



Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward

Katherine Owen, Jane Hubert and **Sheila Hollins**, Division of Mental Health, St George's, University of London, Cranmer Terrace, London SW17 0RE, UK (E-mail: jhubert@sgul.ac.uk)

Accessible summary

- Eleven women with intellectual learning disabilities who had lived empty lives shut away in a locked ward of an old intellectual disability hospital were moved out when the ward was closed down.
- This study found that moving home was very hard for the women. This was mainly because they were not told what was going to happen, and they were not given any choice about where they would move to or who they would live with.
- When they got to their new homes the people who were looking after them had not been told much about them, or about their lives, or what they liked and didn't like.
- Eight of the women moved to a new home in the hospital grounds. It was better than the old ward in some ways but their lives didn't change very much. There were still lots of rules, and they still didn't have much to do, or have the chance to make new friends.
- Three women moved to houses out in the community. Their lives did get better to some extent. One woman, especially, was able to live a much fuller life, making her own choices in her daily life, and making new friends.

Summary

Previous research into deinstitutionalization has largely ignored the perspective of people with intellectual disabilities, especially those with severe intellectual disabilities. This research aimed first to understand how women with severe intellectual disabilities experienced transition from a locked ward of an old long-stay hospital into other homes, and second, to determine the extent to which their lives changed in their new homes. Ethnographic methods were used, including participant observation, interviews and document analysis, in order to get to know the eleven participants and the nature of their daily lives. The study found that the experience of the move was largely negative for all the women: they were not involved in the process of their move, little information was transferred to their new homes and they were insufficiently supported. The study also found that for the majority of the women little changed in their lives in their new homes, although this depended on where they moved to. Those who moved to a campus home continued to lead lives restricted by rigid routines, strict rules, few daily activities, and few opportunities for relationships beyond the staff team. Those who moved to homes in

the community had more opportunities to make choices, learn new skills and explore new activities. The study found that, in general, the women continued not to be acknowledged as unique individuals, who have pasts, close relationships, clear preferences, abilities and rich emotional lives. The study highlights the needs of women with severe intellectual disabilities in their move out of long-stay hospitals, and in the planning of their futures.

Keywords *Community living, deinstitutionalisation, institutionalisation, severe intellectual disability, vulnerable adults, women*

Introduction

There have been many studies of deinstitutionalization (e.g. Collins 1992; Robertson *et al.* 2004; and see Emerson & Hatton 1994 for a comprehensive review of 71 research studies). Most research has focused on the outcomes of deinstitutionalization, in terms of such things as quality of life, adaptive behaviour skills and community integration. Few have focused on the actual process. A notable exception is Johnson's (1998) study in Australia, in which she documented the lives of institutionalized women before, during and after their transition to the community. Many studies of deinstitutionalization have relied on information from staff, rather than from people with intellectual disabilities themselves. Again, Johnson (1998) is an exception (and see also Jahoda *et al.* 1990; Booth *et al.* 1990; Johnson & Traustadóttir 2005). Furthermore, almost all the studies that have focused on the perspectives of people with intellectual disabilities have used quantitative methods, and have therefore concentrated on people who can communicate verbally (Hewitt 2000). Thus very little is known about the experience of deinstitutionalization from the perspective of people with more severe intellectual disabilities in general, and even less from women with severe intellectual disabilities.

Methods

Study

The 3-year study was set up in 1999 by the Department of Psychiatry of Disability (now the Department of Mental Health – Learning Disability) at St George's Hospital Medical School, and funded by the Judith Trust. The research arose from a similar study, which focused on men living in a locked ward of the same hospital (Hubert & Hollins 2006), aimed to find out how women with severe intellectual disabilities experienced the process of hospital closure, and their adaptation to their new lives over the first year after transition, as far as possible from their own perspectives.

Participants

The study followed the lives of 11 women (aged between 29 and 72) living together in a locked ward. All were described as having intellectual disabilities, most with severe intellectual disabilities; several were on the autistic spectrum and some also had additional mental health problems. All were said to have 'challenging behaviour'. The participants were chosen because the ward was planned to close the following year. Eight of the women, who were deemed to need continuing NHS care, moved to a purpose built 'campus' home in the grounds of the old hospital site. The other three women moved into separate residential care homes in the community.

