



Northern Ireland Audit Office

Resettlement of long-stay patients from learning disability hospitals



REPORT BY THE COMPTROLLER AND AUDITOR GENERAL
7 October 2009



Northern Ireland Audit Office

Report by the Comptroller and Auditor General for Northern Ireland

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Resettlement of long-stay patients from learning disability hospitals

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KJ Donnelly
Comptroller and Auditor General

Northern Ireland Audit Office
7 October 2009

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For further information about the Northern Ireland Audit Office please contact:

Northern Ireland Audit Office
106 University Street
BELFAST
BT7 1EU

Tel: 028 9025 1100
email: info@niauditoffice.gov.uk
website: www.niauditoffice.gov.uk

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Abbreviations

BBC	British Broadcasting Corporation
DHSSPS	Department of Health, Social Services and Public Safety
DRD	Department for Regional Development
DSD	Department for Social Development
EHSSB	Eastern Health and Social Services Board
MHLD	Mental Health and Learning Disability
NIHE	Northern Ireland Housing Executive
OFMDFM	Office of the First Minister and Deputy First Minister
POC	Programme of Care
RPSG	Regional Project Steering Group
RQIA	Regulation and Quality Improvement Authority
UK	United Kingdom

Executive Summary



Executive Summary

Background

1. Around one per cent of the population of Northern Ireland has a learning disability. One quarter of these people have severe or profound learning difficulties and around five per cent suffer with severely challenging behaviour.
2. Prior to the 1970s, people with learning disabilities who could not be cared for at home were placed in institutionalised settings, primarily large hospitals which provided care, protection and segregation. Three learning disability hospitals remain in Northern Ireland: Muckamore Abbey Hospital (Belfast Trust); Longstone Hospital (Southern Trust); and Lakeview Hospital (Western Trust).
3. Attitudes have changed significantly over the years, to the extent where it is now widely recognised that those with learning disabilities have a right to live inclusively and independently within the community. In 1995, a decision was taken by the Department of Health, Social Services and Public Safety (the Department) to resettle all long-stay patients from the three learning disability hospitals in Northern Ireland to accommodation offering a better life for the patient. Resettlement is only pursued where it offers "betterment" for the patient in that it is clinically appropriate, meets the patient's needs, has the potential to better the life of the patient and is in line with the wishes of the patient's family. The decision to resettle all patients within the community has not been universally welcomed. Some of the families of learning disability patients consider that the needs of their relatives are

most appropriately met within the hospital setting.

4. In the 10 year period to 2002, the number of long-stay patients in learning disability hospitals in Northern Ireland fell by almost 50 per cent from 878 to 453. However, in the United Kingdom in 2002, Northern Ireland had the highest proportion of people with learning disabilities resident in long-stay hospitals – 222 beds per million population, compared with 15 beds per million in England and Wales and 163 beds per million in Scotland.

Strategic Development

5. In 1997, the Department set a target that all patients in long-stay learning disability hospitals would be resettled by 2002. However, by that time, only half of patients had been resettled (paragraph 4) and none of the three hospitals had been closed to long-stay patients. In subsequent years, various deadlines have been set and, while we accept that targets can be varied for a number of reasons, in our view the continual revision of time targets has hindered the momentum of the resettlement process. We are pleased to note that the Programme for Government 2008-2011 includes the following clear target:

"By 2013, anyone with a learning disability is promptly and suitably treated in the community and no-one remains unnecessarily in hospital".
6. The Department pointed out that it has set annual resettlement targets and has

exceeded these in recent years. The Department considers that it is making good progress towards the 2013 target.

7. A group was established in 1999 to oversee the resettlement process. However it ceased operating in 2002 pending the outcome of the Bamford Review (see Appendix 1). A further resettlement team was established in 2007, following completion of that Review. In our view, the absence of an oversight group for a five year period suggests a lack of strategic focus and energy. While normal commissioning of services would have continued during this period, we consider that the interests of patients with learning disabilities may not have been championed as effectively as they should have been. However the Department points to the setting of targets and the increased resources allocated year-on-year to resettlement as evidence that momentum has been maintained.
8. In October 2006, the Department advertised what the then Minister of Health considered to be a "crucial" new post - Director of Mental Health and Learning Disability – to take forward the Government's response to Bamford. The recruitment process was unsuccessful. A second recruitment exercise also proved unsuccessful. In May 2007, the Minister announced the setting up of a Mental Health and Learning Disability Board (MHLDB Board) to act as one of the driving forces in delivering the reforms recommended by the Bamford Review. Appointments to the Board were announced in June 2007.

9. It is disappointing to note that the recruitment of a Director of MHLDB, regarded by the Minister as "crucial", was unsuccessful on two occasions and that the favoured alternative, the MHLDB Board, did not meet for the first time until August 2007, 10 months after the Director post was first advertised. However the Department assured us that during this time robust arrangements were in place between it and the Trusts to ensure delivery of the March 2008 resettlement target.

Resourcing

10. Boards and Trusts told us that delays in resettling patients arise primarily because of a lack of sufficient resourcing for alternative forms of provision. Within Northern Ireland, expenditure on learning disability services per head of population has been significantly lower than elsewhere in the United Kingdom and, as a result, progress in resettling patients has been much slower. However, the Department's view is that relative expenditure on learning disability services in Northern Ireland is reflective of the £600 million under-funding of health and social care services when compared with England. We acknowledge that the Department faces real difficulties in meeting current demand for resettlement. However, if the latest target for full resettlement is to be met, learning disability must be given a higher funding priority.
11. In the view of service commissioners, over-emphasis on resettlement, without development of associated care and support services in the community,

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jeopardises the likely success of placements. In extreme cases, this can result in re-admission of learning disability patients to hospital. The Department told us that recent revisions to funding mechanisms will ensure that service commissioners have the appropriate flexibility to decide how best to meet the needs of their patients.

12. Service commissioners are best placed to assess the appropriate balance of funding between the three strands of resettlement, assessment and treatment, and provision of community support, which should be seen as a continuum of care. We welcome the changes introduced to funding mechanisms and share the Department's view that this will help service commissioners to better meet the needs of all learning disability patients.
13. It is clear that significant additional investment will need to be secured to fulfil the policy commitment of full resettlement, to deliver services in line with the Bamford recommendations and to ensure that people with learning disabilities have meaningful choices in where and how they live. It is also important that patients' assessed needs are fully met in their new environment. In recognising that there are limits to available resources we consider it essential that funding strategies should address the three strands of service provision (paragraph 12). We welcome the Department's assurance that its new target to reduce delayed discharge will ensure that a new long-stay population does not develop.

The Long-Stay Population and Options for Resettlement

14. At 31 March 2009, 256¹ patients remained in long-stay hospitals in Northern Ireland. Almost three quarters of these patients have lived in long-stay hospitals for ten years or more. In our view, these patients need to be resettled with the minimum delay as any further extension to their hospital stay may diminish the likely success of their resettlement as dependency on hospital care continues to grow.
15. The Department pointed out that it has set clear targets for resettlement up to 2011. As part of this resettlement programme, all children were resettled by March 2009. The long term target is that by 2013, no-one remains unnecessarily in hospital (see paragraph 5).
16. Of the 200 or so long-stay patients resettled in the six years to March 2009, almost 55 per cent were resettled to either a nursing home or residential home setting. Trusts told us that alternative accommodation options were often very limited and, in view of the level of care required by resettled patients with learning disabilities, transfer to nursing or residential homes sometimes offered the most viable way forward. The Department told us that when targets for resettling long-stay patients from hospitals were first introduced, it was necessary to select people who could appropriately be accommodated in vacant places in nursing and residential homes. As a result, those long-stay patients who required and requested supported living options remained in hospital.

¹ Figures obtained directly from the three learning disability hospitals show that the number of long-stay patients at March 2009 was 264. However the Department does not agree with this figure and told us that the long-stay population at that date was 256.

17. In future, we recommend that resettlement plans not only ensure that the physical care needs of individuals are met but also enhance the level of integration of people with learning disabilities into the community, enabling them to make friends and have access to community services. The development of a wider range of accommodation options, in line with Bamford's recommendations, should facilitate this. The Department told us that it has pursued, and will continue to pursue, its policy of resettlement where it offers "betterment" for patients, in that it meets both their clinical and social needs and is in line with the wishes of the patients' families.
18. The *Supporting People* initiative, which was launched in April 2003 and is funded by the Department for Social Development (DSD), has given Trusts access to funding to increase the independence of people with learning disabilities. While the initiative undoubtedly assists in providing quality resettlement for people with learning disabilities, differences in planning and funding cycles may create difficulties in a number of schemes.
19. A number of proposed schemes do not comply with the recommendations of the Bamford review in that they provide for more than five beds per unit for people under 60 years of age. A decision to fully comply with Bamford recommendations will have cost implications which will have to be weighed up against the wider health benefits. The Department and service commissioners must continue to give full consideration to all factors, not just cost, before taking any decisions. Again the Department told us that the principle of "betterment" for the patient is paramount and it is on this basis that decisions are made.
20. Agreement needs to be reached between the Department, DSD and the Northern Ireland Housing Executive (NIHE) on the standard of accommodation to be provided. Enhanced accommodation may be required to fully meet the needs of learning disability patients. Where this is the case, additional funding would need to be secured before a decision to progress with such schemes could be taken.
21. Bamford also points out that thought must be given to the future needs of those who currently live with their families. He estimates that there could be as many as 1,600 people requiring alternative accommodation in the next 5-10 years, in addition to the hospital population. People with a disability are living longer and have changing needs throughout their lives. These are key considerations for future policy and funding decisions and have been acknowledged as such by the Department.

The Resettlement Experience and Quality of Outcome

22. The Department considers that, with careful and sympathetic management, resettlement can be successful for all patients – regardless of the length of time the individual has spent in hospital. Careful planning is, of course, imperative. Service

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commissioners and Trusts work closely, not only with the patient and their family but also with various government bodies, to ensure the accommodation is suitable, an adequate care package can be provided and access is available to the full range of public services within the community.

23. A review of cases shows the success of resettlements to date. Of the 157 patients resettled in the five year period to March 2008, only two were so unsettled in their new environment that they were returned to hospital.

24. The view that all long-stay patients can be resettled successfully is not shared by all. The Society of Parents and Friends of Muckamore fully supports the resettlement of delayed discharge patients and those long-term patients who want to be resettled. However, it believes that patients with the most complex needs, who receive a high quality of care, should not be resettled into the community where this is against the patients' wishes and the wishes of their families. The Department believes that, with careful funding and planning, it can improve the lives of those who have been in learning disability hospitals for a very long time by enabling them to live in the community. It continues to meet regularly with the Society of Parents and Friends of Muckamore.

25. Patients with the most complex and challenging needs have still to be resettled and community provision for this level of need has not yet been fully tested. We consider that a proactive response to Bamford's recommendations, and

appropriate resources, will be critical in ensuring that any resettlement of the most complex cases is a positive experience for all concerned.

26. The difficulties and risks involved in ensuring quality health and social care services for learning disability patients have been highlighted by a recent review in England. The review identified a number of failings such as poor communication, poor discharge planning and insufficient involvement of family members. It is important that the findings of this review are noted in Northern Ireland and any relevant lessons learned so that learning disability patients resettled in the community, including those with the most complex needs, do not experience similar failings. The Department told us that it takes careful note of all relevant reviews, considers issues raised and determines whether learning can be applied.

