'And people said they will never do it!'

Staff Stories of Resettlement from Institutions for People with Learning Disabilities in the North West of England

Duncan Mitchell and Melanie Chapman

Manchester Learning Disability Partnership and Manchester Metropolitan University

May 2008

Working towards better futures for people

PREFACE

The North West Training and Development Team and North West Regional Valuing People Support Team commissioned this piece of work in conjunction with NW ADASS, the TUC and RCN in order to celebrate the North West Workforce following a request made by the Regional Health and Social Care Lead Officers Group.

The North West Training and Development Team has been in existence since 1984 and has supported the region to make the transformational changes we have seen in those years and will continue to do so supported actively by the North West Association of Directors of Adult Social Services.

In the North West we have lead and experienced transformational change to the way the support available to people with a learning disability and their families is arranged.

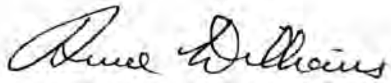
- We closed our long stay hospitals in the early 1990's in this region which is getting on for almost 20 years ahead of other areas of the country – something the health and social care workforce, people with a learning disability and their families should be rightly proud of.
- In Control was 'borne' in Wigan, lead by individuals and families and supported by a workforce wanting to further push the boundaries to ensure that all people have control to live the life they want with the support that best meets their needs.
- Oldham and Manchester head up the league table in terms of the number of people with an individual budget nationally.

Lots is written about the Government's 'personalisation' agenda and you will recognize many of the comments made in this report in relation to hospital closure as those currently reported in relation to personalisation. We wanted to evidence that the North West is keen to embrace this agenda, we have done it before when we were told 'It will never work' and we will do it again.

We don't know all the answers yet, and perhaps we never will nor should strive to as that would create complacency, but we do know that the way we do things at the moment does not work for lots of people who are entitled to health and social care support.

The North West workforce has faced, head on, major changes to our working practise before, embraced them, resolved the difficulties and because we share the values underpinning this agenda, together with individuals, their families and communities the North West health and social care workforce will once again rise to the challenge to ensure that we facilitate the full inclusion of people in community life, through partnerships with people with disabilities, families and organisations.

This report shares our learning about what helped the workforce (individually and strategically) meet the challenges to working practice faced during those days of resettlement from long stay hospitals in the hope that what we learned can support the workforce meet the challenges on the next stage of our journey.



Anne Williams – NW ADASS/ Chair NWTDT Commissioning Group

Charlie Barker – NW ADASS/ Regional Task Force

Lynn James-Jenkinson – Director NWTDT

Dave Spencer – NW VPST/ CSIP

CONTENTS

Acknowledgments .... page 5

Executive summary .... page 6

Introduction .... page 8

Method .... page 9

Findings

i. Reasons for coming into the work .... page 12

ii. Remember Remember .... page 13

iii. Drivers for change .... page 18

iv. Stories of change .... page 21

Discussion and conclusion .... page 36

References .... page 40

Appendices

i. Participant Information sheet

ii. Consent form

iii. Interview guide

Pathways Associates Community Interest Company TRAINING & DEVELOPMENT

NORTH WEST TRAINING & DEVELOPMENT TEAM nwtdt

Acknowledgements

This research was funded by the North West Training and Development Team, The Royal College of Nursing and The Trades Union Congress. Thanks particularly to Dene Donalds and Lynn James-Jenkinson for commissioning the research.

The authors are grateful to Sandra Gallagher and Gail Sullivan for helping with the typing and interview transcripts.

A special thank you to the twenty people who agreed to give up their time to be interviewed. Several others offered to participate for this project and a number of people suggested potential participants.

Also a big thank you to the Royal Albert Project web site **www.unloockingthepast.org.uk** for allowing the use of pictures from their image library.

EXECUTIVE SUMMARY

Background

The main purpose of the research project was to explore the impact of major change in service provision on the learning disability workforce and to identify factors facilitating and hindering how members of the workforce deal with such change. The focus of the research was on the experiences of people who worked in services provided for people with learning disabilities during the resettlement process from large institutions. This information will be used to inform the process of change within current learning disability services.

Methods and Participants

Twenty people, all of whom worked in long stay institutions for people with learning disability and transferred to community settings were interviewed.

Key findings

Participants were asked about their experiences in the institutions and their responses have been categorised as:

- Shame and pride. Whilst there was a sense of shame and embarrassment about the conditions in the institutions staff also felt that there were examples of good work within difficult conditions.
- Stories of deprivation. Participants recalled many stories of extremely poor conditions in the institutions.
- Staffing and work. Institutional life was characterised by poor staffing levels and difficulty in retention of staff.
- Power and control. Participants suggested that power within the institutions lay with both charge nurses and domestics.

There were a number of drivers for change at a national, regional and local level. These included national policy and legislation, philosophies such as normalisation, social role valorisation, the regional implementation group and Model District Service, and local champions. However, some people were unaware why change was happening and there was some sense that people with learning disabilities, their families and staff were not adequately involved in planning for change.

There were three main reactions to first hearing about community care which have been categorised as pragmatic, enthusiastic and doubting. Several of the participants who had been sceptical about whether people with learning disabilities would be able to manage in the community changed their minds in the light of experience. All of the staff adjusted to the very different working circumstances and despite some caveats became enthusiastic about community care.

There were four significant features connected with the move to working in the community:

- Resettlement was a process, not a sudden event. Some staff as well as some people with learning disabilities moved in and out of institutions before finally settling in community settings.
- Things did not always go smoothly. There were initial problems for people with learning disabilities and staff in working in the community.
- There were contradictory views about freedom and support although staff generally appreciated the freedoms that they gained in working in the community.
- Moving into community settings did not mean an immediate shift of power and control to people with learning disabilities or to support staff within the staffing hierarchy.

Conclusions of the research in relation to contemporary issues are that:

- It is important that those planning future change identify potential drivers for change and clearly communicate both the need for change and the planned process of change to staff, people with learning disabilities and their families.
- It is important that the workforce, people with learning disabilities and their families are involved in planning change.
- Major change can be achieved even when members of the learning disability workforce have doubts about proposed change. However, it can be useful to consider the concerns the workforce may have when planning for change.
- A range of factors can help influence reactions to change and reassure the workforce, including:
    - Information about reasons for change
    - Involvement in planning change
    - Witnessing and hearing about positive change
    - Secondments and security of terms and conditions

- Change may lead to challenges as well as improvements for some people with learning disabilities
- There are a number of ways in which the workforce adapted to change and grew in confidence:
    - The passage of time
    - Support from colleagues
    - Exchange of information and advice
- When considering how to attract people to work in learning disability services and retain staff it is worth bearing that people have a range of motivations for working in this field, including: pragmatic, an interest in working in a caring role, or prior experiences with people with learning disabilities.

INTRODUCTION

At the beginning of 2007 the North West Training and Development Team (NWTDT) asked the authors to conduct a series of oral history interviews with people who were involved in the direct care of people with learning disabilities in large institutions in the North West of England at the time of resettlement.

The history of large institutions for people with learning disabilities in the UK has been recorded elsewhere (see for example, Atkinson, Jackson, & Walmsley, 1997; Thomson, 1998; Wright & Digby, 1996). The largest institutions in the North West of England were the Royal Albert in Lancaster which opened in the nineteenth century and Brockhall and Calderstones in the Ribble Valley which both opened as what were then known as Mental Deficiency institutions soon after the First World War. With the exception of Calderstones, a small part of which remains as an interim secure unit, the large institutions along with the slightly smaller ones have now closed. The process of

closure took place during the 1970's, 1980's and 1990's and in the North West followed the policy laid out in the Model District Service (North Western Regional Health Authority, 1982).

In the North West, since the closure of the institutions people with learning disabilities have been supported by statutory and independent agencies in ordinary housing under the model broadly envisaged for a Model District Service. Whilst this model has generally been considered a great success the context of service delivery is changing. Policy and service development in the 21st Century is being informed by personalisation, in other words a system in which people with learning disabilities have control over their own lives.

Changes in services will affect many people including people who work in learning disability services. The research reported here is about the potential impact of change on staff, many of whom may be understandably nervous about changes in the way that they work.

The NWTDT commissioned this research to influence current policy development. The researchers were asked to interview people who had worked in institutions and then transferred to community settings. The purpose was to identify stories of change that would inform current debates about employment patterns.

Following this introduction, the report describes the research methods used and the participants who took part in the research. Two sections follow, the first reports on what participants said about the institutions and the second presents stories of change. This is then followed by a discussion of the findings and conclusions in relation to the implications for future changes for learning disability services.

METHOD

In depth semi-structured qualitative interviews were carried out with twenty people.

