications for services for people with a learning disability have safeguarding requirements adequately highlighted and that arrangements for monitoring are explicit.
- HSC Trusts should review visiting arrangements for family carers to ensure flexibility and a culture of openness so that families access their loved one's living environment rather that a visiting room.

Appendices

Appendix 1: The Review Team

The HSCB appointed a 2 person review team who were required to possess a strong understanding of health and social care policy and practice in Northern Ireland and Great Britain along with extensive experience in leadership roles directly related to health and social care.

The review team comprised:

Bria Mongan

Ian Sutherland

Appendix 2: Biographies

Bria Mongan and Ian Sutherland

Bria Mongan

Bria has significant Executive level experience within Health and Social Care organisations. Bria completed a Masters in Social Work in 1980 and remains registered as a social worker with the NISCC. Bria retired in May 2020 following a forty year career in Health and Social Care services working across all programmes of care. Prior to retirement, Bria was the Executive Director of Social Work and Director of Children's services in South Eastern HSC Trust. Bria previously was the Director of Adult Services and Prison Healthcare and was accountable for leading mental health and learning disability services including leadership in resettlement programmes. Bria is currently an associate with the HSC Leadership centre.

Ian Sutherland

Ian is an experienced leader in health and social care. He is a psychology graduate, who trained as a social worker in Nottingham in 1986, and completed an MSc in Health and Social Services Management at the University of Ulster in 1994. He has worked as a practitioner and senior leader in both Northern Ireland and England, holding three Director posts. His most recent leadership role was as Director of Adults and Children Services in Medway Local Authority, England. In this role he led partnership commissioning between health and social care in relation to delivery of the Better Care Fund objectives. He has served as a Trustee of the Social Care Institute for Excellence, and is currently an associate with the HSC Leadership Centre in Belfast.