Part One: Introduction and Scope



Part of Longstone Hospital

Part One: Introduction and Scope

One per cent of the Northern Ireland population is categorised as having a learning disability

- 1.1 The term '*learning disability*' describes a lifelong condition, arising before the age of 18, which significantly reduces an individual's ability to:
- learn new skills or understand new or complex information (impaired intelligence); and
 - live independently (impaired social functioning).²
- 1.2 Levels of learning disability can vary considerably, from those with mild to those with profound disability. Impairments may be sensory, physical or mental.
- 1.3 In Northern Ireland, an estimated 16,400 people (one per cent of the population) have a learning disability. More than a quarter³ of these people have severe or profound learning difficulties. Approximately five per cent⁴ of people with learning disabilities present severely challenging behaviours.

Care for people with a learning disability is provided in a number of ways

- 1.4 People with a learning disability generally require some degree of direct care or support for most, or all, of their lives. This support is provided either:

- solely by family members;
- by family members with assistance from service commissioners⁵ and Health and Social Care Trusts (Trusts); or
- by specialists employed within the health and social care sector.

Traditionally, institutionalised care for those with learning disabilities has been provided in long-stay hospitals

- 1.5 Prior to the 1970s, people with learning disabilities who could not be cared for at home were placed in institutionalised settings, primarily large hospitals which provided care, protection and segregation. Three learning disability hospitals remain in Northern Ireland: **Muckamore Abbey Hospital** (Belfast Trust); **Longstone Hospital** (Southern Trust); and **Lakeview Hospital** (Western Trust).



Lakeview Hospital

2 *Valuing People: A New Strategy for Learning Disability for the 21st Century*, Department of Health White Paper, March 2001

3 *Administrative Prevalence of Learning Disability in Northern Ireland*, R McConkey, M Spollen, J Jamison, 2003

4 *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*, Quereshi (1994) in Emerson, E., McGil, P., & Mansell, J. (1999), Cheltenham: Stanley Thomas

5 Prior to April 2009, the four Health and Social Services Boards (Boards) were the service commissioners. In April 2009, the Boards were replaced by one Health and Social Care Board for Northern Ireland, supported by five area-based local commissioning groups.

Figure 1: Location of the three Northern Ireland hospitals for people with learning disabilities



In recognition of the need to integrate and include those with learning disabilities in the community, the Department has adopted a policy to resettle all long-stay learning disability patients

1.6 Attitudes to, and services for, people with learning disabilities have changed significantly over the years. Concerns about the appropriateness of long-stay hospitals and the right of patients to live more inclusively and independently have led to a desire, across the United Kingdom (UK), to resettle those with learning disabilities

into the community. Appendix 2 provides details of key commitments across the UK.

1.7 As a result of changing attitudes, the Department of Health, Social Services and Public Safety (the Department) took a decision to resettle all long-stay⁶ learning disability patients into the community. It is important to note, however, that not all stakeholders share the view that those with learning disabilities should live within the community. Some of the families of learning disability patients believe that a long-stay hospital is the most appropriate setting

⁶ "Long-stay" is a technical term used to refer to a very specific group of patients. The definition of long-stay is at paragraph 3.2.

Part One: Introduction and Scope

to meet the very complex needs of their relatives (see paragraph 4.5).

Despite the desire to resettle those with learning disabilities into the community, many still remain in long-stay hospitals

- 1.8 Patients with a learning disability, in any setting, face significant barriers to social and economic participation in the community. Resettlement is intended to promote independence and increase choice, control and inclusion in the community. Despite the desire to provide long-term care for people with a learning disability within the community rather than in hospital, in Northern Ireland at 31 March 2009, 256 learning disability patients remained in long-stay hospitals. Around two-thirds of these were in Muckamore Abbey Hospital. The majority of these patients were less than 60 years old but there was no-one under the age of 16 years (see paragraph 3.3).
- 1.9 Progress in England, Scotland and Wales appears to have been timelier, with most long-term learning disability patients no longer in long-stay hospitals. In the 10 year period to 2002, the number of long-stay patients in learning disability hospitals in Northern Ireland fell by almost 50 per cent from 878 to 453. However, in the UK in 2002, Northern Ireland had the highest proportion of people with learning disabilities resident in long-stay hospitals – 222 beds per million population, compared with 15 beds per million in England and Wales and 163 beds per million in Scotland.⁷ In 2002, the

Department initiated a major, wide-ranging and independent review of the law, policy and provision affecting people with mental health needs or a learning disability in Northern Ireland, known as the Bamford Review (see Appendix 1). This followed similar exercises in England and Scotland.

- 1.10 The Department told us that, in England, patients were not resettled directly from hospital to the type of accommodation recommended by Bamford. Long-stay hospitals in England were replaced by NHS campuses. These are operated by NHS Trusts and comprise housing, some of which is clustered on one site, with some shared central facilities. Those moved from hospitals to campuses rather than into the community were generally those who had other conditions aside from their learning difficulty, such as a mental health problem or a physical disability. Campus accommodation has been found to lack adequate facilities and practices that cater for the health problems that are common in people with learning disabilities. This was one of the fundamental reasons behind the goal to close all NHS campuses by 2010. In addition, in England patients were also transferred to private learning disability hospitals, the growth of which can be tracked from the time statutory hospitals started discharging patients. There are still some patients in these private hospitals.

There have been obstacles to the timely resettlement of learning disability patients

- 1.11 The slower progress in resettling patients in Northern Ireland has been due partly

⁷ *The Bamford Review of Mental Health and Learning Disability (Northern Ireland)*, series of reports June 2005 to August 2007

to limited resources but also a shortage of suitable alternatives in the community, which require input from the Department for Social Development (DSD) and the Department for Regional Development (DRD) in relation to housing and transport. In addition, there has been resistance to resettlement from a significant number of patients' carers and relatives. The Department pointed out that the resettlement process is, to an extent, complicated by the need to compassionately address the concerns of those within pressure groups such as "The Society of Parents and Friends of Muckamore Abbey Hospital" (Friends of Muckamore), many of whom believe that the needs of their relatives are best met within a hospital setting (see paragraphs 4.5 to 4.10).

1.12 Resettlement requires a lengthy lead-in time to ensure:

- appropriate placement;
- provision of required community support services;
- construction of accommodation;
- full involvement of patients and their families; and
- compatibility of patients within the group.

1.13 A number of key criteria⁸ must be fulfilled before resettlement can be finalised. More specifically:

- no patient should be resettled until the services necessary to meet their assessed needs are in place in the community;
- all aspects of the process must respect the human rights and needs of individual patients;
- any change in service provision should result in betterment for patients;
- patients and their families should be fully involved in decisions; and
- patients should have the necessary support to enable them to express their views.

Delaying discharge from long-stay hospitals can have serious consequences

1.14 The potential consequences of delayed discharge can include:

- causing unnecessary stress, boredom and anxiety to patients;
- increasing the risk of serious incidents and aggression on wards; and
- reducing the likelihood that the patient will cope post-discharge.

Following a 1995 decision to resettle all long-stay patients from the three learning disability hospitals in Northern Ireland, progress has been slow. None of the three hospitals is now likely to be closed to long-stay patients before 2013. The

Part One: Introduction and Scope

annual cost of running the three hospitals is around £40 million (2007-08 figures). The Department has pointed out that this includes the costs of providing other services such as specialist assessment and treatment. It has also pointed out that the costs of resettlement will be partially offset by the costs of maintaining patients in long-stay hospitals. Further, the intention is not to close the facilities as they serve purposes other than long-stay accommodation.

The consequences of not resettling patients have been highlighted in the media and recognised by the Department as a failing

1.15 Perceived failings by the Department and the Eastern Health and Social Services Board (EHSSB) to execute the timely discharge of long-stay patients from Muckamore Abbey Hospital to the community were reported in the media in early 2007. BBC Northern Ireland ran a series of related news items which focused on delays in the discharge of over 100 adults from Muckamore Abbey Hospital. In particular, reference was made to the case of a man who had been ready to leave hospital for ten years.

1.16 The media reports identified a significant reason for continued hospitalisation as being a lack of funding for appropriate community care. They also highlighted a related problem – because of the amalgamation of patients from both locked and unlocked wards, it was reported that around 20 adults awaiting discharge had been locked up, even though they had never been assessed as needing secure

accommodation.

1.17 The Department recognised that this was a failing and that the resettlement programme needed “new attention”. In January 2007, an action plan was announced to address the issues involved, including:

- no learning disability patient to stay in hospital for longer than 12 months depending on the level of treatment and assessment they need; and
- by 2014, no learning disability patient to have a hospital as a permanent address.

Since January 2007, a number of targets have been developed, for both adults and children, to drive forward the resettlement programme. These include the Programme for Government target that, by 2013, anyone with a mental health problem or learning disability is promptly and suitably treated in the community and no-one remains unnecessarily in hospital.

This review examines the progress made in resettling patients, accommodation options available and the impact of resettlement on patients

1.18 We examined the Department’s management of the resettlement process. We reviewed:

- the strategic commitment to resettlement and the adequacy of funding (Part 2);
- the extent to which the resettlement needs of long-stay patients are

being met through the provision of appropriate resettlement options (Part 3); and

- the experiences of those resettled and the quality of the outcome (Part 4).

1.19 To assist the study, we obtained expert advice and comment from Dr Owen Barr, Head of School of Nursing, University of Ulster.

Part Two:
Strategic Developments and Funding



Part Two: Strategic Developments and Funding

In Northern Ireland, service commissioners have adopted a three-stranded approach to the resettlement of long-stay patients

2.1 In Northern Ireland, the intention to resettle people with learning disabilities into the community dates from a 1995 policy review⁹. Responsibility for achieving full resettlement falls to the service commissioners (see footnote 5) and Trusts, working in conjunction with the Department, DSD and DRD. Commissioners have adopted a three-stranded approach¹⁰ to future care and treatment of learning disability patients, as follows:

- resettlement from specialist hospitals into the community;
- provision of short-term assessment/treatment facilities at each of the existing three hospital sites; and
- development of community facilities, both to support those resettled thereby preventing re-admissions, and to support learning disability patients already living in the community so that they do not require admission and become a new long-stay population.

Various target dates have been set for full resettlement of long-stay patients but this has led to uncertainty over when the objective will be achieved

2.2 The initial time target for resettling long-stay hospital patients with learning disabilities was set out by the Department in 1997

but has been subject to several subsequent changes (see Figure 2).

2.3 During this same period, the Department set an annual target¹¹ for the number of learning disability patients to be resettled:

- 2001 - 02 – 35 people to be resettled
- 2002-03 – no specified number for resettlement
- 2003-04 – minimum of 50 people to be resettled
- 2004-05 – minimum of 50 people to be resettled
- 2006-07 – no specified number for resettlement
- 2007-08 – 40 people to be resettled
- 2008-09 – 60 patients to be resettled compared to the March 2006 total (and a further 60 by March 2011).

2.4 We note the early progress to 2002, which saw the number of long-stay patients in learning disability hospitals fall almost 50 per cent (see paragraph 1.9) and consider it commendable that the Department has continued to set annual resettlement targets. However, it is clear that even with these achievements, the planned numbers for resettlement have not been sufficiently challenging to meet the desired time targets. The Department points out that it is not targets themselves that dictate whether resettlement is achieved

⁹ *Review of Policy for People with a Learning Disability*, DHSS, 1995

¹⁰ *A Model of Community Based Services for People with Learning Disabilities*, Eastern Board, September 1996
Promoting Ability, Northern Board, October 1998
Strategic Review of Services for People with Learning Disability, Southern Board, June 2000
A Strategy for Learning Disability, Western Board, 1996

¹¹ Targets were published in the annual strategic planning document *Priorities for Action*. Appendix 3 provides details of specific commitments on learning disability.