Potential participants were identified through snowball sampling (R. Atkinson & Flint, 2001). The research team asked people who they knew had worked in institutions and people who had worked in learning disability services for some time if they knew of anybody who would be eligible to take part. As people were interviewed they were asked if they knew of anyone else to contact.

In order to take part participants had to have worked with people with learning disabilities in large institutions (for example, NHS campus or hostel) in a hands-on role and to have continued to work in a hands-on role with people with learning disabilities following resettlement into the community. Participants could now be retired or no longer working with people with learning disabilities. People who were currently employed by the NHS could not take part as NHS ethical approval was not sought due to the timescale of the project (ethical approval was gained from Manchester City Council and the Manchester Metropolitan University). Potential participants were sent a letter inviting them to take part and information about the research (a copy of the letter is provided in Appendix 1). People who agreed to take part signed a consent form (see Appendix 2).

Standard questions were asked of all interviewees. Participants were asked why they came into the work in the first place, their experiences of working in a large institutional setting, when they first heard about community care, why they decided to move to a community setting and their experiences in the different working environment. Interviewees were also asked what hindered, or helped them in the new role. The interview guide can be found as Appendix 3.

Interviews were recorded and the majority of interview tapes were transcribed in full. Other interview tapes were transcribed in part and listened to in full with detailed notes being written. The transcripts and notes were then closely analysed to draw out common themes. Each of the authors carried out an initial thematic analysis of the interviews separately, reading and re-reading the transcripts and recording the themes arising from each interview. The authors then met to discuss the themes within the interviews and the patterns emerging across interviews (Aronson, 1994).

All interviewees were offered the option of retaining their tape, of the tape being destroyed or of the tape eventually being placed in an oral history archive. Most respondents were happy with their tape being retained with the intention of eventual deposition in an archive. A small number of tapes were not of sufficient quality (in term of recording rather than content) to retain in an archive but all could be transcribed and were used for the research.

Participants were given clear assurances that the report would be anonymised. The number of participants was relatively small and the number of institutions even smaller. As a result of this we have avoided the use of any information that might connect people to specific institutions. The use of other identifiers, including gender has also been avoided.

PARTICIPANTS

Twenty people were interviewed between August 2007 and March 2008. Twelve women and eight men were interviewed. Participants were aged between 36 and 65 years at the time of the interview. All of the participants described themselves as White British. The research team did not try to achieve a social mix and merely applied the criteria for inclusion to the people who were suggested through the snowballing process. Further comment about this is made in the discussion.

The interviewees had worked at institutions across the North West Region as follows:

Newchurch 1
Newchurch and Cranage 2
Calderstones 2
Brockhall 4
Calderstones and Brockhall.............. 2
Offerton House 1
Lisieux Hall 3
Royal Albert.. 2
Various Local Authority Hostels 3

One of the interviewees started working in the institutions in the 1960s, 10 in the 1970s and 9 in the 1980s. The period in which they left the institutions to work in smaller settings ranged from approximately 1979 to 2002.

FINDINGS

The findings are organised in four sections. The first section summarises how people first came to work in the institutions.

The second section describes participants' experiences within the institutions. This section goes beyond the original research brief but is important because many of the respondents were keen to talk about their experiences within the institutions. Some such stories have been told before (Mitchell and Rafferty, 2005). However this is the first time that some of the respondents' stories have been told and there is some fresh material that it is important to highlight. This background information about life in the institutions also provides insight both into why change was necessary and also into how much the nature of work changed for the learning disability workforce.

The third section discusses the drivers for change which emerged from the interviews and the fourth section, the stories of change, explores the experiences of working in a new setting.

1. REASONS FOR COMING INTO THE WORK

All interviewees were asked why they came into the job in the first place. The reasons have been divided into three broad themes as follows:

Reasons for coming into the work	N
Could have been any job	
Hours were convenient	2
By accident (needed a job, came across it)	5
Interested in the work	
Wanted to work in care	2
Wanted to work with people	1
Wanted to do something different	1
Wanted to be a nurse	1
Prior personal contact	
With people with learning disabilities	4
With family who worked in the institution	3
With other staff	2

People therefore came into work with people with learning disabilities for quite different reasons.

2. REMEMBER, REMEMBER

Participants spoke in great deal about their experiences working in the institutions. Working in these settings clearly had a great impact on them and it is important to have some knowledge about life in the institution to realise why change was necessary and to understand how great the change in work was for the learning disability workforce.

Shame and pride

Several participants had ambivalent attitudes towards the institutions. They were free with their criticism of the poor conditions in the past. However, several also did not like to hear others criticise the institutions:

> I mean I don't like criticism of the institutions. Where people talk very negatively about it. Because yes, there were a number of staff who you wouldn't want to look after your relatives, you will always get people who are not right for the job. The vast majority of staff were doing what they thought was the best in the circumstances and they weren't on their own. The medical profession, social services, or whatever they were called before they were called social services, welfare departments, they pushed putting people in institutions because there were no alternatives for families at home.

There was a clear sense that participants felt that whilst all of the large institutions were bad, some were better than others and within each there were very different standards. For some there was something akin to tribal pride. One participant for example who moved from one institution to another for promotion found that this was 'much to the annoyance of my family' who worked at the original institution. Others had experience of working in different institutions and were very clear that the standards did not compare. It is apparent that there were differences between and within the institutions. One respondent for example described how one unit was different from another within the same institution:

> Much different environment. That was a semi-detached house, much smaller numbers, around 20-25 people, which doesn't sound a lot, but another 5 or 6 people with additional problems makes a big difference. It was a homely environment, people had their own clothes, their own wardrobe, their own space, so it was completely different, the same hospital, but completely different environment, and completely different attitudes from staff. It was almost as though, there were three wards that were purpose built.....wards and if you ended up being on one of those wards, either staff, or as a person who lived there, then you had an additional label tagged to you, you were either a problem staff, or you were a problem person in the institution and therefore lost out on certain rights and privileges. It was never said, explicit, but it was implicit.

There were references to particularly bad wards that had very poor standards and to some members of staff who were particularly feared for their brutality.

Some participants expressed shame that they had been part of life in the institutions:

> Looking back now I remember some of the things, because I'm so embarrassed, to think that I thought that was ok.

However, there was a great pride in being able to make changes within the institutions. One participant for example recounted how their ward was the first to get a washing machine so that clothes didn't get ruined at the industrial laundry. Another vividly remembered the first ward to have a carpet and how staff would visit from others wards just to see this innovation. Others felt that they were able to get to know the residents really well and were able to give individual care and bring pleasure into people's lives in very difficult circumstances. Despite these circumstances some residents did have opportunities in terms of work, freedom to move around the grounds and local communities and relationships. Most of the participants shared this contradictory view of the institutions, in one part of the interview they would be giving examples of how bad things were and in others would be pointing to positive elements within the institutions.

Deprivation

Many participants gave harrowing examples of the poor conditions that were experienced in the institutions. This provides further evidence of overcrowding, poor staffing levels and dehumanising conditions that existed. Examples of practices that had become accepted in some areas included several people being bathed without the water being changed, children being fed while they sat on their potties, and several men being shaved with one razor. Participants were highly critical of the examples of life within the institution that they gave, even when they had been involved in them themselves. For example one participant described some measures that were taken to ensure that everyone had something to eat:

> It sounds appalling but the food was served and put on the bottom of everybody's bed or put at the side of the chair and the poor person who got their dinner last they would be stone cold. In the early days and again it is embarrassing, I blush to myself when I say it, we used to put everything in the one dish and I used to feel queasy feeding – they put the dinner, pudding and tea in the one bowl and it just went down.

Often people did not have their own personal possessions or clothing, sharing communal clothing or items:

> So the first ward, children's ward that I went on, nobody had a toothbrush, nobody had any shoelaces. So it meant they couldn't walk anywhere because they had no shoes, everybody had hospital issue lace up shoes so they couldn't go out anywhere. So, one of the first things that I did when I got there was to go to the stores and ask for 25 toothbrushes and 25 sets of shoelaces and the store man said, we've never had an order like that, it's not on the

> supplies list, you know, so there wasn't any expectation, and there hadn't been, nobody bothered, the expectation was that well somebody eats shoelaces on that ward so we're not bothering replacing them because they'll get eaten again. So it wasn't, I don't think it was malice, it was just that expectations were absolutely rock bottom.

Frequent themes arising within and across interviews were that people with learning disabilities who lived in the institutions lacked opportunities for individuality, privacy, dignity, choice and control. They were often deprived of contact with their family and the local community, day-time activities and the opportunity for development. These seemed to be common features of the institutions there were exceptions within the institutions and attempts were made to improve this situation.