Ethnographic methods

Ethnographic methods were used because they seek to understand experience from the point of view of the participants, and because they study people in their normal surroundings (Denscombe 2003). These methods involve participant observation and in-depth interviewing (where possible). In this study, over 300 h of participant observation were carried out to get to know the women and the nature of their daily lives. On average, the ward and campus home were visited for a 5-h period every 2 weeks, at all times of the day and night, for over 18 months. The three women who moved into community homes were visited in their new homes for between 5 and 7 h, at different times during the day, approximately every 3 months, for over a year.

Informed consent, based on full comprehension of the nature of research in general, and of this study in particular, could not be obtained from the individual women themselves because of the severity of their intellectual disabilities. In circumstances such as these, process consent, i.e. the negotiation and renegotiation of consent with the participants throughout a project, is an appropriate method of monitoring responses to the presence of the researcher on a continuous basis (Usher & Arthur 1998).

Permission to do the research was gained from the leading consultant psychiatrist in the institution and from the independent local research ethics committee.

Analysis

A grounded theory approach was used in the analysis of the data (Strauss & Land Corbin 1990). It involved the coding and identification of themes from the research data, and the continual process of going back and 'checking out' assumptions through the collection of new data. The computer software NVivo was used to aid the organization of data.

Results

The women's experience of transition

All the women in the study experienced the process of transition as largely negative. However, their experience differed depending on where they were moving to. The eight women who were going to live in the campus home in the grounds of the old hospital experienced more chaos and confusion during the transition, including an unexpected move to a temporary home for 10 months. This involved a number of staff leaving, resulting in an increase in agency staff unfamiliar to the residents, and a decrease in daily activities.

The three women who were going to live in residential homes in the community did not have to move to a temporary home, and in that sense the transition was less traumatic than for the other women. However, they experienced more losses. Apart from the loss of their home, which all the women experienced, they also lost relationships with all the staff whom they had known for many years, and who understood their ways of communicating, and their individual needs and preferences. They also lost their relationships with all the women they had lived with for many years. In addition, they no longer had the comfort of being known by people in the immediate surroundings of the ward, including the day centre, and other units in the hospital grounds. When they moved into their new homes they were, in all senses, very much alone.

Before the first move, the constant talk of moving, and the feelings of insecurity among staff, coupled with the lack of information about what was actually going to happen, heightened the overall sense of insecurity among the women. This was further increased by the departure of two of the women to their new homes in the community. The women who were left behind did not seem to know that the two were not coming back, and some of the women became aware that they too would be leaving their home. Eva was particularly disturbed, and said very clearly 'I don't want to go' – looking wide eyed and shaking her head.

During this period she was said to talk a lot about death. The behaviour of other women was also said to have become 'worse'.

The move to temporary homes

The move to the temporary house increased the women's sense of insecurity. Some asked for their old home. The unsettling effects of the temporary move are illustrated by Jody's reactions:

At breakfast, Jody was silently crying as she ate her porridge. Tears were streaming down her face and her eyes were closed. I went over to her, put my hand on her arm and asked her if she was all right. She did not really respond in any way. Later while Staff C sat next to Jody, I asked her if Jody often cried. Staff C said that 'Oh yes she can cry and she can scream'.

Jody was no longer surrounded by people who knew and understood her, and she withdrew into herself, spending large amounts of time on her own. Her frequent self-injury was described by staff as 'attention-seeking'. She often screamed loudly, upsetting the other women. One woman shouted at her, others left the room, but wherever they went in the house they were aware of the sound of Jody's screaming. It is poignant that some 14 years earlier it was said at her case conference that '[Jody] does not need permanent residence in a hospital', but she was not one of three women chosen to move into the community.

During this period some already hostile relationships between the women deteriorated further:

A scuffle broke out between Anita and Eva. Eva threw the cutlery tray at Anita...Anita fell backwards and toppled onto the floor. She started to cry. Eva started to move the table... Staff B took Eva next door. [When] she returned...Eva was still fraught. She started to kick Sally. Sally moved away with her chair. The staff told her to stop kicking. Eva started to hit her head. She wailed...She started to play with her cutlery. She picked up her knife and made a movement towards herself, then she picked up her fork and scraped it down the side of her cheek. The staff intervened at this point and took her away. There was screaming from the next door room.

