The realities of life for people with severe and profound intellectual disabilities and mental health problems

Citation for published version (APA):

de Barge Hubert, J. E. (2009). *The realities of life for people with severe and profound intellectual disabilities and mental health problems*. [Doctoral Thesis, Maastricht University]. Datawyse / Universitaire Pers Maastricht. <https://doi.org/10.26481/dis.20091203jb>

Document status and date:

Published: 01/01/2009

DOI:

[10.26481/dis.20091203jb](https://doi.org/10.26481/dis.20091203jb)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

The realities of life for people with severe and profound intellectual disabilities and mental health problems

‘Over himself, over his own body and mind, the individual is sovereign’
(John Stuart Mill in ‘On Liberty’ 1859)

ISBN 978 90 5278 883 8

© Copyright Jane Hubert, London 2009

Cover illustration: 'Cowering figure', stone sculpture by Jane Hubert
Printed by: Datawyse B.V., Maastricht, The Netherlands.

The realities of life for people with severe and profound intellectual disabilities and mental health problems

DISSERTATION

To obtain the degree of Doctor
at the Maastricht University,
on the authority of the Rector Magnificus,
Prof. dr. G.P.M.F. Mols,
in accordance with the decision of the Board of Deans,
to be defended in public
on Thursday 3rd December 2009, at 16.00 hours

by

Jane Elizabeth de Bargue Hubert

Supervisors

Prof. dr. L.M.G. Curfs

Prof. dr. S. Hollins (St George's, University of London, United Kingdom)

Assessment Committee

Prof. dr. G. Kok (chair)

Prof. dr. M.P.F. Berger

Prof. dr. H. W. van den Borne

Prof. dr. G. Grant (Sheffield Hallam University, United Kingdom)

Prof. dr. R. ter Meulen (University of Bristol, United Kingdom)

This thesis is one of the outcomes of the ongoing collaboration between the Governor Kremers Centre, Maastricht University (Netherlands) and St George's, University of London (UK). The studies presented here were carried out at St George's, University of London, Division of Mental Health, London, UK, and the University of Southampton, UK.

The studies were supported by grants from the Joseph Rowntree Foundation (chapter 7); Surrey Oaklands NHS Trust (chapters 4 and 6); the Judith Trust (chapter 5); the Hayward Fund (chapter 9); London Borough of Merton (chapter 8).

Contents

Chapter 1	Introduction	7
Chapter 2	The use of ethnographic research methods with people who have severe or profound intellectual disabilities <i>Submitted to British Medical Journal</i>	27
Chapter 3	Ethnographic research in closed institutions: ethical issues <i>Research Ethics Review 2007, 3 (4): 122-126</i>	35
Chapter 4	Men with severe learning disabilities and challenging behaviour in long-stay NHS hospital care. Qualitative study <i>British Journal of Psychiatry 2006, 188: 70-74</i>	45
Chapter 5	Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward <i>British Journal of Learning Disabilities 2008, 36 (4): 220-226</i>	57
Chapter 6	Leaving the institution? A follow-up of men with severe intellectual disabilities and challenging behaviour <i>Submitted to Journal of Policy and Practice in Intellectual Disabilities</i>	69
Chapter 7	'My heart is always where he is'. Perspectives of mothers of young people with severe learning disabilities and challenging behaviour living at home <i>Submitted to Disability & Society</i>	83
Chapter 8	Family carers' views of services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London borough <i>Disability & Society 2006, 21 (3): 259-272</i>	99

Chapter 9	'I don't want to be the mother of a paedophile': the perspectives of mothers whose adolescent sons with learning disabilities sexually offend	115
	<i>Journal of Child Psychotherapy 2007, 33 (3): 263-376</i>	
Chapter 10	Discussion	129
	Summary	163
	Accessible summary	169
	Samenvatting	189
	Eenvoudige samenvatting	197
	Acknowledgements	216
	Curriculum Vitae	217

CHAPTER 1

Introduction

Aims and objectives of the thesis

Men and women who have severe or profound intellectual disabilities, and also have mental health problems and challenging behaviour, are among the most vulnerable people in Britain. Many have lived socially and physically excluded lives in long-stay hospitals since childhood. Little is known about their individual lives and experiences, and in a world that is focussed on visible material and financial achievement they are easily forgotten. How much has changed since the old hospitals have closed? To what extent have these men and women become part of the communities in which they now live?

The overall aim of this thesis is to provide insights into the experiences of people who have these complex disabilities, and to portray them as the multifaceted individuals that they are. It also examines the perceptions that others have of them, not only in the wider community, but also the staff who have cared for them, until recently in the long-stay hospitals and now in residential homes.

The closure of the old long-stay hospitals in the UK provided an opportunity to document the experiences of a group of people who have lived most of their lives in a closed institution, to follow their transition into smaller units in the 'community', and chart the extent of changes, and possible improvements, that have occurred in their lives since the move. Central to this are two ethnographic studies of men and women who had lived since childhood in locked wards of an institution in Southern England. Their lives within the institution, and after they moved out, are also compared and contrasted with the experiences of a different group of men and women, with similar complex problems, who have spent all their lives at home with their families. How are these men and women who live at home perceived by others? To what extent are they socially excluded, even although not physically excluded? To what extent do they retain their identities? The thesis also looks at a group of young people with intellectual disabilities, living at home, who have been labelled as sexual abusers. To what extent are they also marginalised from society?

Introduction

Men and women with intellectual disabilities, who also have mental health needs, are disadvantaged and stigmatised on both these counts. Those who have severe or profound intellectual disabilities suffer more than others in the context of the provision of services and negative perceptions of them, especially if they have severe challenging behaviour (Mansell 2007; Royal College of Psychiatrists *et al.* 2007). Many have in the past been segregated in large-scale institutions and, more recently, in smaller institutions. Others still live with their families, who struggle to care for them at home (Hubert 1991).

Many people with severe intellectual disabilities have other characteristics which people in the wider community tend not to want to confront in their daily lives, such as epilepsy, mental illness, challenging behaviour, physical disabilities or physical abnormalities. It is perhaps unsurprising that the men and women who remained segregated from the rest of society the longest, in the bleak wards of the old institutions, were those with the most complex and severe disabilities, and challenging behaviour (Shepherd *et al.* 1996).

According to Mansell *et al.* (2007):

The segregation of disabled people in institutions is a human rights violation in itself. Furthermore, research has shown that institutional care is often of an unacceptably poor quality and represents serious breaches of internationally accepted human rights standards (Mansell et al. 2007: 2).

And yet institutional care has continued. What does this say about the nature of our society? Why have we segregated these men and women over the last 200 years, and to what extent are we still, in the 21st century, socially and physically excluding them? What are the emotions and attitudes regarding this highly vulnerable group of people that have enabled this situation to continue for so long?

Numbers of people with intellectual disabilities in the UK today

In the white paper 'Valuing People' it was estimated that there were around 1.2 million people in England with mild or moderate intellectual disabilities, and about 210,000 with severe or profound intellectual disabilities (Department of Health 2001: 15). About 60% of the total number of people with intellectual disabilities lived at home with their families and 40% lived in some kind of residential care, or in supported living.

Until recently, as seen above, many people lived in large old institutions, in segregated and deprived conditions. These have gradually been closed down, and most people have moved into smaller residential homes in the community, although a number of people (around 3000), mainly those with the most complex needs, now live in 'campus' homes on the old NHS hospital sites. In 2005 there were over 58000 adults with intellectual disabilities living in residential homes (average 8 places), and approximately 2500 still living in institutions (Mansell *et al.* 2007). In the last few years the remaining institutions have finally closed.

Definitions of intellectual disability

The ICD 10 Classification of Mental and Behavioural Disorders has been used internationally for many years, but has been criticised for its static nature. Harris (2006), for example, criticised the continued use of this designation because it 'implies a static, unchanging condition rather than one that can change over time'. The World Health Organisation, in its 10th revision of the ICD, added a statement acknowledging that there can be changes over time, and defines mental retardation as:

A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition.

Degrees of mental retardation are conventionally estimated by standardized intelligence tests. These can be supplemented by scales assessing social adaptation in a given environment. These measures provide an approximate indication of the degree of men-

tal retardation. The diagnosis will also depend on the overall assessment of intellectual functioning by a skilled diagnostician.

Intellectual abilities and social adaptation may change over time, and, however poor, may improve as a result of training and rehabilitation. Diagnosis should be based on the current levels of functioning (WHO 2007).

Another classification commonly used in Europe is the International Classification of Functioning, Disability and Health (ICF) (WHO website, accessed July 1 2009: <http://www.who.int/classifications/icf/en/>):

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed, ICF... records the impact of the environment on the person's functioning (<http://www.who.int/classifications/icf/en/>).

The American Association on Intellectual and Developmental Disabilities defines intellectual disability as:

... a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 (AAIDD website: www.aamr.org 2009).

The AAIDD lists three types of adaptive behaviour in which limitations may be found:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
- Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone (AAIDD website: www.aamr.org Retrieved July 2009).

In addition, the AAIDD stresses the importance of environment and culture, pointing out that professionals should be aware of 'linguistic diversity and cultural differences in the way people communicate, move, and behave' (AAIDD website: www.aamr.org Retrieved July 2009).

In the UK, learning (intellectual) disability is widely defined as:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);

- which started before adulthood, with a lasting effect on development (Department of Health 2001: 14)

‘Valuing People’ adds that low IQ is not enough to determine an individual’s needs, and that an assessment of social functioning and communication skills should also be taken into account (Department of Health 2001: 14-15).

Definitions of challenging behaviour

The definition of challenging behaviour given by Emerson and Hatton (1994) is the one most commonly used in the UK:

Culturally unusual or unacceptable behaviours, such as self-injury or aggression, that place the health or safety of the person or others in jeopardy or are likely to lead to the person being excluded or denied access to ordinary settings (Emerson and Hatton 1994: 17).

However, this has been recently revised in a report by the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007), which states that the attribution for responsibility for challenging behaviour should be taken away from the individual:

It is our belief that there needs to be a firm reaffirmation of the term in its original context and a clear shift of emphasis back to the responsibilities for change being with the systems around the individual. We believe that ‘challenging behaviour’ is a socially constructed and dynamic concept. In order for an individual’s behaviour to be viewed as challenging, a judgement is made that this behaviour is dangerous, frightening, distressing or annoying and that these feelings invoked in others are in some way intolerable or overwhelming. The impact on others, and therefore the characteristics of the observer(s) have to be incorporated in the application and understanding of the term challenging behaviour (Royal College of Psychiatrists et al. 2007).

Accordingly, they modify the definition of challenging behaviour:

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion (Royal College of Psychiatrists et al. 2007:10).

Methodology: the use of ethnographic methods of research

The use of ethnographic methods of research in health settings, and specifically with people who have severe or profound intellectual disabilities, is discussed in Chapter 2. What follows here is a brief history of the use of these methods.

Social anthropology and the nature of ethnography

Ethnographic research methods were traditionally used by social anthropologists in the study of small-scale societies, usually in distant parts of the world. They would often live there for a year, or even for a few years. They tried to become as much part of the society they lived in as possible, learning the languages, or languages, and studying every aspect of the community they lived in – law, politics economics, family structure, religion etc. – and the interrelationships between every aspect. This involved learning the language (or languages) and living within the community for long periods of time. It involved listening, watching and participating in the life of the community.

In the past, it was considered acceptable for anthropologists to walk into someone else's community, partly because these communities were considered to be 'primitive', and then to analyse and interpret the data they collected, sometimes imposing their own cultural, religious and individual structures on to the material. For example, Lambek (2002) writes of Evans-Pritchard, one of the foremost British anthropologists, who lived with the Nuer and other Nilotic peoples in southern Sudan in the 1930s:

It is sometimes remarked that Evans-Pritchard portrays Nuer religion in a manner not dissimilar to Roman Catholicism, or rather that the arguments he makes to explain Nuer refractions of spirit, or the material symbolism of spirit are not altogether different from the way in which a Catholic theologian might defend the concept of the Trinity and the Communion (Lambek 2002: 145-46).

This tendency for anthropologists to try, to some extent, to 'fit' the beliefs of another cultural group with (but not into) their own belief system, may be inescapable. It is not possible to analyse, or even document, the beliefs and practices of another culture, without it reflecting, to a small degree at least, the cultural perspective of the observer.

The French anthropologist, Lévi-Strauss (1967), wrote:

When [the ethnographer] goes into the field... however scrupulous and objective he may want to be, it is never either himself or the other whom he encounters at the end of his investigation (Lévi-Strauss 1967: 15).

Over recent years there has been a move towards the view that it is not morally acceptable to assume that being an anthropologist brings with it an entitlement to enter another society, to watch, listen, interrogate and judge, especially where the power relationship is very unequal (Caplan 2003). Anthropology as a colonialist discipline is described by Owusu (1979):

As an academic discipline, social anthropology is closely associated with the latter 19th century and the first decades of the 20th century – the high tide of Western imperialism and colonialism. Though today 'colonial anthropology' may be dead in many areas of the non-Western world, it is perhaps true to say that the average Western anthropologist, himself hardly a colonialist or imperialist, was, as a highly privileged white person, invariably identified with the colonial system of white domination by the people he studied (Owusu 1979: 18).

Similarly, Asad writes:

The bourgeois disciplines which study non-European societies reflect the deep contradictions articulating this unequal historical encounter, for ever since the Renaissance the West has sought both to subordinate and devalue other societies, and at the same time to find in them clues to its own humanity (Asad 1995: 103-104).

In America, anthropologists could stay at home to do their exotic anthropology, as the British anthropologist Ian Lewis points out somewhat caustically:

The American Indians, or what was left of them, constituted a convenient ethnographic resource for anthropological research... American anthropology was thus a rescue-operation, directed towards salvaging as much as possible from an archaic world smashed to pieces in the process of colonisation (Lewis 2004: 125)

Current debate tends to view the old anthropology not only as colonialist, but often also as unethical (Said 1994; Savage 2000). There was also, in the past, no attention paid to the effects that the research might have on the communities concerned, and their position in the power structure of the wider society in which they lived. This was particularly true in countries in which there were (and are) indigenous minority populations who had been oppressed and exploited by generations of colonialist settlers. Strang (2003), with reference to her own anthropological work with Australian Aboriginal communities, writes:

The particular ethical questions... are whether anthropologists have the right to represent 'the other' at all, and whether, in doing so, their representations should be controlled and directed by the people about whom they are writing, or by their own, independent judgements about the issues that should be raised (Strang 2003: 172-3).

There was also no concept of 'consent' – a concept that is nowadays very much in the forefront of research of all kinds.

Over recent years some anthropologists in Australia, through their extensive and intensive knowledge of the people and their kinship (and ancestral) relationships, and also knowing the Aborigines' close relationship with the topography of the land they live in, have, in fact, become very useful to the Aboriginal communities they have lived among. They have come to play a vital role in the struggle of the Aborigines to claim back their land and, in some cases, in their claims for the return of their ancestral remains from many parts of the western world (Hubert and Fforde 2001).

Anthropologists used to believe that if they immersed themselves in a small society - on a remote island, for instance, learning the language and following the cultural rules, then they would actually be accepted as an indigenous member of that society. Many anthropologists are very proud when they are given clan names, which give them a position in the classificatory kinship system. But, in fact, they always remain an 'other' - no one ever forgets who they are. Living (as anthropologists) in a remote village in East Bali, we (JH and family) were treated alternately as clever, worldly wise people who had access to the outside world, and as fools, who did not understand basic concepts and who behaved in unacceptable and dangerous ways.

But it is important to become as much part of the society as possible, and this means trying to experience and interpret what happens from the perspective of those being studied: the 'emic' perspective (i.e. the perspective of those within a culture) as opposed to the 'etic' perspective (i.e. the perspective of outsiders). We did learn many of the cultural rules, but nowhere near all of them. We lowered the washing line because it was strung above the level of the courtyard shrine and was therefore in danger of offending the ancestors. We stopped letting the children ride their bicycles near the crossroads of the earthen village roads at dusk, because that was when the spirits would come out, and might have harmed them. Walking through the village alone at night, it was hard not to be afraid if an unfamiliar shadow or form appeared in the darkness, in case it was the physical manifestation of a spirit. At one level I (JH) knew it was not a spirit, but to some extent it is necessary to suspend one's disbelief in order to understand the beliefs of a different culture, and to understand how others feel; it is really only a form of empathy.

Thus, wherever one carries out ethnographic research, although it is obviously necessary to remain objective, at the same time one has to be aware of other people's spirits and be prepared to see other people's ghosts.

Working in the locked ward of an institution in England, with men who had little or no speech, the same applies. By living as much as possible with the men who lived there, it was possible to begin to learn the culture and ethos of the ward, and to understand, to some small extent, the essential nature of each individual - and to become aware of at least some of their demons and ghosts. This sort of work involves, just as it does in any foreign country, often looking ridiculous, making many mistakes, and resisting the desire to believe that one has ever got the whole story.

Ethnographic methods at home

It is now common practice to carry out social anthropological research in 'western' cultures, often in the anthropologists' own culture, or even sub-culture.

Transferred to 'Western' society, ethnography has often had to adapt to the very different social structure and patterns of behaviour that exist. For example, in an early anthropological research project carried out in England, a study of extra-familial kinship in North London (Firth *et al.* 1970), participant observation in kin meetings and family occasions was necessarily limited. It was only possible to actually document what was happening within an individual household when the researcher was there at the same time as a visiting member of the kinship group. Nothing was to be gained by standing on a street corner and watching what people did, mainly because social and kinship activities existed behind closed doors, and often at the other end of a car journey (Hubert *et al.* 1968). As a result of the geographical mobility of urban populations (Hubert 1965), many relationships with kin were seldom manifested in the form of face-to-face contact. In those circumstances, the research was based mainly on intensive interviews over a period of a few years, with some participant observation.

There are also pitfalls in the study of the researcher's own culture, especially if it is also their own sub-culture. Many of the people interviewed in the North London Kinship Project could loosely be called members of the 'professional middle class'. Some were academics,

two even anthropologists. When a researcher goes into a household of this kind it is appears very familiar in many ways, and they will have preconceptions about many aspects of the family's life. Equally the family under study will know to some extent what the researcher is expecting to find. This situation is complex, but over time (in this case more than two years) these complications resolve themselves, as relationships develop.

At the other extreme from this, when anthropologists went to live on remote islands in distant oceans, they arrived there with absolutely no idea what to expect. They had no preconceptions about what they would find in any sphere of life – economic, political or religious, or what kinship system existed, or what their beliefs were about anything. Malinowski, the first, and one of the leading anthropologists in Britain, spent long periods living in the remote Trobriand Islands, off the coast of New Guinea. He recalls the dangers of assuming that people in other cultures had the same beliefs as 'us':

I remember talking to an old cannibal who... had heard news from missionaries of the Great War raging then in Europe. What he was most curious to know was how we Europeans managed to eat such enormous quantities of human flesh, as the casualties of a battle seemed to imply. When I told him indignantly that Europeans do not eat their slain foes, he looked at me with real horror and asked me what sort of barbarians we were to kill without any real object (Malinowski 1937: vii).

Following in the footsteps of generations of anthropologists who went to live in isolated, unknown corners of the world, carrying out ethnographic fieldwork in the context of health and disability in the UK sounds rather tame. But it is not always easy (Hubert and Hollins 2006). Walking for the first time into a locked ward to do participant observation with people who are not only known to be violent, but who also appear very strange in the way they look and move and sound, can be quite terrifying.

Only by getting to know the apparently unknowable do perceptions change. Gradually, the strange shapes and movements and sounds in [the ward] turned into individuals, and the initial shock and fear soon evaporated (Hubert 2000: 202).

This, perhaps, sums up the value of ethnographic research. First impressions can be misleading, and only over time can the seemingly bizarre and unrelated elements of people's lives begin to form a coherent and meaningful pattern.

Details of the methodology used in the five projects (Chapter 4 to Chapter 9)

The ethnographic methods of research used in the projects described in this thesis are discussed in Chapter 2, and some of the ethical issues that arise in this kind of participatory research are examined in Chapter 3.

The methods used in the projects described in Chapters 4 – 7 included both participant observation (Dewalt and Dewalt 2002) and interviews with parents over time. However, the proportions of time spent in the two methods of gathering data varied according to the situation. In the two research projects carried out with men and women in long-term residential care (Chapters 4, 5 and 6), the main body of material was gathered through participant observation in the wards, and the subsequent new homes of the people with severe

and profound intellectual disabilities. Although some (especially the women) had a little speech, interviews with them were still not possible. In addition to the participant observation in the wards, interviews were held with parents or other family members wherever possible. Formal interviews were not held with staff, although they were included in the participant observation, and informal discussions were held with them. In both projects it was felt to be important to try not to make the members of staff feel they were under scrutiny.

The project with the men in the locked ward (Chapter 4) was reflective, i.e. what was learned about the men was fed back into the formal, institutional transition process, as discharge plans were made and implemented. This was in order to contribute to a significant change in their lives, and also, inextricable from that, to a change in peoples' perceptions of them. The material, and the insights that arose from it, were fed back into the transition process before, during and after the men moved out. This was done, first, by contributing to their individual care plans and documentation being drawn up for each man in preparation for the transition; second, by feeding the material into the transition process and by working with the men's future carers and managers before, during and after the move.

A significant part of the documentation relating to the men consisted of detailed pen portraits of each man. These were based on the long periods spent with them in the ward, in an attempt to describe each one, not as someone who has intellectual disabilities, autism, a mental illness and challenging behaviour, but as an individual, with his own hopes, fears, feelings, memories and ways of communicating. These vignettes described twenty very different people, but at the same time they reflected the shared reality of the locked ward in which they lived, the ward that shaped their lives, and the memories of which will continue to be a powerful influence in their current life. The material was given to staff at all levels who were involved in the transition, and also given to and discussed with the eventual managers and care staff in their new homes.

In both institutional studies, the medical files of the men and women, dating back to their first admission as children, were examined in order not only to ascertain the individuals' recorded histories, but also to find out how they had been perceived and described by the professionals over the years.

In the research outlined in Chapter 7, in which young adults with severe and profound intellectual disabilities and challenging behaviour lived at home, the intensive interviews with parents and siblings over two to three years formed the major part of the research, with participant observation in the home complementing and substantiating the interview material.

The research discussed in Chapter 8, with families from Black and ethnic minority groups, was a shorter project, based on interviews, with no substantial participant observation.

The research discussed in Chapter 9, with young boys who had been abused as children, and who were now abusing others, used a range of qualitative and quantitative research methods, including interviews over time with the boys themselves, their parents, keyworkers and therapists. At the same time, a range of clinical measures were used to assess the outcomes for individual boys after a period of time in group therapy.

Chapter 9 focuses on the qualitative material from interviews with the mothers of the adolescent boys.

Consent

In the hospital projects, the hospital management and the local research ethics committee approved the research (consisting of observation on the ward, access to the men's case records, and family interviews) and its publication. The participants in the study were unable to give informed consent because of the severity of their intellectual disabilities. The primary aim was to consider the vulnerability of members of a severely disabled and excluded group who do not have capacity, and so it would not have been appropriate to replace the participants with people with milder learning disabilities.

Since the majority of the men and women had been living in institutions since childhood (the majority before the age of eight), parental responsibility for them, with very few exceptions, had been handed over many years ago to the ward managers and hospital management. Although some families maintained minimal contact with the hospital, very few had regular direct contact with their relative. It was decided not to seek consent from these relatives. Interviews were conducted with a number of relatives who were in direct contact with their family member, none of whom expressed concerns about the study. The parent representatives on the men's ward closure project board, to whom the researcher made regular presentations, stated explicitly that they appreciated the researcher's understanding and perceptions of their sons, and approved publication of the material (e.g. 'It doesn't matter how uncomfortable it makes people feel' and 'I want everyone to hear this').

In English law no one else can consent on behalf of an adult without capacity. Even under the recent Mental Capacity Act (2005) there is nothing in law that gives relatives formal decision-making rights on behalf of an adult relative with learning disabilities with regard to research. Although it is now considered good practice to obtain the written consent of the next of kin (Royal College of Psychiatrists 2001), in 1997 our decision not to do so was consistent both with research practice and with practice within the hospital.

Background

The three chapters at the core of this thesis are about men and women who have spent their lives in institutions. It is thus appropriate to look at the history of institutions in the UK, as background to those which survived until the beginning of the 21st century.

It is also relevant to the following chapters to examine, albeit briefly, the perceptions of people with intellectual disabilities over time, and the attitudes towards them that resulted in the physical and social exclusion of those men and women who have the most severe disabilities, and are some of the most vulnerable people in our society.

Brief history of institutions in the UK

In Britain, the first identifiable institution - though not initially specified as a 'mental' institution - was perhaps the most famous one of all, the Bethlehem Hospital, founded in 1247,

more widely known as Bethlem, and subsequently as Bedlam (Arnold 2008). A hundred years later it became a place specifically for 'mad' people, and the term 'Bedlam' has become synonymous with madness, in its most uncontrolled and violent sense. In the medieval years the diagnosis of 'madness' covered a wide range of disorders, including epilepsy, intellectual disabilities, dementia and hydrophobia (Arnold 2008). Anyone who was perceived to be 'dangerous' was locked away. It is noteworthy that, in the 16th century, Bedlam also became a convenient place for political prisoners to be locked away - a use of psychiatric institutions which still exists today in some parts of the world, e.g. in China (Munro 2002) and Russia (Adler and Gluzman 1993).

With the 1808 County Asylums Act some institutions began to provide a degree of social welfare, and the clinical practice of psychiatry as a medical discipline was also initiated. Bethlem itself, however, became the subject of numerous scandals and horrific tales about the ill-treatment and neglect of its inmates (Arnold 2008). The asylums, in spite of the new therapeutic aims, were still said to be:

... instruments of social control, prisons disguised as hospitals, where the poor and the incurable could be swept out of sight (Arnold 2008: 5).

The concept of 'idiots' or 'fools', as opposed to mad people or lunatics, appears in early writings, but it was not until the 19th century that asylums specifically for people categorised as 'subnormal' (as opposed to 'mad') were introduced in Britain. This was seen as a positive development, and it was intended that idiots would be 'trained', and then returned to live at home with their parents. In practice, however, most families refused to have them back, with the inevitable result that their relatives had to stay in the asylum for the rest of their lives. The number of residents in these institutions therefore increased dramatically, and whereas there were only about 400 people in asylums in 1864, by 1881 there were over 29,000, resulting in the inevitable disregard of individual identity and the mass organization of daily life (Ryan and Thomas 1987).

The concept of 'care in the community' for people with intellectual disabilities dates back to the establishment of the National Health Service in 1948, and was given impetus in 1951 by the publication of a pamphlet, '50,000 outside the law: report on the treatment of those certified as mental defectives' (National Council for Civil Liberties 1951). This pamphlet led to the setting up of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency (Departments of State and Official Bodies and Royal Commission on the Law relating to Mental Illness and Mental Deficiency 1957).

The implementation of care in the community was slow to develop. In the late 1960s and early 1970s a number of scandals and enquiries into the mental 'subnormality' hospitals, e.g. Ely Hospital, Cardiff (Department of Health and Social Security 1969) and Farleigh Hospital (NHS 1971), gave further momentum to the policy to close them down. In 1971, the Government white paper: 'Better services for the Mentally Handicapped' (DHSS 1971) laid the foundations for care in the community, but this, and later government papers, did not radically increase the speed of change. In fact, many of the old hospitals have only fully closed in very recent years, in spite of 60 years of government policy of care in the community. The Normansfield Enquiry, in 1978 (House of Commons 1978), led to the creation of the Department of Psychiatry of Mental Handicap at St. George's Hospital Medical School.

Normansfield was eventually close down in 1998. The last remaining hospital, Orchard Hill, in Surrey, finally closed in April 2009. Three bungalows at Orchard Hill remain open, but have been leased to a Housing Association, which has given short tenancies to the occupants (Sutton and Merton Primary Care Trust Board Meeting, 19th May 2009). As the Board states: 'This has closed a chapter in British social history' (Sutton and Merton Primary Care Trust Board Meeting, 19th May 2009).

Closing the institutions does not mean that the people who lived in them, and others like them, are necessarily going to live socially included lives. 'Valuing People Now' (Department of Health 2009) states that seven years on from 'Valuing People' much remains to be done, and that the Social Exclusion Task Force has 'identified people with moderate and severe learning disabilities as one of the most excluded groups in our society' (Department of Health 2009: 28).

Those who were the last to leave the wards of the old institutions were mainly those who were considered the most difficult to place in a community environment – men and women with severe and complex disabilities, mental health problems, challenging behaviour, and those who were perceived as 'dangerous' (Collins 1992; Hubert 2000). A number of people still live on the old hospital sites, but in new, often purpose-built, 'campus' homes. In many of these an institutional culture has continued, and residents are said to have a poorer quality of life than those living in residential homes in the community (e.g., Emerson *et al.* 2000). Because of the negative findings, it is now planned to close most of these 'campus' homes (planned to be completed by 2010), and to resettle the 3000 or so men and women living in them, thus disrupting their lives yet again.