The level to which people who lived in institutions were deprived of some of the most common experiences is illustrated by the following story from a member of staff who took a group of residents on holiday:

> We went and it was a lovely hotel and the first morning at breakfast they put a rack of toast on the table and I was chatting away to one another and I suddenly realised that the one who was autistic kept looking at this toast ....and he scratched it and sniffed it and then he kept looking at me so I took a piece and put it on my plate and I took some butter and I buttered it so he copied me so then I put a bit of marmalade on and he copied me and so I bit it and when I did he did, and his little face lit up, and I said to my staff nurse 'look at that.' I never realized before he does not know what toast is because all the meals came in a metal container, and you got bread, and all you had in the kitchen was a geezer. We didn't have any cooking facilities at all. There was an oven where you could keep stuff warm, a big oven with no gas ring or anything cos they were dangerous weren't they? So we had no facilities. So when we got back we had a bit of a natter and I said 'well, why can't we have a toaster on the breakfast trolley.'

The respondent went on to describe the struggle that took place, eventually involving an exchange of correspondence with the Director of Nursing to get the toaster. This demonstrates how achieving apparently small changes could be difficult in such an institutionalised environment.

Staffing and work

Often participants had begun to work in the institutions at an early age and were young and inexperienced. Several talked about the initial 'shock' of working in the institution, particularly those who had no experience of people with learning disabilities. Some people spoke about how they did not receive information, training and support around institutional routines and how to provide personal care:

I remember clearly, giving someone a bath and nobody told me anything about giving somebody a bath and it's quite a hard thing to do. I mean when you're 18, 19. Like how much water do you put in. And things were locked away. So you don't know where the towels are. You had to make sure you put towels on the floor. And the bathrooms were very big. They were literally like a bath in the middle, they were very cold.

The staffing levels were poor with low numbers of staff to support large numbers of people with learning disabilities. Some of the older participants recalled that people with learning disabilities used to work on the wards:

Every ward had three or four service users who came from other wards and who were paid to work on the wards. So they helped with the cleaning, laundry. They would have specific responsibilities and they would come to help with the meals......On that first ward I went on seventy odd had to be fed at mealtimes.

The work was described as 'hard' and 'arduous' with long working hours. This difficult working environment led to problems retaining staff as can be demonstrated by the drop out rate:

Loads of people dropped out....My experience of....was you started with an intake of students, you were lucky if you ended up with 50% at the end. It was usually the good ones that dropped out.

There was little opportunity for promotion:

There wasn't anywhere to go, because the people who were sisters and deputies had been there for years and years, so as staff nurse you were always going to be.

Many of the participants could easily recall the routines that they worked in the institutions. The patterns of work and shift patterns were rigid and staff would know what they were doing from one day to the next. Their days were often very busy and this contrasted with many of the people who lived in the institutions who had less purpose in their lives. When asked to describe the routine of someone living in an institution a response from someone who worked with young people in an institution was:

It would be, get up at half past seven, breakfast around half past eight, sit in the lounge all day, walk in the lounge all day, lunch at around one o'clock, sit in the lounge all day, tea about 5 o'clock, sit around all evening, bath-time or wash-time around eight o'clock, bed around nine o'clock. And that was the day to day structure.

However, whilst the work could be stressful and there was little hope of advancement, several participants expressed a sense of satisfaction from working hard and having done something useful. There was also a strong sense of a staff community, camaraderie and culture within the institutions with many staff living on site, although people could feel victimised if they tried to challenge the prevailing culture. Several people felt that they had gained

valuable experience and skills by working with such a large number of people with learning disabilities with wide-ranging needs.

Power and control

Control within the institutions clearly did not lie with the residents. Life was organised in terms of what was convenient for staff, rather than what was best for people with learning disabilities:

> The wards quite often were influenced by the charge nurses and their philosophy on life. And the other powerful influences would be the domestics. So you'd have a core influence of established staff and then you'd have your student nurses. … you'd notice that at 10 o'clock that people wanted to use the loo and everything, but because a domestic was mopping the floor they weren't allowed to go out so they'd end up soiling themselves and so the people were deemed to be incontinent.

A number of respondents noted that the power lay with the cooks and domestics who might have been assumed to be fairly low in the hierarchy:

> Well they ran the place, had all the power. So you had to get on with the domestics or they would make your life very difficult.

There were clear hierarchies within the institution between management and nursing staff and amongst the nursing staff themselves:

> …even your dining room, the staff dining room, had its own hierarchy. You had what you called the subs table where all the nursing officers, and then you'd have the charge nurses and sisters would have their own table, and then like down the pecking order, so if you were a cadet coming in the other end you might get a table by the door sort of thing.

Hierarchies also existed amongst people with learning disabilities who lived in the institutions:

> The patients were referred to as low grade and high grade and that was, if you referred to a high grade patient as low grade it was an ultimate insult to them. If another patient or staff said you were low grade it was ultimate thing, so there was like a caste system.

In such a hierarchical system there was the potential for people to abuse their power, leading to bullying, abuse and 'brutality':

> Brutality, it's sort of brutality, different sorts of levels, not just not just physical but I think mentally, emotional, sort of things that people did….A combination of to and from staff and the patient and between staff themselves and between staff and people that lived there.

Some participants were reluctant to talk about their experiences or alluded to abusive practices. Others were clear that there were examples of financial, physical, emotional and sexual abuse within the institutions.

3. DRIVERS FOR CHANGE

The previous section shows that in general conditions in the institutions for people with learning disabilities and for many staff were poor. This section highlights the drivers for change that were apparent to the participants. A number of high profile scandals in the 1960s and 1970s showed that the poor standards were common nationally and helped to drive moves to close the institutions. A number of additional factors driving the move from institutional to community care were evident from the interviews. These existed at national, regional and local level. Legislation and the political drive towards hospital closure and community care was a national driving force:

> Enoch Powell had started it off I think in 1960 something when he was health minister. I mean the 1959 Mental Health Act had done quite a bit in making people informal. Up until then people had had to be certified to, they couldn't leave, there was no freedom. 59 saw a change, people were either formally held there or they were informal and could walk out of the door anytime. And a few did, I'm told. But in 1960s Enoch Powell, and I think that's widely available that speech he made was about the closure of institutions towards more normal living. Which always surprises people that it stemmed from...and a decision was made then to stop admitting children to the hospital.

At a regional level the Model District Service published in 1982 provided a model of how community services should be developed and a regional resettlement implementation group (RIG) was set up to develop and monitor a hospital closure plan:

> And then they got the closure plan for the hospitals and how the release of money and staff would help develop services that they'd outlined in the Model District Service. And the RIG was the, membership of the senior people from the hospitals and the senior resettlement people from each of the districts which were participating in the resettlement of the North Manchester region. And it was a very good watchdog. Because the Model District Service was the bible and somebody would be very brave to try and do anything that wasn't in that and had to face the wrath of you know 50 people sat around a table, and it actually did work, it was very good at keeping up the standards that had been set.

However, whilst these plans played an important role in driving change it appeared that sometimes the wishes and needs of individuals with learning disabilities were subjugated to the push to close the institutions and meet specific targets:

> People wouldn't be forcibly moved back to, say somebody was from [one city] but their established friendship was with two people from [another town] they'd try and accommodate that. But everything seemed to go out the door. And I'd be working with two people off one ward and another guy off another ward on the Friday and then on the Monday I'd go

> and I'd be wanting to work with those 3 people to help them with resettlement to [the local town] and the whole game plan had changed and they'd gone onto fast track and it were basically they were emptying wards at a time so I couldn't work with this guy over here, he was out of the equation, I had to find someone else off the same ward because that ward was being emptied. And people were put on bonuses for closing wards. So it became very challenging for us, it must have been mighty challenging for the service users and it was very challenging for the staff who were committed, who were still working there.

The development of the philosophies of normalisation, social role valorisation and inclusion also played an important role:

> I think that we were being taught by people who you know in the schools of nurses, that practices, in those days it was called normalisation, was the thing, and it was all about having, giving people the same values as we would expect sort of as individual people. And that was sort of cascading down then.

Often people had learnt about these principles during their training so the older members of staff may have remained unaware of these concepts. One participant mentioned how it was expected that those people trained in these concepts would initiate change within the institutions:

> But we got a new manager at that time....His job was to close the hospital and he was fantastic. He did lots of [Social Role Valorization] teaching. ...... And he did a 4 week induction for us and it was all about Social Role Valorisation and moving things on and individualised care and these were the people that he wanted to change it, and then he took on the role of closing the hospital as well.

As with the person above, several participants spoke of key individuals or 'champions' at management level within the institutions who played a vital part in pushing change forward:

> He was a very enlightened man and there was a nurse senior to him..... [who] headed up the nursing side, the ward side of it. And a man called [XXXXX]. And very quickly, with the support of the two consultant psychiatrists who were there, changed the whole, changed the hospital you have to say. Don't know how he did it, he'd have had a lot of opposition I'm sure but you wouldn't be privy to that sort of thing at that point.

