



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

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

**A REPORT FOR THE NORTHERN IRELAND HOUSING EXECUTIVE**

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## KEY FINDINGS AND CONCLUSIONS

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### Findings

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

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

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

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

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

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

Other limitations to betterment included:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

### **Conclusions**

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

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

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

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

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

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

## BACKGROUND: THE BAMFORD REVIEW

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

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

those charged with delivering the resettlement programme at that time, and families who sometimes felt that their family member would be better off in hospital.<sup>2</sup> In 1995, the Northern Ireland Minister of Health at the time gave a public assurance to families that a member of their family living in hospital would only be resettled into the community if there was clear evidence of betterment for the patient and provided that it was not against their wishes<sup>3</sup>. This commitment has been restated by successive Ministers and remained in place during the period of time being examined for this research (April 2012 – March 2016).

5. The term was used in the *Equal Lives* report to indicate that if a person was resettled there would need to be an improvement in their circumstances outside hospital compared with their lives in hospital. There were three tests of whether betterment had taken place: resettlement of the individual was clinically appropriate; it met the patient's needs; and it had the potential to improve the patient's life.

## THE RESEARCH

6. The Northern Ireland Housing Executive (NIHE) has played a significant role in helping to deliver the post-Bamford resettlement programme. Housing Executive officers have worked alongside the Health and Social Care Board and Trusts in commissioning new services for learning disabled people being resettled; a significant proportion of the social housing new build programme, which is planned by NIHE, is dedicated to the provision of housing for people who have additional support needs or who need to live in supported housing; and the support element in these schemes is funded by the Supporting People Programme for which NIHE has administrative responsibility.
7. This is the second phase of this research; it was commissioned by NIHE in its capacity as the strategic housing authority and Supporting People administrative body for Northern Ireland. The overall aim of the research was to provide NIHE and its partners<sup>4</sup> with an insight into how and to what extent the lives of learning disabled people who have been resettled from long stay hospitals<sup>5</sup> have changed since taking up their new accommodation.
8. The research has been divided into two phases, each looking at the resettlement programme from a different perspective.

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

<sup>3</sup> Northern Ireland Audit Office (2009), *ibid*, page 2, para 3

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

<sup>5</sup> There were three long stay hospitals in Northern Ireland specialising in provision for people with moderate to severe learning disabilities and mental health issues - Muckamore Abbey Hospital, Antrim, operated by the Belfast H&SC Trust; Longstone Hospital, Armagh, operated by the Southern H&SC Trust; and Lakeview Hospital, Derry/Londonderry, operated by the Western H&SC Trust.

## Phase 1

9. Phase 1 of the research was undertaken by North Harbour Consulting in partnership with Fiona Boyle Associates with advice from the Housing and Support Alliance. The main focus was on the institutional delivery of the resettlement programme including:
- the evolution of the learning disability resettlement programme<sup>6</sup> since the Bamford Report;
  - the models of housing, care and support provision on which the resettlement programme was based;
  - the characteristics, quality and costs of those housing and support services that were funded from the Supporting People programme; and
  - the perceptions of policymakers, commissioners and service providers involved in the resettlement programme about the way resettlement had been carried out, issues affecting the provision of housing and support, and the overall effectiveness of the programme from a policy and delivery point of view.
10. Phase 1 of the research concluded that:
- Progress had been slow in establishing mechanisms for assessing whether betterment had occurred in peoples' lives following resettlement;
  - Each Health & Social Care Trust was developing its own approach;
  - No overall assessment of this critically important aspect of the learning disability resettlement programme had taken place;
  - However, good practice developed by commissioners and providers in other parts of the UK were being considered for adoption by the Trusts and the NIHE Supporting People team.

## Phase 2

11. Phase 2 of the research has been led by Fiona Boyle (Fiona Boyle Associates) with the support of John Palmer (North Harbour Consulting) and Gillian Greer (NIHE Research Team). This second phase of research reports on the experiences of people who have been resettled in the period April 2012 to March 2016 following a major reorganisation of the resettlement programme.
12. The focus of Phase 2 has been to interview service users<sup>7</sup>, their families and the support staff who work with them to establish whether they thought that the resettlement programme had been successful for resettled learning disabled people and whether betterment in their lives had been achieved in the ways advocated by Bamford.

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<sup>6</sup> The description 'learning disability resettlement programme' has been adopted here and elsewhere in the report to differentiate this aspect of hospital resettlement from a parallel programme that resettled people with mental health issues from the same three hospitals.