Figure 2: Time Targets for Resettlement

Policy Statement	Time Target
<i>Regional Strategy for Health and Wellbeing 1997-2002</i>	By 2002, all remaining long-stay patients to be resettled
<i>A Healthier Future; A Twenty Year Vision for Health and Wellbeing in Northern Ireland 2005-2025 (DHSSPS, 2004)</i>	By June 2010, all people with a learning disability living in long-stay hospitals should be able to relocate to appropriate and supportive community accommodation, with the option of holding their own tenancy
<i>Action plan for Discharge of Patients from Learning Disability Hospitals, DHSSPS, January 2007</i>	By 2014, no learning disability patient will have a hospital as a permanent address
<i>Programme for Government 2008-11, OFMDFM, January 2008</i>	By 2013, anyone with a learning disability should be promptly treated in the community and no-one should remain unnecessarily in hospital
<i>Priorities for Action, DHSSPS, April 2008</i>	By March 2009, Trusts should ensure that all children are resettled from hospital to appropriate places in the community

and it would be premature to suggest that the 2013 target will not be met or is not sufficiently challenging, considering that interim resettlement targets have in recent years been surpassed.

- 2.5 The latest Programme for Government¹² sets a target that, by 2013, anyone with a learning disability should be promptly treated in the community and no-one should remain unnecessarily in hospital. In June 2008, the Department issued a consultation document on how it intends to deliver the vision of the Bamford Review. This replicated the latest Programme for Government target.

2.6 While we accept that targets can be varied for a number of reasons, in our view the continual revision of time targets has hindered the momentum of the resettlement process. We are pleased to note that the Department has now set a clear target date of 2013 for the resettlement of people with learning disabilities.

2.7 If this target is to be achieved, it must be supported by a realistic action plan and related funding which address the three-stranded approach outlined at paragraph 2.1. Any subsequent changes to the target must be clearly documented and published together with an acknowledgement and explanation of the failure to achieve resettlement within proposed timescales.

12 *Programme for Government 2008-11*, OFMDFM, January 2008. The Programme for Government highlights the key goals and actions the Northern Ireland Executive will take to drive forward its priority areas. One of these is to promote tolerance, inclusion and health and well-being.

Part Two: Strategic Developments and Funding

Oversight and direction of resettlement has largely emanated from the Regional Project Steering Group and latterly from the Bamford Review

2.8 In 1999, the Department established a Regional Project Steering Group (RPSG) to provide direction and oversee the resettlement process. The Group contained representatives from the Department, the four Boards, and the North and West Belfast Trust¹³ - which had responsibility for the management of Muckamore Abbey Hospital - and operated until the Department commissioned the Bamford review in 2002 (see paragraph 1.9). During this period, resettlement was planned on a ward-by-ward basis so that monies could be released into community provision following ward closure. Two wards were successfully closed but, due to competing calls on available resources, these efforts were not sustainable. In 2007, as part of the Health Minister's action plan (see paragraph 1.17), the Department formed another group, the Regional Resettlement Team, with responsibility for overseeing the discharge of long-stay patients from learning disability hospitals across Northern Ireland. This Team represents all major stakeholders including service commissioners, Trust and hospital staff, representatives from DSD, the NIHE, the voluntary and community sectors and the Friends of Muckamore (see paragraph 4.6).

2.9 Bamford's report on learning disability¹⁴ was published in 2005. It noted major changes in service provision over the previous 20 years, such as a considerable reduction in the size of the three learning disability hospitals, a growth in the

provision of alternative accommodation and the availability of a wider range of day centres. It concluded, however, that the failure to fully achieve the aspirations of the 1995 policy review was due to:

- the absence of sufficient resources to build the required community infrastructure;
- the lack of robust implementation arrangements which hold departments and agencies accountable for their actions;
- a misplaced belief that learning disability needs can only be met by the health and social services sector; and
- a failure to fully involve patients and carers in service development and provision.

2.10 Bamford identified 12 core objectives and made 74 recommendations for improving the lives of people with a learning disability. These included two core objectives and ten recommendations in relation to resettlement. These are summarised at Appendix 4.

2.11 In October 2006, the Department advertised what the then Minister considered to be a "crucial" new post - Director of Mental Health and Learning Disability - to take forward the Government's response to Bamford. The recruitment process was unsuccessful. A second recruitment exercise also proved unsuccessful. In May 2007, the Minister announced the setting up of a Mental

13 The North and West Belfast Trust is now subsumed within the new Belfast Trust

14 *Equal Lives Learning Disability Report*, Bamford Review of Mental Health and Learning Disability, September 2005. This was one of a series of reports, the final one being published in August 2007.

Health and Learning Disability Board (MHLD Board) to act as one of the driving forces in delivering the reforms recommended by the Bamford Review. In June 2007, the Department appointed a panel of experts to serve on the MHLD Board, providing advice on, and challenge to, the implementation of the Bamford recommendations. The Board met for the first time in August 2007.

- 2.12 In October 2007, two years after publication of Bamford's Equal Lives report, the Health Minister said *"It is widely recognised that mental health (and learning disability) has for too long been the Cinderella service within health. I fully accept all the recommendations from Bamford and am committed to their full and effective implementation. I will be working with my Executive colleagues to ensure that mental health (and learning disability) provision is given the attention and finance that it clearly requires and deserves."*
- 2.13 The Government's formal response to Bamford required input from a range of departments. In its Priorities for Action 2006-08, the Department said its response, including an action plan, would be in place by the end of 2006-07. This was not achieved. A revised date of July 2007 was announced but again this could not be achieved as the Bamford Review was not completed until August 2007.
- 2.14 In June 2008, the Department issued its consultative document, *Delivering the Bamford Vision*. A series of public consultation meetings was held before the consultation period closed in October

2008. The Department told us that, subject to Executive approval being given in autumn 2009, a cross-departmental action plan will be published in late 2009. Implementation of the action plan will be taken forward by a Health and Social Care Task Force led by the Health and Social Care Board.

2.15 The RPSG, established in 1999 (see paragraph 2.8), ceased operating in 2002 pending the outcome of the Bamford Review. A further resettlement team was established in 2007, following completion of the Bamford Review. In our view, the absence of an oversight group for a five year period suggests a lack of strategic focus and energy. While normal commissioning of services would have continued during this period, we are concerned that the interests of patients with learning disabilities may not have been championed as effectively as they should have been. The Department points to the setting of targets and increased resources allocated year-on-year to resettlement as evidence that momentum has been maintained.

2.16 It is also disappointing to note that the recruitment of a Director of MHLD, regarded by the Minister as "crucial", was unsuccessful on two occasions and that the favoured alternative, the MHLD Board, did not meet for the first time until August 2007, 10 months after the Director post was first advertised. The Department told us that appointments to the Board were announced in June 2007 and assured us that, during this time, robust arrangements were in place between it

Part Two: Strategic Developments and Funding

and the Trusts to ensure delivery of the March 2008 resettlement target.

- 2.17 Bamford's Equal Lives Learning Disability report was published in 2005. The final report of the Bamford review was published in August 2007. The Department told us that the Executive plans to publish its cross-departmental action plan for the period 2009-2011 in late 2009. In our view, the formal response and action plan must be issued as a matter of urgency.

Boards told us that, in their view, limited resources constrained full resettlement

- 2.18 Successful implementation of a policy requires strategic commitment and adequate resourcing. We noted from our discussions with Boards and Trusts, and review of Board minutes, that limited resources was considered by them to be one of the main constraints to the full resettlement of people with learning disabilities. The Department considers that the views we identified from interviews and review of Board papers are those of individual Board members and are not necessarily the official view of each Board.
- 2.19 Members of one Board said that the resettlement process needed the same level of attention that was given to reducing hospital waiting lists. They said that resettlement had not been receiving the resources and recognition it deserved, and identified a need for *"committed year-on-year funding to win the confidence of partners in jointly-planned housing*

schemes".¹⁵ In response the Department told us that, from 2008-09, it is providing three-year allocations which identify:

- available resources;
- areas to which resources are to be targeted; and
- expected outcomes.

- 2.20 In response to media publicity surrounding resettlement issues at Muckamore Abbey Hospital, another Board reported that in its view resourcing had been *"piecemeal"* and that there had been *"no truly decisive policy initiative"* to deal with the problem.¹⁶

Progress on resettlement in Northern Ireland has been considerably slower than elsewhere in the United Kingdom. This is due, at least in part, to the limited resourcing in Northern Ireland

- 2.21 In 2005¹⁷, it was identified that Northern Ireland expenditure on learning disability per head of population was significantly lower, at £89, than expenditure in other areas of the United Kingdom. Comparative figures for England, Scotland and Wales were £107, £95 and £119 respectively. In overall terms, given the per capita difference and differing levels of need, expenditure on learning disability in Northern Ireland was 79 per cent less than levels in England. The Department told us that relative expenditure on learning disability services in Northern Ireland is reflective of the extent to which health and social care services are underfunded

15 Board minutes, Eastern Health and Social Services Board, 11th January 2007

16 Board minutes and attached update paper on the situation at Muckamore, Northern Health and Social Services Board, February 2007

17 *Independent Review of Health and Social Care Services in Northern Ireland*, Professor John Appleby, August 2005

compared with England. It has calculated that, based on the needs of the Northern Ireland population compared with England, health and social care here will be underfunded by £600 million by 2011.

