Life after living in hospital

The experiences of people with a learning disability

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Foreword

It is with great pleasure that I introduce this report which represents the experiences of people with a learning disability and their families in relation to resettlement from long stay learning disability hospitals in Northern Ireland. This report highlights the experiences of people while living in hospital, their experience of moving out of the hospital and adjusting to living in the community.

The findings clearly show that people are keen to move out of hospital and be involved in decisions affecting their own resettlement journey. Life in the hospital was viewed negatively by many particularly in relation to the lack of freedom and choice. The majority of people interviewed felt that their lives had improved since leaving hospital and felt that they missed nothing about living in the hospital. It is clear that moving to the community with the right support and adequate preparation can lead to an increase in opportunities as well as in the range of activities and level of choice available. The family members interviewed provided a poignant insight into the emotional impact of supporting a family member through the resettlement process.

I would like to express my thanks to the people who took the time to take part in interviews as well as the staff and family members who supported them to participate. Their honesty and insight are of value in understanding the personal impact of resettlement and the importance of inclusion in decision making. We will strive to ensure that the voices in this report will be heard and acted upon.

Yours sincerely

Maeve Hully
Chief Executive of the Patient and Client Council
Summary

The Programme for Government 2008-2011 included 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.” This was reinforced as a target for delivery in the Bamford Vision Action Plan 2009 – 2011 (DHSSPS, 2009) published by the Northern Ireland Executive in October 2009.

Aim
The Bamford Monitoring Group of the Patient and Client Council set out to capture the views and experiences of people with a learning disability who have moved from living in a hospital, to live in a home in the community i.e. ‘resettlement’.

Our Approach
As part of this study 15 people with a learning disability who had been resettled from Muckamore Abbey Hospital and Longstone Hospital from 2008 until present day were interviewed about their experiences. Two family members also shared their experience of these long stay hospitals and their relative’s move to the community.

Our Findings
Some of the main issues identified about life in hospital included the lack of freedom and choice, lack of privacy and isolation. Positives of living in hospital were identified as the support received from staff, friendships and day opportunities.

People had varying experiences of moving out of hospital. In some cases people felt excluded from decisions about when to move and where to move to. Other people felt that they benefited from a phased move out of the hospital.

Since moving to the community the majority of people felt that they had increased access to activities, opportunities and basic liberties.
1.0 Introduction

In Northern Ireland it is estimated that 16,366 people, nearly one per cent of the population, have a learning disability. More than a quarter of the people have severe or profound learning disability (McConkey, Spollen and Jamison, 2003). The term ‘learning disability’ describes a lifelong condition:

Learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development. (DH, 2001)

Traditionally, where people with a learning disability were unable to be cared for at home, they were placed in hospitals to live. This has resulted in generations of people with a learning disability living in institutional settings, with no independence or choice.

In 1995, a policy decision was taken by the Department of Health, Social Services and Public Safety to move all long-stay patients from the three learning disability hospitals in Northern Ireland (Muckamore Abbey Hospital, Longstone Hospital and Lakeview Hospital) to live in the community (DHSS, 1995). This is known as resettlement. The initial target was to resettle all learning disability patients from long-stay hospitals by 2002. However, this target was not met and by 2002 only half of patients had been resettled.

In 2002, the Department initiated a review of the law, policy and services for people with mental health or learning disability needs in Northern Ireland, known as the Bamford Review of Mental Health and Learning Disability. The Equal Lives report (DHSSPS, 2005) on Learning Disability was published in September 2005. It clearly stated that “people should not live in hospital accommodation” and recommended that “by June 2011, all people living in a learning disability hospital should be relocated to the community” (DHSSPS, 2005, p.64).
Subsequently The Programme for Government 2008-2011 included 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.” This was reinforced as a target for delivery in the Bamford Vision Action Plan 2009 – 2011 (DHSSPS, 2009) published by the Northern Ireland Executive in October 2009.

Unfortunately today, in 2012, there are still individuals with a learning disability who have no home outside of hospital. As of March 2012, long-stay patients remained in the three learning disability hospitals.

The many targets to resettle ALL people with a learning disability have been set and missed throughout the years. More recently ‘Transforming Your Care: Vision to Action’ (DHSSPS 2012) commits to closing long stay institutions and completing the resettlement process by 2015.

1.1 Patient and Client Council

This research study was initiated by the Bamford Monitoring Group of the Patient and Client Council. The role of the Patient and Client Council is to provide a powerful, independent voice for people by:

- *listening and acting on people’s views*;
- *encouraging people to get involved*;
- *helping people make a complaint*; and
- *promoting advice and information*.

1.2 Bamford Monitoring Group

The Bamford Monitoring Group was set up by the Patient and Client Council to find out how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability are affecting people and communities.
The group works to understand if people have experienced any changes to services in their area, and if so what has been the effect of the changes on their health and wellbeing. Ultimately they aim to find out if changes making a positive difference in people’s lives or not.

2.0 Background

The Bamford Monitoring Group of the Patient and Client Council set out to capture the views and experiences of people with a learning disability who have moved from living in a hospital, to live in a home in the community i.e. ‘resettlement’. Where people with a learning disability were unable to speak for themselves, we have captured the views and experiences of parents, carers and family members.

2.1 Aims and Objectives

The objectives of this study were to:

(1) *Find out what people with a learning disability think about living in hospital*;

(2) *Capture the views and experiences of people with a learning disability about moving from hospital to live in the community*;

(3) *Find out what people with a learning disability think about where they live in the community and how this compares with living in hospital*;

(4) *Understand how people with a learning disability were communicated with and involved in the process of moving from hospital to live in the community*;

(5) *Explore how people with a learning disability believe the process of moving from hospital to live in the community could be improved*; and

(6) *Capture the views and experiences of parents / family members / carers regarding their experience of the resettlement process and to highlight how they feel it affected their relative (In circumstances where an individual with a learning disability is unable to consent or participate themselves).*
2.2 Research Approval Process

Formal research approval to proceed with this research study was gained through the Office of Research Ethics Committees Northern Ireland (ORECNI) and Health and Social Care Research and Development Offices in the Southern and Belfast Health and Social Care Trusts using the Integrated Research Application System (IRAS).