Changing the physical surroundings that people live in is not the answer, at least not the whole answer. There is no reason to believe that the attitudes of the people who care for them will change with the environment, or that ostensibly living 'in the community' will result in social inclusion for the men and women who have been physically and socially excluded since early childhood. In this context, staff training is obviously a key factor, but this remains an under-resourced and under-researched area. In their report on deinstitutionalisation and community living in Europe, Mansell *et al.* (2007) report that no data was available in the UK on numbers and type of staff for adult services, and none on staff training (Mansell *et al.* 2007: 20).

Eugenics and 'otherness'

In Western cultures of the world, in which success is measured in terms of academic and career success, independence and making enough money to accumulate goods and property of all kinds, attitudes towards people with intellectual disabilities have tended to be negative, sometimes to an extreme. In many Western countries eugenics policies were enacted in the early 20th century to prevent the spread of 'unwanted' characteristics in the population, including mental illness and intellectual disabilities. Countries with eugenics policies included Norway, Sweden, Denmark, Finland and Japan, Alberta and British Columbia in Canada, and many states in America (Kevles 1999). In 1942, the *American Journal of Psychiatry* carried a debate about whether 'feeble-minded' children should be killed or not (Joseph 2006). The proponent of killing children (which was supported by an anonymous

editor) was a neurologist, Foster Kennedy, who proposed that if a child with severe disabilities reached the age of five years, then 'it is a merciful and kindly thing to relieve that defective - often tortured and convulsed, grotesque and absurd, useless and foolish, and entirely undesirable - of the agony of living' (Kennedy 1942: 14). This was not abortion, nor simply letting babies die after birth, but the proposed killing of children.

The extreme limit of physical and social exclusion is death. As recently as the early 1940s the German 'euthanasia' programme killed thousands of intellectually and physically disabled children and adults. It could be argued that the record in Britain during the war was not exactly blameless - during the years of food shortages, civilian staff shortages and reduced funding, the death rate of people living in institutions was far higher than that among the general population (Fakhoury and Priebe 2007). This was also true in France (Chapireau 2009).

Most eugenics policies were rescinded before or during the 1970s. However, eugenics policies are not totally in the past. For example, in China, the *Maternal and Infant Health Care Law* was enacted as recently as 1994 (United Nations Economic and Social Commission for Asia and the Pacific website). This stipulates that, before a couple can marry, they must undergo a medical examination in order to identify any serious genetic diseases, infectious diseases or 'relevant' mental diseases. If one or the other is found to have any of these then the marriage cannot take place. The woman must embark on long-term contraception or undergo tubal ligation, so that she cannot conceive. When it has been established that she is unable to bear a child the marriage can take place. Not surprisingly, this Act has been described as a 'gross violation of medical ethics and human rights' (Reichman *et al.* 1996).

Britain has never had a formal eugenics policy, in spite of the existence of a powerful Eugenics Society in the past, whose archive is now held by the Wellcome Institute for the History of Medicine in London (see Hall 1990), and a continuing thread of eugenicist thinking. An example of this thinking in the past is enshrined in the report of the Mental Deficiency Committee (Board of Education and Board of Control 1929), which suggested that if the families of people classified as subnormal were investigated:

[The families] would be found to contain a much larger proportion of insane persons, epileptics, paupers, criminals (especially recidivists), unemployables, habitual slum dwellers, prostitutes, inebriates and other social inefficients than would a group of families not containing mental defectives... If we are to prevent the racial disaster of mental deficiency we must deal not only with the mentally defective persons but with the whole subnormal group from which the majority of them come... The relative fertility of this (subnormal) group is greater than that of normal persons (Board of Education and Board of Control 1929) [Quoted in Ryan and Thomas 1987].

Britain may not have had a eugenics policy, but it has tended, since medieval times, to shut away the 'tortured and convulsed, grotesque and absurd, useless and foolish' (Kennedy 1942: 14) from sight, and generally also out of the consciousness of the rest of the population. Segregating people in single-sex environments also has the effect of ensuring that men and women are unable to procreate.

Arnold (2006), in her discussion of attitudes in the 14th century, writes of the 'fear of the mad and distaste for their visible presence'. These attitudes can still be found in the 21st century, some 700 years later.

In every culture there are people, or groups of people, who are perceived as 'different', and hence as dangerous in some way, and excluded by the majority population. The criteria for inclusion or exclusion may vary in different cultures, according to what is seen as 'difference' or 'dangerousness' but everywhere there is a concept of otherness. As Marks writes (1999: 153): 'Our sense of citizenship and community is defined by boundaries which demarcate zones of inclusion and exclusion'. Not all societies, however, stigmatise or exclude people who are considered mad. If madness, for example, is considered to be simply the occupation of the body, as it is in some cultures, then it can be accommodated within the community; the 'selfhood' of the person who is mad is not affected because his body is considered to be simply housing the madness (Last 1990). In European cultures the opposite tends to be true, and the health or ill-health of the mind is inextricably bound up with the self. Who will be excluded from society thus varies according to the nature of a range of sociocultural factors.

In western cultures there is a fear of madness, and 'mad' behaviour. Gilman (1988) believes that we try to rid ourselves of the fear of our own mental and physical disintegration by locating it in someone else: 'The fear we have of our own collapse does not remain internalized. Rather, we project this fear on to the world in order to localize it... For once we locate it, the fear of our own dissolution is removed' Gilman (1988: 1). In this way we protect ourselves by projecting all that we deem ugly or mad onto others. Furthermore, to be even safer, we have tended not only to socially exclude such people, but also physically exclude them.

Historically, in Britain, this is what we have done for centuries. In the old days 'mad' people were locked away, segregated from society. Everyone has heard of Bedlam, which housed the lunatics. The public used to pay to watch them. We are still mired in this history, this cultural memory of madness over the generations. In spite of attempts to treat and educate institutionalised men and women in the past and present, attitudes to people who behave in what are seen as inappropriate and 'dangerous' ways have ensured that they continue to live segregated and marginal lives.

Nowadays society is more tolerant of people with intellectual disabilities, as long as the disability is not too severe, and the people concerned behave pretty 'normally', but we still seem unable to tolerate people who look very strange and who behave in uninhibited and sometimes frightening ways. Children who are separated from their parents at an early age and are cared for in institutions lose all chance of learning normal social behaviour, and thus become socially 'unacceptable'. It is much easier to exclude people from social life, not to have to see them, and thus not to have to acknowledge their existence. It is easier to think of them as not really human, and if they are not human beings then it does not matter how they are treated. Hence the levels of institutional abuse that still persist, such as 'poor care standards, lack of positive responses to complex needs, rigid routines, inadequate staffing and an insufficient knowledge base within the service' (Department of Health 2000), as well as physical, sexual and emotional abuse of all kinds.

The question of whether people are believed to be fully human or not is illustrated by Charles Dickens, in *Barnaby Rudge*, in his portrayal of the man he describes as an 'idiot':

Startling as his aspect was, the features were good, and there was something even plaintive in his wan and haggard aspect. But, the absence of a soul is far more terrible in a living man than a dead one; and in this unfortunate being its noblest powers were wanting (Dickens 1973 [1841]: 73-74).

Since we believe that all human beings have souls, what then are the implications of this belief that 'idiots' have no souls?

The research

1. **What can the use of ethnographic methods offer in the field of research with very vulnerable people? Are there specific ethical issues that arise in research of this kind with people who are unable to give verbal consent? How can these issues be addressed?**

Chapter 2 describes the history, nature and advantages of ethnographic methods of research. Chapter 3 examines some of the ethical issues that are sometimes raised in the context of these methods.

2. **What is the nature of life in a locked ward? What are the effects of living in an institution? In what way does confinement in a locked environment affect the mental state of those confined? What effect does social and physical exclusion have on identity?**

Chapter 4 describes an ethnographic study of men with severe or profound intellectual disabilities and challenging behaviour living in a locked ward of an old 'mental handicap' institution. Chapter 5 describes a second ethnographic study with women living in a locked ward of the same institution.

3. **Are there gender-related differences in the way men and women are perceived and treated in the single-sex wards of the institution?**

Based on the two studies described in Chapters 4 and 5, issues of gender and sexuality are discussed, and staff attitudes and treatment of the men and women are compared and contrasted.

4. **When institutions close, do those who move out now live different lives, approximating to the 'normal' lives led by the majority population? Are they still physically and socially excluded? Do they regain their lost identities? Are they still subject to stigma and prejudice?**

Chapter 5 follows the group of women through the process of transition to their new homes in the community and in a 'campus' home on the old hospital site, and documents the nature of their lives their new homes. Chapter 6 examines the nature of the men's lives in their new homes, again both in the community and in a 'campus' home on the hospital site.

5. How different are the experiences of people with severe intellectual disabilities and mental health problems who were not institutionalised, but have lived all their lives at home with their families? Are they perceived differently from people who live in institutions?

Chapter 7 describes the experiences of a group of young people with similar severe and profound intellectual disabilities and challenging behaviour, who have lived all their lives at home with their families. Their experiences, the perceptions of them, and attitudes towards them, are compared and contrasted with the experiences of the men and women in the locked wards (Chapters 4 and 5), who have been institutionalised since childhood. Chapter 8 documents the experiences of carers from Black and ethnic minority groups and their adult children, who have also lived at home all their lives.

6. How are adolescent boys with intellectual disabilities who have been labelled as 'sexual abusers' perceived? Does the label affect how they are perceived and treated by the professionals who work with them (as it does in the locked ward)? How does it affect the way that their futures are projected?

Chapter 9 describes the experiences of a group of adolescent boys with intellectual disabilities attending a psychotherapy group, who were abused as children and who are now abusing others.

This thesis seeks to answer these questions in relation to the experiences of people with severe intellectual disabilities and challenging behaviour. It begins with a discussion of the chosen methods of research: ethnographic methods involving intensive interviewing and participant observation over time (Hubert, Curfs and Hollins, submitted). The ethical issues that arise in the context of ethnographic research with people with severe and profound intellectual disabilities are also discussed (Hubert and Hollins 2007). The experiences of men and women living in a locked ward are documented, based on two ethnographic studies carried out in single-sex wards (Hubert and Hollins 2006; Owen, Hubert and Hollins 2008). When the locked wards closed, the men and women were followed through the transition from the long-stay hospital, and into the 'community', to document in what ways, and to what extent their lives changed in their new homes (Hubert and Hollins, submitted; Owen, Hubert and Hollins 2008).

The thesis then compares and contrasts the experiences, treatment and perceptions of these men and women with severe and profound intellectual disabilities and challenging behaviour, who have spent their lives in a closed institution, with the experiences of those who live at home with their families, based on an ethnographic study in southern England

(Hubert 1991, 1992, 2000, Hubert submitted), and also draws on a study of people with intellectual disabilities from Black and ethnic minority groups living with their families (Hubert 2006).

The thesis examines the nature of total institutions, and the powerful effects they have on those who live within them, as well as on the attitudes and beliefs of people who live outside in the normal social environment. The discussion explores concepts of social exclusion, powerlessness and identity, and includes one further chapter relating to this theme, the experiences of adolescent boys who have been sexually abused as children, and who are now abusing others, and the experiences and perceptions of their mothers. It also examines the effects of being labelled as a 'sexual abuser' on the projected futures of the boys (Hubert *et al.* 2007).

References

- American Association on Intellectual and Developmental Disabilities (2009). Definition of intellectual disability. Website: http://www.aamr.org/content_100.cfm?navID=21 (Retrieved July 15 2009).
- Adler, N. and Gluzman, S. (1993) Soviet special psychiatric hospitals. Where the system was criminal and the inmates were sane. *The British Journal of Psychiatry* 163: 713-720.
- Arnold, C. (2008) *Bedlam: London and its mad*. London: Simon and Shuster.
- Asad, T. (1995) *Anthropology and the colonial encounter*. New York: Prometheus Books.
- Board of Education and Board of Control. (1929) *Report of the Mental Deficiency Committee, Part III – The Adult Defective (The Wood Report)*. London: HMSO.
- Caplan, P. (2003) Introduction: anthropology and ethics. In *The Ethics of Anthropology: debates and dilemmas*, Caplan, P. (Ed.). London: Routledge. 1-34.
- Chapireau, F. (2009) Mortality of psychiatric inpatients in France during World War II: A demographic study. *Encephale* 35 (2): 121-8.
- Collins, J. (1992) *When the eagles fly: a report on resettlement of people with learning difficulties from long-stay institutions*. London: Values Into Action.
- Department of Health (2000) *No Secrets: Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse*. London: Department of Health.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationery Office.
- Department of Health (2009) *Valuing people now: a new three-year strategy for people with learning disabilities*. London: The Stationery Office.
- Department of Health and Social Security (1969) *Report of the Committee of Inquiry into allegations of ill-treatment of patients and other irregularities at the Ely Hospital*. London: HMSO.
- Department of Health and Social Security (1971) *Better Services for the Mentally Handicapped*. Command Paper. London: The Stationery Office.
- Departments of State and Official Bodies and Royal Commission on the Law relating to Mental Illness and Mental Deficiency (1957) *Royal Commission on the Law relating to Mental Illness and Mental Deficiency, 1954 - 1957*. Report. London: HMSO.
- Dewalt, K. M. and Dewalt, B. R. (2002) *Participant Observation: A Guide for Fieldworkers*. Alta Mira, CA: Alta Mira Press.
- Dickens, C. [1841] (1973) *Barnaby Rudge, a tale of the riots of '80*. Harmondsworth: Penguin.
- Emerson, E. and Hatton, C. (1994) *Moving out: relocation from hospital to community*. London: HMSO.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., Walsh, P. N. and Netten, A. (2000) Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal of Mental Retardation* 105: 81 -102.

- Fakhoury, W. and Priebe, S. (2007) Deinstitutionalization and reinstitutionalization: major changes in the provision of mental healthcare. *Psychiatry* 6 (8): 313-316.
- Firth, R., Hubert, J. and Forge, A. (1970) *Families and their Relatives*. London: Routledge and Kegan Paul.
- Gibbs, G. (2002) *Qualitative Data Analysis: explorations with NVivo*. Buckingham: Open University Press.
- Gilman, S. (1988) *Disease and Representation: images of illness from madness to AIDS*. Ithaca and London: Cornell University Press.
- Hall, L. A. (1990) The Eugenics Society archives in the Contemporary Medical Archives Centre. *Medical History* 34 (3): 327-333.
- Harris, J. C. (2006) *Intellectual Disability: understanding its development, causes, classification, evaluation and treatment*. New York: Oxford University Press.
- House of Commons. Committee of Inquiry (1978) *Report of the Committee into Normansfield Hospital*. London: HMSO.
- Hubert, J. (1965) Kinship and geographical mobility in a sample from a London middle-class area. *International Journal of Comparative Sociology* 4 (1): 61-79
- Hubert, J. (1991) *Home-bound: crisis in the care of young people with severe learning difficulties: a story of twenty families*. London: King's Fund.
- Hubert, J. (1992) *Too Many Drugs, Too Little Care: parents' perceptions of the administration and side-effects of drugs prescribed for young people with severe learning difficulties*. London: Values Into Action.
- Hubert, J. (2000) The social, individual and moral consequences of life in long-stay institutions. In *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'* Hubert, J. (ed.). London: Routledge. 196-207.
- Hubert, J. (2006) Family carers' views of services for people with learning disabilities from Black and ethnic minority groups: a qualitative study of 30 families in a south London borough. *Disability & Society* 21 (3): 259-272.
- Hubert, J. (submitted) 'My heart is always where he is': Perspectives of mothers of young people with severe learning disabilities and challenging behaviour living at home.
- Hubert, J. and Fforde, C. (2001) Introduction: the reburial issue in the twenty-first century. In *The Dead and Their Possessions: repatriation in principle, policy and practice*, Fforde, C., Hubert, J. and Turnbull, P. (eds.). London: Routledge. 1-16.
- Hubert, J. and Hollins, S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay NHS hospital care: qualitative study. *British Journal of Psychiatry* 188: 70-74.
- Hubert, J. and Hollins, S. (2007) Ethnographic research in closed institutions: ethical issues. *Research Ethics Review* 3 (4): 122-126.
- Hubert, J. and Hollins, S. (submitted) Leaving the institution? A follow-up of men with severe intellectual disabilities and challenging behaviour.
- Hubert, J., Curfs, L. and Hollins, S. (submitted) The use of ethnographic methods of research with people who have severe or profound intellectual disabilities.
- Hubert, J., Flynn, M., Nicholls, L. and Hollins, S. (2007) 'I don't want to be the mother of a paedophile': the perspectives of mothers whose adolescent sons with learning disabilities sexually offend. *Journal of Child Psychotherapy* 33 (3): 263-376.
- Hubert, J., Forge, A. and Firth, R. (1968) *Methods of Study of Middle-Class Kinship in London: A working paper on the history of an anthropological project 1960-65*. London: Department of Anthropology, London School of Economics and Political Science.
- Joseph, J. (2006) *The Missing Gene: psychiatry, heredity, and the fruitless search for genes*. New York: Algora Publishing.
- Kennedy, F. 1942 The problem of social control of the congenital defective - education, sterilization, euthanasia. *American Journal of Psychiatry* 99: 13-16.
- Kevles, D. J. (1999) Eugenics and human rights. *British Medical Journal* 319 (7207): 435-438.
- Lambek, M. (2002) *A Reader in the Anthropology of Religion*. Oxford: Blackwell Publishing.
- Last, M. (2000) Social exclusion in northern Nigeria. In *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*, Hubert, J. (ed.). London: Routledge. 217-239.

- Lévi-Strauss, C. (1967) *The scope of Anthropology*. Inaugural lecture, Chair of Social Anthropology, Collège de France, January 5th 1960. London: Jonathan Cape Ltd.
- Lewis, I. M. (2004) *Arguments with Ethnography: comparative approaches to history, politics and religion*. Oxford: Berg.
- Malinowski, B. (1937) Introduction. In *The Savage Hits Back*, Lips, J. E. (Ed.) New Haven: Yale University Press. vii-xii.
- Mansell, J. (2007) *Services for people with learning disabilities and challenging behaviour or mental health needs: report of a project group. Revised edition*. London: Department of Health.
- Mansell J. Knapp M. Beadle-Brown J and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.
- Marks, D. (1999) *Disability: controversial debates and psychosocial perspectives*. London: Routledge.
- Mental Capacity Act 2005. London: The Stationery Office.
- Mill, J. S. [1859] (1964) *Essay on Liberty*. London: Everyman's Library.
- Munro, R. J. (2002) Political psychiatry in Post-Mao China and its origins in the cultural revolution. *Journal of the American Academy of Psychiatry and the Law* 30: 97-106.
- National Council for Civil Liberties (1951) *50,000 outside the law: an examination of the treatment of those certified as mentally defective*. London: National Council for Civil Liberties.
- National Health Service (1971) *Report of the Fairleigh Hospital Committee of Enquiry*. London: HMSO
- Owen, K., Hubert, J. and Hollins, S. (2008) Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities* 36 (4) :220-226.
- Owusu, M. (1979) Introduction. In *Colonialism and change: essays presented to Lucy Mair*, Owusu, M. (Ed.). London: Mouton de Gruyter. 17-24.
- Reeves, S., Kuper, A. and Hodges, B. D. (2008) Qualitative research methods: ethnography. *British Medical Journal* 337: a1020.
- Reichman, J. M., Brezis, M. and Steinberg, A. (1996) China's Eugenics Law on Maternal and Infant Health Care. *Annals of Internal Medicine* 125 (5): 425-426.
- Royal College of Psychiatrists (2001) *Guidance for researchers and for research ethics committees on psychiatric research involving human participants*. RCPsych Report CR82. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists (2007) *Challenging Behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. RCPsych Report CR144. London: Royal College of Psychiatrists.
- Ryan, J. and Thomas, F. (1987) *The Politics of Mental Handicap*. London: Free Association Books.
- Said, E. (1994) *Culture and Imperialism*. London: Vintage.
- Savage, J. (2000) Ethnography and health care. *British Medical Journal* 321 (7273): 1400-1402.
- Shepherd, G., Muijen, M., Dean, R. and Cooney, M. (1996) Residential care in hospital and in the community - quality of care and quality of life. *British Journal of Psychiatry* 168: 448 - 456.
- Strang, V. (2003) An appropriate question? The propriety of anthropological analysis in the Australian political arena. In *The Ethics of Anthropology: debates and dilemmas*, Caplan, P. (Ed.). London: Routledge. 172-194.
- Sutton and Merton Primary Care Trust Board Meeting: 19th May (2009) Website: <http://www.suttonandmerton.nhs.uk> (Retrieved June 24th 2009).
- United Nations Convention (2006) Convention on the Rights of Persons with Disabilities. Website: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> (Retrieved June 24 2009).
- United Nations Economic and Social Commission for Asia and the Pacific. Website: http://www.unescap.org/esid/psis/population/database/poplaws/law_china/ch_record006.htm (Retrieved April 27 2009).
- World Health Organisation (2007) International Statistical Classification of Diseases and Related Health Problems 10th Revision, Version for 2007: Chapter 5 Mental retardation (F70-F79). Website: <http://apps.who.int/classifications/apps/icd/icd10online> (Retrieved June 28 2009).
- World Health Organisation (2009) International Classification of Functioning, Disability and Health (ICF). Website: <http://www.who.int/classifications/icf/en/>. Retrieved July 15 2009)

CHAPTER 2

The use of ethnographic research methods with people who have severe or profound intellectual disabilities

Jane Hubert
Leopold Curfs
Sheila Hollins

Submitted to the *British Medical Journal*

Introduction

Ethnographic research methods will be introduced and their place in the existing hierarchy of research methods available for use in health settings explained. Participant observation will be briefly described and the methods of recording and analysing data summarised. The rationale for the use of participant observation with people with severe cognitive impairments, specifically people with intellectual disabilities will be illustrated with examples from published research.

Background

Ethnographic methods were traditionally used by social anthropologists in the study of small-scale, so-called 'primitive' societies, originally in far-flung parts of the world, where they would live, sometimes for years. Becoming as much part of the community as they could, they studied all aspects of the social organisation of a particular society, i.e. its social customs, politics, economics, law, religious rituals and beliefs, family and kinship relationships - and the interrelationships between all these aspects of society. This involved learning the language (or languages) and living within the community for long periods of time.

Ethnographic methods are concerned with the meaning of people's actions, rather than simply with the number of times they occur. This involves getting to know the people being studied, watching and listening and taking part in their lives, not just on one occasion, but over a period of time, i.e. immersing oneself in the culture. The two main strands of this kind of research are intensive unstructured, or semi-structured, interviews and participant observation (Dewalt and Dewalt 2002) over time.

Qualitative versus Quantitative research: validity and reliability

Ethnography in health research

In the context of people's health and well-being, ethnographic research seeks to provide answers to questions about *why* individuals people act as they do in this context: why, for example, they follow or fail to follow medical advice, or why they take, or do not take prescribed medication. What factors are relevant to when and why they seek medical help or advice? What are their beliefs about disease, illness, doctors and drugs? What have individuals experienced in the past that makes them think and behave as they do now?

Qualitative research has often been criticised as being unscientific, 'which is peculiarly damning in an era when scientific knowledge is generally regarded as the highest form of knowing' (Mays and Pope 1995: 109). The Cochrane reviews, for example, which are systematic evidence-based reviews of healthcare interventions, are mostly based on randomised controlled trials (Cochrane Collaboration website 2009).

Concato *et al.* (2000) identify the accepted hierarchy of research methods, which puts randomised, controlled studies at the top, observational studies (cohort and case-control studies) in the middle, and descriptive and expert opinion at the bottom. They carried out a comparison of randomised, controlled studies and observational studies (which used a

cohort or a case-control design) to test the accepted view regarding the validity of the two research designs. Their results challenged the current hierarchy:

The popular belief that only randomized, controlled trials produce trustworthy results and that all observational studies are misleading does a disservice to patient care, clinical investigation, and the education of health care professionals (Concato et al. 2000: 1892).

Case control studies are often used to test the effectiveness of interventions, involving large cohorts of subjects and the use of control groups (Coggon et al. 2003). Qualitative methods, including ethnography, are not suited to these large numbers, and thus their effectiveness cannot be measured in the same way, i.e. the populations under study are too small to be analysed statistically. Nor does it usually make sense to include control groups. Furthermore, as Kuper et al. (2008) state:

The differences between what are commonly called quantitative and qualitative research run deeper than the presence and absence of numbers. In general, quantitative research focuses on answering the questions “what?” “how much?” and “why?” whereas qualitative research focuses on answering the questions “why?” and “how?” Qualitative research also allows for the generation of rich data and the exploration of “real life” behaviour, enabling research participants to speak for themselves (Kuper et al. 2008: a288).

In recent years, the use of qualitative methods in health research has become more widely accepted, and is now reported in prestigious medical journals. The British Medical Journal has published two series of articles on qualitative methods of research (1995 and 2008).

Quantitative methods of research focus on specific aspects of a situation, or certain attributes of a person, or compare a number of specific items or events over a large number of people. Ethnographic methods can approach problems or situations from many different directions, getting beneath the surface of questions and answers, and can find answers to many questions that need to be asked if a health service, at any level, is to be effective and human at an individual level. These in-depth methods can help to elucidate the questions that may later be researched quantitatively.

Kuper et al. point out that although qualitative research is often talked about as though it is one single method of research, the term in fact covers a range of different methodologies (Kuper et al. 2008). One of these is ethnography, and Savage (2000) draws attention to its uses in health research:

Ethnography can be applied to healthcare issues in numerous ways. It has been seen as a way of accessing beliefs and practices, allowing these to be viewed in the context in which they occur and thereby aiding understanding of behaviour surrounding health and illness. It is therefore particularly valuable as patients’ views on the experience of illness or delivery of service are becoming recognised as central to a modernised NHS. Ethnography can show, for example, how the effectiveness of therapeutic interventions can be influenced by patients’ cultural practices and how ethnocentric assumptions on the part of professionals can impede effective health promotion (Savage 2000: 1401).

Reeves *et al.* (2008) sum up the key features of ethnographic research as:

- A strong emphasis on exploring the nature of a particular social phenomenon, rather than setting out to test hypotheses about it
- A tendency to work primarily with ‘unstructured data’- that is, data that have not been coded at the point of data collection as a closed set of analytical categories
- Investigation of a small number of cases (perhaps even just one case) in detail
- Analysis of data that involves explicit interpretation of the meanings and functions of human actions; the product of this analysis primarily takes the form of verbal descriptions and explanations (Reeves *et al.* 2008 337: a1020).

The main methods used in ethnographical research are intensive interviewing and participant observation (Dewalt and Dewalt 2002). Participant observation involves watching and listening and participating in the field situation, to find out about behaviour and interactions in people’s own ‘normal’ environments. There is always a degree of discrepancy between what people say they do and what they actually do - direct observation can not only pick this up, but also provide clues to why there is this discrepancy (and see Hubert and Hollins 2007).

Key aims of Ethnographic Research

Reeves <i>et al.</i> (2008)	to provide rich, holistic insights into people’s views and actions as well as the nature of the location they inhabit
Savage (2000)	to access beliefs and practices, and the experiences of patients
Dewalt and Dewalt (2002)	to understand the experiences of other people as far as possible
Hubert (2007)	from their own perspective, and in their own ‘normal’ environment

Qualitative methods in general have become increasingly prevalent in medical and other health research (Kuper *et al.* 2008: a288), providing additional ways for health workers to

... explore and explain the contexts in which they and their patients function, enabling a more comprehensive understanding of many aspects of the healthcare system (Kuper et al. 2008: a288).

Ethnographic methods are particularly appropriate for health research because, in the heterogeneous culture in which we live, there is a wide range of different beliefs about almost everything. At one level there are scientific ‘facts’, which themselves change beyond recognition over time as new evidence emerges – and then there are the numerous different social and cultural beliefs and practices, some of which are part of our individual family socialization, and some that we pick up on the way throughout our lives. Some of the beliefs that are held may be self-contradictory, but can still be powerful influences on the way people behave. Ethnographic methods can be invaluable in unravelling the meanings underlying what people say and do.

Participant Observation - how data is recorded and analysed

Analysis: grounded theory

Participant observation is recorded in detailed fieldnotes. This material is usually analysed using a grounded theory approach (Strauss and Corbin 1998; Pope *et al.* 2000; Lingard *et al.* 2008). The main aim of grounded theory, which was developed in the 1960s by Glaser and Strauss (1967), is to generate understanding and theories which are grounded in the material (Lingard *et al.* 2008).

The analysis of large quantities of material from transcriptions of unstructured interviews, and fieldnotes from participant observation, is a very time-consuming process. The fieldnotes must be read and re-read throughout the research process, within the framework of the ideas and concepts that are developed before and during the fieldwork phase. At every stage of the data collection, the material must be examined in order to identify emerging concepts and thematic categories evolving from the material, and to identify relationships between categories. Some researchers use the computer software, NVivo (Gibbs 2002), to help in the organization of data, although this is not used alone. It is vital in research of this kind that a very thorough knowledge of all the material is obtained, so that no elements or 'themes' will be missed. Expressed feelings, emotions and sequence of the often non-verbal communications, the expressions and gestures, and the complex interactions that take place in intricate social situations, must all be documented and analysed.