Other women became aggressive towards other residents and staff. Eva, for example, became uncharacteristically unpredictable and aggressive:

Eva turned round to me and hit me in the chest... [A staff member] said that she should be on 1:1 again as 'she can't go around hitting people'. At one point Eva got up and walked over to Molly who was sitting on the seat by the TV. She bent over and whacked Molly in the stomach. Molly curled up, moaned and began to cry.

In fact, the restrictions on Eva's freedom which would inevitably result from her aggression towards other people may not have been wholly negative for her. The provision of a member of staff to be beside her the whole time may well have provided her with some of the reassurance and human contact that she so obviously wanted, as expressed in her relationship with the researcher, someone who was prepared to spend time with her and listen to her expressions of unhappiness and anxiety. Eva was one of a few women who were able to express their fears and anguish verbally:

She said that she felt like a baby and wanted to be held...She talked about various things all in a low mumbley voice...a resident who she had lived with in the past; a ward where she had lived many years ago...the old ward [which they had just left], dying, being scared...At one point she started to cry...[she] said that she wanted 'to go home', Staff B said that this was her home now and that they would all be here to keep her safe.

And on another visit:

I sat next to Eva. She was crying...At one point she turned to me and speaking very quickly talked at me...It ended in a half question 'And you can't save me can you?'...As I left that evening...I said to her 'Look after yourself' to which she replied, 'I can't look after myself'. At one point I heard her say 'This place is a prison, there is no way of getting out alive'.

During this already chaotic period in the women's lives the staff themselves were stressed and exhausted, and increasingly took sick leave. What they saw as their own unfair treatment by the management made them angry and depressed. Among these staff there seemed to be no sense of planning for a new future for the women, but simply a need to get through each day. The mood of the staff did not improve the women's sense of insecurity, and yet the women's expressions of anger and anxiety rarely seemed to be understood in the context of the trauma of the move. The staff repeatedly talked of the women's 'attention seeking behaviour', thereby separating their own experiences of loss and insecurity from those of the women.

The move to permanent homes

Lack of preparation

The eventual move to their permanent home in the hospital grounds, caused somewhat less upheaval than the previous move, but again was not fully understood by the women, who found it hard to comprehend that this was going to be their home for good, and that they were not going to go 'home' sometime soon.

Of the three women who moved into community homes, two had made visits to their new homes before they moved in. The third was considered too intellectually disabled and was therefore not prepared in any way. The three women showed their insecurity in various ways, including incontinence, crying, destructiveness, self injury and withdrawal:

She was curled up under her duvet...I uncovered her head and said hallo...I asked her how she was, she said 'bed'...she pulled the covers back over head.

It is perhaps unsurprising that the transition appeared to be a negative experience for all the women. None of them had been involved in the more important aspects of moving, and they were given little preparation and almost no direct information about what was going to happen.

The women were not invited to their own discharge meetings, and there were no clear rituals marking the impending transition. They were not present at meetings about where they were moving to, nor involved in choosing who they could live with. They also lacked any control over the process of their move. Those who were considered more able than others were taken to visit their new home, or saw it as it was being built, but it is not clear how far they understood that this was where they were going to live. Those who were considered to be less able did not see their new homes until the day they moved into them.

Lack of support

Inadequate support from the people around the women also had a negative impact on their experiences of transition. As already discussed, the staff on the ward were often too preoccupied by their own anxieties about the closure, and whether they would be re-employed, to be able to deal with the women's emotions. They tended to be focussed on their own survival, because they themselves felt unsupported and alone, and although they were aware that the women were suffering they were unable to give adequate support to them, be constructive or try to reduce their fears.

Other avenues of support available to the women were also limited. Only three of the 11 women had contact with their families more than once a month, and these women were supported both emotionally and practically in the move. However, the majority of the women had little contact with their families and four had no contact at all. One woman had a close relationship with an independent advocate, but this relationship ended after the move to the community home, which was too far away for the relationship to be maintained.