Figure 1: Research Approval Process
3.0 Our Approach

3.1 Who was eligible to take part?

A list of all individuals resettled in the Southern Health and Social Care Trust and the Belfast Health and Social Care Trust since Programme for Government 08/11 target set was collated. Some people who had been long term patients in Longstone Hospital but were not part of the defined resettled population also received letters inviting them to take part. It was agreed by the research team and Southern Trust to include these individuals in this study.

Participation in this study was limited to people in the Southern and Belfast Health and Social Care Trust areas due to time and resource restrictions. Also the majority of people who remain in longstay learning disability hospitals reside within the hospitals within these Trust areas, and therefore learning about the experiences of from people in these areas would be most valuable to inform change and improvement.

3.2 How were people invited to take part?

The Southern Health and Social Care Trust and the Belfast Health and Social Care Trust sent a letter from the research team in the Patient and Client Council to all people with a learning disability resettled in their respective Trust areas from 1st April 2008 until commencement of the study. The letter was in easy read format, explained the project and said that a named person from the research team would like to visit them to talk about the project (see Appendix 1). It explained that if the person did not want to be visited they could contact a named person in their local Health and Social Care Trust and tell them that they didn’t want anyone to visit. Where relevant a letter was also sent to managers of supported accommodation or housing where people with a learning disability now live to inform them about the project. This letter explained that residents / tenants would get a letter inviting them to take part in the project and requested them to provide support to the residents/ tenants to respond if they needed help.
After 2 weeks the research team requested a list of names from the Health and Social Care Trusts; this excluded those who said that they didn’t want anyone to visit them. The research team then visited each person with a learning disability in order to explain the study and invite their participation.

During this initial one to one session it was be determined if the person was able to participate. The person was taken through the participant information sheet and the content of the sheet was explained and any questions were answered at that time. If the person wanted to take part s/he signed the consent form.

3.3 What did taking part involve?

People with a learning disability took part in three one to one interview sessions where they were asked to talk about:

1) *Experiences of living in a long-stay learning disability hospital;*
2) *Experiences of the process of moving from a long-stay learning disability hospital into the community;*
3) *Experiences of living in the community.*

There was a short period of time (at least 24 hours) between the initial session to discuss the information sheet and sign the consent form and the three one to one interview sessions. The purpose of this was to allow a ‘cooling off period’ so that the person with a learning disability could take the time to fully consider if they wished to take part.

It was important to ensure that the most effective means of communication for each individual was used. Therefore, guidance was sought from all relevant professionals and support workers who knew the people with a learning disability, prior to the one to one interview sessions, and where necessary throughout the process. This was to assist in understanding what approaches work best when communicating with each person.
The 'tools' for communication chosen ensured that work was at an appropriate pace and level for each person, that it was empathetic to their needs, respectful of their circumstances, and resulted in the most comprehensive responses possible. Communication 'tools' such as pictures, signs and symbols were used as appropriate to enable people with and without verbal communication to participate.

One to one interview sessions were carried out in people’s own homes or at a mutually agreed neutral location. The duration of each one to one session was dependant on the abilities and needs of people taking part.

### 3.4 What if people with a learning disability could not take part?

If during the initial one to one session the research team determined that the person with a learning disability did not show a clear understanding of what the study was about, what was being asked of them to take part or could not clearly respond to show that they understood the content of the information sheet and the topics that they would be asked about, it was decided that the person could not give consent and they did not take part in the study.

In these circumstances the Health and Social Care Trusts sent a letter to a parent / family member / carer on behalf of the research team to explain the project and invite them to take part. The appropriate person was identified by the Health and Social Care Trusts. Parents / family members / carers were asked to share their experiences of the resettlement process and how they felt it affected their relative. If the parent / family member / carer decided to be involved they took part in an interview with a member of the research team.

Where it was found that a person with a learning disability could not be involved, and that s/he did not have a parent / family member / carer to invite to share their views, the research team sought the nomination of an advocate or staff member (from the Health and Social Care Trusts) who knew the individual well to invite them to share their views about the individual's journey.
The research team gave this process a lot of thought and believed it was a fair approach toward ensuring that all individuals’ experiences were represented at some level. It ensured that those people with severe and profound disabilities who could not speak for themselves would have their stories represented.

### 3.5 Data Collection

Where possible individual interviews were audio recorded with the permission of the participant. Recordings were then transcribed by the project team. No one was named or able to be identified from these recordings. Where it was not possible to record interviews, the interviewer scribed notes as a record of the discussion.

### 3.6 Ethical Issues

There were several key ethical and design issues arising in this research, these are discussed below.

Consent to participate followed a clear process. Each potential participant with a learning disability met with the project team staff member to discuss the project and what it entailed using an easy read project information sheet. Those people indicating that they wished to proceed, and who were assessed as having the ability and comprehension to participate were taken through the information sheet and consent form on a one to one basis and signed the consent form prior to taking part. This was considered the most appropriate approach to allow potential participants the opportunity to consider if they wish to be involved using a partnership working, person-centered approach.

If it was deemed that the person with a learning disability did not have the capacity to consent then they did not participate in the project. This decision was based on a holistic understanding and observation of the potential participant's ability.

It was acknowledged that people with a learning disability taking part in this study may find talking about their experiences difficult and as such were vulnerable to being
adversely affected through participation. In order to minimize the impact and effect that an interview might have had on participants it is important to note the following safeguards were put in place:

- People were not obligated to be involved. They are able to withdraw from the project at any time if they chose. This did not affect the person’s current or future health and social care services;

- If at any time throughout the project the person was reacting adversely to the discussion about their experiences, the interview was halted and only resumed as and when the individual was willing and able; (in two of the interviews the decision was made, following completion of the questions about the community, not to talk about hospital as it was causing the interviewees distress); and

- A ‘Protocol to safeguard adults’ was in place but was not required.

All patient information was confidential to the Patient and Client Council. Names of participants were only available to researchers within the Patient and Client Council. Participants were asked to consent to sessions being recorded before each interview. All audio recordings of sessions, including notes were stored securely for the duration of the study and will be destroyed.
4.0 Our Findings

In total, 17 people were interviewed as part of this study; 15 people with a learning disability and 2 parents and carers. The interviews focused on three aspects of resettlement: Living in hospital, moving out of hospital and living in the community. Each of these three aspects will be discussed in the sections below. Responses to prompts from the interviewer on these three topics were varied and as such each section will outline the amount of people who provided responses to individual sections.