Ethnography with people with severe intellectual disabilities

Although, traditionally, ethnography includes intensive interviews as well as participant observation in the 'field', there are some settings in which interviews are not possible. When those involved in the research have severe or profound intellectual disabilities and have little or no speech, participant observation is the central method of research. In order to get to know people, how they communicate, what their experiences and hopes and fears might be, what their relationships are, it is necessary to spend time with them, not only once or twice, but often, over a prolonged period of time.

When people cannot speak for themselves, research has generally focussed on what staff and others say the people they care for do, and what they say about individuals' likes and dislikes. Participant observation, on the other hand, by taking part in the life of people e.g., living in a locked ward, over a period of time - initially as a stranger, with no other role or relationship with anyone there - it is possible to begin to understand what is going on, and go some way towards representing the views of the individuals themselves. By constant observation and interaction, one can begin to see patterns of behaviour and the shape of relationships, and begin to identify and understand the wide range, and often almost imperceptible ways, that people without speech try to communicate (Hubert and Hollins 2006; Owen *et al.* 2008). Research of this kind can reveal the sorts of things that Goode (1994: 49) has called 'the lived realities of everyday life', which are beyond the reach of quantitative methods of research.

Research projects carried out at St George's, University of London, used ethnographic research methods in two locked wards of an old long-stay hospital, with men and women who had severe or profound intellectual disabilities. Although the majority had no useful speech, the research generated a substantial body of rich, in-depth material from participant observation in the wards (Hubert and Hollins 2006; Owen *et al.* 2008). Ethnographic research methods were also used in other projects, including a palliative care project with people with intellectual disabilities (Tuffrey-Wijne and Davies 2007), and semi-structured interviews were used in a further project with specialist palliative care professionals (Tuffrey-Wijne *et al.* 2008), part of a programme of palliative care research carried out in collaboration with the Governor Kremers Centre at Maastricht University.

One of the criticisms of this kind of research is that the researcher will change the nature and dynamics of the interactions and behaviour within the group, simply by being there. However, reflexivity is an important element of ethnographic research. The nature of the effects that the presence of a researcher has in the field is in itself further qualitative material about the culture and ethos of the community under study.

Summary Box

People with severe intellectual disabilities are a heterogeneous group

Interviews are not possible with non verbal, cognitively impaired participants

Participant observation provides insights into the health experiences and relationships of an under-researched population

Staff observations and interviews provide supplementary information

Conclusion

Ethnographic research does not set out to answer specific questions, but gathers material of all kinds in a specific environment. One of the most valuable uses of ethnographic methods in health research is to provide hypotheses and insights which can then be followed up with more quantitative research (Savage 2000).

References

- Cochrane Collaboration website: <http://www.cochrane.org/docs/descrip.htm> (Retrieved July 18 2009).
- Coggon, D., Barker, D. and Rose, G. (2003) *Epidemiology for the Uninitiated* (5th edition). London: Wiley-Blackwell.
- Concato, J., Shah, N. and Horwitz, R. I. (2000) Randomized, controlled trials, observational studies, and the hierarchy of research designs. *New England Journal of Medicine* 342 (25): 1887-1892.
- Dewalt, K. M. and Dewalt, B. R. (2002) *Participant Observation: a guide for fieldworkers*. Alta Mira, CA: Alta Mira Press.
- Gibbs, G. (2002) *Qualitative Data Analysis: explorations with NVivo*. Buckingham: Open University Press.
- Glaser, B. G. and Strauss, A. L. (1967) *The Discovery of Grounded Theory: strategies for qualitative research*. Chicago: Aldine Publishing Company.

- Goode, D. (1994) *A World Without Words: the social construction of children born deaf and blind*. Philadelphia: Temple University Press.
- Hubert, J. and Hollins, S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay NHS hospital care. Qualitative study. *British Journal of Psychiatry* 188: 70-74.
- Hubert, J. and Hollins, S. (2007) Ethnographic research in closed institutions: ethical issues. *Research Ethics Review* 3 (4): 122-126.
- Kuper, A., Reeves, S. and Levinson, W. (2008) An introduction to reading and appraising qualitative research. *British Medical Journal* 337: a288.
- Lingard, L., Albert, M. and Levinson, W. (2008) Grounded theory, mixed methods, and action research. *British Medical Journal* 337: a567.
- Mays, N. and Pope, C. (1995) Qualitative research: rigour and qualitative research. *British Medical Journal* 311: 109-112.
- Owen, K., Hubert, J. and Hollins, S. (2008) Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities* 36 (4): 220-226.
- Pope, C., Ziebland, S. and Mays, N. (2000) Qualitative research in health care: analysing qualitative data. *British Medical Journal* 320: 114 -116.
- Reeves, S., Kuper, A. and Hodges, B. D. (2008) Qualitative research methodologies: ethnography. *British Medical Journal* 337: a1020.
- Savage, J. (2000) Ethnography and health care. *British Medical Journal* 321 (7273): 1400-1402.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: techniques and procedures for developing grounded theory*. Newbury Park, CA: Sage.
- Tuffrey-Wijne, I. and Davies, J. (2007) This is my story: I've got cancer. 'The Veronica Project': an ethnographic study of the experiences of people with learning disabilities who have cancer. *British Journal of Learning Disabilities* 35: 7-11.
- Tuffrey-Wijne, I., Whelton, R., Curfs, L. and Hollins, S. (2008) Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine* 22: 281 - 290.

CHAPTER 2

Ethnographic research in closed institutions: ethical issues

Jane Hubert
Sheila Hollins

Published in the *Research Ethics Review* 2007, 3 (4): 122-126

Abstract

This paper discusses a number of ethical issues that arise in the context of ethnographic research with people with severe intellectual disabilities and mental health problems living in closed institutions. These very vulnerable people have tended to live emotionally and physically deprived lives in segregated and bleak environments, and because they cannot communicate through speech, and often have seriously challenging behaviour, they have tended to become socially and physically isolated from society.

Most research with people who do not communicate verbally has been quantitative, or conducted through informal and formal carers. Ethnographic research, on the other hand, involves spending long periods of participant observation with people in their 'natural' settings, providing intensely qualitative material, in order to present data as far as possible from each individual's perspective. Such research provides rich and emotionally powerful material which is often distressing and even shocking. This raises a number of ethical issues in relation to the conduct of such research, including questions regarding consent - who can give consent for someone who does not have the capacity to give consent themselves? The ethics of publication of such research are also discussed. This paper outlines the reasons why such research, and its publication, is vital for the futures of institutionalized men and women with severe intellectual disabilities.

Introduction

This paper discusses some of the issues that arise in the context of ethnographic research with people with severe and profound intellectual disabilities, who are among the most vulnerable men and women in our society, specifically those who live in closed institutions and are thus even more vulnerable and disempowered than those who live in the community. It arises from a recent situation in which a paper (relating to men living in a locked ward of an old 'mental handicap' hospital) was submitted to the BMJ. The paper underwent close scrutiny over a period of eight months, and was eventually rejected on the advice of the BMJ internal ethics committee. The paper was later published in another journal in full knowledge of the BMJ's decision (Hubert and Hollins 2006).

Background

The views and perspectives of people with severe intellectual disabilities and mental health problems living in institutions, whether in 'mental handicap' hospitals as in the past, or in residential homes, have seldom been sought. Many have lived in institutions since early childhood, and because they cannot communicate through speech, and often have challenging behaviour, their social, individual and gender identities tend to be lost, replaced by medical records that present a picture dominated by their physical and intellectual impairments and challenging behaviour (Hubert and Hollins 2006; Owen 2004).

Research with people such as these has tended to be quantitative, often consisting of psychiatric and psychological assessments, which provide clinical and diagnostic material, but lack depth and insight about the individual as a human being. In other research, material is collected from care staff, thereby representing their perspectives rather than that of the individuals they work with. Different sets of health professionals 'know' their patients in terms of their various professional categorisations of them, and it is understandable that staff will adopt and maintain professional ideas and concepts about individuals. It may be easier for an outsider, such as an anthropologist, to see people without all the accoutrements of the labels that cling to them throughout life.

The use of ethnographic research methods in an institutional setting

Qualitative approaches often seem alien to those in the health professions who are used to the experimental, quantitative methods traditionally used in clinical research, but it is now becoming accepted that there is a very real place for qualitative studies, to provide depth and to find out about those parts of life which quantitative methods cannot reach.

Ethnographic research involves spending long periods of participant observation with people in their everyday environment. Participant observation (Dewalt and Dewalt 2002) differs from simple observation in that the researcher interacts with the participants in the research and, to a greater or lesser extent (depending on the circumstances), participates in their daily life. This enables the researcher to understand and present the data as far as possible from each individual's own perspective, to understand the nature of their relationships, and the cultural context and ethos of the environment in which they live.

Participant observation is the most effective method of collecting data in the case of people with little or no speech. Most qualitative research with people who do not communicate through language focuses on what staff and others say people do, and what *they* say about individuals' preferences and dislikes. By participating in the life of a ward, or unit, not as a carer, and with no initial emotional involvement, a researcher can go some way towards representing the views of the individuals. By observing and participating, it is possible to begin to discern patterns of behaviour, likes and dislikes, non-verbal methods of communicating, and the shape of relationships.

Material gathered through fieldwork can be fed back into the system to enhance and elaborate what is known about each participant, and thus help to improve their lives through the provision of appropriate and sympathetic environments for them in the future. As a result, such research can help to re-establish individual, social and gender identities of people whose identity has been lost over many years of institutionalization.

Ethnographic research gets beneath the surface of superficial questions and answers. It can provide answers to questions about why people act as they do and discover what has happened to them in the past, and is happening now, which makes them think and behave as they now do. Such research is not concerned simply with the occurrence or non-occurrence of an 'event', but with the meaning and significance that it has for the people involved, and their experiences of it. Ethnographic research does not provide quantified answers to predetermined research questions, but leads to the development of concepts, hypotheses and insights about social phenomena as they occur.

To find out what people feel, what their attitudes and beliefs are, what relationships are significant to them, what their hopes and fears are, then it is necessary to spend time with them, over a long period, building up rapport and trust. Human behaviour cannot be researched in isolated goblets. The strands of people's lives are too closely interwoven, and form a fabric whose pattern is too complex to be understood by analysing its single threads.

Ethnographic research can provide rich and emotionally powerful material. In the case of people with severe intellectual disabilities living in institutions, this material is likely to be disturbing, even shocking, to those unfamiliar with this environment, and with the realities of life within it. In fact, the circumstances described in the research outlined above (Hubert and Hollins 2006) were apparently unknown even to many who worked within the same service, but whose work did not bring them into direct contact with the ward.

Many of the men and women living in closed institutions have characteristics which other people tend not to want to see or come into contact with in daily life, such as epilepsy, mental illness or physical disabilities. Even more relevant, perhaps, is that they behave in ways that offend and disturb other people – they may injure themselves or others, fling themselves at the floor and walls, bang their heads, strip off their clothes, and roar and scream.

In the ward referred to above (Hubert and Hollins 2006) all the men displayed 'challenging behaviour' of this kind. This was seldom responded to with sympathy, or a desire to find out why someone behaved as they did.

The long periods of observation on the ward revealed that all of the men, even those without any speech, spent a considerable amount of their time trying to communicate their

feelings and needs. There was often little recognition of or response to these attempts to communicate, and thus there was a rejection of the men as interactive, social beings. It is clear that only by 'listening', watching and interacting can any degree of understanding be reached. With people who have little or no spoken language, participant observation provides the means to discover and interpret ways of communication other than speech: touch, gesture, non-verbal sounds, eye contact, facial expressions and behavioural manifestations of sadness, joy, contentment, anger, affection and unease. At the same time, the relationship which builds up over time with a sympathetic and increasingly familiar researcher may bring out unexpected reactions and verbalisation. In the research referred to above (Hubert and Hollins 2006), over 250 hours were spent with the men on the ward. One man, who was spreading urine and faeces over himself and the walls, responded to a sympathetic approach by asking 'Where's Daddy?' Another interrupted his violent behaviour to sit at the researcher's feet, take her hand to stroke his head, and say 'Mummy' (Hubert and Hollins 2006: 71). Responses of this kind indicate emotions and memories that are often ignored in the context of a closed institution. Material of this kind demonstrates the apparent dichotomy between the outward appearance of someone i.e. as violent, or spreading faeces, and so on, and the inner worlds of such people, which far more closely resemble the inner worlds that we all have. Both aspects need to be described in order to emphasize that people who appear 'different', even to an extreme, should not be judged on this superficial 'otherness'.

Because of the nature of the material, and the level of incapacity of the individuals involved, a number of ethical issues are raised. The nature of ethnographic research necessarily results in personal and intimate data and, as already suggested, in the case of people with severe disabilities living in institutions, this can be distressing and unsettling to people who are not aware of the deprived conditions in which many men and women have lived for much of their lives. The material differs from the clinical and scientific data more familiar to medical journal readers. However, this is one of the reasons why such methods are invaluable, because they throw light on who patients are, and the nature of their individual emotional, physical and social needs.

Consent

One of the issues raised by such research is the question of informed consent. This becomes highly problematic when people cannot speak for themselves, and who do not, at any stage, have the capacity to give consent. Much has been written about this, and there are currently many relevant sets of guidelines relating to research with human subjects. These have been issued by institutions such as the General Medical Council (2002), the Medical Research Council (2000), the Royal College of Psychiatrists (2001), the Council for International Organizations of Medical Sciences (2002), the UK Government Department of Health (Department of Health 2002), the British Psychological Society (2006), the British Sociological Association (2002), the Association of Social Anthropologists (2001), and the International Association for the Scientific Study of Intellectual Disabilities (Dalton and McVilly 2004).

Some people, however, fall through the net of these guidelines, not only because they cannot give consent themselves, but also because it is not clear who can give consent on their behalf.

The Royal College of Psychiatrists' guidelines (2001: 6, 5.6 B) stipulate that 'the assent of the individual's closest relative or cohabiting partner, the support of both the person's professional carer and an independent clinician' must be obtained. However, the assent of the closest relative may not be relevant in cases where an individual has been institutionalized in the relatively distant past, and responsibility handed over to the 'authorities'. Obtaining the assent of a close relative when people have been institutionalized since childhood may involve searching for ageing parents who handed over a small child, up to 30 or 40 years ago, to a children's hospital. Many will have become cut off from what has happened to their child since then, although this does not necessarily imply that they have forgotten them.

It can be questioned whether professionals and researchers should have to stir up disturbing emotions in order to seek assent for a piece of observational research, especially since such parents are not being consulted on the intrusive lived realities of their child's daily life in an institution. Some parents, who decided many years ago to have no contact with their son or daughter, nevertheless still have strong and unresolved emotions about their child, and about what happened in the past.

Furthermore, it is not clear whether parents who have not had contact for many years still retain rights over what happens to an adult son or daughter from day to day. Obviously those parents who are still involved in the lives of their son or daughter will at least have a moral right to be asked whether they approve of 'intrusive' research if it is likely to affect the well-being of their relative. However, under the Mental Capacity Act (2005) there is nothing in law that gives relatives formal decision-making rights on behalf of an adult relative with intellectual disabilities with regard to research. Research with 'incapacitated' individuals must be approved by a Research Ethics Committee (or similar body) and researchers must identify someone close to the individual who can be consulted about the appropriateness of the individual's involvement (Mental Capacity Act 2005). In Scotland, under the Adults with Incapacity (Scotland) Act 2000 (2000), research may be carried out with adults without capacity, subject to approval by the Multi Centre Research Ethics Committee for Scotland, and provided it follows a number of general principles.

In the case of research consisting only of participant observation in an institutional setting, there would be little, if anything, for relatives to consent to, other than to the publication of the findings, although courtesy and respect for parents might suggest that those still involved should be consulted.

In the case of people who have been institutionalized since childhood, seeking consent from relatives may not be practical, or desirable. There are also few advocates actively involved with people who have severe and complex disabilities living in institutions. Thus the majority will have neither a relative nor advocate who might be able to give assent based on contemporary knowledge of the individual and his or her own preferences. Managerial and care staff currently responsible for the well-being of residents from day to day, are in a better position to give informed consent on their behalf.

Furthermore, the individuals themselves will make it quite clear if, on occasions, they do not want the researcher to sit near them or talk to them, i.e. withhold their consent for interaction with a researcher. This is 'process' or 'behavioural' consent, which is continually reactive to the responses of the individuals involved in the research.

Publication of ethnographic research

A crucial issue that arises in the context of ethnographic research with people with severe intellectual disabilities living in institutions is the question of publication. Reluctance to publish such material by editorial boards may be based on unease about the distressing and intimate nature of the material, as well as on concerns about anonymity. However, in our view, alleged worries about the infringement of people's rights through publication of (anonymized) material about them is an example of double standards. These men and women have been physically and socially segregated in the most extreme deprived conditions since early childhood, and subjected to emotional, physical and social deprivation and abuse that in all other circumstances would invoke outrage, if not criminal proceedings. Publication of these circumstances, provided individuals and contexts are totally unrecognizable, is likely to be beneficial to the individuals concerned, and those who follow them in contemporary institutions. There are a number of reasons why publication of this material is vital:

- In-depth material of this kind provides a different and more rounded perspective on people who traditionally have been perceived mainly in terms of their impairments and challenging behaviour. Ethnographic research describes them as men and women who have their own individual, social and gender identities. People who have been institutionalized for most of their lives have, in general, been perceived as less than full human beings, rather simply the sum of their impairments and challenging behaviour, with little acknowledgement of their human qualities. In order to demonstrate the past failures in care, it is self-evidently necessary to describe the individuals and the environment in which they live. Through participant observation over a long period, these men and women are shown to have similar feelings, emotions, needs and memories as everyone else. If such material is not published this remains unknown to the rest of society, who still perceive them as more or less totally 'other'.
- The past - and this is the very recent past - must not be forgotten by those who now have responsibility for the people who have moved out of long-stay institutions. Service providers (and society in general) need to be made aware of the past failures in the care of such men and women, including those carers who have worked in the old institutions and now work in the new 'campus' homes or residential homes in the community. How else will they realize and confront the fact that they have been part of this institutional abuse over the years – not because they themselves instigated it, but inherited by them as part of the system that had survived over generations, and which had become part and parcel of the environment in which they worked. Equally important is that new carers and health teams will generally have very little knowledge about the nature of the previous institutional lives of the people now in their care. If

the future lives of these men and women are to be improved then it is vital to identify and acknowledge the failings of past models of care.

- Institutional attitudes and practices die hard. What has been happening until very recently in institutions in the UK should be made known, however painful it may be, so that the attitudes and practices are not carried over into NHS campus homes and homes in the community. The failure of the NHS to confront the issues of institutionalisation is borne out by recent evidence suggesting that an institutional culture has continued in the NHS campus homes (Emerson *et al.* 2000), and these are now to be closed down as well (Department of Health 2006). Recent reports of the investigations into the Cornwall Partnership NHS Trust (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006) and Merton and Sutton PCT (Commission for Healthcare Audit and Inspection 2007) also provide evidence that institutional abuse still abounds.

Other anxieties regarding the publication of ethnographic material relate to the question of anonymity of individuals, and confidentiality of personal 'in-depth' material. However, the location of research, and the identity of the Trusts, hospitals and individuals involved can quite easily be disguised and anonymized. Responsible qualitative researchers are accustomed to ensuring that neither families nor the press will be able to identify places or people. Since the data is not identifiable it does not come under Section 60 of the Health and Social Care Act 2001, which concerns 'identifiable patient information' (Health and Social Care Act 2001).

Given the stringency of research ethics regarding anonymity and confidentiality, especially relating to very vulnerable people, it is noteworthy that no one seems to dispute that government enquiries should have been published (and are freely available on the web). The reports use the real names of the hospitals (and of individual wards) and residential units. In one of the Trusts the press managed to get access to members of some of the families involved, who have spoken openly to journalists, resulting in widespread coverage, not only of the report, but also of individual service users and their families. If this disturbing report can be made public then there is no reason why equally disturbing research results should not also be published, especially since these results are fully anonymized, unlike in the reports. Suppressing unpalatable research findings relating to an intensely vulnerable and deprived group of NHS service users does nothing to reduce the risks of institutional practices continuing in community settings. Only by 'coming clean' about the treatment of these people in the past can it be ensured that this abuse does not continue. The 'ethical' reasons behind the reluctance to publish disturbing research results pale into insignificance in the light of information currently emerging from the Healthcare Commission enquiries (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006; Commission for Healthcare Audit and Inspection 2007).

It cannot be 'good practice' to avoid publication until it becomes necessary for the Healthcare Commission to carry out a formal investigation, which inevitably becomes headline news. Such investigations tend to dissipate anonymity and confidentiality, thereby allowing the identification and journalistic pursuit of vulnerable men and women and their families.

The in-depth, intense and personal material obtained from ethnographic research with people who have severe and complex disabilities can be deeply disturbing. This is not a justification for repressing it – rather it is a powerful reason for making it public, in the hope that the unease that it provokes will lead to significant and genuine changes in the quality of services, and a sea-change in perceptions and attitudes towards these highly vulnerable and marginalized men and women.

References

- Adults with Incapacity Act (Scotland) 2000 (2000) London: The Stationery Office.
- Association of Social Anthropologists (2001) *Ethical guidelines for good research practice*. London: Association of Social Anthropologists.
- British Psychological Society (2006) *Ethical principles for conducting research with human participants*. London: British Psychological Society.
- British Sociological Association (2002) *Statement of ethical practice for the British Sociological Association*. London: British Sociological Association.
- Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection (2006) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*. London: Commission for Healthcare Audit and Inspection.
- Commission for Healthcare Audit and Inspection (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London: Commission for Healthcare Audit and Inspection.
- Council for International Organizations of Medical Sciences (2002) *International ethical guidelines for biomedical research involving human subjects*. Geneva: Council for International Organizations of Medical Sciences.
- Dalton, A. J. and McVilly, K. R. (2004) Ethics guidelines for international multicenter research involving people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 1: 57–70.
- Department of Health (2005) *Research governance framework for health and social care*. London: Department of Health.
- Department of Health (2006) *Our health, our care, our say: a new direction for community services*. London: Department of Health.
- Dewalt K. M. and Dewalt, B. R. (2002) *Participant observation: a guide for fieldworkers*. Lanham MD: AltaMira Press.
- Emerson, E., Robertson J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Jarbrink, K. and Netten, A. (2000) Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal of Mental Retardation* 105: 81–102.
- General Medical Council (2002) *Research: the role and responsibilities of doctors*. London: General Medical Council.
- Health and Social Care Health Act 2001 (2001) London: The Stationery Office.
- Hubert J. and Hollins S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay hospital care. Qualitative study. *British Journal of Psychiatry* 188: 70–74.
- Medical Research Council. (2000) *Personal information in medical research*. London: Medical Research Council.
- Mental Capacity Act 2005 (2005) London: The Stationery Office.
- Owen, K. (2004) *Going Home? A study of women with severe learning disabilities moving out of a locked ward*. London: Judith Trust.
- Royal College of Psychiatrists (2001) *Guidelines for researchers and for research ethics committees on psychiatric research involving human participants*. Council Report CR82. London: Gaskell.

CHAPTER 4

Men with severe learning disabilities and
challenging behaviour in long-stay hospital
care. Qualitative study

Jane Hubert
Sheila Hollins

Published in the British Journal of Psychiatry 2006, 188 (1): 70-74

Abstract

Background Community-based health and social care professionals have little knowledge of the past experiences of people with severe learning disabilities and challenging behaviour who are living in institutions.

Aims To gain a greater understanding of the experiences and needs of men who are living in a locked ward.

Method The study sample consisted of 20 men who were living in a locked ward of a long-stay institution. Qualitative (ethnographic) methods were used, involving participant observation (for around 250 hours) on the ward. All traceable families were interviewed. The analysis used grounded theory, and material was fed back into the resettlement process throughout.

Results The men's lives were emotionally, socially and physically deprived. Their individual, gender and social identities were not recognised, and their general health and mental health care needs were inadequately addressed.

Conclusions People who live in long-stay institutions, segregated from society, lose their individual and social identity, which complicates the presentation of mental health and behavioural problems, and raises important adult protection issues.

Introduction

Human rights and adult protection issues have a poor record in the history of institutions worldwide. In the UK, people living in National Health Service (NHS) hospitals have been largely excluded from the remit of adult protection concerns (Royal College of Psychiatrists 2003), although there is a statutory obligation on local authorities to implement adult protection procedures if a vulnerable adult is at risk in the community (Department of Health 2001a). As a result of physical and social exclusion, people who have spent their lives in institutions have become invisible to the outside world. The remaining long-stay hospitals in England are due to close by April 2006 (Department of Health 2001b). Some of the most vulnerable individuals are among the last to be resettled. Many of them have multiple or severe disabilities, mental health problems and challenging behaviour (Collins 1992; Shepherd *et al.* 1996), and when they do move they are often resettled in newly built homes on NHS campuses.

Method

The research project (conducted from 1997 to 2000) was an ethnographic study of 20 men living in a large locked ward of a long-stay hospital, before (and for some time after) it was closed as part of the hospital closure programme. All of them had severe learning disabilities and challenging behaviour, and most of them had psychiatric diagnoses and autism. Almost all of the men had been institutionalised since childhood.

The project was set up to complement the quantitative clinical outcome measures, such as the Life Experiences Checklist (Ager 1998), Adaptive Behavior Scale (Nihira *et al.* 1993) and the Health of the Nation Outcome Scales (Ashok *et al.* 2002) which were being administered by clinical psychologists. Those findings will not be reported here (further details available from the author upon request).

The fieldwork consisted of an observer (J.H.) spending extended periods of time in the ward. Little was known about the men as individuals, and the aims of this study were to get to know them by sharing their lives, albeit to a limited degree, and to describe them as individuals, as far as possible documenting their lives from their own perspectives, and thereby attempting to retrieve and restore their individual identities. A further objective was to gain an understanding of the ethos and culture of the environment in which they lived, and the nature of the relationships within that environment.

This paper describes the first stage of the research, before the ward closed. The second stage of the project, which followed the men's lives after the closure of the ward, will be discussed in subsequent papers.

Consent issues

The hospital management and the local research ethics committee approved the study (consisting of observation on the ward, access to the men's case records, and family interviews) and its publication. The participants in the study were unable to give informed consent because of the severity of their learning disability. The study could not have been

conducted with people with milder learning disabilities because the primary aim was to consider the vulnerability of members of such a severely disabled and excluded group who do not have capacity.

Since the men had been living in institutions since childhood, parental responsibility for them had, with very few exceptions, been handed over many years ago to the ward sister and hospital management. Although 12 families still maintained at least minimal contact with the hospital, few had direct contact with their family member. It was decided not to seek consent from these relatives. None of the men had effective advocates. However, interviews were conducted with 10 relatives, none of whom expressed concerns about the study. The parent representatives on the ward closure project board, to whom the researcher made regular representation, stated explicitly that they appreciated the researcher's understanding and perceptions of their sons, and approved publication of the material (e.g. 'It doesn't matter how uncomfortable it makes people feel' and 'I want everyone to hear this').

In English law no one else can consent on behalf of an adult without capacity. Although it is now considered good practice to obtain the written consent of the next of kin (Royal College of Psychiatrists 2001), in 1997 our decision not to do so was consistent both with research practice and with practice within the hospital.

Research process

The study employed ethnographic methods, which consisted mainly of long periods (over 250 hours in total) of participant observation (DeWalt and DeWalt 2002) of the men at all times of the day and night. The aim was to get to know them, to establish what their relationships were, to determine how they communicated, to absorb the ethos of the ward, and to try to discover - from people who mostly cannot express themselves in speech - what their experiences, hopes and fears might be. The men's medical files, which dated back to their first admission as children, were examined in order to ascertain their recorded histories and the care professionals' perceptions of them over the years. Family members were interviewed wherever possible.

Field notes from the extensive periods spent observing on the ward were written up comprehensively. The material was then analysed using a grounded theory approach (Strauss and Corbin 1998; Pope *et al.* 2000). The field notes were read and re-read throughout the research process, within the framework of the ideas and concepts that were developed before and during the fieldwork phase. Further concepts and thematic categories evolved during this familiarisation with the material, and relationships between categories were identified. Thus the analysis was firmly grounded in the data.

The project was also reflective, in that what was learned about the men was fed back into the transition process at all stages.

Results

Loss of individual and social identity

As young children, all of the 20 men had lived at home with their families. When their behaviour became too difficult for their parents to manage, or for other family reasons, they were placed in children's hospitals on a long-term basis (the majority from 4-8 years of age), and they were eventually moved to this locked ward of an adult institution.

Since their early years the men had been continually investigated and assessed by a wide range of professionals. However, the documentation of these quantitative assessments only described certain aspects of the men, such as their challenging behaviour or their intellectual and sensory impairments. Their medical records, which extended back to early childhood, did not describe them as individuals, so that little was known about the men as social beings with their own unique identities.