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

### Identification of the resettled population and sampling

13. There were believed to be around 220 people still living in Muckamore Abbey and Longstone long-stay hospitals in March 2012<sup>8</sup>. The majority of these people had been resettled by March 2016. The research team made a number of approaches to the Health & Social Care Board and the five Health & Social Care Trusts during the period 2014 – 2016, requesting information about the characteristics and location of the people with a learning disability resettled from long-stay hospital from 2012 onwards. This information was not available on the grounds of confidentiality and because Health and Social Care Board stated that the information was covered by the Data Protection Act 1998. An alternative approach was therefore adopted. This involved constructing a sampling framework based on information that was available from NIHE's Supporting People team and from housing associations and housing support providers.
14. NIHE's Supporting People team, which was closely involved in the resettlement programme and had funded housing support services for a substantial number of the people who were resettled, provided the research team with information about supported housing schemes that had played a part in resettlement. This included the service provider's name and landlord, the scheme name where resettled people were thought to be living, and the addresses and number of units for each scheme. This information suggested that the locations of around 80 resettled learning disabled people<sup>9</sup> living in housing support schemes that were funded from the Supporting People programme were known to the Housing Executive. In discussion with the NIHE research and SP teams it was agreed to use this information as a basis for constructing a sample of 25 resettled people, their family members and their support staff who would be interviewed as part of the research. 22 interviews were completed (27.5% of the identified population of people resettled between 2012 and 2016).
15. A considerable amount of administration was involved in making contact with landlord housing associations and their managing agents who operate these schemes, with briefing managers and then negotiating access to the schemes, and with seeking consent from resettled people and their families to take part. In the process, it became clear that some of those who were identified for interview had moderate to profound learning disabilities, lacked sufficient comprehension to understand the aims and requirements of the research, and had weak communication skills. In these cases, where family members who were the responsible adults for the individuals concerned gave their consent, interviews took place with the family and with members of the staff team.
16. Table 1 (following page) provides information on the number of contracted places in schemes identified by the SP team. In addition, the table shows the number of interviews targeted from each provider and the number of interviews achieved.

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<sup>8</sup> Based on discussions with the Health and Social Care Board in 2015.

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

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

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

## Research process

17. The research process was undertaken in line with Social Policy Association Guidelines on Research Ethics<sup>10</sup> and the general ethical principles for research with vulnerable groups<sup>11</sup> in Northern Ireland. Particular emphasis was placed on the obligations to research participants in terms of protection from harm and in relation to their rights; as well as requirements in terms of informed consent, confidentiality and the sharing of research findings and safe storage of data.
18. Access was obtained in the first place via the housing association and service provider. Depending on the nature of the learning disability exhibited by individuals (ranging from low to moderate to severe) advice was obtained from families (parents/adult siblings) and providers on the best means of obtaining informed consent to take part. Where informed consent was possible, and where the individual gave their consent, interviews were arranged directly with service users with the help of their family member or service provider. However, where there were issues of mental incapacity or lack of communication, the principles of 'best interest'<sup>12</sup> were applied. In cases where informed consent could not be provided an interview was requested via a family member (parent or adult sibling) or a member of the service provider's staff working with the person we wished to interview.
19. All the housing associations and service providers identified in Table 1 were approached to participate in the research and were briefed about the research process. The majority agreed to facilitate access to service users and family members, thus enabling representation across the schemes and geographical locations.
20. A written briefing was given to family members and service users before they were asked whether they wished to take part in the research. The latter was in an easy to understand format including photos. These documents are attached in Appendix 1.
21. A total of 22 interviews were undertaken directly with service users and family members. Additional feedback was provided by service managers and support staff with knowledge of the individual. The interview questions are outlined in Appendix 2. These were primarily for use with service users; but were adapted as appropriate for interviews and discussions with family members and service managers and staff, when responding about service users who could not provide consent and/or did not have communication skills.

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<sup>10</sup> [www.social-policy.org.uk/downloads/SPA\\_code\\_ethics\\_jan09.pdf](http://www.social-policy.org.uk/downloads/SPA_code_ethics_jan09.pdf)

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

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

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## RESEARCH FINDINGS

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

### Theme 1: Experience of the resettlement process

#### Service users and their families

24. Service users, family members and carers were asked about their experience of the move from a long-stay hospital to their supported accommodation in the community (the resettlement process). In particular they were asked whether and how they chose the location and type of accommodation, who had helped them make the decision, what options they had been given (location and type of housing), what information they had been provided with, how easy they had found the move, and how easy they had found it to settle in their new home.<sup>13</sup>
25. In most cases resettlement had been based on a staged approach<sup>14</sup> in which hospital patients had visited a scheme, had then perhaps stayed there overnight, and had then been given the opportunity to stay for a slightly longer period before finally deciding to move there permanently.