4.1 What people with a learning disability said

4.1.1 Life in Hospital

Of the 15 people interviewed, 13 people were happy to answer questions and talk about what life was like for them in Muckamore and Longstone Hospitals. Of the two people who didn’t talk about hospital, 1 person made the decision for themselves not to talk about their time in hospital while for the other person the interviewer made this decision as it was judged that talking about hospital was causing distress.

Figure 1: Length of time spent in hospital as reported by the 13 respondents

<table>
<thead>
<tr>
<th>Amount of time</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 years or less</td>
<td>6</td>
</tr>
<tr>
<td>Over 5 years but less than 10</td>
<td>1</td>
</tr>
<tr>
<td>Over 10 years but less than 20</td>
<td>2</td>
</tr>
<tr>
<td>Over 20 years but less than 30</td>
<td>0</td>
</tr>
<tr>
<td>Over 30 years</td>
<td>1</td>
</tr>
<tr>
<td>Most of my life</td>
<td>1</td>
</tr>
<tr>
<td>Couldn’t say</td>
<td>1</td>
</tr>
<tr>
<td>A good while</td>
<td>1</td>
</tr>
</tbody>
</table>
Accommodation

When asked about what it was like to live in hospital people talked to us about the room which they were allocated to live in during their stay there. Eight people talked about living in a dormitory style room, 4 people said they had their own room and one person chose not to talk about their accommodation in hospital.

Two people talked about how they enjoyed sharing a room with other patients, one of whom took pride in looking after the shared space:

“I liked sharing a room. We had to change the beds every Monday. I made up all the beds and tidied up the bedroom. You have to keep your own room nice and tidy and all the beds made.”

However, for 3 of the people interviewed sharing was not such a positive experience. They had not been used to sharing with other people and this impacted on their ability to get a good night’s sleep:

“I was in the dorm for a while but they kept the light on all the time. I couldn’t sleep or nothing. It was giving me a sore head the noise and lights.”

Another issue identified by 2 people was the lack of privacy they experienced while in hospital. This made them feel uneasy and impacted on their sense of personal space:

“They watched you every day in through the window; they had a wee blind that moved. I used to lock my door.”

“It was noisy, you couldn’t sleep or anything. There was lots of banging, shouting. People knocking on your window to see if you were sleeping or not. It wasn’t like here, I can go to bed anytime I want after I get my supper.”
Four people had a room of their own but shared a bathroom. They did not enjoy sharing a bathroom and this was especially problematic in the morning times:

“I had my own side room and shared a bathroom. It was hard, you had to wait for a shower. There were 20 other residents on the ward that were up waiting on their shower.”

However the people who had their own room spoke positively about the peace and quiet which this allowed them. They appreciated having their own space at a time when they were not in good health:

“My room was quiet, not nobody in to disturb me, it was nice and quiet.”

**Freedom and Choice**

Of the 13 people who talked about life in hospital only one person felt unable to answer questions about freedom and choice. Of the 12 people who answered these questions 10 people felt unhappy about the level of choice while 2 were happy.

When asked to talk about their daily life in hospital 4 people talked about not being able to do what they wanted to do on a regular basis. This impacted on many aspects of their daily life. One person talked about challenging the staff about these restrictions when he wanted to spend the weekend at a friend’s house. He was told by staff that he did not have permission to spend the night away from the hospital. He felt that this was unfair as other people went away for overnight stays and weekends and he was not provided with an adequate reason to explain why he couldn’t do the same. This person eventually went against the instruction of staff and spent the weekend away from the hospital. Another person talked about how he enjoyed gardening during the day but the supervision of staff made him feel uncomfortable. One respondent did not enjoy the daytime activities at all and in particular their repetitive nature and the lack of any other options to choose from:
“It was rubbish. You had to go to bed at the same time, you had to get up at the same time. Even at weekends. You couldn’t make your own tea. You weren’t allowed to go down the town, you had to have someone with you in case you didn’t come back.”

“I told the staff ‘I’m going’ and they told me that I wasn’t allowed. I went anyway. It wasn’t fair as other people went away for the weekend and came back. It wasn’t fair. I was told ‘this isn’t a half-way house, you can’t do that’.”

“I worked in the gardens. I like working in the gardens but you were escorted. You had no freedom at all. Like a prisoner.”

“You weren’t able to do your own thing, you weren’t a free man, you had to go to day care every day, and it was the same thing all the time. We were told on our schedule what to do every day. The staff decided”

While 2 of the respondents discussed how the presence of too many staff impacted on their sense of freedom one person highlighted how the lack of staff had the same effect:

“You couldn’t even go for a walk. You had to be accompanied by a staff member and there weren’t enough to take you for a walk. There was nothing to do. You were stuck in there 24/7, just looking at the walls. It was awful.”

One person was allowed access to the kitchen and laundry and enjoyed the freedom of being able to look after himself:

“I done my own thing. I washed my own clothes, put them in the tumble dryer and all. I done my own dinner and all, I didn’t like their dinners.”
Staff and support

Eight people out of 13 who answered questions about hospital found the staff to have been supportive and easy to get on with. Staff were praised by many people for being helpful and for providing care when you were sick.

“I wasn’t well and the doctors and the nurses made me feel better”

Two of the people interviewed talked about members of staff that they got on well with and how they benefited from a relationship of mutual trust and respect. This view was echoed by another person when he highlighted the good relationship he had with some of the staff:

“They treated me like a man there. The staff treated me with respect. I respected them.”

“The good ones listened to you. The bad ones just pretended to listen and didn’t care. I got on well with some. They trusted me”

In the instances where people talked about members of staff that they did not get on well with this was due to their strict manner, their attitude and how they were treated:

“He had a bad temper and he was fighting and shouting and going on all the time”

Of the 13 people who were asked about the level of support they received in hospital, 12 said that they got enough support from the staff when they were there. Three people mentioned particular staff members who they would approach if they needed help, while 2 people said that they found all of the staff friendly and helpful. Only one person said that there was too much support, to the extent that you felt overwhelmed by it:
You were watched 24/7 it was too much. It was unnecessary. There was too much support.