One participant spoke about how a local champion moved a group of people considered most challenging into a community setting first. Seeing that living in the community could work for this group meant that people realised that resettlement could be achieved for the other people living in the institution.

These various drivers and the experiences of working within the institutions were leading to a growing awareness amongst a proportion of staff that life for people with learning disabilities needed to be improved so change was also being driven by individual staff members and teams:

> I think it's a personal thing that made you change your mind and drive something on. And from my point of view I wanted people who I was held responsible for to have a better quality of life than what they'd had previously. That was certainly another stepping stone for them moving out into the community. So yes, peers and people who I admired, other people, the senior people who were more influential than anything like written down shall we say, from Professors or whatever, or Americans driving things through... Mr Wolfensberger etc.

One participant spoke of how 'there were really two resettlement processes, one for the residents moving and one for the staff'. Attempts to encourage staff to move on from working in an institutional setting by providing secondment opportunities, holding job fairs and producing videos so that staff could get a clearer idea of what working in the community would be like and how their skills could be put to use in a community setting:

> And a video was done, and the job fairs that were held at the hospitals, all to convince staff that moving on was the thing to do.

However, whilst aware that change was taking place, the interview revealed that many people did not know why change was happening:

> I think by then I'd worked out that was going to happen anyway because the community team was being set up, but I wasn't aware it was a national policy and why it had come about, it was just something that was happening.

Some participants expressed dissatisfaction at the lack of involvement of staff members, people with learning disabilities and families in planning for resettlement:

> At no point were families and people with learning disabilities themselves consulted, it wasn't even thought of. So people with learning disabilities were sent back to places like [a local city], and never even asked. And they weren't consulted about who they were going to live with, that sort of thing wasn't seen at the time as being important.... People thought it was positive but that they were dismayed at the planning process, so that people didn't feel included in the planning process, and at [the institution] it felt like the discharge process was particularly fast, I think [the institution] was a late starter in terms of starting to discharge and once it started people were discharged very rapidly and the staff felt like it had been too fast and they weren't even consulted.

Therefore, although the need for change was clear and systems for change were established, the process of change was not always a smooth, positive experience for people with learning disabilities and staff.

4. STORIES OF CHANGE

This section is divided into two parts. First the initial responses to the planned changes are described. Secondly participants' experiences once working in the community setting are explored.

First reactions to hearing about community care

When asked about their reaction to community care participants gave a range of responses which have been categorised as follows:

- Pragmatic
- Enthusiastic
- Doubting

It s important to note that the categories help describe the responses, not the people who were making them. Some respondents for example talked about the views of other people rather than their own. Others did not give an indication of their first response to hearing about community care but what it felt like when they first started working in community settings. None of the respondents were personally hostile to community care although some did refer to others who were. There were stark differences in experiences. For example, one respondent who trained in the early 1980s said that all their training had been based on the expectation that future care would take place in the community. Another who trained in the late 1980s said that they had not heard about community care 'not even in the [nurse training] school.'

Pragmatic

Often the views that people remembered about first hearing about community care were pragmatic. There is a sense that people felt that they would 'give it a go':

> You move onto other things. We do it without thinking some times. I know the day I left the hospital was walking down the road and I remember my colleagues were driving past, I was walking down into [the local town] and I didn't think I was leaving the hospital at all. I was going to another experience. I had no expectations that I was going to leave. I just left and never looked back.

For some the motivation to work in the community was more the result of personal factors (such as convenience for childcare, health reasons or marriage breakdown) than a commitment to the philosophy of community care. Others said that they just fancied a change. Some of the pragmatic comments reflect the way in which people made the best of the situation they were in. One respondent who moved from a large hostel to a smaller setting explained that:

> If you would have asked me twenty years ago if I enjoyed working in the hostel I would have said 'yes, I love it, it's great. We do a great job.' If you ask me now I'd say exactly the same thing, but there's a vast difference between the two.

Two of the pragmatic comments were made by people who simply assumed that it was inevitable. One felt that they had been sold community care enthusiastically throughout their training and the other felt that the assumption was due to their relative inexperience in the work.

Enthusiastic

In contrast, other participants reported that they felt that community care fit with their personal ideology and ethos:

> I can't ever remember a time when I didn't think it was the right thing, never. Never have I doubted it.

Many people were enthusiastic about the idea; indeed one said that they were 'smitten by the idea of community care.' Some said that community care simply made sense and that it was the institutional setting that was strange. When asked at their job interview what they thought of community care one respondent thought:

> Surely people living in the community in their own houses would be a good idea and why not? It seems to me the question was more not why should people go to the community, but why should they not go there? Why should people not be entitled to whatever everybody else was?

Doubting

Whilst some people were immediately enthusiastic about community care, others had their doubts. In retrospect, some participants felt bad about their initial doubts about community care:

> Probably the same as every other person in the same line. 'Oh, that'll never work. It's not going to work, you can't do that, they're happy together.' Thinking about that now is terrible, but all the training we'd had was that people are better in this environment so suddenly to be told, 'no they're not actually, we're going to do this', there was a lot of opposition.

One participant was able to share the process that they went through in their thinking:

> I have to say, hand on heart, I was still of the frame of mind sort of in the 79, 80 period, that, community care, what's that all about, that will never work, you know, people here have got a good lifestyle. Ok, it's a segregated service and setting but what are they going to experience when they go out. And it was only when people that I respected, who were my colleagues, friends, and they were saying, 'look this could happen, no, honestly, it is, it's happening, people are actually starting to live in their own homes and this and the other'.....'they're living in a home and they're having a life.' It was only when I started to hear that from my peers

> that I actually firmly started to believe that it could happen, and that maybe what we were doing was probably, good and well intentioned, but probably not the right thing for people in the future.

Participants often talked about the doubts expressed by other people working in the institutions. Often doubts were of a practical nature. For example one respondent said that it was not that other people thought that it was not right but ‘we can’t see how this is going to be done’. This was similar to the view of another respondent who felt that she had been so used to institutional ways that when she went to work outside the institution she worried about how the hospital food would arrive from the kitchens that were now twenty miles away.

Another respondent reflected that there was a great fear of the unknown and that many people did not want to work elsewhere. She said that there were fears about jobs and that her views were initially about her own position:

> I don’t think I really thought about it from the [point of view of] the people we support.

Whilst there were concerns about their own future after resettlement some of the staff also drew attention to fears that they had had for the people that they supported and whether they would be accepted by the local community:

> You know, talking to people later, and certainly to relatives, and staff, were of the view that people with a learning disability would find it incredibly difficult outside, because at places like [names two institutions], they were accepted. They weren’t always liked by everyone who worked there. Some of the people who lived there were very unpopular. But everyone who worked there, not just the medical staff and the nursing staff, but the cleaners and the gardeners and the laundry workers, they were accepted in that community. There were no stares about people who’d got physical disabilities or odd movements, or tics and things, nobody blinked because you went about your work with an acceptance of them and their disability with whatever it presented to you.

There was also a feeling expressed that resettlement was not going to work, at least for some people, whom it was assumed would not be able to manage in the community:

> If you’d said to somebody in 1971 to 1978, you know, ‘this guy’s going to live in his own house in the middle of Manchester and he’ll do really well,’ they’d have just laughed at you. The people who would have had that mentality would have just laughed. In fact, to be fair, at some point, there were people in there who would have said, ‘no way,’ you know, they really could not manage, but they do, and people have been proven right in pushing for the closure of hospitals.

Even those who supported resettlement had concerns about whether the appropriate resources and planning were in place to make community care a success:

> It was definitely seen as a positive thing at [the institution], especially from students, couldn't wait for people to get out of that environment generally speaking, it was the older staff who were more difficult to, and it wasn't that they were saying, this isn't right, what they were saying was, we can't see how this is going to be done. And doubting that there'd be enough resources to support people in the community, and more worried about the consequences if it went wrong. So it wasn't, you know, it wasn't that people were being obstructive, it was that people were genuinely worried, because the planning was utterly haphazard.

As alluded to in the above quote, it could be hard to visualise what the future would bring, particularly without knowing what would replace life in the institution:

> Whilst you knew it was going to close there wasn't much closing activity going on. It was hard to imagine that one day that building wouldn't have people with a learning disability at all. That the kind of day to day activities would stop. That was really hard to imagine.

There were clearly many doubts about resettlement. These doubts surrounded whether change was necessary, how change would be achieved and whether the appropriate resources and planning were in place. Some members of the workforce had concerns about their own future, whether people with learning disabilities would be able to manage in the community and whether the community would accept them. It was difficult to visualise what the future would bring. The next section explores what did happen once people with learning disabilities and staff moved into a community setting.