When the men were admitted to hospital as young children, they were often simply described as youngsters who were difficult to manage, but after 30 or 40 years of institutionalisation many of them now appeared to fulfil the popular stereotype of 'mad' people in institutions. They flung themselves at the floor and walls, banged their heads, roared and screeched, tore their clothes, spread faeces and injured themselves or each other.

Over the years the social invisibility of the men had contributed not only to their desocialisation but also to a degree of dehumanisation. One of the most powerful ways in which this occurred was by representing them as sexually dangerous. Of all the wards in the hospital, this was the least popular one in which to work.

When J.H. entered the ward for the first time, she had no idea what she would find. The following extracts are taken from her field notes and research diary.

When the self-locking door had slammed behind me and I stood in the ward, I was both appalled and terrified. It was a very chastening experience, exposing fears and prejudices which until then I would have furiously denied. The ward consisted of three huge bare rooms, like community halls rather than places in which to live. Some of the 20 men were sitting rocking in padded metal chairs that were bolted to the floor. Others ran round in circles, some shouting or whooping. One sat, naked, roaring loudly. One banged his head repeatedly against the wall. Another leapt and twisted and threw himself at the wall and the floor with great force. A blind man sat and rocked back and forth, screeching. In this tumult of unfamiliar sounds and movements I could see no member of staff. I was paralysed by fear, and that night I wrote in my field notes that 'I thought I was alone in the ward'.

The statement 'I thought I was alone in the ward' revealed my own acquiescence in the concept of the men's social invisibility, for of course the room was full of people. I was excluding them from my own social world because of the way they looked and moved and sounded, because they were locked in this bare, deprived environment, and because I was terrified.

Gradually these emotions faded. The better I got to know the men in the long periods of the day and night that I spent with them, the more moved I was by their individuality,

their desperate desire to communicate, and the extent of their individual physical and emotional suffering.

Because most of the men in the ward were unable to communicate by means of speech, they seemed to be perceived by others as essentially unknowable beyond the superficial sum of their impairments, basic needs and challenging behaviour. There was little acknowledgement of their more individual qualities, and few members of staff had built up meaningful reciprocal relationships with them as individuals. Some staff paid little attention to the men's hygiene and dress, and ignored ways of behaving which ensured that these men would be perceived as 'beyond the pale' in the outside world, perhaps thereby justifying the decision to physically exclude them.

Communication

The long periods of observation on the ward revealed that all of the men, even those without any speech, spent a considerable amount of their time trying to communicate their feelings and needs. There was often little recognition of or response to these attempts to communicate, and thus there was a rejection of the men as interactive, social beings. This was manifested not only in terms of daily non-communication, but also in the lack of acknowledgement of the possible reasons why the men behaved as they did.

One man frequently spread urine and faeces over himself and around the walls and floor. One day when he was doing this - very angry and red-faced, and making obscene gestures as I drew near - I asked him what was the matter. He stopped shouting and making gestures, and asked quietly - 'Where's Daddy?'.

Another man spent much of the time throwing himself with great force, shoulder first, at the floor and at the wall. He was immensely strong, and roared loudly, appearing very threatening, and his face was usually bruised and bloody. Then suddenly his behaviour would change. He would stop throwing himself around and would sit down at my feet, take my hand to his head to stroke his hair, and say 'Mummy'.

Loss of family identity

It is significant that these two men, and others in the ward, felt themselves to be sons. However, as part of their loss of social and individual identity, they had gradually lost their familial and kin identity. Except for the few who had a parent or other relative closely involved in their life, they were not perceived as sons, or brothers, or nephews or uncles. Instead, their identities were constructions by others. Their personal histories had been lost over the years, to be replaced by other people's records made for other people's purposes.

When I told Joey that I had visited his family, and explained to him how much his father cared about him, he took a loose strand of my hair and pressed it against first one of his eyelids and then the other. He did other. He did this a few times, and then he touched his eyelids again and smiled. I wondered whether talking about his father had conjured up some memory from childhood - perhaps of hair touching his face as he was kissed goodnight.

For many of the men, the vital linking into the fabric of their families was lost, yet there was evidence that the men still felt and craved this link. Despite the extent to which the outside world had been shut off from them, and irrespective of whether their parents still visited them, they continued to be aware of themselves as a member of a family.

Leroy constantly pulled anyone he could towards the locked door of the dormitory area. If he was allowed in he hunted for his best clothes - a shirt and suit - and wanted to be changed into them. He had done this for years, because he used to wear them for his father's visits. In fact his father had retired to the Caribbean without him, many years earlier, but Leroy continued to try to get him back, maintained the link with him, and perhaps tried to will him to come and see him, by trying to dress up for him.

Loss of gender identity

One of the most significant consequences of the physical and social exclusion of these men was their loss of gender identity and roles. For example, one man, David, always tore up his clothes, and would quickly become naked. All attempts to clothe him were futile, and his nudity had become accepted on the ward. In 'normal' society we do not accept nudity in our everyday social environment. The ward may not have appeared to be a very 'normal' environment, but there were 19 other residents and around 40 male and female staff members working on shifts, as well as domestic staff, maintenance men, psychologists, psychologists, psychiatrists, and day-centre staff, who were part of this 'social' environment.

Because David was always naked, he was perceived neither as a social adult nor, it could be argued, as an adult man. To all intents and purposes his sexuality was denied and, at a significant level he was de-sexed and de-gendered. This attitude towards David and his nakedness was perhaps surprising, since there was constant vigilance and concern about possible sexual abuse on the ward. Any touching or feeling, or signs of sexual arousal were discouraged, yet among the men there was an individual who was always naked. It seemed to be assumed that because the staff no longer perceived David as a man, that the men he lived with did not do so either.

After visiting his parents, I talked to David about them, and about the house where he had lived as a child. I said that I expected that he missed them. He stopped roaring and looked at me as I spoke, and then suddenly said, out of the blue, 'Bless you'. I had never heard him say anything spontaneously before that was not a one-word demand, and I was completely taken by surprise. No one around us disputed what he had just said. But those two appropriate words, dredged up from somewhere, indicated that he had understood, and emphasised the fact (usually ignored) that he had feelings as well as needs, and that he had memories, too.

David's story was true, to a greater or lesser extent, of all the men in the ward. Their stories show how a group of young children, instead of being helped to develop into men whose adulthood and gender were acknowledged and respected had, over the years, gradually been allowed to turn to ways of behaving that led them further and further into the category of 'other'. There seemed to be little acknowledgement of their individual desires,

needs, hopes and fears as adult men, or of the possibility that they might have normal sexual feelings for each other. They were largely perceived as dangerous, or at the very least unpredictable, and in many cases this had been used as the justification for controlling them within a locked environment. Yet at the same time they were denied normal gender roles, and to some extent their sexuality was mocked.

The effects of sensory disabilities

The individual identities of the men were further compromised by frequent lack of attention to the implications of their sensory disabilities. For example, Sam was blind. He sat doing nothing all day, often sticking his thumb deep into his eye socket. He was not given things to hold and feel, to listen to or to smell, although it was clear that his other senses were very acute. If Sam had not been living in a closed institution, he would have been given the care and services appropriate to someone who was blind. In fact, although he had lost his sight around 20 years previously, he had not yet been registered as a blind person.

Watching Sam, it was quite obvious that he was listening all the time - he responded differently to different movements, voices and footsteps. Touch was extremely important to him, but he encountered very little, because he was inclined to grab hold of people very tightly and scream, so most people avoided getting too close to him. He had almost no contact with other human beings, instead spending long periods of time sitting alone, totally isolated in a roomful of people.

It was clear that he was well aware of his blindness, which had been caused by self-injury. He only had a few words, but at times he would say 'blind, blind, blind', over and over again, becoming increasingly distressed. Sometimes he sat with tears running down his face. Usually no one took any notice. Other men cried, too.

There also appeared to have been lack of attention to some aspects of the men's physical health. The volumes of past medical notes showed that six of the men had cataracts, which were presumably becoming increasingly serious, but they had not been treated, although for one man a decision had been made that surgery would be too difficult. Other men were recorded as having poor eyesight or hearing impairments. There appeared to be no acknowledgement that such impairments might present continual problems for the men, or that these circumstances might provoke them to react in ways that would then be labelled as 'challenging behaviour'.

Emotional needs

Similarly, the emotional well-being of the men went largely unnoticed from day to day, or was responded to with a diagnosis that merited treatment with psychotropic medication. Many of the men appeared depressed and anxious, some even seemed to be scared, and there was a general disregard of individuals' anxieties.

Jed appeared to be obsessed by the possible death of his parents. He repeated his fears over and over again to anyone who would listen. But discussions with him went round in circles, and he became agitated and distressed, so most of the staff tended to ignore and avoid him as much as possible. However, Jed's anxieties were always apparent, and his lack

of intellectual understanding of death and separation, and his unpopularity, were allowed to mask his emotional confusion and fears.

This neglect of the men's conspicuous physical and psychological suffering had, over many years, become an integral part of the ethos of the ward, and to the succession of changing staff over the years this was regarded as simply part and parcel of life on this locked ward. Yet it has long been known that many of the problems experienced by people who have lived in institutions are the result of such factors as early separation from parents, living in emotionally and physically deprived environments, and emotional, physical and sexual abuse. These legacies of the past could have been addressed for many of the men in this study. It is now widely accepted that 'individual and group psychotherapies may be surprisingly effective contributions to working with those who prove highly challenging to the services and to society as a whole' (Royal College of Psychiatrists 2004:14). However, these men had been offered neither psychotherapy nor counselling, and their fears remained unacknowledged and untreated.

Discussion

Vulnerable adults in closed institutions

Cultural and attitudinal barriers have prevented people with severe learning disabilities, especially those segregated from society, from being perceived as fully human. Many of these individuals have lived unbearably deprived lives, both physically and emotionally, since childhood. The poor conditions in which they have lived and the abuses that have been perpetrated towards them have been condoned, or simply gone unrecognised, for many years. It is often assumed that these issues have been effectively addressed, yet this research suggests that important issues may still remain unresolved.

Despite increasing acknowledgement of the unacceptable conditions in which they have lived, the violation of the individual human and civil rights of men and women such as these has continued (Department of Health 2000). It is unclear whether this is the result of 'deliberate intent, negligence or ignorance' (Department of Health 2000: 10), but ignorance must surely be a less appropriate excuse than it has been in the past, especially in the context of the United Nations Global Programme on Disability, which is currently drawing up an international convention on the protection and promotion of the rights and dignity of people with disabilities (United Nations Department of Economic and Social Affairs, Division for Social Policy and Development 2004, 2005).

Hospital closure

The large residential houses that are currently being built on some NHS campuses, to accommodate many of the individuals who used to live in the hospitals, already house around 3000 people (Emerson 2003). Recent evidence suggests that an institutional culture frequently continues in such homes, and also that they are often of significantly poorer quality than community-based homes (Emerson *et al.* 2000; Owen 2004).

Given that many years of Government policy and adult protection guidelines failed to have a significant impact on the old order within NHS long-stay hospitals, it is vital that, with the closure of these hospitals, this situation is not permitted to continue either in the new NHS campus homes or in residential homes in the community.

Moving on

The men described in this research project are among the most vulnerable in our society, and are thus at the greatest risk of abuse. Many other men and women similar to the individuals described here will also have moved into NHS campus homes or homes in the community as a result of hospital closure programmes. Their new carers and health teams will generally have no idea of the nature of their previous life. Identifying the failings of past models of care (as this paper does) and establishing the enduring effects on individuals will be vital if better futures are to be created for the vulnerable people in our care.

Taking responsibility

Both the hospital management and the commissioners have agreed with us that the public interest would be best served by the publishing of our findings, even though public reaction is unpredictable. Will readers recognise a wider societal responsibility for the inadequate resources available to care for such needy and vulnerable people who lack a voice to speak for themselves?

It has not been our intention to criticise the care staff working in the institution. In general, they should not be blamed for institutional failings. However, it is crucial that further studies are undertaken to try to understand the feelings and perceptions of staff who, until now, have worked in the context of long-established institutions. It may then be possible to find effective ways to provide more appropriate training and support, so that institutional practices are not carried forward into the new homes and futures of these very vulnerable men and women. New community homes should be accountable to the public, and must support lay involvement and advocacy so that the people in their care remain visible to the outside world.

Future lives

The ward described in this paper was closed 5 years ago, and the 20 residents now have the chance of a different life. However, a huge change in attitudes both within the community and among care staff, managers and even families will be needed to restore the social and individual identities of these men.

The men described here were once children. If it is hard to restore their social and individual identities, and to radically improve their mental and emotional health at this stage in their lives, the least we can do is to ensure that the same thing does not happen to children with similar disabilities today. We must ensure that they are given the support and encouragement necessary to enable them to retain their individual, social and gender identities, and to develop as socially included and emotionally healthy men and women.

Clinical Implications and Limitations

Clinical Implications

Clinical records are an inadequate basis for care planning if detailed attention is not given to individual experiences, needs and relationships.

The iatrogenic damage and deprivation that are experienced in National Health Service long-stay institutions will need to be actively addressed - for example, with individualised attention, and even the establishing of therapeutic relationships - if the lives of these men are to improve.

Staff in new homes will need to dedicate time to individual residents, to talk and listen to them, and to provide sensory stimulation and activities for them.

Limitations

This is only the first stage of a study that is following the lives of residents of a long-stay ward and their resettlement in new 'community' homes.

No standardised measures of behaviour have been included.

The study does not consider the perspectives of ward staff.

References

- Ager, A. (1998) *The BILD Life Experiences Checklist*. Kidderminster: British Institute of Learning Disabilities.
- Ashok, R., Matthews, H., Clifford, P., Fowler, V. and Martin, D. M. (2002) Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD). *British Journal of Psychiatry* 180: 61-66.
- Collins, J. (1992) *When The Eagles Fly: A Report on Resettlement of People with Learning Difficulties from Long-Stay Institutions*. London: Values into Action.
- Department of Health (2000) *No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: Department of Health.
- Department of Health (2001a) *The Care Standards Act 2000*. London: The Stationery Office.
- Department of Health (2001b) *Valuing People: A New Strategy for Learning Disability for the Twenty-first Century*. London: The Stationery Office.
- Dewalt, K. M. and Dewalt, B. R. (2002) *Participant Observation: A guide for fieldworkers*. Alta Mira, CA: Alta Mira Press.
- Emerson, E. (2003) *An Analysis of NHS Long-Stay Beds and Residential Places for Adults with Learning Disabilities*. London: Department of Health.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., Walsh, P. N. and Netten, A. (2000) Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal of Mental Retardation*, 105: 81-102.
- Nihira, K., Leland, H. and Lambert, N. (1993) *Adaptive Behavior Scale - Residential and Community* (2nd edn). Austin, TX: Pro-Ed.
- Owen, K. (2004) *Going Home? A study of women with severe learning disabilities moving out of a locked ward*. London: Judith Trust.
- Pope, C., Ziebland, S. and Mays, N. (2000) Qualitative research in health care: analysing qualitative data. *British Medical Journal* 320: 114 -116.
- Royal College of Psychiatrists (2001) *Guidelines for Researchers and for Research Ethics Committees on Psychiatric Research Involving Human Participants*. (Council Report CR82). London: Gaskell.

- Royal College of Psychiatrists (2003) Parliamentary Briefing: The Abuse of Vulnerable Adults in England and Wales. <http://www.rcpsych.ac.uk/press/parliament/vulnerableAdults.htm>
- Royal College of Psychiatrists (2004) *Psychotherapy and Learning Disability* (Council Report CR116). London: Royal College of Psychiatrists.
- Shepherd, G., Muijen, M., Dean, R. and Cooney, M. (1996) Residential care in hospital and in the community - quality of care and quality of life. *British Journal of Psychiatry* 168: 448 -456.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Newbury Park, CA: Sage.
- United Nations Department of Economic and Social Affairs, Division for Social Policy and Development (2004) *Report of the Working Group to the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities: Annex I Draft Articles*. New York: UNDESA. Available at: <http://www.un.org/esa/socdev/enable/-rights/ahcwgreportax1.htm>.
- United Nations Department of Economic and Social Affairs, Division for Social Policy and Development (2005) *Media Alert: Committee on Treaty on Persons with Disabilities Concludes Fifth Session*. New York: UNDESA.

CHAPTER 5

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

Katherine Owen
Jane Hubert
Sheila Hollins

Published in the British Journal of Learning Disabilities 2008, 36 (4): 220-226

Accessible summary

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

Summary

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

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

Introduction

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

Methods

Study

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

Participants

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

Ethnographic methods

Ethnographic methods were used because they seek to understand experience from the point of view of the participants, and because they study people in their normal surround-

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

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

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

Analysis

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

Results

The women's experience of transition

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

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

Before the first move, the constant talk of moving, and the feelings of insecurity among staff, coupled with the lack of information about what was actually going to happen, heightened the overall sense of insecurity among the women. This was further increased by the departure of two of the women to their new homes in the community. The women who were left behind did not seem to know that the two were not coming back, and some of the women became aware that they too would be leaving their home.

Eva was particularly disturbed, and said very clearly 'I don't want to go' – looking wide eyed and shaking her head. During this period she was said to talk a lot about death.

The behaviour of other women was also said to have become 'worse'.

The move to temporary homes

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

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

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

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

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

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

Eva turned round to me and hit me in the chest... [A staff member] said that she should be on 1:1 again as 'she can't go around hitting people'. At one point Eva got up and

walked over to Molly who was sitting on the seat by the TV. She bent over and whacked Molly in the stomach. Molly curled up, moaned and began to cry.

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

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

And on another visit:

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

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

The move to permanent homes

Lack of preparation

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

Of the three women who moved into community homes, two had made visits to their new homes before they moved in. The third was considered too intellectually disabled and

was therefore not prepared in any way. The three women showed their insecurity in various ways, including incontinence, crying, destructiveness, self injury and withdrawal:

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

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

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

Those who were considered to be less able did not see their new homes until the day they moved into them.

Lack of support

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

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

Inadequate information transfer

The women's distress continued after they had moved to their new homes. This was clearly the result of various failings in the planning and implementation of the transition process. One of the most significant was the lack of inadequate information transferred between the ward and the new homes. This was due both to delays (and misplacement) of hospital notes and an absence of personal information. It meant that staff in the new homes did not know about individuals' family histories, their pasts, their likes and dislikes, their preferred means of communication, their personal care routines and sometimes even their medication. New staff were not aware of personal preferences, such as whether someone liked a

hot drink before bedtime, suffered from travel sickness, liked to sleep naked. In the case of one woman, no one seemed to know when her birthday was.

When attempts were made to pass on information, for example, through the use of 'memory books' made by the staff on the ward, they were rarely used in the new homes. This was both because staff in the new homes saw the institutional past as negative and wanted to move on from it, and partly because the books were hard to use. They did not include written information about who was in the photographs, and were therefore difficult for staff to use to help residents remember their pasts.

Changes for the better

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

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

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

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

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

Discussion

Lack of involvement and support during the transition process

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

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

The women were insufficiently supported because:

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

Failures in the transmission of information to the new homes

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

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

Experience of new homes

- The women's experiences of their new homes varied for a number of reasons:
- Staff attitudes towards the women, their disabilities, their capabilities and their similarities to others, varied between the homes, and this had considerable impact on the number of opportunities available to the women, what activities they were offered,

the new skills they were taught, and how involved they were in the home and in the community.

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

Conclusions

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

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

The results of this study are supported by Johnson (1998), who also found that changing the physical environment of the women she was studying did not succeed in changing the fundamental ways in which they were viewed. The perception of them 'was swamped by the existing discourse which constituted the women as objects' (Johnson 1998: 186).

People with severe intellectual disabilities are seen as being too different, too disabled and too challenging to lead lives like 'us'. They are not thought of as people who have pasts, have emotions, who experience feelings of loss, who grieve for old friends, who feel anxious about change, who have sexual needs or who suffer from loneliness. Furthermore, it is still often believed that the reason for these perceived differences lie in their disability, rather than in what they are taught, the opportunities they are given, how they are supported, and the expectations of those around them.

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

The Department of Health White Paper, *No Secrets* (Department of Health 2000) defines institutional abuse as 'poor care standards, lack of positive responses to complex needs, rigid routines, inadequate staffing and an insufficient knowledge base within the service' (Department of Health 2000: 10). Recent inquiries into two services for people with intellectual disabilities in the UK, both in hospitals and homes in the community, have highlighted this persisting institutional abuse (Commission for Healthcare Audit and Inspection 2007; Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006). The inquiry into Cornwall NHS Trust stated:

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

The report into Sutton and Merton PCT concluded that:

This type of institutional abuse was largely unintentional, but it was still abuse. It was mainly due to lack of awareness, lack of specialist knowledge, lack of training and lack of insight. It was exacerbated by low staff morale, shortages of staff, inadequate supervision and a lack of leadership (Commission for Healthcare Audit and Inspection 2007: 73).

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

References

Booth, T., Simons, K. and Booth, W. (1990) *Outward bound: relocation and community care for people with learning difficulties*. Buckingham: Open University Press.

- Bott Spillius, E. (1990) Asylum and Society. In *The social engagement of social science, vol. 1, the social psychological perspective*, Trist, E. and Murray, H. (eds). London: Free Association Books. 586-612.
- Bridges, W. (1991) *Managing transitions: making the most of change*. Reading: Addison-Wesley.
- Collins, J. (1992) *When the eagles fly: a report on the resettlement of people with learning difficulties from long-stay institutions*. London: Values Into Action.
- Commission for Healthcare Audit and Inspection (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London: Commission for Healthcare Audit and Inspection.
- Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection (2006) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*. London: Commission for Healthcare Audit and Inspection.
- Denscombe, M. (2003) *The good research guide: small scale social research projects*. Buckingham: Open University Press.
- Department of Health (2000) *No secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: Department of Health.
- Department of Health (2006) *Our health, our care, our say: a new direction for community services*. London: The Stationery Office.
- Emerson, E. and Hatton, C. (1994) *Moving out: relocation from hospital to community*. London: HMSO.
- Hewitt, H. (2000) A life story approach for people with profound learning disabilities. *British Journal of Nursing* 9: 90-95.
- Hubert, J. and Hollins, S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay hospital care. Qualitative study. *British Journal of Psychiatry* 188: 70-74.
- Jahoda, A., Cattermole, M. and Markova, I. (1990) Moving out: an opportunity for friendship and broadening social horizons? *Journal of Mental Deficiency Research* 34: 127-139.
- Johnson, K. (1998) *Deinstitutionalising women: an ethnographic study of institutional closure*. Cambridge: Cambridge University Press.
- Johnson, K. and Traustadottir, R. (2005) *Deinstitutionalization and people with intellectual disabilities. In and out of institutions*. London: Jessica Kingsley Publishers.
- Mansell, J. (1994) Specialized group homes for persons with severe or profound mental retardation and serious problem behaviour in England. *Research in Developmental Disabilities* 15: 371-88.
- Oliver, M. (1990) *The politics of disablement*. London: The Macmillan Press.
- Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D. *et al.* (2004) Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation* 109: 332-344.
- Sinson, J. C. (1993) *Group homes and community integration of developmentally disabled people. Micro-institutionalisation?* London: Jessica Kingsley Publishers.
- Strauss, A. and Land Corbin, J. (1990) *Basics of qualitative research grounded theory procedures and techniques*. London: Sage Publications.
- Usher, K. J. and Arthur, D. (1998) Process consent: a model for enhancing informed consent in mental health nursing. *Journal of Advanced Nursing* 27: 692-7.

CHAPTER 6

Leaving the institution? A follow-up of men
with severe intellectual disabilities and
challenging behaviour

Jane Hubert
Sheila Hollins

Submitted to *Journal of Policy and Practice in Intellectual Disabilities*

Abstract

Background The closure of the old 'mental handicap' hospitals, which is almost complete, has opened up opportunities to improve the lives of institutionalised people from residential care to campus homes and homes in the community.

Specific aims To gain understanding of the experiences and needs of men with severe learning disabilities and challenging behaviour living in a locked ward, and to determine the extent and nature of changes in their lives when they move 'into the community'.

Method The study sample consisted of 20 men who had been institutionalised from childhood, and were now in transition from a locked ward of an old institution. Ethnographic methods were used, involving participant observation on the ward (over 250 hours) and in their new homes. The analysis used grounded theory.

Findings The men's lives were better in material terms in their new homes, but seemed to be limited possibilities of making other significant changes in their lives. To a great extent they still lived within the old paradigm of social exclusion and denial of individual identity and autonomy. There appeared to be few fundamental changes in personal and social attitudes, and as a result men such as these continue to live social excluded and forgotten lives.

Discussion Despite wide acknowledgement of the unacceptable treatment of people living in institutions, there is evidence that the individual human and civil rights of men such as these continue to be ignored in spite of the closure of the institutions.

Keywords: deinstitutionalization, severe intellectual disabilities, challenging behaviour, community living.

Introduction

This paper describes the later phases of a project set up (at St George's, University of London) to document the lives of 20 men living in a locked ward of a long-stay hospital, which was being closed as part of the national hospital closure programme (Hubert and Hollins 2006). The project described the lives of the men in the ward, their experiences of the transition, and their lives in their new homes. All the men had severe or profound intellectual disabilities and almost all had mental health problems, and autism, and exhibited severely challenging behaviour. All except one had been institutionalised since childhood, the majority between the ages of four to eight years old. Often admitted simply as difficult to manage children with intellectual disabilities, after more than 30 years of life in a closed institution they had all developed severely challenging behaviour. Some attacked others, or injured themselves through head-banging with their fists or on walls, or throwing themselves at the floor and walls, others ripped up their clothes or spread faeces and urine on themselves and the walls, or ate unsuitable objects.

Although it had been Government policy for many years to close the old 'mental handicap' hospitals, the process has been long and drawn out. The men and women who were the last to be resettled were mainly those with complex disabilities, including mental health problems. They were, and are, the people with the most difficult problems to manage, especially those with severely challenging behaviour, and who are often perceived as 'dangerous'.

Most of these very challenging and vulnerable men and women have been isolated from society for much of their lives, and because of their physical and social exclusion they have become invisible to the outside world. They are among the most vulnerable in our society and at the greatest risk of abuse, including what the white paper *'No Secrets'* (DOH 2000) identified as 'institutional abuse', i.e., 'poor care standards, lack of positive responses to complex needs, rigid routines, inadequate staffing and an insufficient knowledge base within the service'. These factors underlie the other forms of abuse that existed within these closed wards.

The main aim of the St George's research was to try to understand the lives of the men on the ward and to identify the adult protection issues and abuses that existed, so that a substantial, meaningful improvement could be made to their lives after transition to NHS campus homes or homes in the community. Little was known about the men beyond their persona as men with severe impairments and challenging behaviour, and the purpose of the first phase of the study was to get to know them in order to be able to describe them as individuals, and to document their lives as far as possible from their own perspectives. This first phase of the project, covering their lives in the locked ward, lasted for 33 months because of delays in the closure of the ward. The results relating to this phase of the project have already been published (Hubert and Hollins 2006). The current paper describes the later phases of the project – the men's experiences of their transition from the locked ward, and the nature and quality of their lives in their new homes.

Method

The study used ethnographic methods, consisting of long periods of participant observation of the men (over 250 hours had been spent on the ward). Follow-up visits were made to the men in their new homes at intervals, with a final visit made nine years after the closure of the ward. By that time three of the men had died.

The first phase of the work was the most comprehensive, generating a comprehensive body of material about each man, and about the culture and process of life in the ward. This material, and the insights that arose from it, were fed back into the transition process before, during and after the men moved out. This was done, first, by contributing to their individual care plans and documentation being drawn up for each man in preparation for the transition; second, by feeding the material into the transition process and by working with the men's future carers and managers before, during and after the move; and third, the material was given to and discussed with the eventual managers and care staff in their new homes. A significant part of the documentation relating to the men consisted of detailed pen portraits of each man. These were based on the long periods spent with them in the ward, in an attempt to describe each one, not as someone who has intellectual disabilities, autism, a mental illness and challenging behaviour, but as an individual, with his own hopes, fears, feelings, memories and ways of communicating. These vignettes described twenty very different people, but at the same time they reflected the shared reality of the locked ward in which they lived, the ward that shaped their lives, and even now continues to be a powerful influence in their current life.

These were given to staff at all levels who were involved in the transition, and to staff and managers in the men's new settings, as part of the 'feed-back' process.

The aim was to get to know them, to understand their relationships with other residents and staff and, since very few of them had any speech, to discover how they strived to communicate with each other and with care staff. In this way it was hoped that it would be possible to determine what their individual experiences, hopes and fears might be.

In addition to participant observation, the men's medical files, dating from their first admission as children, were examined. These contained the only recorded histories of the men, and revealed the perceptions and priorities of those who had worked with them, rather than presenting the men as individuals with their own personal histories, who had developed and changed over the years from childhood to middle age.

The men's parents or siblings were interviewed, wherever possible, and a total of 11 families were interviewed. In most cases these discussions centred round the men as children. Most parents (although there were a few notable exceptions) no longer really knew who their sons were in any meaningful sense, and had little idea of the nature of their everyday lives and experiences.