Activities
Of the 13 people who talked about how they spent their day at hospital, 10 said that they were happy with how they spent their day. The activities included puzzles, jigsaws, arts and crafts, cooking, workskills, thinking skills, going out for trips, washing cars, gardening, football, going out for walks, shopping and swimming.

Six people talked about how much they enjoyed going on trips with staff into the neighbouring town. Getting off the hospital premises and into the local community was welcomed by these respondents however it was felt that the trips were too infrequent:

I went out just now and again. I wanted to get out more but there wasn’t the staff.

Another daytime activity which was enjoyed by 3 of the respondents was the contract work undertaken during the day. For men especially this was reported to be an enjoyable activity:

I went to workskills 9 to 4 every day. We would sort out dog bones, lots of sorting, I enjoyed it.

One person also mentioned that while they enjoyed going to day care during the week they felt at a loss at weekends as there were no structured activities to take part in:

I was bored at weekends, there was no day care
Three people talked about the reasons why they did not enjoy the day activities. This was due to the lack of stimulating activities and limited choice of things to do:

“I didn’t like daycare much. It was boring- not much to do, playing games and that. Games and magazines”

“I was bored of day care. I couldn’t do anything by myself, you had to be with staff all the time. I liked it but I was just bored.”

**Friends**

Three people said that they felt part of a family when living in hospital. This was due to the opportunity to make new friends there and being able to spend time with friends, especially in the evenings. Two of the people interviewed talked about keeping themselves to themselves and not mixing with the other residents. Three people also talked about issues they had with other patients, mainly personal items being broken and stolen and the upset that this had caused.

**Other things people talked about**

People also talked about food and the ‘lock-up’. Two people enjoyed the food and eating with the rest of the residents whereas 6 people talked about their dislike for the food in hospital; this was due to the poor quality of the food and lack of selection and variation. Two people also talked about the dietary restrictions which were enforced in hospital as they felt that their weight was being too closely monitored.

Two people also talked about being in the ‘lock-up’ when they first arrived in hospital. They both explained that they were unhappy there and were glad to move to a different part of the hospital after a period of time. For both of the respondents their time there was remembered in a negative light and was marked by having to obey the orders of staff:
“It was awful. They made you do chores like toilets and bathrooms and wash dishes and make beds everyday. Except weekends. They made you. They put you in a side room for a couple of hours if you didn’t do what you were asked.”

“Hell. Lock-up was hell. There were no birthdays in lock-up. You had to get up at 6am for physical training outside, no matter what the weather was like. You had to clean floors with a toothbrush. Staff weren’t nice to you there. You had to do exactly what you were told. There was no chance of getting out.”

What do you miss about hospital?

Of the 10 people who answered this question, 8 people said that they missed nothing about being in hospital. Only 2 people talked about things that they missed. For one person it was the good friends that they had there and for the other person it was washing cars and having something to do during the day.

“What, I’m just glad I’m out of there. I will never set another foot back near it.”

For a full list of responses about what people liked and disliked about hospital please see Appendix 4 and Appendix 5.
4.1.2 Moving out

Meetings about moving out of hospital

Of the 13 people who answered questions about moving out of hospital, 10 people spoke about going to meetings about moving out of hospital. Three people were unable to remember details about the move.

Of the 10 people who talked about the process, 2 people said that they were told by staff that they were going to move and that they were *not involved* in this decision. Another 2 people talked about the difficulties they experienced at these meetings due to the language and the concepts discussed:

“The doctor used big words, it was hard to understand.”

“I didn’t get to say what I wanted, it was always the doctors and they would talk over me a little bit.”

However 6 of the people interviewed talked positively about the meetings and how they were provided with the opportunity to have their say. Four people also said that their family attended at least one of the meetings and helped them to choose where they would move to. One person said he had benefited from the assistance of the self-advocacy TILI group and The Law Centre in attending meetings and helping to organise their move to the community.

What worked well when moving out of hospital?

Of the 10 people who talked to us about the process of moving out of the hospital, 5 people (3 from the Belfast Trust and 2 from the Southern Trust) told us about a phased move to their new residence. For 4 of the people interviewed this involved an initial visit of a few hours over a mealtime, then a few sleepovers, then a longer stay over a weekend. For the other person this involved a series of one night stays over consecutive Friday nights. All of the people who took part in this phased move found that it was
beneficial to them as it was good preparation for moving and let them get used to their new residence gradually:

“I came here for my tea, one night, two nights, three nights. Then I decided this was the place for me.”

Two people talked about the warm welcome they received at their new residence during the phased move and how much they enjoyed meeting the staff and the other residents. One person also mentioned being able to stay in the flat where he now lives:

“I came here for a couple of Fridays for a sleepover to try it. I stayed in this flat and met the staff and the other residents. I visited other places but I chose to stay here. I liked it here.”

For others the move from hospital to their new residence did not include any sleepovers. Three people talked about visiting their new residence for a couple of hours on separate days. Two people felt that they benefited from this experience while the other person felt that he could have benefited from staying over in order to have made a more informed decision:

“I went to look at the new place four times. I thought it would have been alright. I wasn’t offered the chance to stay over. Others got that chance, it wasn’t offered to me.”

One person said that they went to stay at their current residence “for a holiday” and ended up staying there permanently:

“A doctor came to the ward and told me that I was going to this place for a holiday. I never went back. I think they had to send someone from here to [the hospital], so
it was a swap. After a year they asked me if I wanted to stay on here. I didn’t want to go back to [the hospital].”

Four people talked about living in the Oldstone bungalows opposite Muckamore Hospital as a stepping stone before they moved to their own home. Three people found this to be a beneficial experience as they enjoyed who they were living with and learning to look after themselves again. However, one person added that while he had had a positive experience there he felt that the bungalows were too closely attached to Muckamore:

“We decorated the place, a couple of fellas and me. I got on well with them. But you were still attached to the hospital. It would have been better away from the Abbey.”

One person did not get on well with the other residents he was living with in the bungalows and as such did not enjoy his time there.

What was difficult when moving out of hospital?
Four of the people interviewed found the process of moving relatively straightforward. However, 6 people talked about the mixed feelings they experienced when leaving hospital. Two people talked about the difficulty in deciding if it was the right time for them to move into the community. This ambiguity was felt by another person who had lived in a variety of places in the community on previous occasions and was anxious that the move would not work out.