Views and experiences once working in community settings

Once people had moved from the institution to community settings there was a different range of views. Four significant features in connection with the move are apparent from the interviews:

- A process rather than a sudden event
- A golden age
- There were initial problems and contradictory experiences
- Control

A process rather than a sudden event

For most people resettlement was not a sudden event in which one moment they worked in the institution and the next they were working in the community. This manifested itself in different ways. Some staff moved in and out of the institution as they took on different jobs. Others retained contact with the institution for some time. In many cases this was because the hospital continued to employ them on secondments despite their change of base. People also maintained friendships, had family connections, or in some cases lived in hospital owned accommodation.

There was also a staged process for many participants who moved from a large institution to a smaller institutional setting and then to a situation in which people lived in ordinary houses. Each stage of the move brought challenges and some of the participants were able to reflect on the way that things changed but also the way in which many things stayed the same. One person, for example, moved from a large institution to a setting described as a hostel that had been bought for people to move out of the larger institution.

> How did I find it when I got there? I found it a real culture shock……they had a big lounge in [the hostel], it was bought by the Health Authority, this big old building, and there was a lounge for the people who lived there and then there was a dining room where the staff tended to congregate and sit round chatting. So again, there were divisions there, very similar to what there was in the hospital, where you had a cup of tea you had it separate.

The process was also gradual for some of the people who lived in institutions. While the majority of people moved out and never returned, some needed more than one attempt at living in the community. One participant, for example, described how someone had moved out of the institution, had been very unhappy but was able to move back to the institution. It was eight years before he moved again and the second time was much more successful because he was ready for it and the right support was available for him:

> He's moved out so successfully and he's so happy, and he's got a whole new bunch of friends, he's got a fantastic support team, he's got volunteers, so many people helping him adjust to his new life and it's an absolute brilliant success. And I think the thing that went wrong the first time, he needed more time to adjust. And sometimes when big plans have been made by big people, the smaller people can't catch their breath

A golden age

On the whole respondents were enthusiastic about their new work. One participant described the early days of resettlement as a 'golden age' in their career. Another participant that their early experiences in the community were 'incredible', another 'fantastic, a really good, fun time' and yet another thought that it 'was an exciting time for everyone.' One participant spoke about how it felt 'easy' and 'natural' to be working in the community and how rewarding it was to see that their aim of people living in the community was being achieved and could work 'in practice' even for those where there were doubts about how successful resettlement would be:

No way would these guys resettle, there's no way they would settle in a house after living in hospital for 15/20 years, you have got no chance of it. After the first few weeks, months, we thought 'yes, you're probably right.' Then after a while we were amazed how quickly they became accustomed to the way things were. Not every door was locked in the building. That people knocked on the door. People were able to have a key if they were able to use one. That was one of the best times in my life. I really enjoyed that it felt like we were doing something that was cutting edge. They were going back to their roots – they came from [the City], the guys, and they went back to their family again......they were able to go on buses and do things differently ....As far as I am aware now they've moved into different houses and they are much happier.

People talked about the freedom they had to make decisions, for example choosing furnishing and décor and choosing staff teams. Particularly in the early days of resettlement it seemed that the new services were being well-resourced and that staff teams consisted of people who were committed to the new service model. There was a sense of seeing concrete changes in people's lives, both in their living situation and their quality of life:

So, it doesn't have to be earth-movingly different things but I think small things make big differences to people's lives and people having their own bedrooms, somewhere to keep their own clothes that nobody else would tamper with, or pinch.

Some participants talked about how much easier it was to be able to make change in the community setting and how rewarding it was to see the impact of change:

And we had a very small caseload, of people.... You know the community nurses wouldn't work with people who were very challenging, there wasn't anything really. So we got to go and quite quickly change people's lives. You got to go to somebody who used to smash windows with their head and had splints and quite quickly you could ....you could so easily make a massive difference to someone's life and look like you were effective when you were just doing something really basic. So that was quite rewarding then.

A common theme was that as people were now working with fewer people than they had been in the institution they were able to spend more time with people with learning disabilities and their families to develop more person-centred support:

It was easier in the sense of instead of trying to have a relationship with 10 people in one bungalow, or a relationship with the 2 or 3 hundred people on site because you could meet so many people, your energies were more narrowed down to 4 people. So you had a lot more time to work on relationships and on 1 to 1 interests, shared interests were developing. So it were good in that sense. ....You ended up not just working with that person and getting to know that person you got to know his family and his whole support structure... It's more holistic. [16]

Participants gave many examples of the opportunities for new experiences and personal growth many people had within the community.

There were initial problems and contradictory experiences

In contrast, however, a clear theme running through most of the interviews was that not everything went well immediately within the new arrangements and that some problems may still remain. Whilst there were many benefits to life outside the institutions, workers and people with learning disabilities faced difficulties in the community setting, both in terms of mixed experiences of life in the community and in terms of the new ways of working. These contradictory experiences and some of the ways in which such difficulties were overcome are explored below.

Adapting to life in the community

Sometimes there were immediate problems in that people in the local community did not accept people with learning disabilities:

> We'd go for a meal and get asked to leave and things because we had someone who might sort of make loud noises every so often and things like that.

Using local shops and facilities and developing relationships within the community tended to improve the acceptance of people with learning disabilities and aid their integration into the community.

Another problem is that as well as potential benefits there were potential risks of living within communities:

> The people we support have full community integration and they have full community presence. And surprise, surprise we have loads of problems. Because. There seems to have been a view that the community's made up of lovely people who crochet doilies and make jam. As soon as people start to enjoy full community presence, full community access we got issues around alcohol misuse, drug misuse, interacting with sex workers, exploitation from members of the general community, people acting in a way that could compromise them with the community. In the institutions, even within the hospitals, we never had any issues around police contact. We have a very close working relationship now with the police and it's not unusual for us to have people arrested on quite serious like issues. So the community access and presence, you've got to be equipped for the things that go with it.

Many respondents regretted that they had to limit the freedom of those they supported who may previously have been able to move around the institution and local area safely but were now considered vulnerable in the community or could no longer leave their new home on their own:

I think the freedom [in the institution] even though it was an enclosed freedom but it was freedom none the less. People said right I'll be back at dinner, what time dinner coming around, oh about 12.30pm, right I'll be back then just leave it for me if I'm not back, and you know they might not come back until tea time but you didn't worry… Here we get it all the time phone calls its 10.30pm such and such was going to his local club but he hasn't come back yet, oh my god ring the police. And I don't think we feel secure so I think in our duty of care we could actually subconsciously put restrictions on people cos were frightened cos if anything happened to them its my head that's going to roll.

One participant spoke of how the people with learning disabilities could feel isolated in the community after living in a large institution:

[The institution] was in fact a little village. Everybody knew everybody, they were all on first name terms. They'd either put pleasantries before those names or they'd put obscenities before those names, it was one of those environments. But it was a community that was structurally sound. And one of the biggest things I recall, was the impact on the people who were taken away from that. Because all of a sudden they were isolated and they were on their own. They only had me for five hours, or working 9 hours of the day, whilst when they were in the community they had two or three hundred people all the time. And they go from that to living on a house on their own with a member of staff or another person…..I think a lot of people were quite sad, very sad. Very insecure and some people developed challenging behaviour which resulted in them coming back on site.

A number of participants described how the freedom of people with learning disabilities to have sexual relationships was also curtailed once they moved into a community setting. In one case a respondent reported that this had an enormous impact on one woman's life.

I think the one really negative thing that happened thinking about it was the woman who was semi independent. She had a boyfriend and they'd been together for years and years and years. And he went to (one town) and she came to this other place which was about ten miles away and we tried to keep the relationship going…And I remember going to a meeting near the place where he came from and the psychologist saying that she was in an abusive relationship. She'd have sex with him and he'd give her cigarettes and that weren't right. I was really young then, but she really wanted to, and regardless of whether he gave her cigarettes…….So there were issues and in the end it died a death that relationship.

Of course it is difficult to make a judgement on what appears to be a complex relationship. However, the point that the interviewee made was that there were very different standards in the institution where the couple did have a sexual relationship and the community where they were not able to do so. A similar story was told by someone who had worked in a mainly male environment in which some of the men had had sexual relationships with each other in the institution and were distressed initially when these ended after resettlement. They were supported to keep contact but develop platonic relationships and the participant felt that now people who lived in the institution had more choices in terms of relationships:

> I think that there are people who are enjoying more fulfilled relationships with a variety of people, have had more choice to choose sexual orientation and have made those choices, and they are also in a position that they can maintain platonic relationships with people they had relationships with when they lived on site.