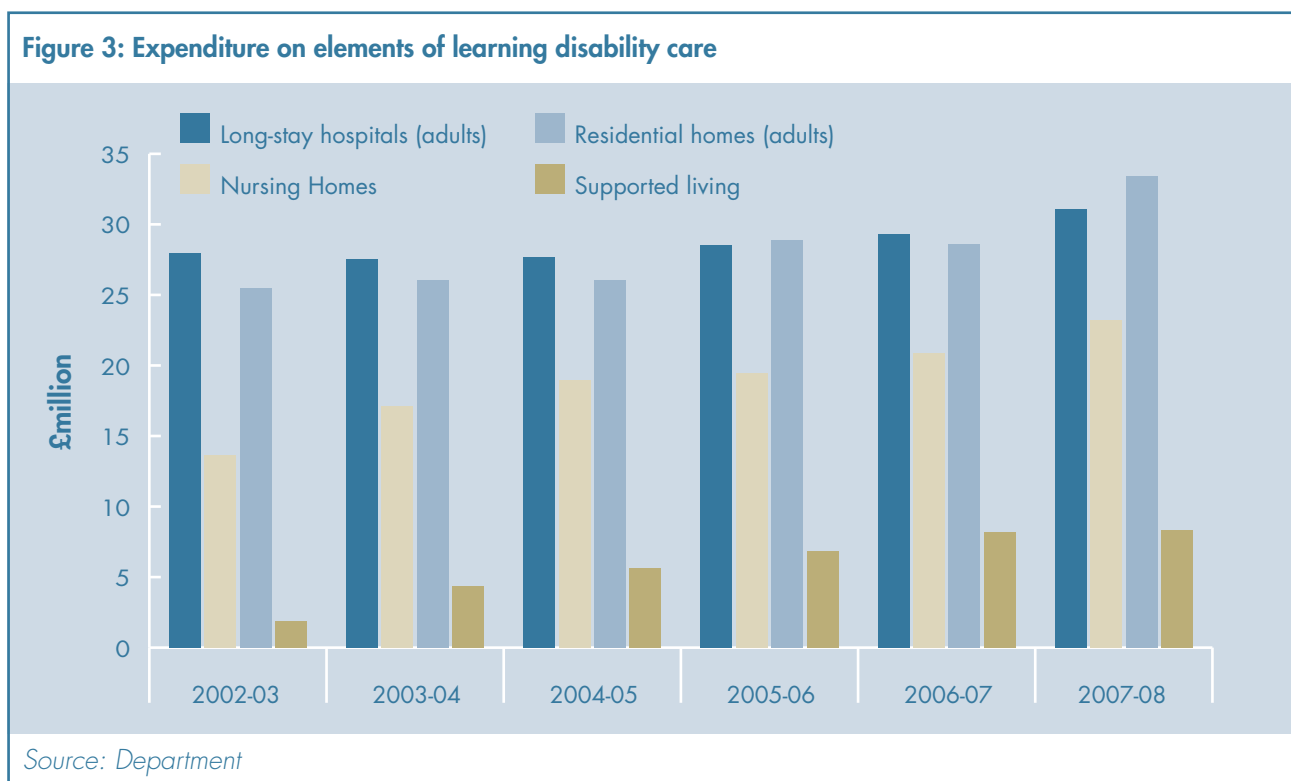
Expenditure on learning disability has risen significantly in recent years but when expressed as a percentage of expenditure on all programmes of care, it has remained constant

2.22 Total expenditure by the Department on the learning disability Programme of Care¹⁸ has increased in recent years from just over £136 million in 2002-03 to just over £200 million in 2007-08, a rise of

47 per cent. However expenditure on learning disability as a percentage of total expenditure on all programmes of care has remained constant at around 7.5 per cent over the period, which indicates there has been no significant diversion of funding to those with learning disabilities.¹⁹

2.23 Further analysis reveals that expenditure on long-stay hospitals has remained reasonably constant over the period while expenditure on nursing homes and residential homes has increased. The most significant increase over the period has been in relation to supported living, where expenditure has increased from £1.9 million to £8.3 million (335 per cent) since 2002-03 (Figure 3).

Figure 3: Expenditure on elements of learning disability care



18 Health expenditure is broken down into nine "programmes of care", one of which is learning disability (POC 6).

19 The Department told us it has also invested over £30 million in capital projects relating to learning disability in the last five years and a further £23 million is included within its planned capital programme.

Part Two: Strategic Developments and Funding

2.24 Boards and Trusts told us that delays in resettling patients arise primarily because of a lack of sufficient resourcing for alternative forms of provision. Within Northern Ireland, expenditure on learning disability services per head of population has been significantly lower than elsewhere in the United Kingdom and, as a result, progress in resettling patients has been much slower. The Department's view is that relative expenditure on learning disability services in Northern Ireland is reflective of the £600 million underfunding of health and social care services here, compared with England. We acknowledge that the Department faces real difficulties in meeting current demand for resettlement. However, if the target for full resettlement is to be met, learning disability must be given a higher resourcing priority.

2.25 In response the Department told us that, as a consequence of the 2007 comprehensive spending review, it has provided additional resources of £7 million, £9 million and £17 million for learning disability for the years 2008-09 to 2010-2011 respectively, to meet a range of specified service developments. These funds are ring-fenced for the purposes defined by the Department. The specific targets to be achieved with the earmarked resources include the resettlement of long-stay patients.

Implementation of the Bamford Review recommendations is expected to require significant additional resourcing

2.26 In May 2007, it was estimated²⁰ that additional Departmental resources of £173 million (at 2004-05 prices) were required to bring existing services for people with learning disabilities in Northern Ireland into line with Bamford's recommendations.

2.27 The health budget for the Comprehensive Spending Review period 2008 to 2011, announced in January 2008, provides an additional £33 million for learning disability, which will enable the resettlement of 80 learning disability patients from long-stay hospitals, an increase in the number of community-based staff and an increase in respite care.

Revised resourcing mechanisms will give service commissioners more flexibility in meeting the needs of learning disability patients

2.28 The Department sets and promotes policy on learning disability and services must be commissioned on this basis. All three policy strands - resettlement, short-term assessment and treatment, and community provision - must be developed and resourced simultaneously if the overall policy objective of resettlement of all long-stay patients is to be achieved. Service commissioners must decide on the appropriate resourcing of each element from within their own baseline funding and additional funding provided by the Department. However, Board officials told us that, in their view,

20 *Reform and Modernisation of MHL D Services: Strategic Priorities for the First Phase of Review Implementation*, Bamford Review, May 2007

Departmental resourcing mechanisms have in the past restricted their ability to meet the needs of all patients.

2.29 Board officials told us that over-emphasis on resettlement, without development of associated care and support services in the community, jeopardised the likely success of placements. In extreme cases, this could result in re-admission of learning disability patients to hospital. The Department told us that recent revisions to resourcing mechanisms will ensure that service commissioners have the appropriate flexibility to decide how best to meet the needs of their patients.

2.30 Service commissioners are best placed to decide the appropriate balance of resources between resettlement, assessment and treatment, and provision of community support, which should be seen as a continuum of care. We welcome the changes introduced to resourcing mechanisms and share the Department's view that this will help commissioners to better meet the needs of all learning disability patients.

Resettlement is intended to improve lives rather than reduce costs

2.31 Resettlement is only pursued where it offers "betterment" for the patient. Individual resettlements only progress where it can be demonstrated that the chosen option:

- is clinically appropriate;
- clearly meets the patient's needs;

- has the potential to better the life of the patient; and
- is in line with the wishes of the patient's family.

In this way, resettlement aims to provide long-term patients with the same rights and choices as the rest of the population. However the process has not been straightforward. The 256 patients still to be resettled include many who exhibit the most severe disabilities and present the most challenging behaviour. They require specialist community accommodation which is often unavailable. Bespoke packages are becoming more costly and Trusts believe individual packages costing in excess of £100,000 will not be unusual. By way of illustration, a recent package arranged by one Trust provides one-to-one care, 24 hours a day, seven days a week. The estimated annual cost of this resettlement is £170,000.

2.32 The changed emphasis on patterns of care initiated under the Department's 1995 policy (see paragraph 2.1) and reiterated by Bamford (see Appendix 4) has led to the expectation that people with more complex needs, who previously would have remained in long-stay hospitals, will live in the community. While available funding has enabled some resettlement of patients with complex needs, the number still to be resettled suggests that, due to competing priorities, resources have not been sufficient to meet the needs of all complex cases.

Part Two: Strategic Developments and Funding

2.33 It is clear that significant additional investment will need to be secured by DHSSPS and DSD to fulfil the policy commitment of full resettlement, to deliver services in line with the Bamford recommendations and to ensure that people with learning disabilities have meaningful choices in where and how they live. It is also important that patients' assessed needs are fully met in their new environment. In recognising that there are limits to available resources, we consider it essential that funding strategies should address the three strands of service provision (see paragraph 2.1). The Department told us that this, together with a new target to reduce delayed discharge, should ensure that a new long-stay population does not develop.

Part Three: The Long-Stay Population and Options for Resettlement



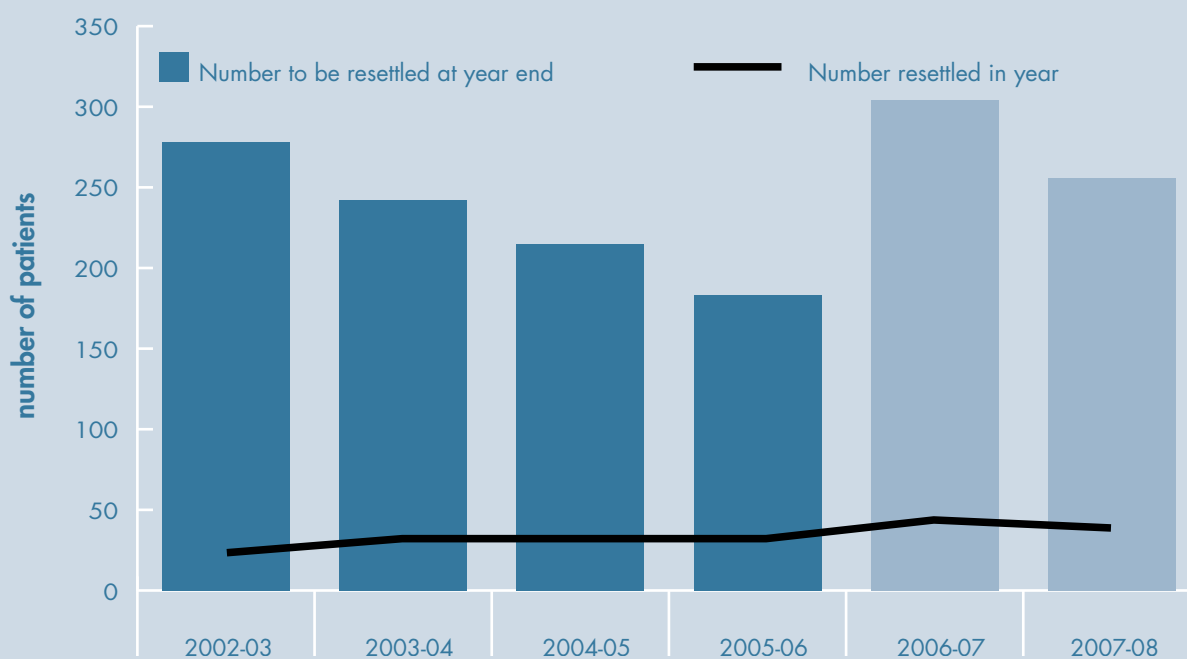
Part Three: The Long-Stay Population and Options for Resettlement

Although progress in resettling learning disability patients has been made, a large number of patients remain in long-stay hospitals

- 3.1 Figures provided by the Department show that at 31st March 2009, there were 256 long-stay patients in the three learning disability hospitals in Northern Ireland. Since 2003-04, the number of long-stay patients resettled each year has increased significantly, from 22 in 2003-04 to 41 in 2007-08, and a further 36 in 2008-09 (see Figure 4).
- 3.2 However Figure 4 shows that, despite the rising resettlement figures, the number of

long-stay patients increased in 2007-08. The Trusts told us that the increase related to a redefinition of patient categories as part of the normal process of clarifying definitions for annual targets. The definition of the long-stay population was revised from 'those patients in designated resettlement wards', to 'those who had been admitted to hospital prior to 1 April 2006 and had been in hospital for 12 months or more at 31 March 2007'. As a result of the redefinition, the number of patients to be resettled rose from 183 at March 2007 to 304 at March 2008, but has reduced to 256 at March 2009.