“It is difficult to move into the community. Do you want to go, do you not want to go. When you are in that place for too long you begin to think that it is your own place.”

“I was anxious, trying to get used to a new place after being in Muckamore so
long. I had been out so many times and it hadn’t worked for me.”

“It is scary moving from one place to a new place. I was nervous, it’s a big thing moving house. You don’t know what you are moving to.”

For one person it was the upheaval of moving to new surroundings which initially caused problems:

“I lived downstairs when I first moved here. I didn’t like it. It was too noisy for me. They wanted to carry on and things like that. I have moved upstairs now, there is more peace and quiet.”

While for others it was getting to know a new set of people:

“I am mixing a wee bit; I don’t really know them that well.”

“It is very hard for me to mix in with people. I am only beginning to know what the community is like because I have been away far too long. When I see a crowd I am still nervous. My social worker says it will take time.”

One person also talked about how they considered leaving their residential facility and getting their own flat earlier in the year but had decided to stay on:

“A few months ago I was a bit down, I wanted to leave this place and get my own flat. But it didn’t happen and I’m glad. I wouldn’t know how to look after my money and I could go back on the drink again. I had to think. I wouldn’t get away on holidays twice a year, I wouldn’t have any carers, money would be hard. I could get into bad company. There is better company here.”
One person also talked about how difficult it was for them to get their benefits sorted out after being in hospital for so long. This took some time and delayed their ability to obtain items they needed for their new accommodation.

**What could be done better when moving out of hospital?**

Eight people were happy with how the process of moving out of hospital had worked for them. Three people talked about the people still in hospital and felt that they should be given the same opportunity that had been provided to them. One person felt that there should be less red tape and a shift in attitudes to facilitate the process of resettlement while another person said that there needed to be better support available and better trained staff to offer help when adjusting to life in the community.

“There needs to be more understanding towards patients. They should be more thoughtful towards people.”
4.1.3 Living in the community

All of the 15 people interviewed talked to us about what they liked and disliked about living in the community. Eleven people talked about an increase in outings while 8 people described the good relationships they had developed with staff in their new place of residence. For 7 people seeing their family more was a benefit they had experienced since moving while new levels of freedom were enjoyed by 6 people. Six people also talked about the benefits of increased social opportunities since moving out of hospital.

Activities

11 out of 15 people who gave feedback on their current residence felt that they benefited from getting out more since moving to the community. People especially enjoyed increased opportunities for shopping trips, walks, holidays, going out for lunch as well as opportunities to integrate into the community:

“I would go to bible study or church during the week. I am making new friends at church, they have taken me in. I am happy since I got saved.”

Six people also talked about the wider selection of different activities now available to them since moving out of the hospital. Cooking, looking after pigeons, playing the X-box, horse riding and drama were described as enjoyable activities which people had taken up after leaving the hospital. The ability to watch your own television and play your own music was also described as a positive change.

Staff

Eight people described how they liked the staff in their new place of residence. They appreciated their kindness, the level of support they offered and their good sense of humour. Two people also talked about how approachable the staff were and how they felt able to talk freely with them:
“They look after you well. If you have a problem you can always go to them.”

However, one person felt that the staff in his new residence did not take him seriously when he contacted them for help:

“If you need anything after 11pm at night they won’t come round. They tell me to phone the police myself if I was concerned.”

Seven people said that they got to see their family more now they lived in the community and 5 said that there family were happy that they had moved.

“My mummy likes me being here, she lives close to here.”

Freedom and Choice
Six people talked about how they now have more choice over how they live their lives since moving out of hospital. One respondent described how this change has had a positive impact on his daily life. One person who had spent several years in hospital talked of the new freedom he has now he is living in supported living.

“I can go as I please. There are no strings tied to you as long as you keep contact and let them know you are safe and well.”

“You can go to bed at any time you want, you can get up in the morning at any time. Even if you are tired in the afternoon you can go back to bed. There are no staff saying ‘no you can’t go to bed’. You can make yourself something to eat. You can make yourself a cup of coffee anytime you want it.”

“I can go to my room when I want. I can stay and watch TV in my room if I want. If it gets too bad in the unit I can always go into my room. Last night I was a bit
annoyed and staff said to me that I can go into my room anytime I want. They don’t make you do anything you don’t want to do here.”

Six people also talked about the benefits of increased social opportunities since leaving hospital as they befriended people in their new residence and in the wider community:

“You meet more people because you are not in that lock up 24 hours per day.”

Three people talked about being more independent since they left hospital. This was felt at home with the added responsibility of looking after a flat. One person also talked about the availability of public transport which made it easy for him to travel into the nearby town:

“I like living here. I can do my own thing, and I do my own washing up and go shopping.”

“I have my independence. It is handy to go into the town or jump on a bus to go to Newry.”

Privacy

Three people were happy with the privacy afforded to them since their move from hospital. They enjoyed having their own space and being able to lock their own bedroom door:

“You have your own privacy and all. I have my own key and all so I can lock my own door.”

“Nobody can see into my room.”
What people do not like about living in the community

Eleven people said that there was nothing bad about living in the community. However, 4 people talked about things that they did not like. Two people were unhappy about moving into the community as they find their new residence to be too noisy:

“There is too much noise and racket. Muckamore was much quieter. All this bawling and shouting annoys me. I have been asked to get moved to another room away from the noise. I sometimes regret moving out. It was quieter there. It is too early to say.”

Another person was unhappy due to the location of his new house, the lack of transport options, difficulties with his neighbours and lack of day opportunities:

“Too much has happened in my new house. There has been a lot of trouble on the estate where I live. I get hassle from other people who live there and had to go to the police. I have put in for a transfer to move.”

“I only go two half days (at daycare) a week. I have asked for more but there isn’t anything else at the minute.”

For 2 other people it was the people they lived with who caused them to dislike their new residence at times. This was due to their behaviour at mealtimes and gossiping.

For a full list of things people told us they liked and disliked about the community please see Appendix 6 and Appendix 7.
4.2 What relatives told us

Two relatives talked to us about their family member’s experience of living in hospital one of whom had moved to a nursing home while the other had moved to the parental home. One relative had spent several years in Muckamore Hospital while the other had lived in Longstone Hospital on two separate occasions.