Another difficulty was that most of the people with learning disabilities had spent many years, or even the majority of their lives, living in the institutions and had become institutionalised:

> I remember one night me and a colleague were stood in the kitchen trying to do some cooking it was like getting dark when we went in the living room we hadn't realized that nobody knew how to switch the light on it was dark and two of the guys were sat in the dark and nobody switch the light and its those sort of thing you never think about it never occurred to us that we had to show someone how to switch the light on because at the hospital the light was always on. Light was always there.

This had implications for staff who were now increasingly expected to focus on skill development rather than providing personal care and doing things 'for' people with learning disabilities:

> I mean, the people we were supporting were very institutionalised. They'd been used to getting up, getting help getting ready, and sitting round all day. So most of them weren't, they were apathetic really, they didn't have any drive. And the staff didn't have any idea really as to what to do with all this time. It was a bizarre situation really. And not pleasant. It didn't feel as rewarding at first. It felt, this is a waste of time.

Indeed, some people lost skills once they left the institution. This could be due to the different setting or because staff did not realise what skills people had whilst at the institution:

> I've worked with guys who've come out of institutions who've sat around about this time and I've asked, are you setting the table? And I knew the guys in the hospital and they were extremely competent people. And they'd set the table. And I said, are you putting the bread and butter out and they'd stare into the fridge in total bewilderment.

Whilst some people who were resettled from the institutions moved to good quality housing in communities which were welcoming, others were housed in poor quality housing in deprived areas. Some participants queried whether the quality of life for these people had really improved:

> There were people being moved out of [the institution] onto the estates within difficult to let houses. You know. There were five people moved. We got access to elderly person's flats one above the other. They were probably 1940's flats, they were basically single person flats, and we got access to them and the team leader accepted them and I felt they had potential for one person living there with support. They knocked through and then there were five people living in these what had been single person flats with alterations done that probably didn't meet building regulations, certainly wouldn't meet today's building regulations. So it was difficult to say how we'd radically improved those individuals' lives. We certainly hadn't done in terms of the immediate living environment. ..But then you did have some really nice houses in some nice areas.

Therefore, whilst there were many benefits for many people with learning disabilities moving to the community some people faced problems in relation to community integration, restricted freedoms, loss of relationships, institutionalisation and poor housing.

Adapting to new ways of working

Some of the staff experienced some difficulties in adjusting to a new working environment. One participant for example whilst saying that they enjoyed their new job missed the institution:

> I must admit that I missed the hospital, I missed everyone there. The friends and the service users that were still there. Because by that time I'd moved out as well a couple of miles up the road from (the institution). So I'd moved house and moved work. There was a lot of, oh well we'll keep in touch, type of thing but then the shift patterns were completely different.

As well as missing the social contact people had at the institution there was also a nervousness about the lack of support and absence of back up that people had been used to in the institutions:

> I think getting used to not having that backup on site. I think when you were in the hospital there were night staff and day staff and there were staff nurses, there were ward rounds, there were this, that and the other. If you were concerned there was always somebody to ask. Thinking about it now, when we moved into the community, there were no on-call systems, no back-up. I think you could just ring anyone but there was no official that person's on call for tomorrow till this time.

There was also some concern about the lack of accountability and control, including financial control. One respondent for example started working at a small group home and on the first morning was shown round by another member of staff who said:

> 'This is the office, this is the sleep room, this is where we keep all the money' and he opened the drawer and there were just £10 notes sticking out – and I said 'how do you account for all of this?' 'Well we don't people just dip in every week from their benefits and we put it in this drawer, and if we need anything we just go and buy it.'

A common feeling was the difficulty in adjusting to different routines, this was usually expressed in terms of moving from days full of structure and business to situations in which there was little or no set patterns to work to. Some participants reported that it had been difficult to adjust from being busy all the time to being able to do things with more care:

> I think probably the greatest difficulty I had was not having a set routine, and not sort of being constantly busy. I would go onto a ward say for 10 to 7 in the morning to start work at 7 o'clock and not finish till turn 8 when I'd handed over, you know, 12 hour days, you might have an hour for your lunch, you might have an hour for your tea if you were lucky, but the days would just fly by because you were so busy. To go from that to working in a 9 to 5, by and large, I used to do a 8 to 4 sometimes, but not having a great deal of structure to the

> day, that was a real problem I had in the early 4 to 6 months, adjusting to that, not being busy, being busy but not being crazily busy you know. Having time to actually read, read about somebody or read about a way of doing something, and having time to record information properly, um, was like really strange, really strange, just having time, you know.

One participant described the move to the community as 'being thrown in the deep end' and undergoing a 'steep learning curve'. People had to adjust to new ways of working and job roles. In the community they had to think on their feet, organise food and shopping, washing and managing money. The focus changed from provision of personal care to one of skill development. Shift systems, rotas and sleepovers were new to many staff compared to the rigid shift system in institutions.

Some of the participants felt a sense of stigma having worked in the institutions. A minority reported hostility from co-workers in new settings. The following is an example of this view:

> They (referring to social services staff) were extremely negative. I did nurse training and my nurse training I still value. We did an extremely full and comprehensive syllabus. The skills and the things I was taught, the practical skills. I worked in Social Services and I did the Certificate in Social Services and you didn't mention. Like I say, you've been in a hospital, that was so last year! You obviously, you battered people and you abused people and you'd no idea what were going on. Excepting for the people who worked in that environment, even now there's no insight into it.

This wasn't simply an issue of perceived hostility between social care and health staff: one participant felt the same sort of negativity having moved from a local authority large hostel to a smaller setting.

However, some people felt that their experiences in the long stay institutions led to a number of personal strengths. A number of participants spoke about how although the long-stay hospitals, the traditional embodiments of institutions, no longer exist, smaller institutions and institutional practices may continue within a community setting:

> I don't care what size it is, it can be a residence with 2 people or it can be a massive place with 500 people, an institution's a state of mind at the end of the day as far as I'm concerned...It's the narrow mindedness of it all. And it's not having the energy or the motivation to take full advantage of everything that's around you.

They felt that they were particularly sensitive to institutional practices and that they were able to identify early warning signs of such practices creeping back into service delivery within the community. In addition, they have a sense of shared history with people with learning disabilities who lived in the institution. This means that they can understand some of the language people use and can sometimes comprehend certain behaviours displayed by people with learning disabilities that have originated from living in an institution. They could also appreciate how much life had changed for some people who had lived in the institutions, and sadly, how little life has changed for others:

I met a guy the other day who I'd not seen for twenty odd years. Who was in a PCT house. And I remembered him from [ward name]. He wouldn't remember me as such. And I suppose one of the saddest things is he didn't look a lot different to what he did when he was at [ward name]. He wasn't doing anything different. He was just sat in a chair with no socks on. He was living in, obviously I only popped in, I was visiting the address. But it would be interesting if somebody could audit the level of experiences he's now having. He might be choosing to have no experiences, he might not want to do anything. But what's different about his life now to what it was then? And on the face of it it didn't look a lot different. His appearance was exactly the same. He wasn't wearing institutional clothes, he was wearing tracksuit bottoms and sloppy top. And again, it's, they criticise the old days and they criticise everything like that, but it's amazing how many people who are in community settings now are wearing clothing that is convenient to wash as opposed to being of their choice.

People who had worked in the institutions clearly faced some difficulties adjusting to different ways of working in the community and in some cases stigma from having worked in the institutions. When asked what helped them to adapt to their new working situation there was some sense of 'just getting used to it' and developing confidence with time. However, there were a number of factors that did support people in their new role.

The support of colleagues was important, particularly those who had also moved from an institutional setting to work in the community. They understood the differences in working environment and working practices and could reassure people.

Colleagues, I suppose, were the main thing. Colleagues. Particularly the nursing officer at the time....she sort of helped me to settle in and she was always there, even though I was feeling a bit isolated she would come down and she would.. other than that, other colleagues that I worked with were the people who helped me to readjust, ...it's different teaching people road safety in a different environment, particularly road safety when there's the possibility that they're going to get knocked down, and having that responsibility, "well you signed them off to say that they can do that", you know, it's that comes back, at the back of your mind that's going to come back and bite me. But because people had gone through all that, saying, well you've documented it right, you've done this, that and the other, and you can safely say that the person can do that, then who's to legislate for one day them forgetting it, if the 99 times out of the hundred they've done it, you know, that one time, it's just life experience isn't it. And that was good that that happened. Yes. It was just really colleagues that helped me to make that mental change as well.

Meeting with colleagues to exchange information about the resources available in the community (for example, health resources, social resources) and ways of working in the community was of use to several participants. Similarly, the sense of isolation seemed to improve through meetings, as the size of staff teams grew and staff got to know each other:

> Well we had lots of team meetings which was helpful and tenants meetings which bought us all together as well. And again, continuity. You work with a team, you build up a relationship with a team and, that works.

Power and Control

This theme proved the most difficult to unpack. The issue of control was raised by a number of respondents in slightly different contexts.