Figure 4: Resettlement activity in the last six years



Source: Health and Social Care Trusts

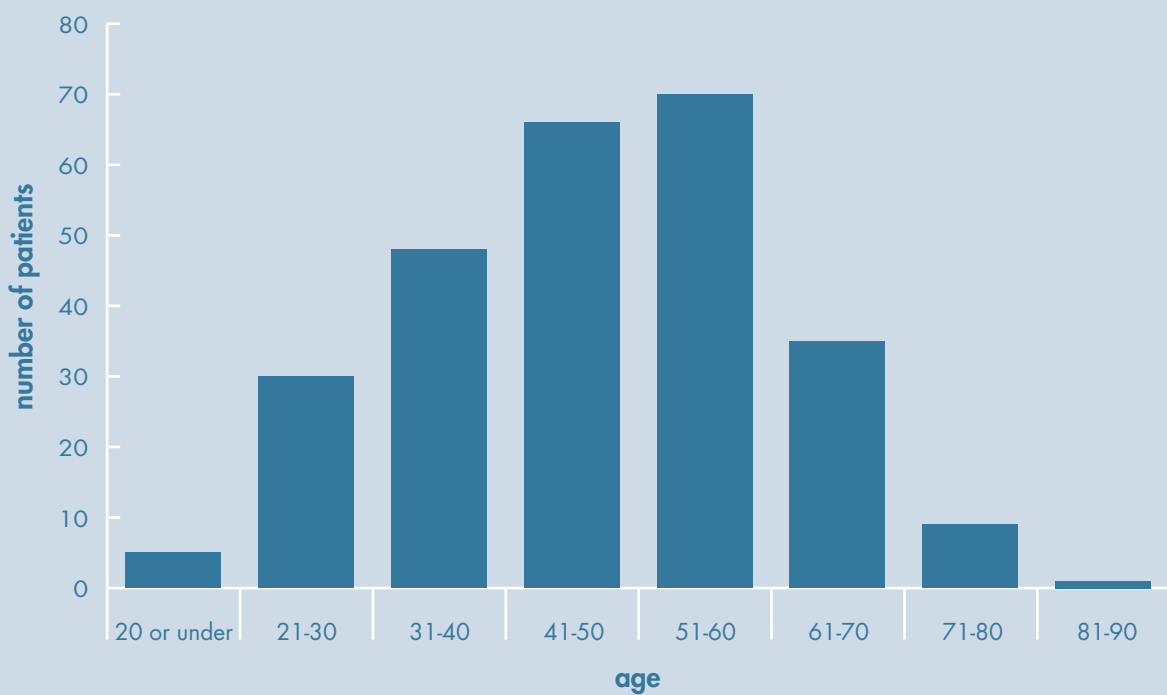
* shading of columns indicates a change in the definition of long-stay population

The majority of long-stay patients are within the 31-60 age range and have been in hospital for at least 10 years

3.3 Figure 5 shows the age-range of the long-stay patients remaining in hospital at March

2009. The majority of these patients (70 per cent) were aged 31-60, a further 13 per cent were aged 30 or younger and finally, 17 per cent were aged 61 or over. There were no children under the age of sixteen.

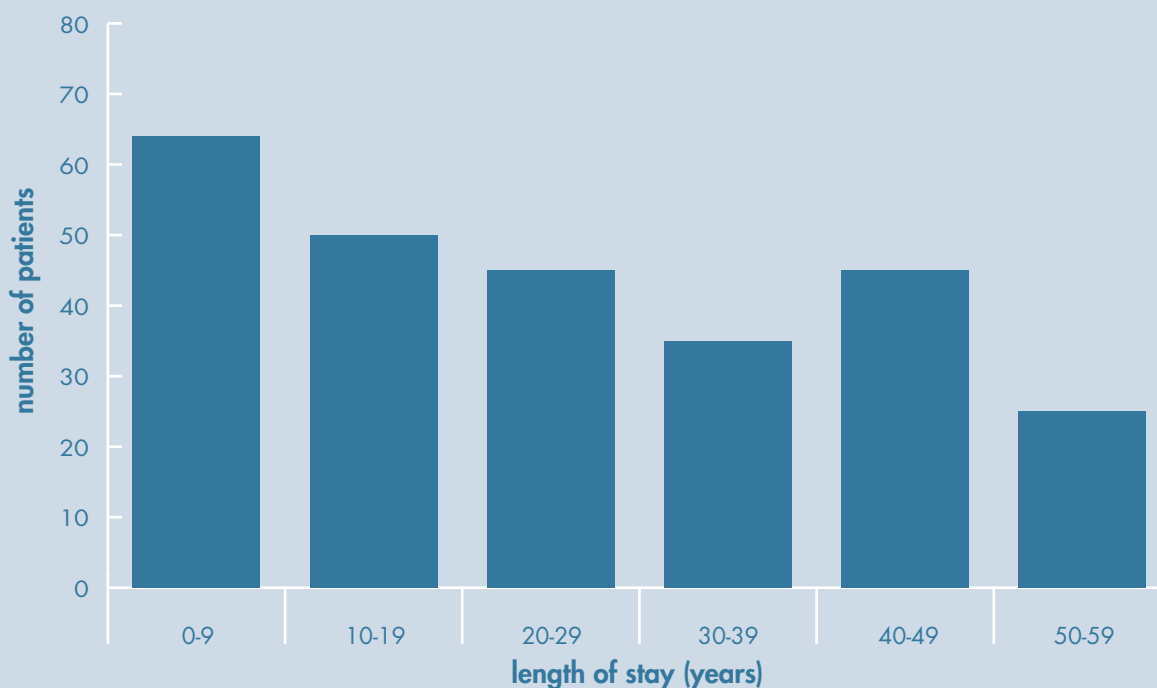
Figure 5: Age range of long-stay hospital population



Source: Health and Social Care Trusts

Part Three: The Long-Stay Population and Options for Resettlement

Figure 6: Length of stay of long-stay hospital population



Source: Health and Social Care Trusts

3.4 Figure 6 shows that, at March 2009, most long-stay patients (76 per cent) had been in hospital for 10 years or more. Almost ten per cent had been in hospital for 50 years or more.

3.5 As shown above, progress has been made in resettling long-stay patients with learning disabilities from hospitals. However, 256 people remain in hospital on a long-term basis, 13 years after the policy of resettlement was adopted. In our view, these patients need to be resettled with the minimum delay as any further extension to their hospital stay may diminish the likely success of their

resettlement as dependency on hospital care continues to grow.

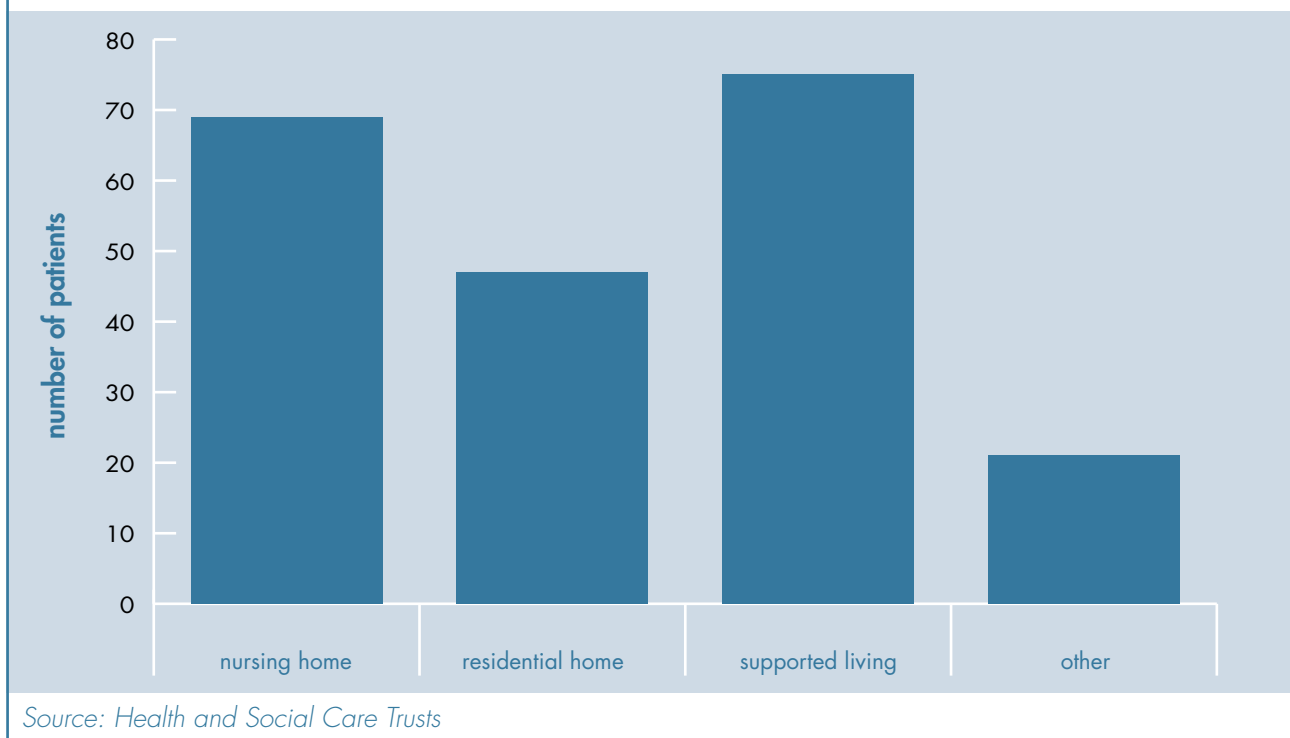
3.6 The Department pointed out that it has set clear targets for resettlements up to 2011 (see paragraph 2.3). As part of this resettlement programme, children were identified as a target group and all children have now been resettled. The long term target is that *by 2013, anyone with a learning disability is promptly and suitably treated in the community and no-one remains unnecessarily in hospital.*

Often, resettlement accommodation offers similar arrangements and conditions to those provided in hospitals for people with learning disabilities, and does not ensure full integration and inclusion in communities

- 3.7 Of the 200 or so long-stay patients resettled in the six years to March 2009, almost 55 per cent were resettled to either a nursing home or residential home setting (Figure 7). Thirty-five per cent moved to a supported living arrangement and ten per cent moved to other settings such as a challenging behaviour unit or a specialist adult placement scheme.²¹
- 3.8 This suggests that while many more people now live in smaller more localised

settings, they are not fully integrated into the community. Trusts told us that alternative accommodation options were often very limited and, in view of the level of care required by resettled patients with learning disabilities, transfer to nursing or residential homes sometimes offered the most viable way forward. The Department told us that when targets for resettling long-stay patients from hospitals were first introduced, it was necessary to select people who could appropriately be accommodated in vacant places in nursing and residential homes. As a result, those long-stay patients who required and requested supported living options remained in hospital. The Department told us that the development of supported living options requires lead-in

Figure 7: Resettlement destinations in the six years to March 2009



21 A small number of agencies have developed adult placement schemes, where families are actively recruited, supported and paid to provide short breaks or long-term homes for selected individuals.

Part Three: The Long-Stay Population and Options for Resettlement

time with housing providers and assurance that revenue for community support will be available following completion.

- 3.9 The Bamford Review noted that *“in many cases the accommodation that replaced the hospitals retained many of their features...most obviously sizeable groups of people who were unrelated to each other living together in...care homes and nursing homes with little engagement with local communities.”* Bamford considered that there was *“a need for both a wider range of supported living provision, to include adult placement services, and to address the deficiencies identified in large-scale group living environments.”*²² The Department told us that the level of integration will depend on the individual patient and the level of their disability.