The staff in hospital

Both family members felt that the majority of staff were very helpful and kind both towards them and their relative:

“The staff are excellent, you can ring them at any time, day or night and say how is she and what she has been doing. Never have they ignored any of our calls. That gives us peace of mind if she ever does have to go back in.”

“The staff were very good.”

One person also talked about the improvements they noticed following an intake of new staff in Muckamore Hospital in recent years:

“The younger staff are really on the ball. They searched and searched for her lost clothes. One of the staff dropped them off to my house. That never would have happened before. If there is anything they are not happy with or she has a small scratch or anything they phone and let you know. The holistic approach, you can really see it at the fore.”

This person also felt that the ward management of Muckamore Hospital had changed for the better in recent years, allowing staff more time to spend with patients:

“Before staff were really stretched with difficult patients who took up a lot of their
time. Now there is better segregation of need so the people with more intensive needs are not in the same place. It is better for everyone, it has really come into this century now instead being old and decrepit.”

However, the other relative interviewed felt that some staff members could have communicated better and shown more respect:

“The social worker could never tell me anything, I got the impression that they thought I was being bad to my [relative].”

Feelings about the hospital
The relatives interviewed talked about mixed feelings they had when they looked back at the time their family members had spent in the hospital. Both shared negative associations they had made between the hospital and a prison:

“Bars on the doors, locks on the doors, it was like she was incarcerated. If it wasn’t for us…there were people there you’d think people had forgotten about, they’d locked them up and thrown away the key. She was incarcerated. If she had been in prison she would have got out a long time ago, that was the only way to look at it.”

“She was apprehensive about going in. I had never heard of Longstone. When I first went to visit her I was taken aback. It was dreadful to be quite honest. Once you are in, you are locked in.”

The relatives also shared the reasons why they were worried about their family member being in hospital. These were due to what they deemed to be an inappropriate environment for their family member’s individual needs and personalities:
“She didn’t like it. It was loud, boisterous. During the day it could have been different but at night it was very loud. It was no place for her, she is a quiet person.”

“I worried about who she was mixing with on the male side. I would still have that concern as she wanders over to the male side. She wanders when she is out of her routine.”

In another example, the family member’s personal dress preferences were overlooked and when a staff member was challenged about this the response was found to be unsatisfactory:

“She loves to be well presented and sometimes there she was dressed in non-matching clothes. She hated that. She loves jewellery and perfume. She loves looking well. I brought this up with the doctor and she said that she wouldn’t know the difference in what she was wearing.”

That being said the same relative recognised the value of hospital at a time when their family member was unwell:

“It is good in the short term. The structure and routine was good for her there when she wasn’t well.”

This person felt that their relative also perceived the hospital as being a place to help her feel better and as such she would not resist being admitted and would only talk about going home once she was feeling better:

“She would go back in with no hesitation then when she was starting to get better she would say ‘I want to go home’ ”
Both relatives talked at some length about the emotional impact of having their family member in hospital and the effect this had on them and their family:

“It is awful hard to leave them. I would be crying when I was leaving, my husband would be saying why are you crying she’s safe there. It hit my youngest daughter the hardest. You had to hide your tears from your kids. My older son would have went up to visit. It was so hard on them. Before it got you down, you would have went up and visited her and came home and felt that there was something missing. It was not having her at home.”

This emotional pain was worsened by a sense of powerless as there was a desire to remove the family members from the hospital but a lack of ability to achieve this:

“I visited her at least once a day, I just wanted her out of there. There was nothing I could do.”

Both relatives talked about going up to visit as much as possible and taking their relative for a drive in the car if possible. One of the people interviewed talked about their family member’s CPN also visiting the hospital:

“The CPN in the community would have come up to have seen her. They were learning from me as well.”
Moving out of hospital
For one of the relatives interviewed the move to the community happened quickly following an incident in the hospital:

“Someone hit her. I took her out of it straight away. After that she got home help-someone came in and lit the fire and seen she was alright.”

This family member was then moved to residential care. This was difficult for the family as they hoped to find somewhere more suited to her needs but had to settle for a residential facility for older people:

“It is the best of the bunch. I know the staff there. You are just there to die. No one ever comes out of there. The home is alright but it’s not home. It’s the best of a bad situation.”

For the other relative the process of moving into the community was more complicated and took many years:

“We constantly said over the 12 years that we wanted her home. I would never give up on her. I had the facilities, the shower room. We didn’t need money, all I wanted was my daughter home. I didn’t want a dream car or a dream home or to win the lottery, I just wanted my daughter home.”

In this case the move was gradual with the family member returning home for dinner, then tea, then a Saturday, then a Sunday, then an overnight stay followed by a weekend. This phased return was suggested by the hospital and worked well for the family:

“It was brilliant. They suggested it, we had wanted her home straight away. It was best for her.”
The transition to the community was not without difficulties, particularly in terms of adjusting to routines and changes in health:

“It took us quite a while to get her settled when she was discharged, mainly because there is no-one coming in to help us. We have had to get her into our routine, how we do things. We are not pressuring her. We are keeping a close eye on her. We let her do what she wants to do. We are so relieved to have her home. It can be hard but you just have to get on with it.”

“The day she came out she didn’t even know herself. She didn’t even know her way round my house. She didn’t know where the toilet was in her own house. She couldn’t stand on her feet.”

Both relatives talked about the difficulties they encountered in trying to organise services in the community once their family member had moved from hospital:

“When I was asking for respite, I had to go to my MLA to get anywhere. I eventually got some but it was unreliable.”

“I asked many times for physio but it never happened.”

“We were told it wasn’t safe, there was no funding, there was no where for her to go in the community, there was no one to help her in the community. She’s out now but there is still no help for us.”
5.0 Conclusions

This study set out to understand what people with a learning disability thought of living in the community after living in a long stay hospital, to hear from them about their experience of moving out of hospital, and to obtain their views as to how their experience could be improved.

On the whole, people were clear that they preferred living in the community. In making a comparison between life in the hospital and the community it is clear that people had more opportunities in their lives since leaving hospital. They valued the freedom, privacy and independence now afforded to them since their move to the community and this has empowered them to live fuller lives. The problems people identified about living in the hospital such as sharing bedrooms and lack of outings were mainly resolved following the move to the community. For the majority of people access to basic liberties increased following their move to the community.