As described earlier, some people initially found it difficult to adapt to the additional responsibility in the community. There was a sense of people having moved from a strictly controlled environment to one in which they had few routines and little support. Views about this were contradictory, the freedom was welcomed but there was a nervousness about the lack of support, procedures, control and structure which of course were the things that restricted freedom in the institutions:

> At the hospital you were restrained by all sorts of things. If you wanted to go out for the day it had to be planned weeks in advance and you had to check the staff rota.....You had to give finance three days notice to get any money out. So nothing was spontaneous. It was very well planned.

Many people found the freedom to make decisions refreshing and rewarding leading to a greater sense of control, autonomy and authority:

> We had freedom to do what we wanted, make our own decisions, with families and people using services, rather than with managers who weren't there. So yeah, it was completely, it couldn't have been any more different.

However, with control also came an increased sense of responsibility should things go wrong:

> ..it was just that initial, oh this is a strange set up, actually going into somebody's house, what do they expect me to do like. It was me learning new skills, skills that I'd used in a .... setting with numbers of people but doing it individually and I suppose being responsible for that person, learning, it's different teaching people road safety in a different environment, particularly road safety when there's the possibility that they're going to get knocked down, and having that responsibility.

There was also the risk that some staff can abuse control or may be attracted to work because of a desire to control. One person discussed the increased need for bureaucracy that was necessary because of the type of people that the work could attract:

> If I've learned nothing else in my…years is that it attracts more of its fair share of undesirables or people who want to control or people who want to make themselves feel good……..so they use that power wrongly, don't they? We do seem to get more than our fair share. Thank goodness we now have the CRB system and we can winckle them out.

However, an ambivalence can be seen in what several of the respondents described as the growth in bureaucracy. Whilst it was acknowledged by some that the bureaucracy was a necessary antidote to the abuse, particularly financial abuse that was evident in the early days, they nevertheless regretted the steady growth of controls and paperwork that they experienced.

The move to the community was seen as providing people with learning disabilities with more choices and control over their lives, and generally this was viewed as a positive development. However, if not carefully thought through, handing too much control to people with learning disabilities could lead to problems. One respondent explained how they felt that one situation had been badly mismanaged because the team had reduced the power differentials between staff and clients who was violent towards the staff working with them. The respondent described how an 'institutional team' had to step in to put boundaries in place. The respondent felt that this ensured that:

> The behaviour was managed, in a much clearer, more consistent way which really worked for that person. Life had got really out of control. There was an awful lot of power without really knowing how to manage that or how to act responsibly, it was too much.

Ultimately, even with the move out of the institutions, the control still remained with the staff.

> But, you know, the control, the control in attitudes was still with the staff. They still saw it that they had to dictate to people what time they went to bed, when they did the shopping, you know, what time they sat down and ate, the focus of control was definitely still with the staff, and there wasn't really any attempts, or there didn't seem really any, anyway that people knew how to break that down.

One participant explained that the atmosphere in the house that they'd moved to work in very much depended on the person in charge. This was similar to the comments about life in the institutions and not surprisingly depended on the seniority of the participant at the time they were commenting about. Other comments reflect the difficulty of shifting control from one group to another and demonstrate how people with learning disabilities still did not have control over many areas of their lives:

> If one of our chaps living in this tenancy has chosen to have cottage pie for tea, he then has to ascertain who's coming on duty and who's going to cook it – and are they going to fry the mince or are they going to boil the mince? Are they going to put garlic in it? Are they going to put Worcestershire sauce in it? Are they going to mash the potatoes so they're lovely and smooth, or will they be lumpy mashed potatoes. And you can't believe the different ways to make cottage pie. And yet it's his home. If I go home tonight, if I make cottage pie, my son knows roughly what it's going to taste like.

These issues of power and control are complex. However, it seems that control ultimately remains with services and the workforce rather than people with learning disabilities and their families. This is increasingly recognised as a reason for further change in learning disabilities:

> The power's with the service, it's not with the people, which is why In Control is so fantastic, which is why self directed support and moving budgets to families is such a critical move.

In addition, the growing bureaucracy, whilst necessary to control the risk of abuse, was seen as increasingly restricting choice and flexibility when supporting people with learning disabilities

DISCUSSION AND CONCLUSION

Lessons for the present and the future

The stories about life in the institutions showed how there was a clear need for change. Whilst there have been great improvements in the lives of people with learning disabilities, some stories about current service provision demonstrate that institutional practices can continue within a community setting and that power and control ultimately remain with services rather than people with learning disabilities and their families.

The key themes arising from this study are outlined below and the implications when planning future change are drawn out.

Drivers for change

The stories of change reveal that drivers for change existed at a number of different levels: international, national, regional, local and individual. There were clear philosophical and ideological drivers for change resulting from both the development of new theories (normalisation and Social Role Valorisation) and a growing recognition amongst the learning disability workforce that changes were needed to improve the quality of life for people with learning disabilities living in the institutions. Champions for change played an important role in raising awareness of the need for change and driving change forward and improvements were happening in the institutions before they closed.

However, although there were clear drivers for change and plans to implement change at a regional and managerial level through the Regional Implementation Group and Model District Service, it appears that the workforce were not always aware of the reasons for change and the process of change was not always smooth. There was insufficient involvement of staff, people with learning disabilities and staff in planning change.

- It is important that those planning future change identify potential drivers for change and clearly communicate both the need for change and the planned process of change to staff, people with learning disabilities and their families.
- It is important that the workforce, people with learning disabilities and their families are involved in planning change.

Reactions to change

The study identified that initial reactions to the proposed changes ranged from doubting to pragmatic to enthusiastic. For many people, change suited their lifestyle or they strongly believed that change was needed. However, other people did not feel that change was achievable for some people with learning disabilities, it was difficult to imagine what the new work would involve. There were concerns about how change would be achieved and whether appropriate resources and planning were in place.

- Major change can be achieved even when members of the learning disability workforce have doubts about proposed change. However, it can be useful to consider the concerns the workforce may have when planning for change.
- A range of factors can help influence reactions to change and reassure the workforce, including:
  - Information about reasons for change
  - Involvement in planning change
  - Witnessing and hearing about positive change
  - Secondments and security of terms and conditions

Adapting to change

These stories of change are a testament to the ability of the learning disability workforce to adapt to major change in the way learning disability services are provided and the impact of change on ways of working. Whilst the changes improved the quality of life for many people with learning disabilities, many people still faced challenges in the new setting with regards to integration, institutionalisation, quality of housing, restricted freedoms and loss of relationships.

The changes also had a number of benefits for staff including increased autonomy, more flexible working, developing relationships with people with learning disabilities and their families and the satisfaction of witnessing improvements in the quality of life of people they supported. Many participants relished these changes. However many people also experienced difficulties adapting to their new working environment, including lack of backup and support, and isolation from other members of the workforce.

- Change may lead to challenges as well as improvements for some people with learning disabilities
- There are a number of ways in which the workforce adapted to change and grew in confidence:
  - The passage of time
  - Support from colleagues
  - Exchange of information and advice

Attracting people to work in learning disability services

The people we spoke to were those who remained in learning disability services as per the remit of the research. It is likely that people left learning disability services at the time of resettlement or shortly after resettlement. This research does not give insight into why members of the workforce may leave at times of change and whether there would have been

ways of encouraging these people to continue working in learning disability services. However, the research did give some insight into what motivates people to work with people with learning disabilities. Participants were drawn to the work because of pragmatic reasons, an interest in working in working in a caring role, or because of their prior experiences with people with learning disabilities. People tended to stay in the work because they enjoyed working with people with learning disabilities and were committed to improving their quality of life.

- When considering how to attract people to work in learning disability services and retain staff it is worth bearing that people have a range of motivations for working in this field, including: pragmatic, an interest in working in a caring role, or prior experiences with people with learning disabilities.

Limitations of the study

The study did not include the views of people from black and minority ethnic groups or continental Europe who may have faced additional issues with the change in learning disability provision. Nor did the study include people currently employed by the NHS such as community nurses or people working in specialist NHS services who may have had different experiences of change and current service provision.

Our task was to interview people who had been involved in direct care work (rather than managers or educators) and had stayed in direct care for a reasonable period of time after moving from the institution in which they originally worked. This proved to be a little bit more difficult than we had anticipated. Assumptions about work are to some extent time specific. People in roles that in the twenty first century might be considered to be management roles with very little hands on care were, in the 1970s, still very much involved with direct care. For example the role of ward charge nurse in the institutions does not exist in community learning disabilities services in the twenty first century. A similar role might be that of network or group manager. However even a cursory breakdown of the roles demonstrates the difficulty of comparison. A ward charge could be responsible for the care of between 20 and 70 individuals and a staff team of between 3 and 6 people. The charge nurse would have been expected to be involved in direct personal care as well as management of the staff and environment. A network manager might be responsible for the support of a similar number of people but with a much larger number of staff divided into a much wider geographical area. It is unlikely that a network manager will be involved in direct personal care.