In fact, very little was really known by anyone about most of the men, except what was recorded in their medical notes and clinical assessments. It was therefore decided, since they were about to be moved out of the locked ward, that more meaningful assessments and descriptions of them, which would be directly useful to their new carers, could be achieved by getting to know them as individuals. In this way it was hoped that their future

lives could be made qualitatively better than the lives they were living now, based not on the rigid demands of the old institution, but on their individual natures and preferences.

Results

In order to identify possible changes in the lives of the men it is necessary to summarise their lives before they moved out of the locked ward. The project had produced disturbing material. The physical conditions in which the men lived, within the confines of a large and bare locked ward, were grim; but even more disturbing was the emotional deprivation, and general disregard of the men's social and individual identity. They were not considered or treated as social beings, or as adult men.

The men's physical and social exclusion had also led to further exclusions from accepted social and gender categories. They were in many cases further desocialized by being represented as sexually dangerous, and all were said to be perpetrators or victims of sexual abuse (or both). This alleged sexual dangerousness, which for many appeared to be absent from the records or current observation of their behaviour, was often seen as the justification for their confinement within a locked environment.

There were many things that contributed to the deprivation in the lives of these men. There was often a disregard of their attempts to communicate. The men seemed to cry out, or indeed did cry out, for communication and comfort. There was a lack of attention to individual skills, and individual preferences, and most staff ignored indications of anxieties, dislikes and fears which, when they were physically expressed, tended to be labelled as challenging behaviour. Furthermore, aspects of their physical health, and the implications of their sensory disabilities, tended not to be taken into account in daily life.

Because the men had little or no speech, the staff working with them did not appear to try to develop reciprocal relationships with them as individuals. In this way staff members avoided getting into a situation where they could begin to understand why someone behaved as they did, and thereby be able to help them change the way they acted, and thus become less disliked, feared and socially excluded.

The men spent most of the time sitting or crouching alone somewhere in the ward, or pacing around from room to room. There was a sense of isolation and loneliness about them. Some spent periods of time on some days in the day centre, but those who were considered difficult to manage stayed on the ward almost the whole time.

The transition

In view of the proposed closure of the hospital, the transition of the men to the 'community' had been planned for a number of years, but in the event it was repeatedly delayed, and there was a prolonged period of turmoil and loss. None of the men were involved in, or present at, discussions or meetings about his own future. The ward manager whom the men had known for many years was moved from the ward, and there was a series of new managers, and many other changes of care staff. The atmosphere in the ward became increasingly fraught, probably because care staff grew more and more anxious about their own futures. They felt increasingly insecure and, especially for those who had worked for

some time in the ward, or in the institution as a whole, there was a significant sense of loss. This insecurity was undoubtedly picked up by the men, who also heard much discussion of the proposed moves. There is no reason to believe that these men, who did not themselves express themselves in speech, were not listening to and understanding some of what was said in their presence. The anxiety and insecurity of the staff and residents was very apparent on the day that the last ten men were waiting in the ward for the bus to come to move them to their new (temporary) home in the community:

The members of staff were sitting together in a bunch on one side of the huge day room. The men were scattered around the room, looking anxious and alone. One man was beating his fist against the door of the dormitory area, trying to get back into the bedroom in which he had slept for many years of his adult life. The scene in the ward was a sort of vignette, highlighting the sense of separateness and isolation and anxiety of both staff and residents (Oct 1999).

Three men moved individually into separate homes in the community. The first group to move were those who were to live in a purpose-built campus home on the hospital site. This transition was perhaps the easiest one, since the seven men remained in familiar surroundings, and had been able to watch the building of the home. They also moved with a few familiar staff. But for them there was to be no further move into the wider social community. Ten years after the move, their home is still in the middle of a derelict site, far from any semblance of a community, which has been awaiting planning permission and the building of a new housing estate.

There were various delays in the move of the remaining ten men into their two new community homes. Because the houses were not ready, they were moved together into a cramped interim home when the ward closed, where they stayed for two years. During the period they spent in this temporary home many of the men showed signs of severe disturbance and distress. When they eventually moved into the two planned 'permanent' homes in the community, even that was not the final move for half of them. Asbestos was found in the roof of one house, and the men were moved again, into a different temporary home, until the following year. Moving house is often a traumatic experience at the best of times, even for people who do it voluntarily, and who choose when and where they will move to, and who they will live with. For these men there was no choice involved at any stage in the process, and the transition, which had been planned to take place in 1997, was not completed for five years, and involved a number of highly disruptive moves, especially for five of the men, who moved house four times in two and a half years.

Life in the new homes

There are many aspects of day-to day life that can be used to measure whether the outcomes for people moving into the community have been successful. These include:

- Having a degree of autonomy, i.e., the freedom to make decisions on a day to day basis, and to take part in life-changing decisions
- Involvement and participation in domestic life and day to day activities

- Participation in community and family life: contact and relationships with people outside the home
- Opportunities to develop individual skills and competency
- Access to health care, and to specialist input when necessary, including mental health specialists

These outcomes can be viewed in the context of the individual's own degree of intellectual disabilities and mental health problems, but equally important is the input from other people, especially the staff who work with the men, and the nature and ethos of the units in which they live. For an individual with severe or profound intellectual disabilities, whether he or she lives a fulfilled life will necessarily depend to a great extent on the input of other people, as reflected in:

- The size of the unit and the ratio of staff to residents
- The organisational structure of the home, the extent of institutional practices, and the existing 'rules' of the house
- What daytime activities are offered and provided
- The degree of encouragement given to maintain or develop family relationships, and relationships with others beyond the residents and staff
- The extent to which each individual's adulthood is acknowledged, including acceptance of sexual needs and preferences
- The extent to which there is active encouragement to communicate, by whatever means an individual offers.

All these factors are important, and necessarily interlinked, impacting on each other in both directions. They will depend on the level and nature of staff training, staff experience and attitudes, and on the attitudes, beliefs and actions of the Home Manager.

Quality of life is notoriously hard to assess for other people. It can only be done by finding out how people experience what happens to them, not simply whether or not an event occurs.

Thus the final phase of this research was the observation and evaluation of the lives of the men in their new homes, again through participant observation, to document the nature of their new lives.

It would be true to say that the lives of all the men in the campus home and the two community group homes have improved in many ways. The houses are smaller, and there are only up to seven residents in each. Food is prepared in the kitchens, rather than being driven 300 miles overnight from Cornwall. The men have access to their own rooms and, usually, access to the garden. Whether they have access to the kitchen varies from house to house. All this means that they are now living lives that approximate more closely, at least at this superficial level, to 'normal' lives. However, these material changes are only part of the complex set of relevant factors. Life in the three new homes varies, and in two of the three houses the quality of life has varied significantly at different times under different managers.

The campus home

In the new campus home, where there has been only one home manager since the move. The quality of life the men has improved in a number of ways, and remains stable. In particular, the men are encouraged to communicate, and their various means of communication are responded to.

In the old ward, it was very noticeable that although the men spent most of their life sitting around doing nothing, there were certain times when they became compliant, skilled individuals. At mealtimes they all, astonishingly, sat down and waited patiently for their food, ate with knives and forks or spoons, carried their plates to the trolley, and put them on the right pile of plates, and put their knives and forks in a bowl on the lower shelf of the trolley, and their mugs on a column of mugs, one on top of the other. They carried the tea pot and milk jug to the table and almost all of them, some with assistance, poured their own tea, and added milk.

In that context the men acted as socialized and skilled individuals, but this did not appear to be recognised, and they were not being engaged in other activities throughout the day that involved similar skills. Now, in the campus home, the individual skills of the men are being recognised, and at least to a small extent, being built upon, in their new environment. Even those with the most severe intellectual disabilities are involved, for example, in artwork of various kinds:

P comes every day to do activities with the men. The garage has been converted into an activities room, with paint, glue, scissors, coloured paper etc. and some wood. B was asked to come in do some sticking on to a picture... with hand over hand guidance, he used the scissors, and then put on some glue and then banged the piece on with his hand (Aug 2000).¹

The men have access to their own rooms, to the office and, when there is a member of staff there, to the kitchen. They are involved in the preparation of snacks and meals. They all eat together, and the staff sit and eat with them. Most of them spend some time every week-day in the day centre they had attended in the past. Others attended another centre in the grounds, set up for those with autism. The men did not appear to do much while they were there, but at least it was some sort of external activity.

The integration of the men into the community outside the hospital site is still minimal, and it may be that the preferences and fears of some of these individuals, who have lived emotionally and socially deprived lives for so many years, may counteract attempts to 'integrate' them. Most of them are at least being given the opportunities, and have the choice to take them up or not.

The men living in the campus homes are now perceived more as social beings and as individuals with their own preferences, dislikes, hopes and fears, and the nature and extent of their day-to-day activities reflect this. However, it is clear that the improvements in the quality of life of the men, and the perception that others have of them, still rely heavily on the beliefs and style of leadership of the individual case manager within the home, who has

¹ Quotations are from Jane Hubert's field notes.

managed the home since it opened. The question remains: have the positive developments in the house become established practice? How easy would it be, with a different manager, for the home to slip back towards the experiences of the past? Without someone there to constantly instil and fulfil the same aims and philosophy the house could be just another mini-institution - which of course it is. Certainly on the days that the manager is not present, there are perceptible negative differences in the treatment of the men.

In spite of the efforts of the home manager, there seems to be little input from psychologists or other professionals to try to understand and confront the men's challenging behaviour. For example, the man who always stripped off his clothes in the locked ward is still naked, some nine years later.

B was lying across a chair, naked, with a strip of red material in his hand, fast asleep. He woke up when I spoke, looked at me closely and started fiddling with strands of thread. He said something which was interpreted as wanting trousers, so he was given a pair of track suit bottoms. He started ripping them up straight away (Jan 2008).

The fact that he will not wear clothes seriously affects his quality of life, not only because it means that he may not be acknowledged or perceived as a social adult inside the house, but also because he cannot step across the threshold of the home into the outside world and interact with the wider community.

One man in the house, however, has changed noticeably:

C used to sit for most of the day in the corner of the ward with a rather 'spaced out' expression on his face. Now he has a range of expressions, and has eye contact... he is active and quite noisy. He looked hard at me, and interacted with the staff frequently. Quite unlike the passive man who was in the ward - probably in part because he has been taken off some of his medication (Sept 2001).

The campus home is undeniably a mini-institution in some respects. The men live a communal life, and they live behind locked doors and gates. They do have more choices than they had before: activities are chosen for them that they have shown enthusiasm for; some pick out the clothes they want to wear; food is tailored to individual likes and dislikes; they are allowed to stay in their rooms if they want to and get up (more or less) when they like, and so on. There is a potentially negative side to this; since the men are given the choice of what they want to do or where they want to be, it tends to mean that anyone who goes off and stays away from everyone else may get left where they are, alone. The blind man, who used to sit alone all day in the middle of the old ward, now sits in his room for much of the day. He listens to music, and this is said to be what he wants to do, but it is not clear that he has many other choices. Although he has finally been registered blind (in his 30s), there are still no services in place for him as a blind person.

The degree to which the men now have control over their own lives is limited. They have not at any stage been involved in major decisions about the direction of their lives. They did not choose who they would live with, probably for the rest of their lives. They may have input into routine day to day decisions, but life-changing decisions are made by other people, and will continue to be, because the men do not have the capacity to make such

decisions for themselves. However, it is likely that more recognition of their preferences and dislikes will now be taken into account in future major decisions.

Houses in the community

Two other groups of men moved into houses in the community. The quality of life for the men in these two houses (House A and House B) has varied widely at different times since they moved in. Both have had a frequent turnover of home managers, and the attitudes and style of each manager have governed the nature of the life in the houses.

House A, was brightly painted, with warm colours and soft furnishings and appeared welcoming. However, the kitchen was locked the whole time, and at lunchtime, for example, the top half of the stable door would be unlocked for as long as it took to hand out a sandwich for each man, and then locked again. The men, for the first few years, sat at separate tables, while members of staff stood around the room. They seldom spoke to the men, except to tell them what to do, and to men who could speak a few words, phrases often addressed to children, such as: 'And what's the magic word?' were used. Conversations were often held across their heads. At a later stage, larger communal tables were introduced.

There were few planned daytime activities. Six months after they had moved only two men had planned activities, once a week, away from the house, and no day activities were brought into the house. A staff member said 'we do things with them', but this seemed to mean taking them for the occasional drive, in pairs, and sometimes not being let out of the car, because of perceived risks. This was a much less active schedule than the men had when they lived on the locked ward and attended the day centre. Six months later they were all said to have some activity outside the house, although they were usually around when I visited, and seemed to be unoccupied in the house. One man, no longer on Lithium, had become more mobile and interactive, and sat up to eat his meals, not, as in the ward, bending over with his tongue out, dribbling and making the same sounds over and over again.

At one stage there was a very warm atmosphere in the house, largely because of the personality of the manager at that time:

J radiates goodwill... she talks about them with affection, and talks to them, smiling and laughing with them (July 2001).

However, there seemed to be scant attention given to those men who did not initially respond, and little appeared to be done to try to get them to interact:

L, as always, seemed to be left to himself... he came in, sat down in his chair, twisted his hands, then went out again. No one spoke to him... It seems that no one tries to engage with L; it is clear that he is aware of people, but this has not been developed (March 2002).

A recent visit (2008) revealed a generally rather cold atmosphere, under another of a series of managers, where staff seemed to have lost control of one resident, whose behaviour caused others to become nervous and demanding, giving the house a palpable sense of instability and unease.

At House B there were also problems with a frequent turnover of home managers and acting-managers, and in an early visit there were only two male regular staff and a number of agency staff. The walls were dirty and cracked, and there were no pictures or colours in the house. The bedrooms were bare and beds unmade. The men had been unable to use the garden throughout the summer because of loose tiles on the roof. As in House A, meal-times - which were the only time that the men were brought together – were very quiet.

No one spoke, to each other or to the men... N said 'drink' and was told he would have some when he had finished. He seemed subdued; there was no atmosphere of company, of a group of people together, but a few men being watched over by silent staff (Dec 2002).

The only man in the locked ward who had been on no medication was now on antipsychotic drugs because his tendency to spread urine and faeces was not tolerated in the new house, possibly because there were soft furnishings and the floors were carpeted. He was one of the more able residents, who could express himself partly in words and partly gestures and facial expressions. On the old ward it was recorded that:

When he is in a good mood he is bright, communicative and funny. He will dance if there is music, and put his hands behind his head and wiggle his hips to the music; he is a good mimic. When he is excited about something he will sit happily, and smile, and come up and hug you and kiss you on the cheek (Oct 1999).

He was now on psychotropic medication. No attempt seemed to have been made to discover why he became angry and distressed, and spread faeces. He no longer danced or teased, but shuffled slowly around the house looking at the floor, or sat on his bed for hours, immobile, without giving eye contact. He has since died.

A recent visit to this home showed that it had much improved. The house was clean and bright. After many changes of manager the current one was trying hard to establish some stability and had succeeded in getting regular daytime activities for the men. The men appeared to be involved in some household activities in the home, and to have access to the kitchen. However, mealtimes were, again, solitary affairs:

Lunch was a separate and unsocial event... the men sat down at different but overlapping times to eat... members of staff stood and watched (May 2008).

K, the most able man among the 20 men who had lived in the locked ward, looked much better than he ever had before:

His skin was clear and he had no bruises or bloody sores on his forehead from banging his head on the wall... His hair was neat and clean. He moved around actively... We sat in the dining room and he talked and talked, though I couldn't understand much of the time (May 2008).

Thus it can be seen that in this house, and in House A, that the quality of life of the men has varied, and presumably will continue to vary, according to the attitude and actions of the house manager, and the resulting ethos of the house. The campus home, in spite of its location on the old hospital site, remains the most stable environment.

Discussion

It is salutary that many things had not fundamentally changed over the nine years that the men had lived in their new homes. These stories show that the quality and stability of the lives of these men with severe and complex needs have improved in a number of material ways, but that there are fundamental issues that have not substantially changed, especially in the homes in the 'community':

- The quality of the men's lives was highly dependent on the attitude and level of dedication of those in direct charge of the homes, and as a result also on the quality and training of care staff employed in them.
- In two of the three homes there had been a constant turnover of staff, including home managers, thus there was little continuity in staff knowledge of the men or in relationships with them.
- Only the long-term manager of the campus home was aware of the existence of the vignettes drawn up about each man. In the other homes the succession of different managers meant that the vignettes had been long forgotten.
- The men still live largely institutionalised lives; they are still, in a sense, just contained, rather than developing their own individual lives.
- Some of the staff working in the homes continue to have an 'institutional' approach; they do not interact with the men as one adult to another, but retain a patronising adult-child relationship.
- We found no evidence that the men are being enabled to develop new relationships outside the confines of the homes. Their social world still consists of co-residents and staff.
- There is limited input from professionals other than to adjust medication reactively, rather than to tackle the anxieties, trauma and memories that are likely to underlie the men's challenging behaviour. Thus the men continue to behave in ways that make them socially unacceptable.
- Only one man had discontinued medication; for the others similar doses of psychotropic medication continued.

Conclusion

The institutions have been closed down, and there is much talk about improving the lives of people with severe intellectual disabilities, but to a great extent this is still being done within the old paradigm of social exclusion and denial of individual identity and autonomy. Their lives may be better than they were in material terms, but within the structure of the system there is only a very limited possibility to actually change their lives. There appear to be few fundamental changes in professional and social attitudes, and as a result men such as these continue to live socially excluded and forgotten lives.

It is widely accepted that, in addition to biological and syndrome specific causes, many of the enduring mental health problems of people who have lived most of their life in institutions are the result of their damaging life experiences, including emotional, physical and sexual abuse which most experienced while living there. It is also clear that the physical and

emotional needs of these men and women are still not being adequately met. In our view it is necessary to go further than just providing a 'better' way of life in the community - there must also be acknowledgement of what has happened in the past. Often their new carers and new health teams will have no idea of the nature of their previous lives. This research has identified the failings of past models of care, and the enduring effects for individuals, and these need to be taken into account in the creation of better, even successful, futures for these very vulnerable people.

The recent Joint Committee on Human Rights report published in the UK (JCHR 2008) states that the recent Healthcare Commission reports (CHAI and CSCI 2006, CHAI 2007) on the treatment of people with intellectual disabilities raise 'substantive issues about the compatibility of such treatment with human rights and equality law under the Human Rights Act 1998... and the Disability Discrimination Act 1995 (as amended), the European Convention on Human Rights... and other international legal standards' (JCHR 2008:11). It also states that 'The extent to which the rights of adults with learning disabilities are currently being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: all key human rights principles, [and] also raises other important issues of substantive human rights law such as... the prohibitions on inhuman and degrading treatment... and unjustified discrimination' (JCHR 2008:11).

Despite acknowledgement of the unacceptable treatment, especially in institutions, of people with severely challenging behaviour, the violation of the individual human and civil rights of men and women such as these appears to be continuing.

Cultural and attitudinal barriers have often prevented people with severe intellectual disabilities being perceived as fully human. Many have lived unbearably deprived lives, both physically and emotionally, since childhood. It will take a huge leap in attitudes within the community, as well as for care staff, managers and even families, to restore their social and individual identity. It is probably too late to recreate the social and individual identities of the men who participated in this study at this stage in their lives. As a society, the least we can do is ensure that children and young people with similar disabilities today retain their individual, social and gender identities so that they are able to develop as socially included men and women, and do not carry with them the tenacious legacy of separateness and stigma throughout their lives.

References

- Commission for Healthcare Audit and Inspection & Commission for Social Care Inspection (2006) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*. London: Commission for Healthcare Audit and Inspection.
- Commission for Healthcare Audit and Inspection (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London: Commission for Healthcare Audit and Inspection.
- Department of Health (2000) *No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: Department of Health.
- Hubert, J. and Hollins, S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay hospital care. Qualitative study. *British Journal of Psychiatry* 188: 70-74.
- Joint Committee on Human Rights (2008) *A life like any other? Human rights of adults with learning disabilities*. London: The Stationery Office.

CHAPTER 3

‘My heart is always where he is’. Perspectives
of mothers of young people with severe
learning disabilities and challenging behaviour
living at home

Jane Hubert

Submitted to Disability & Society

Abstract

Little research has focussed on the perspectives of families caring for someone with severe or profound learning disabilities and challenging behaviour. The main aim of this research was to gain understanding of the experiences and perspectives of families, especially mothers, of young people with these complex needs, including attitudes to long-term residential care.

Ethnographic methods were used, consisting of intensive interviews over two years, mainly with mothers, and participant observation. The analysis used grounded theory.

The mothers' main focus was on their disabled son or daughter. Most were socially isolated, even from close kin. Their negative attitudes to institutions, and fears for the safety and well-being of their sons/daughters, led to determination not to put them into long-term care. Mothers struggled to care for the young people at home, in spite of difficulties, family tensions and social isolation. Lack of effective services, especially around transition to adulthood, increased parents' protectiveness.

Introduction

This paper is based on an ethnographic study carried out with twenty families who had, living at home, an adolescent or young adult with severe or profound learning disabilities and challenging behaviour.

The study was an attempt to gain an understanding of the worlds of these families, including the difficulties and dilemmas they faced in their attempts to access adequate and effective services so that they could continue to keep their son or daughter at home. The study also documented the families' relationships, not only within the household but also with the wider kin group, and others in the outside world.

The aim was to get to know the families well enough to be able to describe their lives as far as possible through their own eyes. The parents in this study felt that people 'outside' tended not to see them in the same way because there was little or no participation in the narrow but intense world in which they lived.

One of the original aims of the study was also to discover what factors influenced parents in their decision to place a young adult in permanent residential care away from home. In the event only two families made this decision during the research period, with the result that this focus changed to the reasons why families decided not to let their adult children leave home.

Among these 20 families there were 16 married couples. Seven of these relationships were mutually supportive, with the inevitable stresses acknowledged and usually contained. Relationships between the other nine husbands and wives ranged from those in which there were considerable tensions to those which were at breaking point. Of these 16 marriages, three were second marriages (including one remarriage). Two other couples had separated in the past, but were now living together.

Methods

The sample

The study was carried out in one county in southern England. The aim was to find a small sample of families in which there was a teenager or young adult (aged from 15 to 22 years old) living at home, who had been classified, by the professionals working with them, as having severe or profound learning disabilities, and who also had severely challenging behaviour. They were initially identified by talking to teachers in special schools, community nurses, social workers, psychiatrists, psychologists, residential care managers and others, and asking them to suggest any young people they considered were within the above categories. Because the views of the professionals varied, the names suggested were cross-checked between them until consensus was reached on 20 young people. There were ten young men and ten young women (this was not by design).

The young people in the sample had little or no speech and could do very little for themselves, needing complete or considerable help with daily tasks such as dressing, washing, eating and toileting. The majority were incontinent, and three quarters were subject to epileptic seizures. Some were almost totally immobile, others highly mobile. Their challeng-

ing behaviour consisted of such things as attacking others (e.g. punching, kicking, head-butting or scratching); self-injury (e.g. through head-banging, biting, eating inappropriate objects) and/or destructiveness (e.g. kicking, chewing, grabbing, throwing or overturning furniture and objects).

Research methods

Ethnographic methods were used (Reeves *et al.* 2008; Savage 2000) in order to try to understand the worlds of these families, and the difficulties and dilemmas they faced both within the family and in their relationships with people in the outside world. The families were visited often, and at length, over a period of two years. Long, unstructured interviews were held, mainly with the mothers, since they were the main carers in all the families. The interviews covered all aspects of their lives, not only those directly concerned with their disabled children - the various strands of people's lives cannot easily be separated out. Where possible, interviews were also held with fathers or husbands and siblings. The interviews, which were taped and transcribed, set out to document their experiences, attitudes and beliefs. The time spent with individual families ranged from 8 to 33 hours. In addition to interviews, the researcher also carried out participant observation with the families whenever possible (Dewalt and Dewalt 2002). The material was analysed using a grounded theory approach (Strauss and Corbin 1998; Pope *et al.* 2000).

Findings and Discussion

Life at home

Eddie lived at home in one of these families. Eddie was tall, dark and handsome, and the apple of his mother's eye. Yet all through his life Eddie had been unwelcome everywhere except at home. His parents had battled constantly for his right to attend school, but even when he did go, they were rung almost every day and asked to come and take him home.

Eddie was frequently violent towards others, and also threw furniture through windows. His mother talked frankly about these violent episodes, but she saw far more to Eddie than this. She saw him as a human being, with intellectual, emotional and social needs. She also realised that he was a very large and energetic teenager who easily got bored if he had nothing to occupy him, like most seventeen-year-olds. At home, Eddie was included in their family life, and his mother spent much of the day listening to him, and trying to understand what he was struggling to tell her. By contrast, at school, and at the respite care centre in which he stayed for occasional weekends, parents felt that the staff related to him only as someone who was potentially violent, and thus was perceived as 'dangerous', and that, as a result, his needs and abilities were not responded to. It seemed to them that teachers and carers tended to avoid him, and did not try to understand what he was attempting to convey to them. At the respite care unit Eddie was often heavily tranquillised, sometimes coming home looking 'like a zombie'.

This difference between the way Eddie's family saw him, and how other people appeared to see him, epitomises the problem that many of these young people with challenging behaviour had in their relations with the outside world.

Eddie's mother's focus on his needs was typical of all the mothers in this study. The daily routine in these households was necessarily very largely focused on the needs of this member of the family. Caring for someone who is very dependent, for whatever reason, is time-consuming and often exhausting. Apart from attending to their basic needs, parents also administered a range of medication (sometimes a long and difficult task) to control epilepsy, deal with challenging behaviour, help them sleep, ensure bowel movements, and sometimes to counteract the side effects of the psychotropic drugs (Hubert 1992). Most of the young adults also required constant vigilance to keep them safe from the consequences of their own actions, from the dangers inherent in their surroundings, and sometimes in order to protect others from their violence.

The daily routine in any household with children is demanding, but for these families there was the added responsibility of a young adult who needed continuous care and attention, not only by day, but also at night. In all these households this responsibility was taken by the mothers, who seemed to 'listen' in their sleep, and attended to seizures, wet beds and general wakefulness during the night. Many mothers slept for at least part of the night in the same room as their son or daughter, some every night, as a matter of course.

Many years ago, these families had made the decision to keep their disabled child at home. They had held to this decision over the years, in spite of the difficulties, and the time and energy that this involved. The mothers were devoted to their disabled children, and were involved in complex reciprocal relationships with them. Although they were often emotionally and physically exhausted, within the context of their relationship with their son or daughter they showed mainly enjoyment and pride. Gordon Grant and his colleagues have written extensively about the resilience of care-giving families (e.g. Grant *et al.* 1998; Grant *et al.* 2007), pointing out that:

Despite the persistence of research-based accounts that depict families with intellectually disabled children and adults in pathological terms, there is mounting evidence that care-giving can have positive attributions and rewards (Grant et al. 2007: 567).

They extend this to care-givers of people with profound disabilities, suggesting that these carers are able to retain their positive attitudes in spite of the apparent lack of response. They propose that the lack of reciprocity may be offset by the fact that parents accumulate 'a huge amount of biographical and highly personal knowledge about their offspring, and in so doing are in a [position]... to act on this in maintaining a buoyant relationship with them (Grant *et al.* 2007: 567).

Hastings *et al.* (2002) also suggest that:

Having a child with more severe disabilities may provide mothers with more opportunities to grow personally and to develop a mature outlook on the world because of the increased challenges posed. That is, rising to these challenges and dealing with them

successfully may enhance feelings of efficacy, which contribute to personal growth and maturity (Hastings et al. 2002: 273).

Grant *et al.* (2007) speak of the lack of reciprocity in the mother-child relationship, but it would be true to say that all the young people in the study were responsive, however minimally, although this was often not apparent at first. This communication was perhaps one of the most unexpected aspects of these young people, who had been classified by professionals as having severe or profound learning disabilities (and see Morris 2001).

Mothers perceptions of their sons or daughters and maternal bonds

Although these mothers knew that their adult children could not look after themselves, they tended to see them, in some ways, as ordinary people with extraordinary needs. To some extent they had ceased to perceive them as having learning disabilities, as one mother of a profoundly disabled son put it:

To tell you the truth I never really think of Tony as being a handicapped person until someone asks me to speak about it. He's just Tony, I don't know how else to put it.

Only in contexts outside the home were they reminded that other people found their son or daughter very strange, in looks and in behaviour, and seemed to find it difficult to relate to them in the same way as they did to other, so-called 'normal' people.

One mother, whose son's appearance attracted many open stares in the street, described him as 'beautiful', and other people's negative attitudes had made her feel more protective than ever:

It's upsetting, and it hurts, I get hurt because of him, and I think, well, he doesn't look like a monster from outer space. I mean he's beautiful, he's got a lovely face on him... He's a good wee soul. He's hard work, but he's worth it, you know, I wouldn't part with him. I keep saying that I'll look after him till every breath in my body goes.