#### **Service User – ‘Doris’**

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

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<sup>13</sup> Full interview questions are outlined in Appendix 2.

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

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

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

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

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

**Family member**

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

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

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

**Family member**

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

**Family member**

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

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

**Family member**

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

**Family member**

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

#### Service managers and front line staff

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

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

**Staff member**

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

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

**Staff member**

41. Staff said that they thought service users had been comprehensively involved in the resettlement process. In many cases customer journey maps<sup>15</sup> had been developed by housing associations and service providers in conjunction with the hospital resettlement team, and service users were shown photos of possible locations and schemes, were then driven past the scheme, and then taken to it for progressively longer periods of time.

**Service User – ‘Sheila’**

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

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

**Theme 2: Betterment for service users**

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

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

### Service users and their families

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

#### **Service User – Tony**

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

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

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

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

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

**Staff member**

46. Examples were given of 'betterment' experienced by service users in terms of the living environment and physical accommodation, and the type of activities service users were now supported to take part in, in their own homes and in the community. These were deemed to be normal everyday activities as well as rights and opportunities available to everyone else – privacy, access to food and drink when wanted, the ability to see visitors at any time, to have personal belongings and personal space. In particular, when asked about what type of support they needed and received, and what type of things they could do themselves or needed support with<sup>16</sup>, responses indicated that service users were now engaged in meaningful day-time activities, related to their mental capacity and ability. Being able to engage in meaningful day-time activities was available to all service users. Participation emerged as a large part of what service users (and their families) viewed as contributing to betterment. Reference was made by those with mild to medium learning disability to the type and range of housework and domestic activities they now participated in.
47. Service users were largely satisfied with their accommodation and the scheme; in particular interviewees mentioning their own bedroom, shared living space, the local neighbourhood and amenities, and the range of things they could do, as a result of living in the community.

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

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

They ... (CONTINUED)

<sup>16</sup> Section 4 of Interview schedule – see Appendix 1.

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

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

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

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

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

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

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

#### Service managers and frontline staff

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

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

52. Service providers qualified their judgement of betterment by noting that not everything in long-stay hospitals had been negative; and equally, not everything about living in the community was positive. It was acknowledged that these factors had an impact on betterment, and that various aspects of life in the community negatively - and often unintentionally – impacted on the concept and reality of betterment. This was particularly true for service users with severe, complex and additional needs<sup>17</sup>.

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

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

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

**Staff member**

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

**Service User – 'Christine'**

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

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

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

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

### Theme 3: Limitations to betterment

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

### **Service User – ‘Michael’**

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

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

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

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

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

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

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

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

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

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

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

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

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

**Staff member**

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

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

**Staff member**

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

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

**Family member**

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

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

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

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

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

**Staff member**

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

**Service User – ‘Patrick’**

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

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

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

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

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



## Theme 5: Family contact and family contentment

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

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

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

### **Service User – 'Phelim'**

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

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

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

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

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

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

The objectives of the research are to:

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

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

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

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

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

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

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

Mrs Fiona Boyle,  
[Address]

Telephone: [ ]

Mobile: [ ]

Email: [ ]

## LETTER FOR SERVICE USERS

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### HOW DO I FEEL ABOUT WHERE I LIVE?

My name is Fiona. This is my picture.



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

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



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



It will not take longer than 15 minutes.



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



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



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

Thank you for reading this.

Yours sincerely

*Fiona Boyle*

Mrs Fiona Boyle

**HOW DO I FEEL ABOUT WHERE I LIVE?**

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

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



I understand that what I say will be private.



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



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

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

Please put a tick in the No or Yes box.

**No**

**Yes**

Please sign your name here: .....

Please print your name here: .....

## Appendix 2: Semi-structured interview schedule

### QUESTIONS FOR SERVICE USERS

#### Section 1 - Who you live with?

*Do you live alone?*

*Do you want to live alone?*

*Would you like to live with others?*

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

*Would you prefer to live with family members?*

#### Section 2 - The type of accommodation you live in?

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

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

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

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

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

*What do you like about this place?*

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

*Which would you say is better?*

#### Section 3 - The type of area you live in

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

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

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

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

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

*Do you need help with any of the following:*

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

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

*Who provides this help and support?*

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

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

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

*Who helped you to make this decision?*

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

*Were you able to understand this information?*

*Who helped you to move?*

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

*Did you settle within the first few days or weeks?*

### **Section 6 - How you feel now?**

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

*Are you happy where you live now?*

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

*Can you tell me why you feel this way?*

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

*Can you tell me why?*

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

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

#### **Probe:**

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