We wanted to interview people who had stayed in care roles for a long period of time after moving out of the institution but this proved to be impossible as careers tended to develop away from direct care work. We eventually decided to use the notion of continuing day to day contact with people with learning disabilities in a residential setting. This excluded community nurses for example but included people who managed a small team working in a small setting.
We also struggled with comparisons in relation to trained staff. Many of the nurses that we interviewed were qualified. Qualified nurses today are unlikely to work as personal assistants or direct support staff. However many of our respondents came into the work expecting it to be direct care. Only a small minority originally wanted to train as nurses and of those who eventually did several did so because it was a natural route for many within the institutions and certainly the only means of advancement. Nurse training was a fully paid apprenticeship system and did not enter higher education (thereby loosing its apprenticeship trappings) until the 1990s. The selection of people who started work in the institutions later to become qualified nurses was therefore consistent with the research brief.

Notions of the size of establishments also caused some difficulties. It was very clear that institutions such as Calderstones, Brockhall and the Royal Albert met the criteria for being very large. However we also wanted to include smaller institutions such as Lisieux Hall and Offerton House that were campus style establishments as well as some hostels that provided homes for about thirty people. This proved to be very helpful as we were able to compare practices in different types of institutions. It also demonstrated the developmental approach to resettlement that was experienced by many people who moved from large 'hospital' to smaller hostel type accommodation that still had many of the characteristics of an institution. The move from institution to smaller setting was very important for the staff that we interviewed regardless of the size of the relative institutions.

Conclusions

Whilst the study did not capture the views of everyone who moved from working in an institutional setting to a community setting, the findings give a sense of the need for change, drivers for change and the impact of change on both people with learning disabilities and the workforce. The study also demonstrates that even when change is clearly necessary the process of change is not always straightforward and may lead to challenges as well as benefits for people with learning disabilities and the workforce. The resilience and adaptability of the learning disability workforce is clear. Complex issues of power and control remain in the community setting, supporting the need for further change. Learning from the past can help when planning future change and hopefully the study findings will play a part in doing this.

REFERENCES

Aronson, J. (1994). "A Pragmatic View of Thematic Analysis." The Qualitative Report 2(1).

Atkinson, D., Jackson, M., & Walmsley, J. (Eds.). (1997). Forgotten Lives: Exploring the History of Learning Disability. Kidderminster: British Institute of Learning Disability.

Atkinson, R., & Flint, J. (2001). Accessing Hidden and Hard-to-Reach Populations: Snowball Research Strategies. Social Research UPDATE (University of Surrey), 33.

Mitchell,D.& Rafferty,AM. (2005) 'I don't think they ever really wanted to know anything about us': Oral History Interviews with Learning Disability Nurses. Oral History. 33.1. 77-87.

North Western Regional Health Authority. (1982). Services For People Who Are Mentally Handicapped. A Model District Service. Manchester.

Thomson, M. (1998). The Problem of Mental Deficiency: Eugenics and Social Policy in Britain, C.1870-1959 (Oxford Historical Monographs). Oxford: Oxford University Press.

Wright, D., & Digby, A. (Eds.). (1996). From Idiocy to Mental Deficiency. London: Routledge.

Information Sheet
Staff experiences of the resettlement process in the North West Region

We would like to invite you to take part in a research project. This information sheet provides information about why the research is being carried out and what taking part would involve.

Background

The North West Training and Development Team (NWTDT) have asked Manchester Metropolitan University and Manchester Learning Disability Partnership to carry out some research looking at staff experiences of the resettlement process in the North West of England.

There is a growing body of work that has sought to record the history of learning disability in the UK from a user perspective. However, there has only been a small amount of attention given to people who have worked in services and there is little written evidence of their contribution. There is a particular scarcity of published material on services in the North West of England; for example, we do not have a history of major institutions such as Calderstones and Brockhall in the Ribble Valley.

This project will help to address this by recording personal stories of individuals who worked in institutions in the North West of England at the time of resettlement into smaller community settings. The research will therefore add to the existing body of knowledge about the history of learning disability and will also provide specific information about the way in which workers experienced the change process at the time of resettlement.

This project aims to:

- Record the experiences of people who have worked in services provided for people with learning disabilities during the resettlement process from large institutions.
- Explore the impact of major change in service provision on the learning disability workforce.
- Identify factors facilitating and hindering how members of the workforce deal with major change in service provision.
- Inform debates about change within the 21st century learning disability services.

We will be carrying out interviews to gather information from people who experienced the resettlement process.

Why have I been invited to take part?

We want to interview twenty people who worked in the large institutions and hostels in the North West (for example, Calderstones, Brockhall, Cranage, Soss Moss, the Royal Albert, Mary Dendy and Newchurch) and then continued to work with people who are learning disabled in a 'hands-on' role in a community setting. Potential research participants may have since retired or no longer work with people who are learning disabled.

We have talked to a number of people who have worked in learning disability services for some time to find out who might be eligible to take part. They have suggested you or have agreed to forward this information on to you.

Do I have to take part?

It is up to you whether you take part. Whether you take part or not will not affect your employment in any way and we will not inform your employer whether you agree to take part.

What will happen to me if I take part?

Interviews will be carried out at a time and place that is convenient to you. We anticipate that interviews will last approximately an hour. Interviews will be semi structured (i.e. flexible interviews which are conversational in style). Interviews will cover:

- Why people chose to work with people who are learning disabled
- The experiences of working in a large institutional setting
- The experiences of the change in work
- Any advantages and disadvantages of the change in work setting
- How any difficulties in the transition were resolved

We will need to tape interviews. The interview tape will be transcribed and any obviously identifying information or defamatory comments will be removed from the transcript. Transcripts will be analysed by the research team reading and re-reading the material and grouping the information provided into themes.

Tapes and transcripts will be retained in a locked filing cabinet until the end of the project. People who agree to take part will be asked to indicate in writing whether they wish the tape and transcript to be destroyed, sent to them, or stored in a named oral history archive.

What will happen with the findings from the study?

A report will be written for NWTDT. A copy of the report will be sent to each participant. It is anticipated that the research will also form the basis of papers in professional and academic journals.

What do I need to do next?

If you wish to take part please contact Melanie Chapman (contact details below) or return the reply slip in the stamped addressed envelope provided.

Please contact us if anything is not clear or if you would like more information. The person to contact is:

Melanie Chapman
Research Associate, Manchester Learning Disability Partnership
Mauldeth House, Mauldeth Road West
Manchester, M21 7RL
Tel: 0161 958 4019
Email: melanie.chapman@manchester.gov.uk

REPLY SLIP

I am interested in taking part in the research project Staff experiences of the resettlement process in the North West Region.

Please contact me about this.

My contact details are:

Name: ____________________

Address: ____________________

____

Telephone number: ____________________

Email address: ____________________

I would prefer to be contacted by post / phone / email

Convenient times for me to be contacted are: ____________________

Manchester Learning Disability Partnership
Quality, Research and Service Development Team

Mauldeth House, Mauldeth Road West, Manchester, M21 7RL
Tel: 0161 958 4019 Fax/ansaphone: 0161 958 4149
Email: melanie.chapman@manchester.gov.uk website: www.mldp.org.uk

Title of project: Staff experiences of the resettlement process in the North West Region

Name of researcher: ____________________

Please initial box

1. I confirm that I have read and understood the information sheet dated 17/7/07 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	☐
3. I agree that the interview tape will be retained in a locked filing cabinet by the research team for a period of at least five years and that at the end of this time period (please select one as appropriate): The tape will be destroyed The tape will be sent to the North West Sound Archive or the British Library National Sound Archive The tape will be returned to me	☐
4. I agree to take part in the above study.	☐

Name: ____________________ Date: __________

Researcher Name: ____________________ Date: __________

When completed: 1 for participant, 1 for research project file.

Head Office: Mark Burton, Head of Manchester Learning Disability Partnership
Mauldeth House, Mauldeth Road West, Chorlton cum Hardy, M21 7RL. Tel: 0161 958 4014

APPENDIX 3 : INTERVIEW GUIDE

	Key Points
Please could you tell me about what attracted you into this field of work in the first place?	
Could you tell me about your work at [the institution name]? (what did it involve, how many people did you work with)	
What were you doing towards the end of your work in the institution?	
When did you first hear about community care? What was your first reaction?	
Why did you decide to move and work elsewhere?	
What did your new work involve?	
How did your new job differ from your previous post?	
Could you tell me about your experiences of working in a different environment?	
Were there things that helped or hindered in your new role?	
Other issues raised	