- 3.10 We concur with Bamford that the integration of learning disability patients cannot be achieved without a range of accommodation options. In future, we recommend that resettlement plans not only ensure that the physical care needs of individuals are met but also enhance the level of integration of people with learning disabilities into the community, enabling them to make friends and have access to community services. The development of a wider range of accommodation options, in line with Bamford’s recommendations, should facilitate this. The Department told us that it has pursued, and will continue to pursue, its policy of resettlement where it offers betterment for patients, in that it meets both their clinical and social needs

and is in line with the wishes of patients’ families.

Since April 2003, the Supporting People initiative has provided significant resources for resettling learning disability patients within supported living accommodation

- 3.11 Since the launch of the national Supporting People initiative in April 2003²³, Trusts have had access to funding to increase the independence of people with learning disabilities. The impact of Supporting People funding is shown in Figure 8, with 35 per cent of resettlements since 2003-04 being provided within supported living accommodation.
- 3.12 In Northern Ireland, the Supporting People initiative is administered by the NIHE and funded through DSD. The initiative operates through a Commissioning Body, which consists of representatives from NIHE, the four health and social services Boards and the Probation Board. Each Board also chairs an Area Supporting People Partnership group which includes nominated representatives from local health Trusts, NIHE and the Probation Board. These groups identify local needs and determine funding priorities.
- 3.13 People with learning disabilities have been the primary beneficiaries of the Supporting People scheme (see Figure 9). In the last six years, revenue funding²⁴ of over £66 million (more than 20 per cent²⁵ of overall Supporting People funding) has been

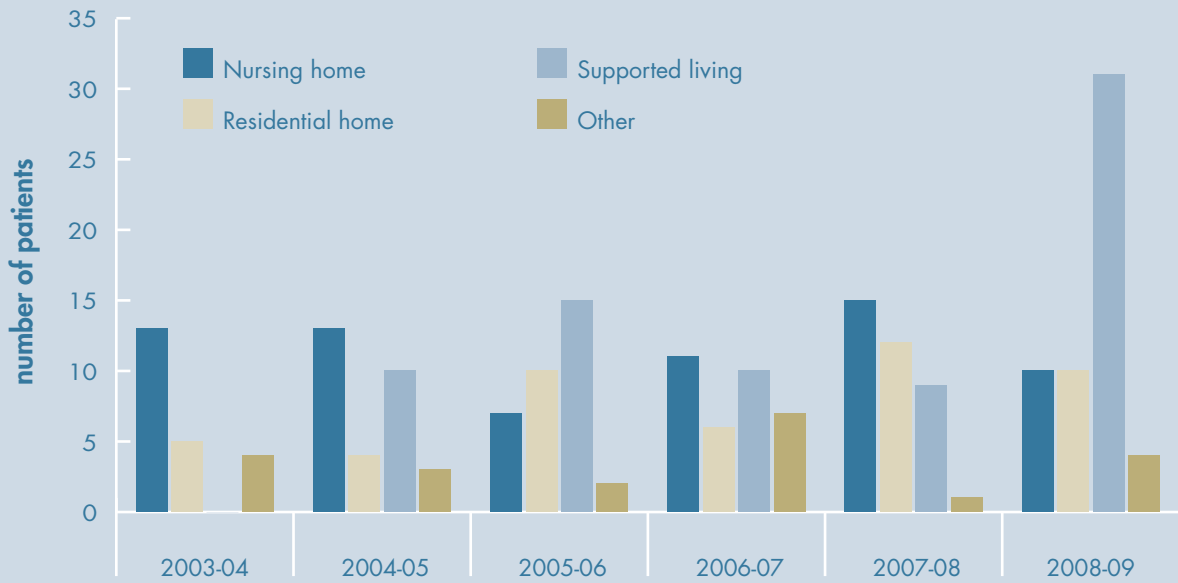
22 *Equal Lives Learning Disability Report*, Bamford Review of Mental Health and Learning Disability, September 2005, paragraphs 6.1 and 6.12

23 Supporting People is a UK-wide reform of housing support services involving statutory, voluntary and community sectors. Prior to 2003, housing support services were largely ad hoc.

24 Revenue funding covers the cost of providing advice, help and guidance to occupants. Available services include provision of wardens in sheltered schemes, finance advice and help with benefit claims, and training in basic skills such as cooking and hygiene.

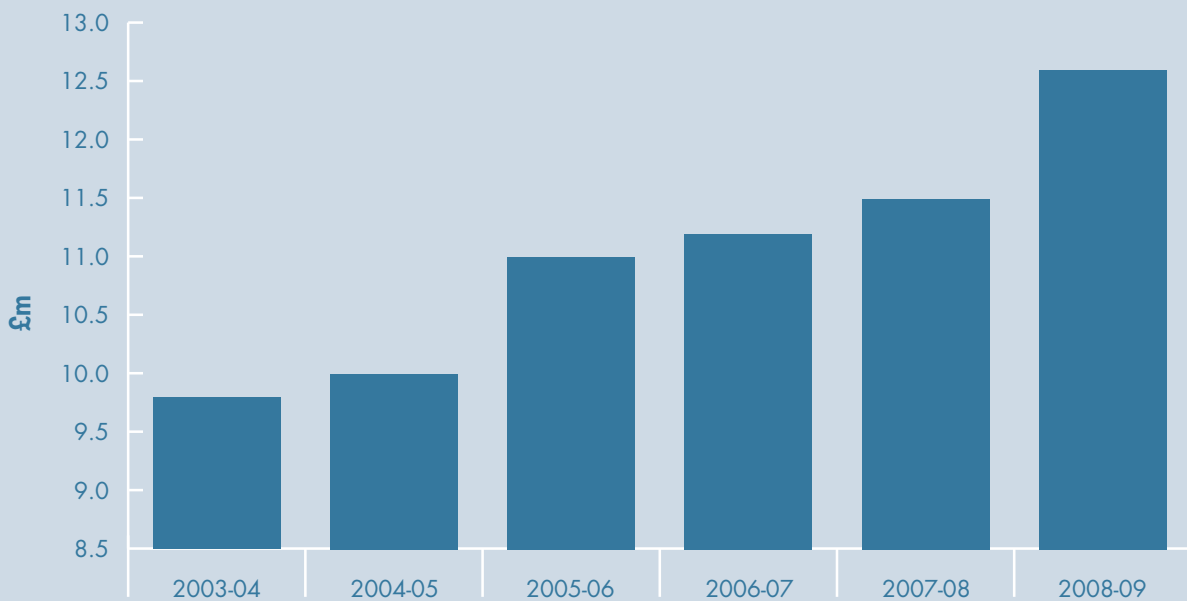
25 *Supporting People Strategy 2005-2010*, NIHE, September 2005

Figure 8: Resettlement destinations by year



Source: Health and Social Care Trusts

Figure 9: Supporting People funding for learning disability schemes



Source: NIHE

Part Three: The Long-Stay Population and Options for Resettlement

provided to resettlement projects. The capital costs of the projects undertaken during this period were funded separately under DSD's New Build Programme and amounted to around £20 million. On-going care costs are funded by the service commissioners.

- 3.14 Over the next three years, 14 supported living schemes are planned under the Supporting People initiative. These include 69 places allocated to learning disability. Funding for these schemes has not, as yet, been guaranteed.
- 3.15 An evaluation into the financial benefits of the Supporting People Programme has recently been undertaken in England and Wales.²⁶ The evaluation concluded that the total net financial benefit of Supporting People for those with learning disabilities was £664 million. DSD told us that its Housing Division will undertake a policy evaluation of the administration of the Supporting People programme in Northern Ireland.

Differences in Departmental planning and funding cycles have, in the past, caused problems in the co-ordination of projects

- 3.16 The Department and DSD explained to us that the main problem in co-ordinating projects is caused by the difference in planning and funding cycles. Capital funding of new-build schemes is typically for a three-year period. However, Supporting People revenue funding from DSD, which provides housing support in the form of advice, help and guidance, is allocated on a yearly basis. Each resettlement scheme can take up to three years to plan, develop and complete and this can be problematic if revenue funding is not guaranteed beyond the first year. Care funding from the Department has, from 2008-09, been allocated on a three-yearly basis.
- 3.17 Boards considered that revision of their funding cycle from one to three years would enable more accurate planning and ensure full access to available funding. Bamford supported this view stating that *"the capital and revenue cycles of...the Department of Health, Social Services and Public Safety and the Department for Social Development need to synchronise for Supporting People schemes."*
- 3.18 A further complication is that Bamford recommended that, by January 2013, all accommodation units for people under 60 years of age with a learning disability should be for no more than five people. We note that 16 of the 36 proposed schemes included in the Supporting People Strategy are designed to provide 10 or more beds. At least one Board had already adopted the "no more than five people" recommendation for all future schemes.
- 3.19 DSD told us that the decision on the number of people per scheme generally falls to service commissioners and is based on care considerations. Any future decisions

Full compliance with the Bamford Review may result in delays to, or revision of, a number of planned schemes which do not meet Bamford's proposed specifications

26 *Research into the financial benefits of the Supporting People Programme*, Capgemini UK plc on behalf of the Department for Communities and Local Government, January 2008

by them to fully comply with Bamford's recommendation will have cost implications in terms of reduced economies of scale, and additional funding would have to be given to meet these extra costs.

- 3.20 In its recent consultation document (see paragraph 2.14), the Department has proposed a pragmatic approach as follows: *"where appropriate and economically viable, DSD will seek to restrict group provision...to no more than five individuals per household"*.

DSD considers that greater clarity and transparency is required in the definition of "housing support" and "care"

- 3.21 DSD and NIHE are responsible for social housing and have guidance and standards²⁷ in place for new build schemes and the support provided within those schemes. They acknowledge and support the different standards required for the various client groups, including those with learning disabilities. However DSD considers that greater clarity and transparency is required in the definition of "support services" and "care" (see paragraph 3.16) to avoid confusion. It considers that this would facilitate clearer allocation of responsibilities.

- 3.22 The Supporting People initiative undoubtedly assists in providing quality resettlement for people with learning disabilities. However, differences in planning and funding cycles have in the past created difficulties in a number of schemes. Bamford stated that planning

and funding cycles needed to be synchronised. NIAO notes that, from 2008-09, the Department has made a three-year allocation of funding.

- 3.23 A number of proposed schemes do not comply with the recommendations of the Bamford review in that they provide for more than five beds per unit for patients under 60 years of age. A decision to fully comply with Bamford recommendations will have cost implications which will have to be weighed up against the wider health benefits. The Department and service commissioners must continue to give full consideration to all factors, not just cost, before taking any decisions. The Department told us that the principle of "betterment" for the patient is paramount and it is on this basis that decisions are made.
- 3.24 If the long-term hospital population is to be resettled in line with Bamford recommendations, there needs to be provision of a greater range of housing options. Bamford notes, for example, that there is a low level of home ownership among people with learning disabilities. Continued co-operation between DHSSPS and DSD will be essential in helping to overcome these barriers.
- 3.25 Agreement needs to be reached between the Department, DSD and NIHE on the standard of accommodation to be provided. Enhanced accommodation may be required to fully meet the needs of learning disability patients. Where this is the case, additional funding would need to be secured before a decision

Part Three: The Long-Stay Population and Options for Resettlement

to progress with such schemes could be taken.