There are a number of key messages from what people tell us about the process of moving out of hospital to living in the community:

- **A phased transition is really important**
  Those who were afforded the opportunity for visits and sleepovers before making a final decision really valued these opportunities. Spending time at the new residence before moving served to reduce anxiety levels associated with the move.

- **People with a learning disability want to be involved in the whole decision making process**
  Having spent a significant part of their lives in hospital, deciding when to move and where to move to were decisions which people wanted to be involved in.

- **Time was needed to think over the options and decide where was best to move to**
  Deciding where to live can be a difficult decision. People need time and support to think over where is best for them to live. Support is needed before, during and after the process of resettlement.
Moving to the community and adjusting to life outside of the hospital had an emotional impact on the people we spoke to and the transition to the community was not without difficulties for people with a learning disability and family members. Mixed feelings about leaving hospital, the upheaval caused through the change, the complicated journey and some difficulties organising services in the community were reasons for the negative experiences in the process of moving out of hospital.

When the transition was facilitated and supported by trusted staff with people with a learning disability and family members involved at all stages of the process it proved most successful.
6.0 Recommendations

Based on the findings of this report, the Patient and Client Council recommends that the following actions are taken to address the issues raised in this report:

- The Health and Social Care Board should ensure that every person with a learning disability moving from living in a long stay hospital is supported via a phased transition to enable them to make an informed choice about where they want to live in the community.

- Health and Social Care Trusts should involve each person with a learning disability and their carer / family in all decisions about moving out of a long stay hospital to live in the community. Information about the process of resettlement should be provided in an easy to read, understandable and accessible format to promote more informed decision making.
7.0 Bibliography and References


Appendix 1 –
Letter to people with a learning disability

Patient and Client Council
Your voice in health and social care

[Insert Full Name]
[Insert Full Address]

[Insert Date]

Resettlement from Long-stay Learning Disability Hospitals

[Greeting Line]

You may want staff, family, or even a friend to help you read through and understand this letter.

<table>
<thead>
<tr>
<th>Hello</th>
<th>My name is [insert name]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I work for the Bamford Monitoring Group.</td>
</tr>
<tr>
<td></td>
<td>It is a group run by the Patient and Client Council.</td>
</tr>
</tbody>
</table>
We listen to what people with learning disabilities and mental health problems think about services.

We check if changes to services are making things better for people.

To help us do this I need to come and talk to you.

I asked the [Southern / Belfast Health and Social Care Trust] to send this letter to you.

I do not know your name or where you live.

I want to talk to you about when you lived in hospital.

I want to talk to you about what it was like to move to your home in the community.
<table>
<thead>
<tr>
<th>Image</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Thumb Up" /></td>
<td>I want to know what was good.</td>
</tr>
<tr>
<td><img src="image2.png" alt="Thumb Up" /></td>
<td>I want to know what was not so good.</td>
</tr>
<tr>
<td><img src="image3.png" alt="Meeting" /></td>
<td>I want to visit you in your home to talk with you.</td>
</tr>
<tr>
<td><img src="image4.png" alt="Stop Sign" /></td>
<td>I will not visit if you do not want me to.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td>If you do not want me to visit tell [insert name HSC Trust staff member]. You can do this yourself, or ask a family member, staff or a friend to help you.</td>
</tr>
<tr>
<td><img src="image2.png" alt="Image" /></td>
<td>These are the ways you, or the people who support you can contact [insert name HSC Trust staff member].</td>
</tr>
<tr>
<td><img src="image3.png" alt="Image" /></td>
<td>[Insert Telephone Number]</td>
</tr>
<tr>
<td><img src="image4.png" alt="Image" /></td>
<td>[Insert Email]</td>
</tr>
</tbody>
</table>
If you want me to visit I will call at your home in two weeks.

If you want to talk to me before I visit you can tell me.

You can do this yourself, or ask a family member, staff or a friend to help you.

These are the ways that you, or the people who support you can talk to me.
<table>
<thead>
<tr>
<th>[Insert Telephone Number]</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Insert Email]</td>
</tr>
<tr>
<td>[Insert Postal Address]</td>
</tr>
</tbody>
</table>

Please tell me if you will need help at our meeting.

Sincerely,

[Insert name]

Patient and Client Council
Appendix 2 –
Consent form for people with a learning disability

**Participant Consent Form**
(Adult with a Learning Disability)
Resettlement from Long-stay Learning Disability Hospitals

[Insert name] will read through this consent form with you.

She needs you to tell her if you agree with the things she will say.

You can ask staff, family or even a friend to help.

If I agree I will tick  

<table>
<thead>
<tr>
<th>I have read, or had the information sheet read to me.</th>
<th>Tick:</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Insert picture research team member]</td>
<td></td>
</tr>
<tr>
<td>I am happy to meet and talk to [insert name].</td>
<td></td>
</tr>
<tr>
<td>I know we will talk about:</td>
<td></td>
</tr>
<tr>
<td>----------------------------</td>
<td>---</td>
</tr>
<tr>
<td>• Longstone Hospital</td>
<td></td>
</tr>
<tr>
<td>• [Insert name of where the person lives now]</td>
<td></td>
</tr>
<tr>
<td>• Moving from hospital to live in the community</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I know [insert name] will be writing down what I say.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree that [insert name] can do this.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I know [insert name] will record / tape what I say.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree that [insert name] can do this.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I understand [insert name] will keep everything that she writes and tapes.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>This will not be given to anyone else.</td>
<td></td>
</tr>
<tr>
<td>I know I can stop our meeting if I want.</td>
<td>☐</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>I understand some of the things I say might be used in the report. I agree to this.</td>
<td>☐</td>
</tr>
<tr>
<td>I know my name will not be in the report.</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please sign or mark your name below:

Witnessed by:

Date:

Thanks to Photosymbols for the pictures.
Participant Information Sheet
(Adult with a Learning Disability)
Resettlement from Long-stay Learning Disability Hospitals

[Insert name research team member] will read through this information sheet with you.

If you need any more help you can ask staff, family or even a friend.