In the now classic article, 'The psychopathology of handicap', Bicknell wrote that mourning the loss of the 'perfect child who has not arrived' (Bicknell 1983: 168) was vital, and that parents' failure to work through the stages of bereavement would cause 'endless unhappiness' within the family (Bicknell 1983: 170). The statements by mothers that they no longer perceived their son or daughter as disabled could be interpreted as denial, and part of a maladaptive bereavement response (e.g. Bicknell 1983; Simpson 2005), but in the context of these families this interpretation would perhaps be an oversimplification. The mothers were perfectly aware that their sons and daughters had severe (or profound) learning disabilities, and it was this aspect of them that took up most of their physical and emotional energy. However, most preferred to focus on the reciprocal and rewarding relationships they had with them.

In most families there was more than just acceptance of what others conceived as differences. Between most of the mothers and their son or daughter there was a fierce love that both displayed, and mothers often admitted to quite explicitly. This apparently unconditional love 'suggests that parents... will extend their labour and commitment to limits that others would not be prepared to endure' (Grant *et al.* 2007: 570). However, as Grant sug-

gests, this may also have the disadvantage of preventing people outside the family being seen as acceptable contributors to the care situation.

This may also apply to husbands, since less than half of them were actively involved in the care of their adult son or daughter. The mothers' intense preoccupation with their disabled child sometimes meant that the 'fragile balance between overstretched physical limits and negotiated arrangements between husband and wife' (Hubert 1991: 78) had ceased to exist.

In some families the husbands had themselves opted out of the situation. The joy and sadness experienced by the mothers was part and parcel of the full acceptance of their child and his or her disability. Some of the fathers, however, were unable to come to terms with the reality of their child's disability, and thus, in effect, exposed themselves only to the sadness of the situation, missing out on the joy.

By the time the children had become teenagers, many husbands had become of secondary importance to their wives. Given a choice between giving up their husband or their child, some mothers said that they would have no hesitation in keeping their child:

I have never felt I didn't want Sheena, in fact in a strange way she has kept me going... If you took her out of my life now I'd have nothing left, my relationship with her is so strong that anything is worth keeping that relationship... My husband knows it as well. He used to say we ought to let her go - I said that I'd sooner let him go than Sheena.

And another:

Definitely Gary wouldn't go... there's no way Gary would be shoved off just to suit my husband.

Some were aware that their bond with their child had pushed their husbands to the edge of their affections and attention. One mother, whose son needed constant help to survive, said:

I'm terrible, I feel right possessive with Joe. Bob used to work away from home a lot and I was left with Joe, and I sort of wrapped my life round him - I used to forget when Bob came home, I was so obsessed with Joe. I wasn't interested in anyone else - I couldn't care less if Bob went away as long as I'd got Joe.

The mothers' devotion and concern for these children was demonstrated by the fact that almost all the parents were struggling to keep them at home in spite of what they perceived as inadequate support from health and social services. For almost all the mothers their severely disabled children had become the centre of their lives:

I tend to avoid cutting across traffic because I don't want to be involved in a car accident - Davey would have to be put away if anything happened to me. It has marked me in such a way that everything I do falls back into Davey's corner... everything I do has got Davey at the end of it or at the beginning of it.

And another mother:

My heart is always where he is... I feel closer to him than to anybody, it's an awful thing to say, really. I'm not worried... about what I'm missing out because none of it, if I didn't have him, none of it is worth anything, anyway. That's just how I feel, that's why it's no big deal to look after him, I'm doing what I want really.

Transition to adulthood

For the families in this study, life had become set in a pattern which they may not have consciously chosen to follow, but which had become an accepted way of living. Although parents had been told, in the first months, that their child was going to be disabled, the extent of their disability had necessarily only become apparent over time. All babies are doubly incontinent, need constant vigilance, cannot walk or talk, and need to be fed, dressed and bathed. There was no distinct point at which parents suddenly became aware that this situation was no longer a 'normal' one. The implications of this had only gradually become clear as the years passed.

As their children became adult, the problems for the families increased. Some of the difficulties arose from their increasing size and strength. Parents often found it hard to lift and carry them, and to control their violent behaviour. Incontinence became less easy to contain and, in some contexts, more embarrassing to deal with. The girls began to menstruate, and this, too, brought added complications - some disliked the feeling of wetness, or of pads, and tried to strip them off; some became more difficult at this time, or had more seizures. Many parents, as their daughters and sons grew up, worried about the risks of sexual assaults when they were away from home, at school or in respite care, especially since they were unable to report the actions of others.

In some cases overt sexual behaviour caused difficulties in public, and sometimes also between husband and wife. Parents were often torn between the dictates of acceptable social behaviour, and their own sympathetic understanding of their adolescent child, whose needs and emotions they felt they knew to be much the same, in many important respects, as for any other adolescent. Parents found that the attitudes of other people, including their own relatives, had become more hostile and fearful as their children grew older.

In spite of the added problems that their children's maturity brought with it, most of the mothers were proud of their sons and daughters, and of the stage that they had reached - and were to some extent proud of themselves, that they had managed to get this far against all odds. As one mother said:

We have a good thing going, me and Joe, in our own way... so many people see him as a burden, and I don't, it's a positive relationship. I am so proud of him, and I am so proud that he's got to 21, whereas most people say 'oh you've had that cross for 21 years', but for me, you see, it's what he's done already.

How they got this far was the result of remarkable persistence and single-mindedness. As their children became adult the services had, with very few exceptions, become less reliable, poorer in quality, and increasingly disorganised (Hubert 1991). Instead of more help and support at this time, when families needed it more than ever, there was generally less during the transition to adulthood (Department of Health 2001; Morris 1999).

Some mothers were given the impression by professionals that they considered them to be over-protective and over-anxious. The mothers themselves, however, felt that they had every right to be protective and anxious about their children, because in most of their dealings with the outside world their fears for them had proved to be justified. The report of the Joint Committee on Human Rights (2008) supports this:

Although comments are sometimes made about families holding back their relatives with learning disabilities or being 'over-protective', the evidence we received suggested that 'for most people, most of the time, their families are their greatest and most reliable allies.' (JCHR 2008: 37).

The mothers felt that their protectiveness of their sons and daughters was accepted when they were children, but was deemed less acceptable as they became adult. But it was at this point, as their adolescent children grew into manhood or womanhood, that the compassion the mothers felt towards them sometimes became even more intense:

I don't like this awful feeling that I get now, that he's so vulnerable... its just that he is a man now, I know that in my mind, he's not a child, and I suppose that's why I feel more sorry. I don't think I had even realised he was a teenager, he was just Will, a little boy, and suddenly he became a man.

Other relationships

All the families in this study had struggled to function over the year as normally as possible, a feat that had inevitably imposed considerable stresses and strains on relationships both within the family household, and with kin and friends outside.

These individual families tended to operate in their own, almost closed, world. Few people seemed to want to enter it, hence few understood that it was as meaningful a world as any other. The result was that, for many of the mothers, their commitment to their disabled son or daughter had been at the expense of diverse social relationships or close ties with their relatives. Many felt very isolated, not only because they were tied to the house, or because people preferred not to visit them, but also because, as their children grew up, they found that they had less and less in common with friends and relatives who had children of the same age. The successes and failures in the lives of these parents often had no counterpart in the daily lives of others, whose sons and daughters lived their own lives.

Few of these families were part of an active kin network which provided even moral support. It appears that in these circumstances kinship rights and obligations are liable to collapse under the strain of asymmetrical and necessarily unfulfilled relationships. Some grandparents effectively disowned their disabled grandchild, and for parents who loved this child as much as, or sometimes more, than their able children, this was difficult to bear. As one father said of his mother:

She disowned him for a number of years to start with, as though he'd never been born... she said 'Oh, I never talk to people as though I'm a grandmother yet'.

Some grandparents seemed to think that the families would be better off without the child at home:

They... think he ought to be in care... that we've given up our life to him, but I don't see it that way, because I'm doing what I want to do... [My father-in-law] said 'don't you think you've done enough, long enough?' as if it was a job of work, you know, I've done this for 15 years, I'm going to change my job.

Some thought that it would be better if the child died:

She's always implying that when he's not alive any more I'll be able to carry on with my life... they've always got him on the slab... They seem to think that if anything happened to him we would suddenly say 'oh, we're free! Now we can carry on'.

It was hard for these mothers, whose lives revolved round their disabled sons and daughters, to understand these attitudes, especially in their own parents. It was particularly ironic that grandparents could believe that life would be so much better for the parents if their son or daughter died, since these parents had spent much of the last twenty years or so desperately trying to keep them alive, sometimes against all apparent odds.

Many parents felt that their own extended families, and people who had been their friends, found it hard to understand very much about their often frenetic way of life, and did not appear to share their own beliefs and perceptions about their disabled son or daughter. As a result these parents found it difficult to communicate with them in any very meaningful way. They felt that many people, instead of helping to integrate them into the community, or into their own social worlds, tended to treat them as though they were separate islands, adrift from the known wider world.

Conflicting emotions

The parents of these young people were aware of the attitudes and feelings of others, and sometimes may even have had similar feelings themselves - but not in the context of their own children. Some mothers (and fathers) said that they would advise any parent that had a baby with as severe physical and learning disabilities as their children not to have anything to do with it. Yet they loved their own children, and wanted to keep them alive, and at home. As one father said:

It's not all sadness and woe, I mean, she's a lovely little kid... you get used to her over the years, you know, what would be an annoyance to other people. It's like the sun comes up tomorrow, you know, its just part of life, isn't it? It becomes part of your life.

One father felt that the life of his family had been 'destroyed' by his son, and resented the extent to which he monopolised his wife's time and emotional energy. Yet there had been many times when he could have let his son's fragile life slip away by not reacting instantly when he choked and stopped breathing:

Several times I've thought 'you're a fool, Greg, you could let this go and no one would ever know' - and if they did know I don't think anything would ever have been said. But there's absolutely no way I could let him go, I've saved his life numerous times.

Although their feelings for their own child were very positive, many mothers said that if one of their other children gave birth to a severely disabled child they should not take on the same task. The complex emotions many of them had about the question of the right to life are very evident in this context. None of the mothers in the study would have preferred that their own severely disabled child did not exist, or that they had died, but at the same time some believed that, in general, such profoundly intellectually and physically disabled children should not be kept alive - if the extent of the disability is clear soon after birth. One mother felt that if she had known what her child's life would be like she might have 'suffocated him at birth' although, since his birth, she had fought fiercely to keep him alive, and at home with her. She does not regret her life - or his - but the fundamental conflict, felt by a number of these parents, is summed up in the strength of her reaction to the thought of one of her other children giving birth to a similar child: 'I hope that I'll have the courage to put a pillow on its face'.

Thus many of these mothers felt it was a different thing when it was someone else's child, and this draws attention to a fundamental problem. It seems that it is difficult for many people, whose children are not physically or intellectually disabled, to understand the nature or strength of the bond between parents and a young adult who cannot talk, may be doubly incontinent, epileptic, disruptive, unable to wash, eat or dress without help, and who may look very different from other people. To these parents, this dependency had been incorporated into the relationship between them, and in fact had created an even closer bond.

Attitudes to long-term care

Professionals sometimes suggested to parents that this close bond with their adult son or daughter was unhealthy, and that they should leave home and become 'independent' as other young people did. Indeed, at this age and stage in life it might have been expected that parents would have been making plans for the future, for the time that they themselves died or were unable to cope with a disabled and difficult adult. But the mothers disagreed with the professionals about the potential independence of their sons and daughters, and felt that they would, necessarily, remain dependent on other people for the rest of their lives, and in fact would become even more dependent, since it was only at home that their complex ways of communicating, and thus their wishes, feelings, dislikes and preferences, were likely to be understood. They also believed that it was only at home that they would continue to receive the love that they were used to, and the physical care that they needed.

Ironically, although it was the provision of short term care that usually made it possible for mothers to continue to keep their adult children living at home (and see Department of Health 2007: 15), it was their experience of these residential units that had made them determined not to let their sons and daughters go into long-term care.

For people with such severe and profound learning disabilities the strong bonding that existed between mother and child was unlikely to be replaced by often transient relationships with a series of different care staff, who would also be caring for others with equally deserving demands.

Parents felt sure that, away from home, their sons and daughters would probably never have another close relationship with anyone, and were afraid that they would be treated as unthinking and non-communicative beings, which they obviously were not. It was clear that although they had little or no speech, they were able to communicate with those who were prepared to take the time to 'listen'.

Faced with the classification of their sons and daughters as people with severe or profound learning disabilities, and aware of the attitudes towards people who are categorized in this way (see JCHR 2008: 45), mothers were reluctant to hand them over to others for their care. However, they could not see any viable alternative and, as a result, most of them felt unable to contemplate the future, and had become 'paralysed about making the right decisions' (Grant *et al.* 2007: 568)

Some of the anxieties about the care of their son or daughter in long-term care varied, depending on their characteristics and needs. For the ones who were immobile and vulnerable, there was the added fear was that they would be forgotten and neglected, and subjected to abuse, and the experiences of short-term care showed that this fear had some basis:

I worry that he [would not be] well cared for, that's what bothers me, who would care for him? If he could speak it would be better - because he can't tell you what happens... I'd rather he died first and then I could think, well, I cared for him all the time. It's wicked, isn't it? But a lot of my friends feel the same.

The parents of those who were mobile and violent had different but equally valid fears. Many of these young people tended to be tranquillised – sometimes even before they exhibited any threatening behaviour (Hubert 1992). Eddie's parents, for example, (see above) were adamant that he would never go into long-term care. His mother said repeatedly that if the day came that she could no longer look after Eddie at home, she would make sure that he had no future at all, rather than let him face a future in permanent care, where she believed he would be tranquillised 'into oblivion' because of his violent behaviour:

No, I think I'd rather kill him, quite honestly, I'd rather give him an overdose, than see him go in there... he'd be better off dead. What sort of life would he have?... They're suffering there because they can't say any different... they might as well be dead, they're just sitting there all day long. You've got to think about the content of life, haven't you, when you're talking about living.

Once their children had gone into long term care, parents were afraid that they would have no control over what happened, as one mother of a very violent daughter said:

She'd probably be heavily drugged, she'd probably go incontinent and, well, I don't know what would happen to her. If ever I thought she would have to live somewhere like that... if I had an illness or something, and I wasn't going to get over it, I'd give her an overdose.

And another, with regard to a local long-term institution (now closed):

To the parents, it is a bit like Dachau... I'd top me and him rather than him go there.

These reactions may appear extreme. However, two recent investigations into services for people with learning disabilities provide some support for these views (CHAI and CSCI 2006; CHAI 2007).

Parents' perceptions of people who lived in institutions

It was not only the institutions themselves that these parents feared to this unnerving extent. They also perceived people who were living, or had lived, in long-stay hospitals as quite different from their own sons and daughters. In some areas people from the long-term institutions were resettled in residential homes that were also used for respite care. One mother was told by staff that her son wheeled his wheelchair away from the residents and into the staff room. She felt sure that he looked at the other residents and thought 'I am not one of them', and it filled her with sadness:

It does grieve me greatly to think that Andy's got to be subjected to staying in an environment where people scream and do odd things.

Another mother said that her son's behaviour had deteriorated since men and women from the institution had moved into the respite care unit.

He's never thrown a plateful of food across the floor until he mixed with those... They're awful, some of them, I mean they are so different... all our kids [who live at home] are different, they've got something about them, it's not nice for [them] having to go in and mix with them.

These parents regarded the challenging behaviour of the men and women from the institution as quite unlike the behaviour of their sons and daughters. To some extent they were probably right. The nature of the challenging behaviour exhibited by the people who had spent their lives in a long-stay institution would have reflected the lack of individual care and the resulting lack of opportunities to form close individual bonds.

The mothers saw their own children as total individuals, with a wide range of distinctive characteristics, and with their own methods of communication - aspects which they were apparently unable to see in their brief encounters with the institutionalised residents. As Hubert and Hollins (2006) wrote:

Cultural and attitudinal barriers have prevented people with severe learning disabilities, especially those segregated from society, from being perceived as fully human (Hubert and Hollins 2006: 73).

Research with men and women living in a locked ward of an old institution (Hubert and Hollins 2006; Owen *et al.* 2008) revealed that they were not treated as full human beings, and had been deprived of their individual, social and gender identities. They had also lost their familial identities - they were not thought of as sons or daughters, brothers or sisters. They were simply seen as they were at this moment, without any acknowledgement of their pasts. In contrast, the people who had stayed at home did have pasts, presents and futures, and enjoyed reciprocal relationships. Although many of the families lived quite

socially isolated lives, their sons and daughters had not been totally excluded from society. They were part of the community in which they lived, and were by no means invisible. They had retained their individual and social identities to a great extent, and were nephews and nieces, uncles and aunts and grandchildren, even if some of their wider kin group tried to exclude them from some of these kinship relationships.

Above all, within the immediate family, they were sons and daughters, beloved by their mothers, and in many cases also by their fathers. They were also tolerated - and often much loved - brothers and sisters, and often also became acknowledged aunts and uncles. Within the immediate family, at least, they were part of - and belonged within - the complex web of family relationships. For the majority of the men and women who had lived their lives in locked wards, these relationships had been lost in early childhood, although it was often clear that they had not been forgotten (Hubert and Hollins 2006: 72).

Conclusion and implications for the provision of services

Given the nature of their relationships with their sons and daughters, it is perhaps unsurprising that these mothers were unwilling to consider a future for their children in an environment where they would have to live without the close relationships and loving care that were part of their life in the family home. Their refusal to contemplate the possibility of long-term care led 15 of the 20 mothers to express the hope that their son or daughter would not outlive them, and in a few cases this was put forward as a statement of intent. This is clear evidence of powerful emotions, whether or not any of the parents would actually harm their son or daughter if the situation arose.

- It is vital that this strength of feeling is taken into account in discussions and planning for the futures of young people who have severe or profound learning disabilities and challenging behaviour.

The implications of the material reported here cannot be simply summed up in terms of the undeniable need for more effective services. The needs of these families go deeper than this. The material shows that the mothers' often single-minded devotion to the care of their son or daughter resulted in mothers struggling against unremitting physical and emotional exhaustion. It can also put marital relationships at risk, and may contribute to the breakdown of relationships with family and friends. It can also result in mothers becoming unwilling to trust anyone else to look after their son or daughter.

- Parents should continue to be the main carer, if this is what they want, but at the same time alternative care situations, acceptable to them, should be offered from the beginning. This may involve someone coming into the house to care for the child at home - the same person each time and on a regular basis, so that the mother, and the child, can become used to a different situation, and a new relationship.

Most parents rely on their own experiences and common sense to deal with the multitude of problems that arise at different stages throughout the life of their son or daughter. However, sometimes they need more than this to deal with the new and unfamiliar circumstances that evolve.

- Parents need someone who will listen to them, and should have access to advice, practical help and counselling throughout the life of their son or daughter.

References

- Bicknell, J. (1983) The psychopathology of handicap. *British Journal of Medical Psychology* 56: 167-178.
- Department of Health (2001) *Valuing People: a new strategy for learning disability for the Twenty-first century*. London: The Stationery Office.
- Department of Health (2007) *Services for people with learning disabilities and challenging behaviour or mental health needs*. London: The Stationery Office.
- Dewalt, K. M. and Dewalt, B. R. (2002) *Participant Observation: a guide for fieldworkers*. Alta Mira, CA: Alta Mira Press.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M. and Keady, J. (1998) Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research* 42: 58-71.
- Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: tracing elements of a psycho-social model. *Journal of Applied Research in Intellectual Disabilities* 20: 563-575.
- Hastings, R., Allen, R., McDermott, K. and Still, D. (2002) Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 15 (3): 269-275.
- Hubert, J. (1991) *Home-bound: crisis in the care of young people with severe learning difficulties: a story of twenty families*. London: King's Fund.
- Hubert, J. (1992) *Too Many Drugs, Too Little Care: parents' perceptions of the administration and side-effects of drugs prescribed for young people with severe learning difficulties*. London: Values Into Action.
- Hubert, J. and Hollins, S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay hospital care. Qualitative study. *British Journal of Psychiatry* 188: 70-74.
- Joint Committee on Human Rights. (2008) *A life like any other? Human rights of adults with learning disabilities*. London: The Stationery Office.
- Morris, J. (1999) *Hurtling into a Void: transition to adulthood for young disabled people with 'complex health and support needs'*. Brighton: Pavilion Publishing.
- Morris, J. (2001) *That kind of life? Social exclusion and young disabled people with high levels of support needs*. London: Scope.
- Pope, C., Ziebland, S. and Mays, N. (2000) Qualitative research in health care: analysing qualitative data. *British Medical Journal* 320: 114 -116.
- Reeves, S., Kuper, A. and Hodges, B. D. (2008) Qualitative research methodologies: ethnography. *British Medical Journal* 337: a1020.
- Savage, J. (2000) Ethnography and health care. *British Medical Journal* 321 (7273): 1400-1402.
- Simpson, D. (2005) *Psychoanalytic perspectives on emotional problems facing parents of children with learning disabilities*. In *Psychoanalytic theory for social work practice: thinking under fire*, Bower, M. (Ed.). Abingdon: Routledge. 106-117.
- Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research: techniques and procedures for developing grounded theory*. Newbury Park, CA: Sage.

CHAPTER 8

Family carers' views of services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London borough

Jane Hubert

Published in *Disability & Society* 2006, 21 (3): 259-272

Summary

In 2001, the UK Government identified the widespread neglect of the needs of people with learning disabilities from Black and minority ethnic communities. In this qualitative study informal interviews were held with 30 family carers of adults with learning disabilities from Black and minority ethnic communities. Their views were sought regarding services received and services needed, and cultural or communication barriers faced in accessing appropriate services. The study showed that although carers were largely satisfied with services actually received, service provision was highly inadequate and ineffective. Even very elderly and ill carers and those caring for people with severe disabilities received little support. Social worker support was negligible, and future planning rare. It is clear that the needs of carers from Black and minority ethnic communities are not being met. The situation would be considerably eased by adequate social worker support. Stereotypes of supportive family networks, (especially regarding south Asian families) proved to be unfounded.

Aims

This short research project was commissioned by the local Learning Disabilities Partnership Board and was carried out in the summer of 2004. The aims of the research were to find out from family carers of people with learning disabilities from Black and minority ethnic groups living in a south London borough which services they currently receive, the appropriateness of these services, what services they feel they need, and whether they experience any social, cultural or communication barriers in accessing, or trying to access, appropriate services, and information (Hubert 2004).

Background

Recent research has clearly shown that people from Black and minority ethnic groups in the UK encounter problems and barriers in accessing services and information, and that the services provided are not always appropriate to their needs. Difficulties arise from poor communication between service providers and families, especially when English is not a carer's first language, and from service providers' lack of knowledge, or disregard, for the different social norms, family structures and cultural and religious beliefs and practices of people who come from a wide range of different cultural backgrounds.

In the last few years there has been increase in awareness of the extent to which the services for people with learning disabilities from Black and minority ethnic groups are failing this population. The Government White Paper *Valuing People* (Department of Health 2001) listed among its major problems and challenges that '[T]he needs of people from minority ethnic communities are often overlooked' (Department of Health 2001: 2). Research commissioned by the Department of Health (Mir *et al.* 2001) highlighted a number of problems, but the situation appears to have changed little over the last four years. In a report on progress, the Valuing People Support Team writes:

In most places plans made by Partnership Boards... gave little evidence of action to improve the situation faced by people from minority ethnic communities... More effort is needed to remove the barriers to equality faced by people from minority ethnic groups' (Department of Health 2005: 33).

It remains to be seen whether the 'Learning difficulties and ethnicity' framework for action (Department of Health 2004) will lead to greater cultural competence among learning disability services.

Many problems involved in access to services have been identified among South Asian families in the UK, including lack of knowledge and information, stigma, language barriers, religious and other beliefs, inability and/or reluctance to get help, alienation, insufficient staff motivation and lack of community efforts towards inclusion (Khan *et al.* n.d.; Baxter *et al.* 1990; Azmi *et al.* 1996; Hatton *et al.* 1997, 1998, 2000; Chamba *et al.* 1999; Mir *et al.* 2001; Emerson and Robertson 2002; Raghavan and Waseem 2004). Furthermore, the stereotype of supportive extended families among South Asian families was not borne out (e.g., Hatton *et al.* 2000; Emerson and Robertson 2002).

The main part of the literature relating to cultural issues focuses on South Asian families. There is a tendency to lump together what are in fact a very diverse range of different cultural groups from South Asia (Mir 2001). Little is known about care needs among other ethnic communities, and few studies have focused specifically on Black Caribbean or Black African communities.

There appear to be no studies that report a fully adequate and effective service, although there are currently a number of services throughout the UK that are quoted as examples of 'best practice' (Mir *et al.* 2001).

Methodology

A sample of 30 families, in which there was an adult with learning disabilities living at home (19 men and 11 women), was obtained from the local Register for People with Learning Disabilities. Carers were aged from 45 to 86 years; more than half were 60 years or over, and a quarter were 70 years or over.

The largest 'groups' of families in the sample originated from the Caribbean and India, though of the ten Indian families, only two had come directly from India, the majority having lived for many years in East Africa before moving to the UK. The majority of families were Christian, Muslim or Hindu. The sample included people with all degrees of learning disability. Two-thirds had moderate or severe disabilities, and many had other problems which affected how much, and what kind of care an individual needed. These included physical health problems, epilepsy, incontinence, visual impairment, challenging behaviour and mobility difficulties.

In 24 of the 30 families (80%) the mother was the main carer, 13 of whom were single carers. In five families the father was the main carer, and in one, a sister. Since the research was specifically aimed at discovering the carers' perspectives, and because there may well be differences in perspective within the family about the needs of a son or daughter, and about the services, it had been hoped that interviews would be held with the main carers in all families. However, of the 24 mothers who were the main carers, five (whose English was very poor) were not interviewed directly (four fathers and one daughter were interviewed instead), though the mothers were present for all or part of the interview, and in some cases did contribute. In two families an adult sibling acted as interpreter, again placing a filter between the main carer and the interviewer. The sister who cared for her brother was interviewed directly.

The interviews, which were informal and varied in length, were taped and transcribed. The material was analysed using a grounded theory approach (Strauss and Corbin 1998; Pope *et al.* 2000). The interview transcriptions were read and re-read throughout the research process, within the framework of the ideas and concepts developed before and during the interviews. This familiarization with the material and sensitivity to the potential emergence of further themes allowed other concepts and categories to be identified.

Findings

Services

Day activities

Twenty-eight of the people with learning disabilities had some kind of day activities away from home, mainly at local day centres, on at least a few days a week. Only two were at home every day. The overall opinion of all the day centres was positive, with carers describing staff as caring and respectful of cultural and religious differences. It is clear that the day centre key workers have an important role as the point of contact with families. There did not appear to be social workers attached to the day centres who took responsibility for the whole family.

Respite care

Twelve of the people with learning disabilities currently made use of respite care services, usually for a week or two twice a year. Almost all carers considered it very good, and sympathetic to their son or daughter's individual needs, as one mother said: 'It's a wonderful place, he loves it there'. One carer, (from Jamaica), said that her daughter was not always very clean when she came home; another said that his son was sometimes 'very reluctant' to go, but that they had no complaints against the respite care home. All the carers said that cultural requirements were met and respected, although one mother (from Jamaica) complained that one carer said she was 'not going to put her hand into the hair oil that we black people use'.

Eighteen (60%) of the 30 families did not get any respite care at all. One mother asked: 'What actually is respite care?' Eight said there was 'no need' for respite care, but it may perhaps be significant that four of the nine fathers interviewed (as main carer or as the one who spoke English) said this, whereas a far smaller proportion of mothers who did not get respite care said the same thing (four out of 14). It is not possible to tell whether the four fathers (from India and Pakistan) were also speaking for their wives, or had decided themselves that respite care was unnecessary.

One carer had used respite care services in the past, but her daughter now refused to go at all. Four mothers said that they did not want respite care, though in three of these families it appeared, to an outsider, that respite care was much needed. However, the situation was not as clear-cut as this. For example, one mother (from Pakistan), although in extremely poor health, and finding it increasingly difficult to manage her daughter, who has severe learning disabilities and challenging behaviour, would not let her go away overnight:

No, I never send her anywhere. She loves it at home, she is used to me. I never send her. I look after her. I never send her anywhere.

In some cases, older mothers said explicitly that they relied on their adult child for company, even though they were having serious difficulties providing for their basic needs, especially physical care that involved bending and lifting. In some families, a system of mutual caring had developed. One widowed mother, aged 72 and in very bad physical health, had been offered respite care but had refused it:

Because it is just the two of us here. I have no company, he's the only help I have here... Sometimes when I [fall] he will make me a cup of tea and things like that. So I can't send him away. They don't understand, they want to know why I didn't take the respite.

This mother is reluctant to let the service providers know how bad her health has become because she is afraid that they might decide that she cannot care for her son any longer, and take him away. For this mother, from Jamaica, there is also a cultural element against 'sending away' a son or daughter, even for short periods: 'You put out a dog and take it back. We don't do family like that in my country'.