- 3.26 Bamford also points out that thought must be given to the future needs of those who currently live with their families. He estimates that there could be as many as 1,600 people requiring alternative accommodation in the next 5-10 years, in addition to the hospital population. People with a disability are living longer and have changing needs throughout their lives. These are key considerations for future policy and funding decisions and have been acknowledged as such by the Department.
- 3.27 We are pleased to note that since September 2007 the Regional Resettlement Team (see paragraph 2.8) meets regularly in order to make progress on these issues. In addition, senior Departmental staff sit on the Supporting People Group which meets regularly to discuss supported housing. We would hope that these groups will make rapid progress in resolving outstanding supported housing issues.
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Part Four: The Resettlement Experience and Quality of Outcome



Orchard House

Part Four: The Resettlement Experience and Quality of Outcome

Resettlements in recent years have largely been successful, with few resettled patients requiring long-term readmission to hospital

4.1 Each of the three learning disability hospitals (see paragraph 1.5) has a Resettlement Strategy Group in place consisting of Board and Trust representatives, health professionals and representatives of patients and carers. These groups meet regularly (often weekly) to discuss overall progress on resettlement and identify individual resettlement needs. The aim of each of these groups is to ensure a planned approach to resettlement, looking at the needs of individual patients and issues of compatibility where grouped settings are planned. Within each hospital, patients with similar needs are grouped together so that when that group is resettled, a ward can be closed. The related funding can then be released

to support development of community services.

4.2 The discharge of patients happens gradually. There is no typical length of time, as resettlement depends on a number of factors. These include the level of the patient's disability (both physical and learning), the availability of suitable alternatives and the wishes of relatives. Initially patients, accompanied by hospital staff, undertake introductory visits to the new setting. In due course, overnight stays are arranged. Next, a trial resettlement begins. A hospital place is kept for the patient during this trial period and the placement is closely monitored. Eventually responsibility for the patient transfers to a community team following a final discharge meeting, and at this point the patient is considered to be resettled.

Figure 10: Resettlement "Breakdowns" 2003-04 to 2007-08

Trust	Breakdowns	Explanation
Belfast	1	One breakdown in 2005-06 due to patient's challenging behaviours
Northern	0	No breakdowns reported
South Eastern	0	No breakdowns reported
Southern	8	During 2006-07 and 2007-08 there were eight cases where resettled patients had to be temporarily readmitted to the Assessment and Treatment Unit because of challenging behaviour but they all returned to their placement
Western	4	A total of four breakdowns, one due to mental health issues, two due to challenging behaviours and one due to complex healthcare needs and dementia. Only one required long-term readmission to hospital

Source: Trusts

- 4.3 In recent years, resettlement has been largely successful. Few resettled patients have required long-term readmission to hospital. Figure 10 provides details of problems which have arisen in each Trust area.
- 4.4 The Department believes that careful and sympathetic management of the resettlement process can result in successful resettlement for all patients, regardless of the length of time they have spent in hospital, the complexity of their needs or the challenging nature of their behaviour. The following case examples show that successful resettlement can happen even in very difficult circumstances.

Case Example 1

Two friends, Mary and Jane²⁸, who had lived in the same ward at a long-stay hospital, were resettled together in a supported living setting.

At the time of resettlement, Mary had been in hospital for over 50 years while Jane had been there for two years. Both Mary and Jane have learning disabilities and severe physical disabilities.

Patients with this level of need are generally resettled in a nursing home setting. However, given the friendship of Mary and Jane, the hospital's Resettlement Strategy Group considered that a supported living scheme would offer more fulfilment to the women.

Mary and Jane now live as tenants of a housing association in a specially adapted bungalow. They receive 24 hour support from

staff employed by a voluntary organisation. The Trust monitors their progress and assists in the provision of other services as required.

Case Example 2

John, a young man exhibiting challenging behaviour, had been resident in hospital for a period of four years.

John was successfully resettled in an adult placement with specialist foster parents. The dedication and experience of John's foster parents and the close partnership with the community key worker ensure that John's behaviour can be managed to the extent where he no longer requires long-term hospitalisation.

There has been some family opposition to the resettlement of the most complex cases

- 4.5 The view that all long-stay patients can be resettled successfully, however, is not shared by all. Some of the families of long-term patients believe that the level and standard of care required by patients with very complex needs can only be provided in hospital.
- 4.6 Concerned families are represented by the Society of Parents and Friends of Muckamore group²⁹ (Friends of Muckamore). Although the group fully supports the resettlement of delayed discharge patients and those long-term patients who want to be resettled, it believes that patients with the most complex needs, who receive a high quality of care, should not be resettled into the community

28 The names used in the case examples are not the patients' real names.

29 This group represents the views of those with family members in Muckamore – mostly Eastern and Northern Board residents. No major concerns have so far been raised by families in the Southern and Western Board areas and there are no formal family groups in these areas.

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where this is against the patients' wishes and the wishes of their families.

profit" private nursing and residential homes.

4.7 The main concerns of the Friends of Muckamore are that:

- because of the complex needs of patients, they consider that the hospital provides a safe environment and believe that these patients would not be accepted into the community. They fear that patients would be subject to bullying and harassment;
- the level of care provided at Muckamore could not be replicated in the community. Muckamore provides doctors, psychiatrists, dental services, pharmacy, physiotherapy, dietetics, nursing and a rapid response arrangement with Antrim and Musgrave Park Hospitals;
- the quality of life for Muckamore patients may diminish as a result of resettlement in the community. Friends of Muckamore consider that access to recreational activities such as swimming, bowling and cinema, and day care facilities to help with communication and social skills, while freely available within the hospital, may be limited in the community;
- the much higher cost of community care packages for those with the most complex needs does not represent the best use of taxpayers' money; and
- there is uncertainty over the likely longevity of resettlement to "run for

The Department and service commissioners are sympathetic to the concerns of family members and in 1995 gave an assurance that resettlement against the wishes of the patient or family would not be pursued

4.8 The Department and service commissioners are sympathetic to the concerns of the Friends of Muckamore. They recognise the importance of family and carer support in the resettlement process and have enshrined their role in resettlement procedures (see paragraph 1.13). The Friends of Muckamore are represented on the Regional Resettlement Team (see paragraph 2.8) and service commissioners have developed advocacy services to work with patients and families to address concerns. These advocates can be health and social care staff, voluntary bodies, or staff from the Patient and Client Council.³⁰ The Friends of Muckamore consider that the advocacy services are not independent and believe they apply "undue pressure" on families. This concern was similarly identified by Bamford who recommended provision of independent advocacy services in Northern Ireland.

4.9 The Friends of Muckamore group was given an assurance in 1995 that "*no-one shall be required to relocate without their consent or against the wishes of their relatives and carers.*" The group told us that it will take legal action where resettlement is enforced against the wishes of patients or their families. However the Department

³⁰ Until April 2009, there were four independent area-based councils which represented the public's views and interests and reviewed the work of health and social services. From 1st April 2009, this role is now undertaken by the new Patient and Client Council.

believes that, with careful funding and planning, it can improve the lives of those who have been in learning disability hospitals for a very long time by enabling them to live in the community. It continues to meet regularly with the group.

4.10 Clearly the Friends of Muckamore remain very concerned about the quality of care that their relatives would receive if they were moved into community settings. Patients with the most complex and challenging needs have still to be resettled and community provision for this level of need has not yet been fully tested. We consider that a proactive response to Bamford's recommendations, and appropriate resources, will be critical in ensuring that any resettlement of the most complex cases is a positive experience for all concerned.

The consequences of ineffective provision for learning disability patients have been highlighted in a recent report in England

4.11 The difficulties and risks involved in ensuring quality health and social care services for learning disability patients have been highlighted by a recent review in England.³¹ This examined six cases where serious failings resulted in prolonged suffering and inappropriate care for the individuals involved. The failings included:

- poor communication, with information not being accurately passed between professionals, and between professionals and families, and then acted upon;

- a lack of partnership working, for example in discharge planning;
- insufficient importance attached to the views of family members; and
- an absence of independent advocacy services, which should be in place to safeguard the rights of vulnerable people.

The review recommended that all health and social care bodies should review urgently their capacity and capability to meet the additional and often complex needs of people with learning disabilities.

4.12 It is important that the findings of this review are noted in Northern Ireland and any relevant lessons learned so that learning disability patients resettled in the community, including those with the most complex needs, do not experience similar failings. The Department told us that it takes careful note of all relevant reviews, considers issues raised and determines whether learning can be applied.

The impact of resettlement on quality of life depends on the suitability of the placement

4.13 The Department emphasises that it is committed to the overriding principle of betterment and says that patients would not be resettled unless they were assured of a better standard of service and quality of life than in hospital. It recognises that resettlements to suit individual needs, especially the most complex needs, will be

31 *Six Lives: the provision of public services to people with learning disabilities*, Local Government and Health Service Ombudsmen, HC 203-1, March 2009

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more expensive than remaining in hospital but says that cost is secondary to quality of life.

- 4.14 We have been made aware of some particularly successful examples of resettlement schemes:

Case Example 3



One success story of a grouped supported living arrangement is Orchard House in Loughgall, Armagh. It opened in 2005 and has 10 residents. Each person has their own bedroom; there are two homely living rooms and a larger communal sitting room. There are two small kitchens where residents can prepare their own food if they wish, and also a communal kitchen and dining area where food is prepared and served centrally by staff. There is 24-hour staff cover. Residents have a range of day care activities and the freedom to go into the village, for example to the hairdresser or shops. Families can visit at any time and the residents can go and stay with their families at weekends or for holidays. Orchard House has been a great success, yet under the Bamford

recommendations, a similar design would no longer be considered as it caters for more than five people.

Case Example 4

One Board undertook a small study of a resettlement scheme, Knock Eden in Portadown, to identify the benefits to patients of living in community settings. The scheme comprises four bungalows, each housing four tenants. Fourteen of the 16 tenants transferred from Longstone Hospital where they had lived for most of their lives. Learning disabilities range from moderate to profound. The benefits identified included improved physical health and well-being, greater choice, more opportunities to use skills, greater community involvement and participation, and a better sense of status and respect. The families of the resettled patients were very positive about the impact on their relatives. This arrangement would be acceptable under Bamford, as each unit is for only four people.

While many recent studies have reported positive outcomes from resettlement, others highlight just how challenging it will be to ensure full integration of those with the most complex needs

- 4.15 A number of studies in recent years have looked at the experiences of people resettled from long-term hospital.³² These have reported positive outcomes: people felt happier, healthier and more independent;

32 Donnelly et al (1996): *One and two years outcomes for adults with learning disabilities discharged to the community*, British Journal of Psychiatry, 168, 598-606
 Donnelly et al (1997): *A three to six-year follow-up of former long-stay residents of mental handicap hospitals in Northern Ireland*, British Journal of Clinical Psychology, 36, 585-600
 McConkey et al (2000): *Moving on from Muckamore Abbey Hospital: The outcomes and lessons as perceived by people with learning disabilities, their key-workers, care managers and relatives*, Belfast, EHSSB
 McConkey et al (2003): *Moving from long-stay hospitals: the views of Northern Irish patients and relatives*, Journal of Learning Disabilities, 7, 78-93

certain aspects of challenging behaviour had improved; all families felt the placement was at least as good as the hospital and 80 per cent felt it was much better than the hospital. The studies noted, however, that around 75 per cent of people surveyed had moved to alternative large group settings – mostly nursing and residential homes. As a result, there was little change of experience in terms of daytime activities and social networks.