Inadequate information transfer

The women's distress continued after they had moved to their new homes. This was clearly the result of various

failings in the planning and implementation of the transition process. One of the most significant was the lack of inadequate information transferred between the ward and the new homes. This was due both to delays (and misplacement) of hospital notes and an absence of personal information. It meant that staff in the new homes did not know about individuals' family histories, their pasts, their likes and dislikes, their preferred means of communication, their personal care routines and sometimes even their medication. New staff were not aware of personal preferences, such as whether someone liked a hot drink before bedtime, suffered from travel sickness, liked to sleep naked. In the case of one woman, no one seemed to know when her birthday was. When attempts were made to pass on information, for example, through the use of 'memory books' made by the staff on the ward, they were rarely used in the new homes. This was both because staff in the new homes saw the institutional past as negative and wanted to move on from it, and partly because the books were hard to use. They did not include written information about who was in the photographs, and were therefore difficult for staff to use to help residents remember their pasts.

Changes for the better

For the majority of the women, the quality of their lives changed very little in their new homes. However, again, their experiences differed depending on where they moved to. Those who moved to the campus home experienced least change for the better. Although they had individual, personalized, bedrooms for the first time, in the main their lives continued to be restricted by rigid routines, strict rules, few daily activities and few opportunities for relationships beyond the staff team.

Two of the women who moved to residential homes in the community experienced some change for the better. They were able to take more control over several aspects of their lives. For example, Christine, who was visually impaired, was given more opportunity to choose what she wanted to wear.

We went through to Christine's bedroom so she could pick her clothes. Staff I encouraged her to stand by her wardrobe and choose. Christine moved her hands over all the trousers. She wanted 'jeans'. Staff I said that they were all in the wash. She tried Christine with another type of trousers. Christine said 'no'...Staff I then went to the laundry to see if any of Christine's jeans had dried.

However, they were still unable to fully explore themselves as individuals, their preferences, their abilities and their interests. For example, the activities offered to one woman were dependent on what the other residents did: trampolining, which she did not enjoy, or a trip on the bus, when another resident needed to be picked up.

Only one woman who moved to a community home experienced dramatic changes for the better. She was encouraged in her individuality, explored new places, learnt new skills, made choices and created her own rhythm for the day. In the first year, she changed from being someone who was locked into a baby role, talked in a baby voice, walked like a toddler, and spoke repetitively, into a woman who was able to speak clearly, communicate directly, and engage more freely with the world as an adult.

Discussion

Lack of involvement and support during the transition process

There are a number of reasons why the women lacked involvement in the process of their moves:

- It was not the policy of the management to include residents in discussions or formal meetings about their individual futures.
- The majority of the care staff lacked practical skills in communicating information to people with more severe intellectual disabilities. As a result, they did not know how to pass on information in an accessible way or how to prepare people for what was going to happen.
- Care staff did not get support and advice from their managers about how to involve the women in the transition process.

The women were insufficiently supported because:
- Care staff had their own anxieties, not only because they themselves were undergoing a sense of loss and insecurity, but also because their individual futures were uncertain.
- Care staff had not been given sufficient training or preparation to cope with the transition.
- Many staff tended to see the women's distress and anxiety as a result of their intellectual disability and mental illness, rather than as expressions of emotion triggered by change and loss.
- The women's relationships with their families and advocates had not been maintained over time because their input was not made a priority, and the value of their contribution was not fully understood.
- There was also evidence to suggest that the staff's perception of intellectual disability continued to be informed by a medical model, rather than a more social understanding (Oliver 1990).

Failures in the transmission of information to the new homes

There are various factors which contributed to the lack of information transfer between the old and new homes:

- Care staff did not recognize the value of the stories and knowledge they held of the individual women.
- The women were not fully regarded as ordinary human beings with pasts, experiences and relationships, that went beyond the context of their present lives and which contributed to making them who they were. In this way, the women could be safely conceptualized as 'other', enabling the staff to protect themselves from the anxieties of working with people with disabilities by avoiding seeing them as people like themselves (Bott Spillius 1990, 604).
- There was a general belief that because the women were supposed to be making a fresh start in their lives, their institutional past should be ignored and forgotten.