In another family (from Pakistan), the behavioural problems and severe needs of a daughter were first given as reasons why she has not gone into respite care, but there was also a strong cultural influence present:

'I think that's something to do with culture. It would be something we wouldn't really do'.

Among the families who specifically said that they needed respite care was one mother (from India) who summed up her predicament:

When she was young I thought when she gets older I will have more help, but... it is really a struggle and I think this is the time when carers like me need help because they are getting older... I think my life stopped 20 years ago... It is really, really difficult and my life is nothing. It is just gone. It is just carrying on. I don't have any, it is as if there isn't any meaning. There is no me anymore.

Assistance with personal care at home

The day-to-day routine at home with someone who is dependent on a family carer for the most basic needs—washing, bathing, dressing, toileting or changing continence pads, eating, carrying and so on, is extremely demanding. For carers of people with these basic needs, and who require constant vigilance, the provision of day-to-day assistance at home is even more vital than time away from home.

Only five families received some care at home, for about an hour in the mornings, to help with bathing, dressing, toileting and eating. Not all families need this sort of help, but there were at least seven other families who badly needed support at home. These were mainly families in which there were a number of complex needs. Not only were the majority of the people with learning disabilities highly dependent on others for all their basic needs, but at the same time their carers were ageing, physically frail and often on their own. Some had serious health problems.

In some cases, the charges were too high for carers to meet:

They give him somebody [to] come and bathe him because he's too big for me... but they're charging, and I don't know where to get the money to pay for it.

It is clear from the stories of these families that many need basic help. Some can no longer carry out the basic tasks for someone who needs almost total care. Some, at least, feel that they have asked for this help but have had no response. Whether the appeals have gone to

the wrong person, have not been understood, or have been disregarded, is not clear. It may be that single carers will sometimes give out mixed messages, because they do not want their son or daughter to be 'taken away' from them. This is a very real fear, and carers need to be reassured that this is not going to happen, though at the same time discussions with carers in this context need also to broach the subject of the future (see below).

Social worker support

Twenty-two (over 70%) of carers said that they did not have a social worker. Of the eight who thought they did have one, only three knew who they were and felt that they had been of substantial use to them. These answers are unlikely to match social services figures, but if the social workers concerned did not visit or make contact with the family regularly the perception was that they were not 'there' for them. A few families were visited by a community nurse.

The accessibility of social workers is clearly a considerable problem to many of these families. A number of carers felt that they urgently needed a social worker, and many others felt that although they did not need one at the moment, they would like to feel they had one to call on if necessary. Almost all the carers said that they would like to be visited at home by someone on some sort of regular basis.

At this stage in their lives many carers are alone and socially isolated. Their perception of social services is that they are not interested in their predicament. One of the most poignant cases is a woman who is too blind to read what comes through the post to her. Another is too exhausted by her illness to try to sort through a small pile of envelopes that lie on the floor beside her: 'perhaps later, when I have had a rest... '.

One mother (from India) said that there is a cultural stereotype in the UK of close knit Indian/Hindu families, and that is why the social workers do not visit her. In fact, she has no family support. Perceptions of the lack of social worker support are illustrated in the following comments:

I never have anybody coming to speak to me about her, or if she needs something. I don't know how to get in touch with them.

Social worker? What social worker? We have been here 40 years, we have never seen any social worker.

I don't know what sort of help we can ask for. I don't mean to say that they should come every month, or every day, but they could visit once in a year or twice in a year, they could come and have a chat, so that we know them and they know us!

I don't know my social worker... they change, and every one of them haven't got time, they apologise that they haven't more time but they are very busy.

We didn't need one when my husband was alive, but now I would, I would, yes, yes, yes!

Nobody comes to see me. How many years? I haven't got a social worker. Nothing. Nobody comes. Nobody bothers. After they are grown up nobody bothers.

I never see the social worker. They never come, they never visit.

We would like someone to visit because we have things to talk about. Nobody comes, nobody. I don't even know who is the social worker.

No. Not for nine years.

I get no help from social services, they have got no use to me. I can't say they are good and I can't say they are bad because I don't get any.

It may well be that some of these families had no use for social workers in the past, and that their circumstances have gradually, or suddenly, changed. The death of a spouse can radically alter living circumstances; advancing age and frailty, physical (and sometimes mental) illness and increasing mobility problems can mean that someone who used to manage perfectly well without support may now have a very great need for material, physical and even emotional support.

Accessibility of information

Many of the families suffered from a dearth of information about the services and support available to them. This was true not only for those who had difficulties understanding English, but also for many carers whose lives are restricted and circumscribed by their life at home with someone who has learning disabilities.

Informal support: family and social networks

Given the lack of effective external services, carers' access to informal sources of support becomes crucial. In most families, however, these were far from adequate, and even those with large families of their own often found themselves isolated and without support. In those families where there was a spouse or partner the caring role was sometimes shared, at least to a small extent, though it was usually the main carer who bore the brunt of the work. In a third of the households there was one or more sister or brother living at home. Of these, two daughters were very supportive of their widowed mothers. Of the others, mainly sons, it was frequently said that they did not have time to help. A few were willing to 'keep an eye' briefly, and in two cases they acted as interpreters for their parents, but on the whole they were allowed to live their own lives, without taking any active role in the task of looking after their disabled sister or brother.

Out of 18 families where there were other children living away from home (most of them quite near), many with their own families, only half the carers said that their children were supportive, and sometimes helpful – almost all of them daughters. Parents of those who were not particularly supportive tended to say that their children had their own lives to live, and their own families to look after. All cultural backgrounds were represented among those who were and were not supportive.

Only one family (Black Caribbean/white background) was part of a very close, extended family group. Another carer described her family as 'close' but said that this did not mean that they provided any support or help to her.

Beyond the immediate family there was very little evidence of extended or closeknit family groups. Only a handful of families had kin who gave any support at all, and these tended to be the occasional relative rather than a supportive group of kin. In some cases there had obviously been support from parents and parents-in-law in the past, but by this time many of them were too old to give more than moral support. One mother said 'we used to be surrounded by family', but now there was no one. One father spoke nostalgically of the past, when the house was always full, with frequent visits from the family from India, but now the house was always empty:

They said to me 'we don't want to come to your house because we feel it is depressing to look at your situation'... They used to come, but I think slowly the love is dying, you know. That is reality.

Social networks

Very few of the carers were part of a social group that offered support, or who even had a friend who could help if necessary. Only one carer described a very full social life. Some carers found company among people attending the same church or temple, but very rarely did members of these groups provide more than that. One exception was a local mosque, which was said to be very supportive, and would advise families where to go for help.

A number of the older women whose English was poor, and who had little contact with anyone outside the home, went to the Hindu temple regularly. This appeared to be their only contact with the outside world. One woman said 'we have the religious community, so it is not that we don't socialize'. Apart from this, however, her life was spent at home, with no apparent contacts in the neighbourhood.

Discussion

Ageing carers

Many of the issues discussed above are not confined to people from Black or minority ethnic groups, but are relevant to all carers, especially those caring for someone with severe learning disabilities. It is clear from the family material presented here that the circumstances of ageing carers, from all backgrounds, must be a primary concern in the assessment of the needs of family carers.

Half of the carers in this study are widowed or separated. The age of these single carers is relatively high compared with the sample of 30 overall – almost four-fifths are 60 or over and over a third are 70 or over. They are thus often battling against a range of problems resulting from increasing age and deteriorating health.

In those households in which there is an elderly carer (especially if they have health problems and/or decreasing mobility) and an adult with learning disabilities, there are a number of complex individual and joint needs. It is at this stage that effective input from services becomes essential. Although some families have managed with few or no services until recently, they often become increasingly isolated from informal sources of support as they get older.

In some families a system of mutual caring has developed, according to the needs and capabilities of each individual, as one son with learning disabilities said: 'She is supporting to me and I am supporting to her'. Although this has obvious advantages, the situation may mask serious difficulties, especially in single-parent households. The family may remain independent of external services while irreversible long-term problems evolve (such as physical ill health, or dementia, of either or both), problems which only come to the attention of the services when crisis intervention becomes necessary. For all these ageing families, whose circumstances are necessarily likely to deteriorate rather than improve over time, external sources of support are needed to act as a safety net, ready to provide appropriate care the moment it becomes necessary.

The needs of people with learning disabilities and their ageing parents, both individually and as a family unit, require coordination of services between health and social services, the voluntary and private sectors, and between generic and specialist service providers.

In about half the families the main carer was in poor health, sometimes very ill indeed. Two had advanced cancer, one was almost blind, others had arthritis, diabetes, heart problems, strokes, respiratory problems, osteoporosis or thyroid problems, and one was said to have serious mental health problems. Some may withhold the extent of their illness from service providers – certainly one mother says she even lies to her children about it – in order to be able to continue at home with their son or daughter. For single carers, ageing and in poor health, the only company, and perhaps support, that they have may come from this adult child with learning disabilities, who has been the focus of their life for the last 30 or 40 years.

Social isolation

As seen above, especially in relation to the lack of kinship and social networks, many carers feel socially isolated. This may sometimes be the result of cultural isolation or language problems, but can also be because there is little chance for carers to get out and about. Life within a family caring for a person with learning disabilities, especially if they have severe or multiple disabilities, presents a constant challenge to maintain close relationships with kin and friends. As a result, some families have become socially isolated, and many live in a narrow social world, with few options to choose from.

The future

One of the inevitable consequences of the lack of family and social support, combined with lack of social worker support, is absence of planning for the future. This was true across all cultural groups. Out of 30 families, 21 had no idea what was going to happen when they died, or were too frail to continue to look after their son or daughter at home. For most of them this was a continual source of anxiety, and many said that it was always in the back of their minds.

Although these parents had cared devotedly for many years, and had resisted suggestions that their son or daughter should go into long-term residential care, almost all of them were adamant that their own children should not take on this role when they were

dead. As one said vehemently: 'No! Not my children! They've got their own lives. I don't expect them to look after him'.

In many instances, this determination that their children should be allowed to live their own lives unencumbered by a sister or brother with learning disabilities was also based on the knowledge that they could not rely on their children anyway in this respect. As seen above, 'They have their own lives to live' was a common response, given to justify the fact that their other children could not be relied on to give help and support from day to day.

In three families (two from the Caribbean and one from Pakistan), an already involved daughter was expected to continue to care for her sister or brother if possible, and in another it was hoped that a daughter would take over if her brother could not be helped to live independently. Only one son (married with a family) had offered to care for his brother when his mother could no longer manage, or died, but this was not considered a very likely option by their mother, since her son gave her very little support from day to day.

In three families other relatives were suggested – aunts or cousins – but in none of these cases had the future been fully discussed or agreed with them; it seemed only to be a vague hope, often contradicted by doubts and anxieties that were expressed about the future. One father said confidently at the beginning of the interview: 'If something happens to me [my sisters] are always going to look after her'. Later, however, when he was talking in a more relaxed way, it became clear that he was not at all sure that this was what would happen, and said that it was a continual source of anxiety: 'This is the one thing that always worries me. It is in my mind – what will happen when we get older'?

Very few carers liked the idea of their son or daughter going into long-term care, but many realized that this was probably going to happen eventually. Fears about residential care for vulnerable adults are not unexpected, especially when an individual is very dependant and cannot communicate in speech. One mother said: 'How can I send her to a residential home? She can't defend herself, she can't explain herself'. It is interesting that these perceptions of long-term care remained highly negative, even though there was overall satisfaction with the current respite care services. Parents knew that when they had to hand over control permanently, their children's lives would become the responsibility of others who may not have the same standards of care, and certainly not the same level of understanding, empathy and love for each individual in their care. One woman, who was becoming too frail to care for her son at home, reluctantly had come to accept that residential care was the only viable option for him:

Because the morning [will] come and I can't get up to go and get him out of bed. It is not easy to come to that decision, it worries me, because, you know, it's your child, he has been at home for 40 years and you just think that you are the only one who can take the best care of him. My only sadness with my illness is my son, and he is the only one who can make a tear come to my eye. For myself I am not afraid, if it is my time I go, but it is my son – what will happen?

The strength of the anxiety about the future, and the lack of anyone to talk to about it realistically, has led many mothers to hope that their child would die before they did, so that they would not have to worry about what would happen to them in the future. One mother, whose son has multiple disabilities, said:

Who is going to take him, if something happens to me... Who is going to look after my son? I am praying every single day, I say, take him before I go... I am really hoping. I shouldn't be but I am. It is not easy to say, but I think it would be safer... because he can't say anything. He'll just get hurt. I don't want him to go into residential care.

And another, who is in very poor health:

I was hoping it wouldn't come to that [residential care] because in my prayer I say, let her go before me... Definitely, definitely, definitely – then I would have done my last bit for her, instead of me having to leave her. I would have been at peace.

The fact that there is so much anxiety about the future is not unexpected. What is going to happen is unclear for almost all the families, and for people whose lives have been spent caring for someone with disabilities, especially for those with severe or multiple disabilities, there will be no easy solution. However, much could be done to help alleviate the anxiety by the provision of someone to talk to families about the future. That no-one visits an ill or disabled 70-year-old to talk about what will happen to their son or daughter is unacceptable. It is possible that social workers believe that they have tried over the years, but this is not the perception of the parents.

Cultural aspects

Language and communication

This is obviously a serious problem in some families, but by no means in all. In five of the 30 families the main carer spoke little or no English, and in two of these families neither parent spoke more than a few words of English. This is a small proportion compared with numbers reported elsewhere. Hatton *et al.* (2004, p. 13), for example, contend that 'most South Asian parents of a person with learning disabilities do not speak, read or write English'.

An added problem is that even when parents do speak some English, they may only speak their first language to their son or daughter with learning disabilities. This means that the latter cannot communicate with other people outside the family, and thus may remain socially isolated in the day centre and respite care units that they attend.

Prejudice

Although only a few people expressed the belief that there was prejudice or discrimination against them because they came from a minority group, it must be noted that this is a subject area which demands much more time and development of rapport than this project allowed.

One carer (from the Middle East) said that 99% of the people she deals with are 'amazing', but that a few seemed to think that she was stupid because her English is not very good. Another (from India) said that some service professionals seemed to feel 'Oh, she doesn't know – let's ignore her'.

A few of the Black Caribbean carers thought they were discriminated against. One mother said bitterly: 'I think there is prejudice everywhere in England, prejudice and dis-

crimination'. Another felt that the limited quota of days of respite care her son had been given reflected prejudice.

The majority of carers did not appear to feel stigmatized or discriminated against because of their ethnic origin. One carer (from Sri Lanka) said: 'There's no distinction between minority ethnics and the others – the others are in the same boat as us'.

Carers were not asked specifically about prejudice and discrimination against people with learning disabilities. However, some Hindu carers brought this up, and spoke of the prejudice they had faced in their own countries of origin, in contrast to England. Others spoke of the belief that having a child with learning disabilities was a punishment for past sins.

Services

Although a few carers felt that access to services was affected by their ethnic origin, when services were received they felt that their cultural needs were catered for to the extent that was necessary from day to day. Black Caribbean carers occasionally complained that they would rather have black carers, for practical reasons, but as one said, that did not mean that all black carers were good and all white ones bad. None of the family carers expressed anxiety about the gender of carers in day centres or respite care units.

With regard to residential care, however, it is clear from this study that service providers need to be aware that cultural attitudes may be added reasons why parents may not let their son or daughter go into residential care. These attitudes were expressed by carers from various cultural backgrounds. Based on such limited contact with the carers, it is hard to assess the true role of cultural factors and the extent to which opposition to long-term residential care simply reflects the views held by many carers from all cultural backgrounds.

Conclusions

The focus of this study was specifically on families from Black and minority ethnic communities. Because there was no matched control group of families from the majority population it is not possible to compare the perspectives of the two groups, though many of the issues discussed are likely to have greater relevance to minority groups. However, many of the problems faced by the carers in this study are faced by all carers, at least to some extent, and this is especially true of those caring for a son or daughter who has severe or complex learning disabilities.

A study of families from the majority population in this borough might well produce some similar results. Research carried out in Hampshire with 20 families from the majority population, caring for someone with severe learning disabilities at home (Hubert 1991), found a very similar picture of parents struggling in the face of unmet needs. Many of the issues were the same, both in the present, and in contemplation of the future.

Although many carers have unmet needs, there are obviously some issues, raised by the carers in this study, which affect people from Black and minority ethnic groups in particular. Communication difficulties (linguistic and cultural) are the most obvious ones, often leading to social isolation. Although social isolation is common among carers (Mir *et al.* 2001), it is obviously more intense for people who cannot communicate with their neighbours, let alone the wider community.

The families in the study raised a number of specific issues in relation to service provision, including the following.

- They do not receive sufficient, or accessible, information about available services.
- There is poor communication between carers and service providers.
- Some have no English and cannot initiate or respond to contact and communications.
- They are socially isolated from the community in which they live.
- They are unable to get access to services they need.
- Some services carry a charge which is not within their means to pay.
- They do not have anyone who visits them on a regular basis.
- They do not know how to contact service providers for help when they need it.
- They feel neglected by the service providers.
- Some are suffering from high levels of stress.
- Some are frail and/or ill and cannot get the help and support they need to continue caring.
- They do not have supportive family groups.
- They have serious anxieties about the future, and need support to start making viable plans.

Many of these issues could be addressed, at least in the first instance, through the investment of time by a dedicated social worker, to visit carers at home, to get to know the family and to encourage carers to talk about the things that are worrying them.

There were some positive aspects of the services. Almost all the carers were enthusiastic about the day centres, and those who used respite care spoke well of it. Younger families caring for a son or daughter with mild or moderate learning disabilities, without any added problems such as challenging behaviour or epilepsy, were also more satisfied with the services as a whole. This paper does not represent or refer to any perspectives other than those of the carers. Service providers may well have different perspectives on the nature and quality of the services. It is undeniable, however, that the picture that emerges from the distressing material in this report is that the services are not meeting the needs of carers from Black and minority ethnic communities who have more complex needs.

References

- Azmi, S., Hatton, C., Caine, A. and Emerson, E. (1996) *Improving services for Asian people with learning disabilities and their families*. Manchester: HERC/MHF.
- Baxter, C. Poonia, K. Ward, L. and Nadirshaw, Z. (1990) *Double discrimination: issues and services for people with learning disabilities from black and ethnic minority communities*. London: King's Fund.
- Chamba, R., Ahmad, W., Hirst, M., Lawton, D. and Beresford, B. (1999) *On the edge – minority ethnic families caring for a severely disabled child*. York: Joseph Rowntree Foundation.
- Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century*. London: The Stationery Office.
- Department of Health (Valuing People Support Team) (2004) *Learning disabilities and ethnicity: a framework for action*. London: The Stationery Office.
- Department of Health (Valuing People Support Team) (2005) *The story so far...* London: The Stationery Office.

- Emerson, E. and Robertson, J. (2002) *Future demand for services for young adults with learning disabilities from South Asian and Black communities in Birmingham*. Lancaster: Institute for Health Research, Lancaster University/ Birmingham Social Services.
- Hatton C., Akram Y., Shah R., Robertson, J. and Emerson, E. (2000) *Supporting South Asian parents of a child with severe disabilities*. Lancaster: Institute for Health Research, Lancaster University.
- Hatton, C., Akram, Y., Shah, R., Robertson, J. and Emerson, E. (2004) *Supporting South Asian families with a child with severe disabilities*. Lancaster: Institute of Health Research, University of Lancaster.
- Hatton, C., Azmi, S. Caine, A. and Emerson, E. (1998) Informal carers of adolescents with learning difficulties from the South Asian communities: family circumstances, service support and carer stress. *British Journal of Social Work* 28: 821–837.
- Hatton, C., Azmi, S. Emerson, E. and Caine, A. (1997) Researching the needs of South Asian people with learning difficulties and their families. *Mental Health Care* 1: 91–94.
- Hubert, J. (1991) *Home-bound: crisis in the care of young people with severe learning difficulties: a story of twenty families*. London: King's Fund.
- Hubert, J. (2004) *Services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London Borough*. London: St George's, University of London.
- Khan, N., Rahim, R. and Routledge, M. (n.d.) *Person-centred planning and people from South Asian communities: some experiences from one locality*. Available online at: <http://www.valuingpeople.gov.uk> (accessed 12 March 2006).
- Mir, G., Ahmad, W. and Jones, L. (2001) *Learning difficulties and ethnicity*. London: Department of Health.
- Pope, C., Ziebland, S. and Mays, N. (2000) Qualitative research in health care: analysing qualitative data. *British Medical Journal* 320: 114–116.
- Raghavan, R. and Waseem, F. (2004) *Ethnicity, young people with learning disabilities and mental health issues: mapping of service use*. Available online at: <http://www.learningdisabilities.org.uk> (accessed 12 March 2006).
- Strauss, A. and Corbin, J. (1998) *Basics of qualitative research: techniques and procedures for developing grounded theory*. Newbury Park, CA: Sage.

CHAPTER 3

‘I don’t want to be the mother of a
paedophile’: the perspectives of mothers
whose adolescent sons with learning
disabilities sexually offend

Jane Hubert
Margaret Flynn
Leanne Nicholls
Sheila Hollins

Published in the *Journal of Child Psychotherapy* 2007, 33 (3): 263-376

Abstract

Background The subject of sexual abuse is a major focus of professional and public concern. Sexual abuse of (and by) people with learning disabilities evokes even greater disquieting emotions, and makes severe demands on the social services, and the criminal justice system.

Aims The aims of the project were (1) to determine whether group psychotherapy produced effective outcomes for adolescent boys with learning disabilities who exhibit sexually abusive behaviour, (2) to explore the perspectives of parents and other care-givers, (3) to document the nature and extent of service support to families. This paper focuses solely on the mothers' perspectives.

Methods A three year project with six boys (under 16) receiving group psychotherapy, using both quantitative and qualitative methods. Clinical measures were used to track changes throughout the course of psychotherapy. Semi-structured interviews (taped and transcribed) were held (separately) with the boys, their parents, paid care-givers, and the therapists.

Results The mothers tried hard to make sense of, and come to terms with, what was happening to their sons and to themselves, they struggled to reconcile their own confused and often conflicting emotions, and to maintain their own sense of identity. They felt almost totally unsupported by the services, both in the past and present, and could see little hope for the future.

Conclusions There is an urgent need for development of effective and sympathetic services for the parents of boys with learning disabilities who have been abused, and who are now showing abusive behaviour.

Keywords Learning disability, sexual abuse, adolescence, family relationships, mothers, psychotherapy.

Introduction

In 1999 a research project was set up in the Division of Mental Health, St George's, University of London, with six teenaged boys (under 16 at the start of the project) with learning disabilities, who were once the victims of sexual abuse and had now begun to sexually abuse others. They were all receiving a psychotherapeutic service, and their progress in group psychotherapy was tracked over a period of three years. Qualitative material was also collected from their parents, teachers and paid carers on their experiences of managing their sons and clients respectively.

This paper focuses solely on the experiences and perspectives of the mothers, drawn from their own narratives. In these families it is the mothers who have been the enduring figures in the lives of these boys who, in the eyes of almost everyone outside the family, have been transformed from victims to pariahs.

The subject of sexual abuse always stirs disquieting emotions and is a major focus of professional and public concern. Furthermore, as Woods (2003: 13) suggests: 'Sexual abuse by young people evokes intense and contradictory reactions... the desire to punish [and]... at the other end of the spectrum [recognition] that offenders are not born but created through a history of neglect and violence'. The phenomenon of sexual abuse of (and by) people with learning disabilities is an even more sensitive subject. It affects many people intensely, over long periods of time, and makes severe demands on local authority social services as well as the criminal justice system (e.g. Brown 1999, 2002; Brown and Thompson 1997; Cooke and Sinason 1998); Department of Health 2000; Farmer and Pollock 1998; Flynn and Brown 1997; Flynn *et al.* 1997; Flynn and Bernard 1999; O'Callaghan *et al.* 2003).

It is known that children and adults with learning disabilities experience sexual abuse more commonly than the rest of the population (Turk and Brown 1993; McCarthy and Thompson 1997). It is also known that those who are abused may become abusers themselves (Sinason 2002). Recent work by Sequeira (Sequeira *et al.* 2003) has shown that the experience of sexual abuse by people with learning disabilities is associated with increased levels of disturbed behaviour such as inappropriate sexual behaviour, aggression, social withdrawal and self injury, and also with increased severity of psychiatric symptomatology, including symptoms consistent with post traumatic stress disorder (Howlin and Clements 1995). Sinason (2002) includes bedwetting, eating disorders, abuse of children, confusion over sexual identity and challenging behaviour among the problems that arise in adolescence and adulthood as a result of childhood sexual abuse, all of which are evident among the boys in this study.

Until relatively recently, people with learning disabilities were 'overlooked or actively excluded' from psychotherapeutic interventions (Banks 2003: 62). The situation has gradually changed and it is now even accepted that individual and group psychotherapy can be effective with people who are 'highly challenging to the services and to society as a whole' (Royal College of Psychiatrists 2003: 14; and see Hollins and Sinason 2000; Allington-Smith *et al.* 2003). In spite of this, few such services exist (Sinason 2002), and where they do, they may not be taken up by professionals. It is significant that the psychotherapy service attended by the boys in this study found that many social workers were reluctant to refer their clients to them.

Methods

Permission was obtained from the local NHS Trust Research Ethics Committee. Participants were then identified via a service offering group psychotherapy to boys and teenagers with learning disabilities, whose sexualised behaviour had evoked the concerns of health and social care professionals and the police. Consent was obtained from the boys participating in the study, and from their parents or legal guardians. There were six boys in the group, all referred to the psychotherapeutic service by local authority social services. One boy's parents were not interviewed because he was living in residential care. He and his family are therefore not included in this paper. Semi-structured interviews with mothers gave them freedom to discuss their own feelings, perceptions and attitudes towards their sons, and to examine their own changing roles and relationships. The transcriptions of the taped interviews form the basis of this paper. In the interests of confidentiality, potentially identifying details have been omitted and some details changed. The interviews were analysed thematically, both through reading and re-reading of the transcripts, and using the NVivo software package.

Results

Of the five mothers whose experiences are discussed in this paper, one is a (married) foster-mother. None of the other four mothers lives with their son's father - two have remarried, one lives with a new partner, and one lives alone. Thus all the boys had experienced disrupted, and sometimes very unstable, family lives.

Most of the mothers found it very hard to talk about their sons as sexual abusers, and some became extremely distressed. They had lived through the anguish and despair of the sexual abuse suffered by their sons as children, and the evidence that their sons were now themselves the perpetrators of child sexual abuse was almost impossible to bear.

All quotations are from interviews with the five mothers.

Early abuse

The impact of the earlier sexual abuse on their sons, and the current abuse for which they are responsible, are profound, with ongoing consequences for their own, and their mothers' physical and mental health, and the well-being of the family. The mothers acknowledge the losses their sons have endured, including their loss of a 'normal' childhood as the result of abuse, their lack of ability to trust others, and the loss of trust and respect accorded to them by others, and their loss of autonomy and freedom from constant supervision, making it impossible for them to live an ordinary adolescent life, and yet at the same time preventing them from becoming adults. One mother added that now even her son's sex 'has been taken from him'.

Adding to their distress was the fact that the effects of their sons' abuse had apparently not been acknowledged by professionals at the time. Many parents were bitter about this, because they felt that things might have been different if their sons' traumatic experiences had been acknowledged, and support provided. In the words of one mother,

I feel he is not responsible for his actions. If many years ago someone had listened to me... [but] they have waited until he has been accused of rape... If something had been done years ago, we wouldn't be in the position we are in now. He wouldn't be like he is now.

In some cases it seems that professionals did not believe parents when they told them that their sons had been abused, in spite of very obvious behavioural consequences:

He was abused about three times when he was young... no one believed him but... I could see there was something wrong with him... he wouldn't go to school and he always loved school and then he told me... what X done to him... and he gave him money to keep quiet about it... he was ripping the sheets... He was shitting in the fridge (crying).

The parents are aware that the earlier abuse is now believed to be the cause of their sons' own abusive behaviour. It is striking that although this experience cast dark shadows in the lives of these boys and their distressed and disbelieving families, little support had been forthcoming over the years. In many cases it was hard to get social workers or teachers to believe that there had been any abuse, even when parents knew for certain. In one case, for example, the three men who assaulted the son on different occasions were people known to his mother. The parents had been left to deal with the consequences alone, not only for their sons, but also for themselves, and their own complex and turbulent feelings. Only recently, as a result of their sons' own sexual behaviour, had the families been offered support in the form of psychotherapy, but little else. One mother expressed all the mothers' frustration at the lack of help and support:

All I am asking for is some help... there is so much pressure on all our lives as a family... With all the pressures from trying to cope with [my son], it is just too great... we're not getting support... It's not my fault and it's not his fault. Social services are failing us... Things are so damn bloody hard.