4.16 Bamford commented specifically on the findings of two reviews³³ of supported living options:

- in the first, people had moved to their own tenancies, with support staff from their Health Trust providing assistance. Tenants were *“happy, settled and achieving a higher level of functioning than in their previous accommodation”* and were better able to live *“normal”* lives within their communities;
- the second review looked at three supported living schemes. Each of the schemes contained clusters of houses within a defined area, with one or two tenants in each property. While the tenants considered they had more choice as to how they lived, the review found that they had not experienced any greater degree of social inclusion.

4.17 The findings of these studies indicate mixed success from the resettlement experience. The patients involved were not those with

the most complex needs and, in the case of the supported living reviews, they had not come from a long-stay hospital setting. If achievement of social inclusion and integration cannot be managed successfully at this level of need, it confirms just how challenging the integration of patients with the most complex needs will be. One of the reviews concluded that the setting alone does not guarantee inclusion and integration; the support network from a range of agencies and initiatives, such as advocacy and befriending, will also be crucial to success.

Quality needs to be a key consideration in the resettlement of learning disability patients

4.18 A major theme of a recent review of the National Health Service in England³⁴ is that quality, rather than quantity, should become the guiding principle of the health care system. It defined quality as a combination of patient safety; effectiveness of treatment and care; and patients' satisfaction with their experience. The Department told us that it is developing a service framework for learning disability services which will set out the specific standards expected. In addition, it emphasised that the principle of betterment for the individual is the main focus of the resettlement programme.

4.19 Quality assurance processes in place within health and social services were strengthened in 2003³⁵ by the introduction

33 Maybin M (2000): *Supported living scheme evaluation*, Newtownards, Ulster Community and Hospital Trust
McConkey R and McConaghie J (2001): *Supported Living: An evaluation of three schemes in Northern Ireland for people with learning disabilities*, Ballymoney, Triangle Housing Association

34 *High quality care for all: NHS Next Stage Review final report*, Department of Health, June 2008

35 Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003

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of a statutory duty of quality in the provision of care, and the establishment of the Regulation and Quality Improvement Authority (RQIA) in 2005. RQIA is a non-departmental public body with overall responsibility for assessing and reporting on the availability and quality of health and social care services in Northern Ireland. It is also required to encourage continuous improvement in the quality of care and services throughout all sectors in Northern Ireland.

4.20 If resettlement of long-term patients is to achieve the aspiration of promoting independence, increasing choice and control, and inclusion in communities (see paragraph 1.8), then more needs to be done to ensure quality outcomes. Quality of care of individual patients needs to be reviewed regularly as part of care planning and care management. The Department told us that yearly reviews are undertaken with all resettled clients and their families, to determine if their needs are being met. We found, however, that there is an absence of regularly reported composite information on service quality. As part of the establishment of RQIA, the Department is developing minimum standards for a range of health and social care settings, which will provide the basis for measuring and monitoring the quality of services for people with learning disabilities.

4.21 In our view, patient satisfaction with resettlement services and continuous improvement of those services must be the driving principles of quality management in learning disability services. The Department must utilise the minimum standards and service framework, as well as feedback from clients and their families, to inform a system of continuous improvement. The Department told us that a culture of reviewing, sharing experiences and learning from outcomes already exists within health and social care. Patient satisfaction and continuous improvement of services are the driving principles of the resettlement programme, which provides bespoke services following individual person-centred planning and risk assessment. Account is also taken of health and safety issues, any other impacting policies and best practice guidance.

Appendices



Appendix One: (paragraphs 7 and 1.9)

Background to the Bamford Review

In 2002, the Department initiated a comprehensive review of mental health and learning disability law, policy and service provision in Northern Ireland.

The findings from the review, known as the *Bamford Review*³⁶, were published in a series of 10 reports over the period June 2005 to August 2007. These reports set out a 10-15 year reform programme designed to improve services for people with mental health and learning disability problems and their families. While many of the recommendations relate specifically to the health and social care sector, several apply to other sectors across the Northern Ireland Executive (the Executive).

The Executive accepted the thrust of the Bamford Review. In June 2008, it issued a consultation document to stakeholders, *“Delivering the Bamford Vision”*, seeking views on the way forward in terms of implementation. The consultation period has now ended and the Executive shortly intends to publish a cross-departmental Action Plan for the period 2009-11. The Action Plan will specify commitments across all Government departments over the next two years. The Executive will also make a commitment to continued reform after 2011. The pace of change will depend on the availability of necessary resources.

Implementation within the health and social care sector will be overseen by the Health and Social Care Taskforce (under the control of the Health and Social Care Board). In addition, an independent group, led by the Patient and Client Council, will be set up with a dual role. Firstly, it will report to the Minister on the extent to which implemented change complies with the Bamford vision and secondly, it will provide a link with service users and carers to enable assessment of the improvement in care, treatment and support provided.

36 The Steering Committee charged with the review operated under the Chairmanship of Professor David Bamford of the University of Ulster and comprised representatives from various professional and other interested groups in the mental health and learning disability fields. The Review, as a result, is more generally referred to as the Bamford Review.

Appendix Two: (paragraph 1.6)

Strategic commitments to resettlement

Date	Strategic Development	Impact
1950	European Convention on Human Rights	Enshrined right to life, liberty and security and respect for a private and family life
1957	Mental Health Act	Ended compulsory certification and enabled the discharge of people with learning disabilities from long-stay institutions
1969	Committee of Enquiry into Ely Hospital (<i>the Howe Report</i>)	Highlighted problems with institutional care – impoverished conditions, lack of privacy, emphasis on physical care and “custodial” attitudes among staff
1971	Government White Paper <i>Better Services for the Mentally Handicapped</i>	Set targets for England and Wales for the next 20 years, to drastically reduce long-stay hospital places (from 52,000 to 27,000) and increase community provision
1979	Committee of Enquiry into mental handicap nursing and care (<i>the Jay Committee</i>)	Emphasised the need for community care and a service philosophy based on “normalisation”
1989	Government White Paper <i>Caring for People</i>	Confirmed commitment to the development of locally-based health and social care services
1994	Welsh Office Circular 30/94	Formalised the objective of full resettlement and hospital closure, with a target date of April 1999
2000	Scottish Executive Report <i>The Same As You?</i>	Set an objective to close all long-stay hospitals in Scotland by 2005
2001	Government White Paper <i>Valuing People</i>	Set target date of April 2004 for the closure of all remaining long-stay hospitals in England
2004	Department of Health, Social Services and Public Safety, 2004 <i>A Healthier Future;: A Twenty Year Vision for Health and Well-being in Northern Ireland</i>	Set a Northern Ireland target to relocate all people with a learning disability, living in long stay hospitals, by June 2010, by providing appropriate and supportive community accommodation
2005	Bamford Review of Mental Health and Learning Disability (Northern Ireland), <i>Equal Lives Report</i>	This will be the basis of the way forward on learning disability policy for the Department

Appendix Three: (footnote 11 at paragraph 2.3)

Departmental Priorities for Learning Disability

<p>Priorities for Action 2002-03 (March 2002)</p>	<ul style="list-style-type: none"> • Set a planning goal to improve community infrastructure to support long-term care of vulnerable groups in the community and facilitate discharge from long-stay institutions • Need to focus hospital services on assessment and short-term treatment • Goal that long-term care should no longer be provided in hospital environments • Priority that learning disability patients should enjoy suitable living arrangements outside hospital where that is appropriate • Boards and Trusts should continue the resettlement programme (no specific target – almost 400 still in hospital)
<p>Priorities for Action 2003-04 (February 2003)</p>	<ul style="list-style-type: none"> • Planning goals include minimising admissions to long-stay institutions and expanding learning disability services • Limited funding identified as a reason for delayed discharges from learning disability hospitals • Priorities include further progress in reducing the number of people in continuing care for whom community care has been assessed as more appropriate • A regionally agreed plan is now in place to resettle those in learning disability hospitals • Boards and Trusts should aim to resettle at least a further 50 people
<p>Priorities for Action 2004-05 (March 2004)</p>	<ul style="list-style-type: none"> • Boards and Trusts should resettle at least a further 50 people by 31st March 2005 • Boards and Trusts should develop community learning disability services to allow a further 80 people to be looked after in the community by 31st March 2005 • Boards and Trusts should ensure no new long-stay admissions to learning disability hospitals

<p>Priorities for Action 2006-08 (June 2006)</p>	<ul style="list-style-type: none"> • Bamford Review, to be finalised this year, will provide strategic framework for learning disability services. This will need to be given priority and specific targets will be set for 2007-08 onwards • Department will provide response, including action plan, to Bamford Review by the end of the year • Director of MHLD will be appointed • No specific target for resettlement • Boards and Trusts should continue to reform learning disability services in the community and move away from long-term institutional care
<p>Priorities for Action 2007-08 (January 2007)</p>	<ul style="list-style-type: none"> • Definitive policies and targets for learning disability will be decided in the context of the inter-departmental action plan to be drawn up by July 2007 in response to Bamford • Principal target - by March 2008, Boards and Trusts should have resettled 40 people from learning disability hospitals • Supplementary target – by March 2008, community learning disability teams should be augmented by 25 staff
<p>Priorities for Action 2008-09 (April 2008)</p>	<ul style="list-style-type: none"> • Trusts should ensure a 25 per cent reduction in the number of long-stay patients in learning disability institutions by 2011 • By March 2009, Trusts should resettle 60 patients from hospital to appropriate places in the community compared to the March 2006 total, and a further 60 by March 2011 • Trusts should ensure that, by March 2009, 75 per cent of patients admitted for assessment and treatment are discharged within seven days of the decision to discharge, with all other patients being discharged within a maximum of 90 days, unless there are exceptional circumstances • Trusts should ensure that, by March 2009, all children are resettled from hospital to appropriate places in the community

Appendix Four: (paragraphs 2.10 and 2.32)

Recommendations of the Bamford Review on the accommodation needs of people with learning disabilities – the Equal Lives report

1. By June 2011, all people with a learning disability living in a hospital should be relocated to the community. Funds need to be provided to ensure that on average 80 people will be resettled per annum over the five-year period from 2006 to 2011.
 2. With immediate effect, all commissioners should ensure that they have resourced and implemented arrangements to provide emergency support and accommodation for persons with a learning disability. Hospitals will not provide this service from 1st January 2008.
 3. With immediate effect, all new housing with support provision for people with a learning disability should be for no more than five individuals with a learning disability - preferably less - within the same household.
 4. By 1 January 2013 all accommodation for people with a learning disability under 60 years of age should be for no more than five people.
 5. An additional 100 supported living places per annum for the next 15 years should be developed to enable people to move from family care without having to be placed in inappropriate settings.
 6. DSD and DHSSPS should develop clear assessments of future housing needs for people with a learning disability including those who currently live with their families, and agree a continuous three-year funding strategy to resource housing and support arrangements.
 7. Housing planners should accumulate and disseminate detailed knowledge on the range of assistive technology that is available to enrich the capacity of people with a learning disability to lead more independent lives in the community.
 8. A strategy should be developed by the Department for Social Development to increase opportunities for people with a learning disability to own their own homes where this is a safe and appropriate option.
 9. Procedures and criteria for applying for Disabled Facilities Grants should be revised to tackle inconsistencies, reduce bureaucracy and reduce the hidden costs to carers.
 10. DSD and NIHE should establish mechanisms to ensure the increased use of floating support linked to an individual's needs, rather than overly relying on accommodation based schemes.
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