<table>
<thead>
<tr>
<th>Insert picture research team member</th>
<th>My name is [insert name].</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I sent you a letter a week ago.</td>
</tr>
<tr>
<td></td>
<td>I said I wanted to talk to you about moving out of Longstone Hospital.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insert picture research team member</th>
<th>Before I can talk with you I need to tell you about what will happen.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This will help you decide if you want to take part.</td>
</tr>
<tr>
<td>Meeting</td>
<td>We will meet three times.</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td></td>
<td>This will be once a week, for three weeks.</td>
</tr>
<tr>
<td></td>
<td>Each meeting will last 30 minutes.</td>
</tr>
</tbody>
</table>

|               | You can have a friend or support worker with you when we meet. |

<table>
<thead>
<tr>
<th></th>
<th>When we meet I want to talk with you about:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Longstone Hospital</td>
</tr>
<tr>
<td></td>
<td>• [Insert name of where the person lives now]</td>
</tr>
<tr>
<td></td>
<td>• Moving from hospital to live in the community</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>I want to hear about what has been good about moving.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>What has made you happy.</td>
</tr>
<tr>
<td>I want to hear about what was not so good about moving.</td>
<td>What has made you unhappy.</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>We are giving lots of people the chance to take part.</td>
<td>This means the work is fair.</td>
</tr>
<tr>
<td>I will write down what you have said.</td>
<td>I will record your voice when you speak.</td>
</tr>
<tr>
<td>I will not do this unless you say it is okay.</td>
<td>All records will be kept in a safe place.</td>
</tr>
<tr>
<td>You can ask for the meeting to stop at any time.</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>I will keep what you have already said to me.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>I will write a report about what all the people tell me.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>I will write the words you say in the report.</td>
<td></td>
</tr>
<tr>
<td>Your name will not be in the report.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>If there is anything you do not understand you can speak to [insert name].</td>
<td></td>
</tr>
<tr>
<td>You can speak to [insert name] on this Telephone number (028) 90 321230</td>
<td></td>
</tr>
<tr>
<td>If anything we talk about upsets you, I will tell your carer or keyworker.</td>
<td></td>
</tr>
<tr>
<td>If you tell me something bad happened to you or that you did something wrong, I will have to tell [insert name] Services Manager, Learning Disability</td>
<td></td>
</tr>
<tr>
<td>If you are unhappy talking to me, you can tell a lady called Gillian McMullan.</td>
<td></td>
</tr>
</tbody>
</table>
You can speak to Gillian on this Telephone number (028) 90321230

Thanks to Photosymbols for the pictures.
Appendix 4 –
What people with a learning disability liked about living in hospital

<table>
<thead>
<tr>
<th>What people liked about living in hospital</th>
<th>Number of responses (people gave multiple responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care</td>
<td>10</td>
</tr>
<tr>
<td>Staff</td>
<td>10</td>
</tr>
<tr>
<td>Trips to town</td>
<td>6</td>
</tr>
<tr>
<td>Watching television</td>
<td>4</td>
</tr>
<tr>
<td>Nothing</td>
<td>3</td>
</tr>
<tr>
<td>Sports days and Christmas parties</td>
<td>2</td>
</tr>
<tr>
<td>Sharing a room</td>
<td>2</td>
</tr>
</tbody>
</table>

Other singles responses were: ‘friends’, ‘the staff helped me to get better’, ‘bus trips’, ‘helping the staff’, ‘walks around the grounds’ and ‘cinema trips’.
Appendix 5 –
What people with a learning disability did not like about living in hospital

<table>
<thead>
<tr>
<th>What people did not like about the hospital</th>
<th>Number of responses (people gave multiple responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noisy</td>
<td>4</td>
</tr>
<tr>
<td>Sharing a room</td>
<td>4</td>
</tr>
<tr>
<td>Sharing a bathroom</td>
<td>4</td>
</tr>
<tr>
<td>You couldn’t do things you wanted to do</td>
<td>3</td>
</tr>
<tr>
<td>Staff attitude</td>
<td>3</td>
</tr>
<tr>
<td>Activities</td>
<td>3</td>
</tr>
<tr>
<td>Food</td>
<td>2</td>
</tr>
<tr>
<td>Money situation</td>
<td>2</td>
</tr>
<tr>
<td>Nothing to do</td>
<td>2</td>
</tr>
<tr>
<td>Lack of privacy</td>
<td>2</td>
</tr>
<tr>
<td>Lock-up</td>
<td>2</td>
</tr>
</tbody>
</table>

Other single responses were ‘staff bullied me’, ‘the same people were always picked for outings’, ‘half a life sentence’, ‘lack of outings’, ‘too big’, ‘watched 24/7’ and ‘nothing to do at weekends’.
Appendix 6 –
What people with a learning disability like about living in the community

<table>
<thead>
<tr>
<th>What people like about living in the community</th>
<th>Number of Responses (people gave multiple responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting out more</td>
<td>11</td>
</tr>
<tr>
<td>Staff</td>
<td>8</td>
</tr>
<tr>
<td>Seeing family more</td>
<td>7</td>
</tr>
<tr>
<td>Better selection of activities</td>
<td>6</td>
</tr>
<tr>
<td>Choosing how to spend my time</td>
<td>6</td>
</tr>
<tr>
<td>Friends</td>
<td>6</td>
</tr>
<tr>
<td>Watching Television</td>
<td>5</td>
</tr>
<tr>
<td>Day centre</td>
<td>4</td>
</tr>
<tr>
<td>Music</td>
<td>4</td>
</tr>
<tr>
<td>Privacy</td>
<td>4</td>
</tr>
<tr>
<td>Decorating my room</td>
<td>4</td>
</tr>
<tr>
<td>Being more independent</td>
<td>3</td>
</tr>
<tr>
<td>Going to football matches</td>
<td>3</td>
</tr>
<tr>
<td>Helping out staff</td>
<td>3</td>
</tr>
<tr>
<td>Lots to do</td>
<td>3</td>
</tr>
<tr>
<td>Own Television</td>
<td>3</td>
</tr>
<tr>
<td>Relaxing</td>
<td>3</td>
</tr>
</tbody>
</table>

Appendix 7 –
What people with a learning disability did not like about living in the community

<table>
<thead>
<tr>
<th>What people do not like about living in the community</th>
<th>Number of responses (people gave multiple responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing</td>
<td>11</td>
</tr>
<tr>
<td>Noise</td>
<td>2</td>
</tr>
<tr>
<td>Other residents</td>
<td>2</td>
</tr>
</tbody>
</table>

Other single responses were ‘transport’, ‘location’ and ‘trouble in the community.’