Experience of new homes

The women's experiences of their new homes varied for a number of reasons:

- Staff attitudes towards the women, their disabilities, their capabilities and their similarities to others, varied between the homes, and this had considerable impact on the number of opportunities available to the women, what activities they were offered, the new skills they were taught, and how involved they were in the home and in the community.
- The organizational structure and culture of the homes influenced the women's experience of their new homes. In the campus home, for example, the hierarchical structure and the rule culture continued as it had done on the ward, resulting in a minimal change to the amount of autonomy the women had in their lives.
- In the new campus home, some staff remained from the previous ward, and their ways of dealing with the women did not change radically. Furthermore, because they knew the women, their actions, beliefs and attitudes were likely to have been accepted and followed by incoming staff.
- In the community homes (especially one) care staff were given greater responsibility and more opportunities to be autonomous and use their initiative in response to the wishes and needs of individual residents. They generally understood the women's behaviour and needs less in terms of their disabilities and challenging behaviour, and more as changeable states that altered depending on people's daily mood, the support they had, and whether they felt safe and relaxed in the situation they were in. In the home where there was the greatest improvement in the woman's life, staff attitudes specifically focused on residents' individual capabilities.
- An important factor was the level of support and training available to the staff in the homes. This dramatically influenced the abilities of the staff to communicate effectively with the women, teach them new skills and carry out tasks alongside them.

Conclusions

It is well known that people find change difficult (Bridges 1991). Moving house can be a traumatic experience at the best of times, but for people who have spent their lives in the closed environment of a total institution, 'moving house' is a momentous and potentially frightening experience. Those involved will experience disruption, confusion, chaos and loss (Booth *et al.* 1990). However, it is surprising that, after many years of hospital closures, the planning process and actual transition appear not to have become smoother and more efficient. Similarly, in spite of evidence over many years of 'micro-institutionalization' (e.g. see Sinson 1993), the lives of people with severe intellectual disabilities in their new homes do not appear to have significantly improved, especially in campus homes (Department of Health 2006).

These experiences can perhaps be explained at one level by the prevailing attitudes towards people with severe intellectual disabilities, who continue to be regarded as being 'not like us'. Because they have little or no speech they tend to be perceived by others as 'as essentially unknowable beyond the superficial sum of their impairments, basic needs and challenging behaviour' (Hubert & Hollins 2006, 71).

The results of this study are supported by Johnson (1998), who also found that changing the physical environment of the women she was studying did not succeed in changing the fundamental ways in which they were viewed. The perception of them 'was swamped by the existing discourse which constituted the women as objects' (Johnson 1998, 186). People with severe intellectual disabilities are seen as being too different, too disabled and too challenging to lead lives like 'us'. They are not thought of as people who have pasts, have emotions, who experience feelings of loss, who grieve for old friends, who feel anxious about change, who have sexual needs or who suffer from loneliness. Furthermore, it is still often believed that the reason for these perceived differences lie in their disability, rather than in what they are taught, the opportunities they are given, how they are supported, and the expectations of those around them.

For people who have severe intellectual disabilities and challenging behaviour, such as the women in this study, there are additional problems. Research has shown that moving out of an institution can be successful, if psychiatric support is maintained, and adequate community resources provided (e.g. Mansell 1994).

The Department of Health (DoH) White Paper, *No secrets* (DoH 2000) defines institutional abuse as 'poor care standards, lack of positive responses to complex needs, rigid routines, inadequate staffing and an insufficient knowledge base within the service' (DoH 2000, p. 10). Recent inquiries into two services for people with intellectual disabilities in

the UK, both in hospitals and homes in the community, have highlighted this persisting institutional abuse (Commission for Healthcare Audit and Inspection 2007; Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006). The inquiry into Cornwall NHS Trust stated:

Little training and the practice of unqualified staff predominantly learning by observing their peers, has meant that practices, some of which were very poor, have become ingrained (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006, p. 64).

The report into Sutton and Merton PCT concluded that:

This type of institutional abuse was largely unintentional, but it was still abuse. It was mainly due to lack of awareness, lack of specialist knowledge, lack of training and lack of insight. It was exacerbated by low staff morale, shortages of staff, inadequate supervision and a lack of leadership (Commission for Healthcare Audit and Inspection 2007).

The sad conclusion must be that dismantling the institutions is not enough. Material surroundings may be improved, but institutional practices, stigma, social exclusion and lack of autonomy continue. As the Cornwall Report emphasized, there is a vital need for the development of training programmes for staff, and also for them to receive the supervision and support necessary to 'deliver care in accordance with the principles of the *Valuing People* strategy (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006, p. 67).

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