The current situation

The family situation, in which there is an adolescent boy who is showing abusive behaviour, is exacerbated by the overall lack of specialist adolescent mental health services, as identified by the Royal College of Psychiatrists (2006):

Clear guidelines are needed in the absence of age appropriate and consistent mental health services for 16–18-year-olds. The interface between CAMHS and adult mental health must be addressed and links established between Tier 4 CAMHS and adult inpatient and community mental health teams. (Royal College of Psychiatrists 2006: 39).

Furthermore:

Until now there has been little development of the specialised psychiatric services required for young people with learning disabilities... Falling between the services provided by learning disability psychiatry and mainstream child and adolescent psychiatry,

many children have been dealt with by the community paediatrician. (Royal College of Psychiatrists 2004: 7).

Adolescence, or the transition from childhood to adulthood, is normally a time of growing independence from parents, the development of social identity (Cotterell 1996) and a time of sexual awakening and experimentation. For these mothers, who have been alerted to potentially abusive behaviour, it is difficult to establish what constitutes acceptable, explorative behaviour of an adolescent, and abnormal sexual behaviour and abuse. As Vizard (2006) suggests, the situation is exacerbated by the widespread confusion about what 'normal' sexual behaviour is in children and adolescents. However, mothers described a range of behaviours which they considered abusive, for example:

He wanted to touch me down below and I said 'No, they're my bits, you have just got to learn to keep your hands to yourself'... He is touching himself in front of people... he is touching girls and boys in the toilet and that... he talks a lot about sex.

He just said, 'I'm all right but I've been in trouble... just sucking and bums. It wasn't much'.

He was supposed to have touched one girl on the bottom and another girl's breasts... [then, after an incident with a young boy] he was arrested for sexual assault.

The mothers were aware of the complexity of adolescence for their sons. One mother said of her son:

He knows he is growing up. He's not a boy no more. I keep calling him a boy and he says, 'I'm not a boy, I'm a man now'.

But developmentally her son's interests are those of a young child, and at odds with his sexual behaviour. She regrets the difficulties and confusion that characterise her son's life and is bewildered by his behaviour and lack of understanding:

He's taking it out on me. He doesn't mean it though. It's just that he is so confused... he's got a load of difficulties. He's a handful because you've got to control him... I know he has got difficulties but he doesn't understand what I am going through... he's confused about sex... No one understands. I don't even understand myself.

The limbo between childhood and adulthood was perhaps a safe place to be. P's foster-mother said that P pretended he could not do things. She said to him:

I said 'If you want to be treated like a grown up... you've got to do what you can do. If you pretend you can't do things, people are going to treat you like a child.' No, he didn't want to be treated like a little child... No, he didn't want to be a grown up. I don't know if he didn't want to be grown up because that's too much responsibility, he didn't think he could cope with it. He just wanted to be in limbo for the rest of his life.

Managing their sons' care

Some mothers had had to give up employment (and thus their identities as employees) to manage their sons at home. Their care-giving roles were taken for granted, without any promise of significant support or assistance. They had to deal with the tensions of managing their individual and family routines while coping with the demands of supervising boys whose behaviour is not only perceived as dangerous, but also, in some cases, as being beyond the expertise even of specialist and generic services. The expectation that they should manage sons who have been harmed in, and yet excluded from, services, irrespective of their own individual lives and commitments, is understandably experienced as an injustice. At the same time, their primary loyalty to their sons contrasts sharply with the belief of support service personnel that their sons can and should transfer to settings with established expertise. One mother was unable to get a foothold in local services, in spite of a volatile family situation at home; beyond proposals that her son required a residential service for offenders, the wells of professional and educational help seemed to have run dry.

One of the main ways that these mothers tried to prevent abusive behaviour was through constant vigilance. As one mother put it,

Someone always needs to watch him... he's going to need supervision for his own protection... we've got to... protect him from getting into situations that he can't get out of.

Echoing the perceived need for vigilance, the words of two other mothers,

He needs constant supervision though he finds this difficult. Young and vulnerable children should not be left alone with him.

You don't leave him alone with other children... when you think he's safe... when he thinks he's not being supervised... he can do things that are unpredictable.

Most mothers found this constant vigilance difficult and stressful with, in some cases, threats of violence from their child or adolescent.

It is unhealthy for him to be tied to me 24 hours a day... I have got to give him leeway now. I can't keep him tied in, [I can't] stop him from going out now... I was getting physically assaulted.

The vigilance of these mothers was partly to protect others from them, but also to protect *them*. They were aware of the vulnerability of their sons, particularly because they tended to want to please other people. As one mother put it,

He wants to make adults happy. I think that if he was approached there would be a danger that he would do whatever somebody wanted him to do because... he wants to please people.

It is clear that most of the abuse perpetrated by these boys takes place in their school environment, thus mothers are aware that they themselves are only dealing with the tip of the

iceberg at home. They are understandably angry that the schools and residential placements do not seem able, or willing, to protect the vulnerable young people in their care from themselves and others.

Making sense of their lives and circumstances

There is little doubt that the mothers of all the boys had been deeply affected by the sexual assaults on their sons when they were younger, and their lives continued to be dominated by their current experiences as parents of boys and young men who were now sexually assaulting others.

The response of professionals at this stage in the boy's lives tended to focus on what they saw as the inevitability of residential placements away from home. The mothers, on the other hand, were more concerned with actually trying to change things for the better. They wanted help and support for their sons, so that these vulnerable teenagers could come to terms with the past, and learn to cope with (and control) their feelings. They also wanted the same for themselves.

The range of emotions experienced by these mothers included anger, fear, anxiety, bitterness, powerlessness and despair. For their sons they felt compassion and protectiveness:

It has been done [to him] so he does it to others... It seems to me a bit unfair because you always think that even if he is a victim, he is the one that is at fault. I feel a bit protective of him, a bit angry about that. There was an incident the other day where a boy was inappropriately touching him but, you know, [my son] is the one who is held up as the sex offender.

I am quite angry now because I was often rung up and told about his 'inappropriate behaviour' but it was happening to him by these older children and he wasn't being watched and looked after as he should have been, so I'm terribly angry about that... He wet the bed a lot... He doesn't know when to stop eating. He will eat, eat and eat... I've seen him heaving because he's so full and still trying to put food in his mouth.

I don't like him having this label. Labelled as a 'sex offender' when it wasn't his fault, the way things happened. It interferes with the way he can relate to people.

The care workers... used to ring me up all the time to tell me about his sexual behaviour but they didn't explain what was going on throughout the school... I am so angry.

The mothers lived in dread of fresh allegations and evidence that their sons were a danger to other children. Most had tried to deny the increasing evidence that their sons had become abusers, but had been forced to face reality:

I've now got to look at the prospects that these allegations are true. Until now, I've blanked them out. As a mother you do.

This mother's reappraisal of all that she considered reassuring dislodged her own sense of self, and she questioned her own competence as a mother. At the same time she felt helpless in this situation, which had spun out of her own control:

It's like you're not in control of your life. I'm not in control of his life. I wonder who is in control of our lives at the moment?

The fact that their sons had learning disabilities intensified the mothers' empathy and protectiveness towards their sons, and added to their anxiety about what would happen to them in the future:

He's got a brain like a seven year old... he doesn't understand... he doesn't sort of mean it.

In the words of another mother,

No one ever... said that one day when he's sixteen he's basically an eight year old. When he's thirty, is he going to be like a sixteen year old? Is he gradually going to creep up or is he always going to be an eight year old in mind?... I feel he is not responsible for his actions... I am watching him develop and not understand his body.

A third mother went on to say,

These children... have got grown bodies but mental ages of about six or seven... He is a little boy a lot of the time that needs a cuddle... he can be very childish.

A further problem was the fact that most of the boys had limited speech. As one mother said: 'Life would be better for him if he could communicate more clearly'.

Although their sense of protectiveness dominated, some of the mothers had conflicting feelings towards the person that their sons had become. One mother, for example, deeply regrets that her son's childhood has been compromised, and that the label of 'sex offender' obscures the fact that her son was himself a victim of sexual assaults. She is concerned about his inability to express himself, and about the impact of his learning disability on his efforts to engage with others. Yet at the same time she is aware of the negative impact of her son's behaviour on her own feelings for him.

Being rung up by the school care workers and told that he has done these sorts of misdeeds, it doesn't make you feel terribly positive towards him. I don't want to be the mother of a paedophile... It quite frightened me at one stage and I was really depressed about it... I don't know if I can put up with this really.

Another mother emphasised the disbelief:

You never want to believe that your own children could be abusers.

They were aware of the stigma that the label of abuser carried with it. One mother, when a new teacher had 'pointed out the stigma' after reading her son's file, said with sadness:

That stigma is going to follow him... I mean, he may pose a threat, a risk, but does it have to be labelled in black and white the way it is, to give him that stigma?

It is clear that the mothers felt they had lost control, and were overwhelmed by the situation they found themselves in. Many had a range of serious family problems, including severe illness of other family members, hostility between siblings and tensions between

their partners and their sons (including one son accusing his step-father of 'interfering' with him'. Some mothers were clearly very depressed, even to a dangerous extent:

I am on tablets to stop killing myself... Too much on my plate... I just want to die. I can't sleep. I can't do anything.

One minute you think you are on a winning line and then, all of a sudden, something will happen and you go downhill again... I am too tired now. I feel as though I am old before my time... I've had a headache, can't get rid of it... it is just stress and tension... I can't get rid of it, I can't get rid of the stress or tension.

However, whatever their sons had done, and however difficult it was to manage them at home, the protectiveness of these mothers outweighed the problems:

He is screaming in the night. It is not right... I should take him to the doctors but I am frightened they might take him away from me. That would do me up altogether... He screams 'Mummy! Mummy!'

In the words of another,

He's always been close to me... he'll still be my boy whatever he does.

The group psychotherapy

The mothers were aware of the circumstances which had led to their sons' referrals to a specialist psychotherapy service. On the whole they welcomed the offer of psychotherapy for their sons, and some were even optimistic about the outcome. They were, without exception, at the end of their tether, and at last it seemed that something positive was being done to help. Some had concerns that the group might make things worse, and make the abuse, as one mother put it, 'become an emphasis in his life'. However all thought that it was worth trying. Their attitudes throughout the two years of therapy fluctuated. There were often concerns that one or two of the other boys were a bad influence:

He has been hearing things that he hadn't thought of... things that have gone on that might give him ideas... He's more like an eight year old in a way... I am concerned about the amount of control over his feelings... he is still in the position of being instinctive and possibly, if the situation is there, he may take advantage of it or be taken advantage of.

On the other hand she says her son feels it does help him: 'He says it stops him having sex with younger boys'. At the end of the therapy she still had mixed feelings, but on the whole was positive: 'He behaves in a more acceptable way and a sort of interactive way... he is slightly more confident'. Her relationship with him is 'a lot better... partly because he expresses himself so well [he has significant speech problems], and he cares... he is aware of the victim feeling uncomfortable and as he gets older he is much less likely to offend'. However, another mother said: 'We are not convinced it is doing him any good. I am concerned that it might actually be harming him', and another: 'the group is not helping him because he is still going for girls and boys at school'. Another mother also felt that some of

the other boys were a damaging influence, but in the end she was pleased because 'He doesn't do things that he was doing before'.

Another mother also felt that the group had helped her son to express what he was feeling and 'on the whole I think it was good'. This was in spite of the fact that her son was suspended from the group following an allegation of rape.

Thus it can be seen that, for the mothers, the outcomes of the group were mixed, but probably more positive than negative. The actual full and continuing effects of the therapy on the boys themselves do not fall within the remit of this paper.

Discussion

The boys' mothers tried hard to synthesise what they knew about their sons' behaviour and 'dangerousness' with their own beliefs and judgements about their sons and their traumatic experiences as young children. They fought against the diminution of their sons' individuality and at the same time their experiences threatened their self-perceived identity as effective parents, and raised inescapable questions about their own adequacies. Their accounts demonstrate their empathy for their sons, and their understanding of the impacts of learning disabilities on their lives, and they were saddened by the limited expressive resources and emotional inarticulacy of their sons.

The strengths and capabilities of these mothers appeared to be eclipsed by the overwhelming stress of fearing further knowledge of assaults (possibly of increasing dangerousness) and anxiety about what would happen to their sons if these things happened. At the same time they were aware that their sons were on the boundaries of the professional skills and range of those responsible for them. As they sought to keep their sons, and others connected with them, safe, it is clear that they lacked competent professional support and practice ideas to guide them. They did everything they could to prevent further assaults through constant monitoring and vigilance, and by trying to reshape behaviour and establish boundaries. However, their efforts became muted over time as they proved unsuccessful. Furthermore, until now, no attempts had been made to understand the roots of the boys' unwanted behaviour, nor to heal the early trauma experienced by the boys themselves.

It is neither new nor unusual to state that the carers of people with learning disabilities receive insufficient support. However, it is striking that even families in such volatile and vulnerable situations found that there was little professional experience or expertise available either to them or their sons, leaving them struggling to make sense of – and come to terms with – what was happening to them.

The mothers sought to reconcile their happier perceptions and memories of their sons as young children with the sexually offending adolescents they now struggled to support, defend and, most important of all, to understand. They tried hard to present evidence of their sons' dawning maturity, as well as emphasising the impact of having learning disabilities, and the effects of emotional inarticulateness in the context of unstable family situations and allegations of sexual abuse.

The two statements 'I don't want to be the mother of a paedophile' and 'He'll still be my boy whatever he does' attest to the suffering of these mothers in their struggle to reconcile their confused and often conflicting emotions. At the same time they try desperately to maintain their own sense of identity as they are forced to acknowledge and come to terms with the reality of the current circumstances, for which there seems to be no respite or resolution.

Although the worlds of these mothers and sons have changed beyond recognition since the early experiences of abuse, there appears to have been no corresponding increase in the support offered to them. It is clear that the extent to which mothers could exert control diminished as their sons' behaviour became more conspicuous and dangerous.

The families' contact with professionals only tended to arise in the context of allegations of inappropriate sexual behaviour, focussing on damage limitation, rather than being part of an ongoing support service to advise and sustain families living each day in intolerable circumstances (and see Sobsey 1994; O'Callaghan *et al.* 2003).

Over the last 10 years, services have started to be set up for children with sexually abusive behaviour in the UK (Vizard 2006). However, 'There are few services available for the more disturbed and dangerous children with sexually abusive behaviour who may be co-morbid for several psychiatric disorders... A further difficulty is the lack of developmentally trained, specialist staff, including CAMHS staff, to undertake assessment and treatment of sexually abusive children in a variety of contexts' (Vizard 2006: 6).

Vizard (2006: 7) writes: "Urgent consideration should be given to the creation of a coherent government policy on children with sexually abusive behaviour to address long term service provision, training and research'.

For the mothers in this study, however, any new specialist services will almost certainly be too late to restore their own, and their sons', lives to any kind of normality.

References

- Allington-Smith, P., Ball, R. and Haytor, R. (2003) Management of sexually abused children with learning disabilities. *Advances in Psychiatric Treatment* 8: 66-72.
- Banks, R. (2003) Psychological treatments for people with learning disabilities. *Psychiatry*, 2 (9): 62-65.
- Brown, H. (1999) Abuse of people with learning disabilities: layers of concern and analysis. In *Institutional Abuse: perspectives across the life course*, Stanley, N., Manthorpe, J. and Penhale, B. (eds). London: Routledge.
- Brown, H. (2002) *Safeguarding adults and children with disabilities against abuse*. Strasbourg, Council of Europe Publishing.
- Brown, H. and Thompson, D. (1997) Service responses to men with intellectual disabilities who have sexually abusive or unacceptable behaviours: the case against inaction. *Journal of Applied Research in Intellectual Disability* 10: 176-197.
- Cooke, L. B. and Sinason, V. (1998) Abuse of people with learning disabilities and other vulnerable adults. *Advances in Psychiatric Treatment*, 4: 119-125.
- Cotterell, J. (1996) *Social Networks and Social Influences in Adolescence*. London: Routledge.
- Department of Health (2000) *No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: Department of Health.

- Farmer, E. and Pollock, S. (1998) *Sexually abused and abusing children in substitute care*. Chichester: John Wiley and Sons.
- Flynn, M. and Brown, H. (1997) The responsibilities of commissioners, purchasers and providers: lessons from recent National Development Team inquiries. In *There are no easy answers - the provision of continuing care and treatment to adults with learning disabilities who sexually abuse others*, Churchill, J., Brown, H., Craft, A. and Horrocks, C. (eds.). Chesterfield/Nottingham: ARC/NAPSAAC with the SSI and DOH.
- Flynn, M., Griffiths, S., Byrne, L. and Hynes, K. (1997) 'I'm stuck here with my poxy Star Chart': listening to mentally disordered offenders with learning disabilities. In *Empowerment in everyday life: learning disability* Ramcharan, P., Roberts, G., Grant, G. and Borland, J. (eds). London: Jessica Kingsley Publishers. 144-155.
- Flynn, M. and Bernard, J. (1999) *Deep trouble! Adults with learning disabilities who offend*. Manchester: National Development Team and Central Council for Education and Training in Social Work.
- Hollins, S. and Sinason, V. (2000) Psychotherapy, learning disabilities and trauma: new perspectives. *British Journal of Psychiatry* 176: 32-36.
- Howlin, P. and Clements, J. (1995) Is it possible to assess the impact of abuse on children with pervasive developmental disorders? *Journal of Autism and Developmental Disorders* 25: 337-353.
- McCarthy, M. and Thompson, D. (1997) A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities* 10: 105-125.
- O'Callaghan, A.C., Murphy, G. and Clare, I. C. H. (2003) The impact of abuse on men and women with severe learning disabilities and their families. *British Journal of Learning Disabilities* 31: 175-180.
- Royal College of Psychiatrists (2003) *Psychotherapy and learning disability*. Council Report CR116. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists (2004) *Psychiatric services for children and adolescents with learning disabilities*. Report CR123. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists (2006) *Building and sustaining specialist child and adolescent mental health services*. Report CR137. London: Royal College of Psychiatrists.
- Sequeira, H., Howlin, P. and Hollins, S. (2003) Psychological disturbance associated with sexual abuse in people with learning disabilities: case-control study. *British Journal of Psychiatry* 183: 451-456.
- Sinason, V. (2002) Treating people with learning disabilities after physical or sexual abuse. *Advances in Psychiatric Treatment* 8: 424-432.
- Sobsey, D. (1994) *Violence and abuse in the lives of people with disabilities: the end of silent acceptance?* Baltimore: Brookes Publishing Co.
- Turk, J. and Brown, H. (1993) The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research* 6: 193-216.
- Vizard, E. (2006). Sexually abusive behaviour by children and adolescents. *Child and Adolescent Mental Health* 11, (1): 2-8.
- Woods, J. (2003) *Boys who have abused: psychoanalytic psychotherapy with victim/perpetrators of sexual abuse*. London: Jessica Kingsley Publishers.

CHAPTER 10

CHAPTER 10

CHAPTER 10

Discussion

Introduction

This thesis set out to gain insight, through the use of ethnographic research methods, into the experiences of people who have severe and profound intellectual disabilities, who also have mental health problems and challenging behaviour. It has examined the ways that these men and women have been, and still are perceived and treated by others – by the care staff and professionals who work with them, by people in the community, and by their families. A central part of this are the two studies of men and women living in locked wards of an old long-stay hospital, and a comparison between the perceptions and treatment of them in the ward and what happens to them when they move out into smaller units. It has also compared and contrasted the experiences of another group of people who have the same kinds of complex problems, but who have lived at home all their lives with their families. The questions that were asked at the beginning of this thesis are addressed below.

In answering these questions it was considered essential to place the material in a wider context, drawing not only on intellectual disability research material, but also on a wider field of literature. By doing this, it is hoped that intellectual disabilities will be seen as only one strand in a spectrum of human experiences. At the same time, the contextual material from other groups of people who have been segregated from society for long periods, in other types of institution, demonstrates that it is not only people with severe intellectual disabilities who may be driven to ‘madness’ by the deprivations of life in a closed institution. In addition, further material is cited from (as yet unpublished) fieldnotes. The first question relates to methodology, and the ethics of using ethnographic methods of research with vulnerable people living in institutions. The second question is the most central to this thesis, and is therefore answered at some length.

- 1. What can the use of ethnographic methods offer in the field of research with very vulnerable people? Are there specific ethical issues that arise in research of this kind with people who are unable to give verbal consent? How can these issues be addressed? (Chapters 2 and 3)**

Ethnographic methods

As described in Chapter 2, ethnographic research methods can provide answers to questions about why people act as they do, i.e. it is concerned with the meaning of people's actions, and of events, rather than calculating the frequency with which they occur. The methods involve unstructured interviews, and participant observation (Dewalt and Dewalt 2002) of people in their ‘normal’ environment. Participant observation means watching and listening and participating in the life of a community or group. In some situations, such as in the research described in this thesis with people in a locked ward who had little or no speech, there cannot be interviews, and so participant observation is perhaps the most viable method of research. In order to identify patterns of behaviour, to see changes over time and to be able to document the shape of relationships, it is necessary to do this over a prolonged period. By participating in the life of a family, ward, or unit, for example, over a period of time, not as a carer, or parent, or advocate, and with no initial emotional in-

volvement, a researcher can go some way towards representing the views of the individuals themselves.

One of the aims of the research with the men and women in the locked wards was to try to restore their identity, to give them back their pasts, and enhance their presents, in order to improve their futures. This may sound glib, but as people living in the outside world, we are treated very differently. Our identities are constantly acknowledged and reinforced. We have pasts that other people are aware of, and on which we, and others round us, constantly build. We all have a wide set of connotations. To a great extent the 'cultural history' of the men and women in the wards is merely the history of the institution. Their individual lives, as opposed to their medical and recorded behavioural lives, are to all extents and purposes unrecorded. One man or woman dies or is moved out and another takes his or her place. They have become invisible to the outside world, because their life in the institution is the only life they have, their only reference point is the inside of a locked ward.

People who live outside, in the wider society, have numerous reference points, e.g. their home, school, college, workplace, other people's houses, clubs, pubs, shops, cafes, and so on. They also have a range of different roles, e.g. as parent, son or daughter, sibling and a range of other kinship roles, colleague, employee, friend, team member, student, and so on. People who are segregated in locked wards tend to have only one 'persona' and one role, and that role is shared by every other individual in the same ward (and see Goffman 1966, below).

In addition, or perhaps integral to this, is the gradual erosion of all the aspects of identity that people in the outside world have. Not only is there loss of individual identity, but also social, family, and gender identity.

To try to redress this, over 250 hours were spent in the ward with the men, and a similar amount of time with the women, at all times of the day and night, getting to know them, discovering the many ways that they tried to communicate, what their relationships were, what they liked and disliked, and so on. In other words, trying to discover who they were, as opposed to the institutional ways in which they were described in the ward notes, i.e. in terms of the severity of their intellectual disability, their challenging behaviour, their inabilities and their autism. As demonstrated in Chapters 4 and 5, through the use of ethnographic methods of research it was possible, at least to some extent, to retrieve the forgotten identities of a group of men and women who have been institutionalised for most of their lives. By getting to know them as social beings it was possible to counteract the institutional identities which had been constructed by other people.

The publications that have emanated from the two projects have presented fuller pictures of the men and women involved, describing them as individuals, as men and as women, and as people who can have reciprocal relationships. In addition, on the basis of the material collected over the three years of observation on the men's ward, long, detailed vignettes were drawn up to give to current and future staff who would be responsible for the quality of life of the men in the future (see Introduction). To an extent it has been possible to restore the men's individual identities, but their future depends on the will of others to help them restore other identities that they have lost, and to respect and hold on to the identities that have been recovered.

It was important to try to assess the quality of life of the men and women in the locked wards, so that those aspects that did not contribute positively to their lives could be changed in the future. However, it is very hard to assess the quality of life of people who cannot tell you how they feel, although they constantly communicate their pleasure or distress. Many assessments of quality of life are made using quantitative measures (too numerous to list here) of objective factors, which are useful in that they establish whether or not certain standards are adhered to or not in service provision, and to a limited extent will provide a general idea about the nature of people's lives within a particular setting. However, as Cummins points out (Cummins 2005a): 'Numerous studies have shown that, except under unusual circumstances, there is remarkably little relationship between objective and subjective variables' (Cummins 2005a: 11), and he advocates the use of subjective indicators (see Cummins 2005b). In the case of people with severe intellectual disabilities, who have little or no speech, even these measures are not practicable, because they require a certain level of specific responses.

The kinds of things that are of fundamental importance to the quality of life of most people include factors which are hard to quantify. They include the recognition of one's individuality; being free to have a range of chosen relationships, and the recognition by others of the importance of these relationships; having independence and also interdependence with others; being loved as well as giving love; sharing, and being included (i.e. belonging); being allowed to give as well as receive; being helped to develop a reason for living and having individual beliefs and values respected. These factors can only be gauged by getting to know people, and understanding their modes of communication and relationships with the people around them.

To find out meaningful information from people such as the men and women living in the locked wards, who have little or no speech, participant observation over time is an effective method of research, in that it does enable the researcher to get to know the individuals they spend time with, and come to understand their relationships with the other individuals they live with, and with the care staff, who are the only other people with whom they come into contact on a regular and frequent basis. The outcomes of the projects described in this thesis illustrate the nature of the insights that have been gained.

It should be added that psychodynamic therapy is another (now widely acknowledged) way of obtaining an in-depth understanding of people who have intellectual disabilities (Royal College of Psychiatrists 2004). Also, the use of nidothrapy (Tyrer and Bajaj 2005) may also yield in-depth material, through its focus on the individual and his or her needs and preferences. Nidothrapy, rather than attempting to change the individual to fit into the existing environment, involves manipulation of both the physical and social environment to 'fit' the individual. Thus 'the first task in nidothrapy is to try to interpret the environment as seen by the patient in a way that gives greater understanding of perceived priorities' (Tyrer and Bajaj 2005: 232). Clear goals must then be set for environmental change, from which improvements in social function should then follow.

Ethics of ethnographic research

There are a number of ethical issues that arise in the context of these methods of research. One is the question of consent, and this is discussed in Chapter 3 in the context of people who have severe intellectual disabilities (and little or no speech), who have been institutionalised since childhood. Men and women such as these fall through the net of the many guidelines that have been published, not only because they cannot give consent themselves, but also because it is not clear who can give consent on their behalf. In circumstances where parents have been out of contact for many years, it is suggested in this chapter that when approval has been obtained from the appropriate ethical committee, and consent given by those now responsible for the man and women concerned, 'process' consent (ESRC 2005) is a means by which the researcher can gauge whether someone accepts or rejects his or her presence on any particular occasion. Chapter 3 refers to this form of consent, but the concept can be expanded further in the words of the Economic and Social Research Council's 'Research Ethics Framework' (ESRC 2005):

In the case of participatory social science research, consent to participate is seen as an ongoing and open-ended process... it is continually open to revision and questioning. Highly formalised or bureaucratic ways of securing consent should be avoided in favour of fostering relationships in which ongoing ethical regard for participants is to be sustained (ESRC 2005: 24).

A second issue that arises in the context of ethnographic research with people with severe intellectual disabilities is the question of publication. In some cases there is reluctance by editors to publish material that is intimate and distressing, and which also implies criticism of current policy and practice. In other cases there is concern regarding the anonymity of personal and intimate data about individuals, but it is no harder to maintain anonymity in this sort of research than in any other kind. Publication of ethnographic material that brings to light the nature of the segregated and deprived lives of people who have lived in institutions is vital. Material of this kind presents the people concerned as full human beings with their own individual, social and gender identities, rather than simply as the sum of their impairments, and second, because it is vital to identify and acknowledge the failings of past models of care, if there are to be significant and genuine changes in the quality of services provided for these highly dependant men and women.

- 2. What is the nature of life in a locked ward? What are the effects of living in an institution? In what way does confinement in a locked environment affect the mental state of those confined? What effect does social and physical exclusion have on identity? (Chapters 4 and 5)**

The ward

Chapters 4 and 5 describe the segregated and socially isolated lives of men and women living in two locked wards of an old 'mental handicap' hospital. They show the emotionally and physically deprived nature of their existence, and the effects of their loss of identity.

It can be seen from the medical records of the men and women in the wards that children who were institutionalised as difficult youngsters often developed more and more serious challenging behaviour. An example of this is the story of Kamal (taken from his medical records and fieldnotes).

In 1964, Kamal, aged 4, was admitted to a long-term hospital for children. His father had left his mother with four children, of whom he was the eldest. He was described in his medical notes as an 'attractive, physically normal little boy', who had been admitted because, in his mother's words: 'My doctor, she said to me, "you can't control the boy"'. At that stage he had a little speech, but the language he knew was not English.

When he was taken from his mother at the hospital he clung to his coat and clutched a ball of wool, which he would not be parted from. Helping his mother to wind her wool had been one of the things he loved to do at home. His mother visited him occasionally at first, and when she did he was said to be very happy, and sat on her knee. Two years later his medical notes describe as miserable, restless, withdrawn and disturbed. Three years later, at the age of nine, he is said to wipe faeces over himself, to have a violent temper, and to be always trying to get out of the ward. He was described as having 'severely challenging behaviour', including self injury through banging his head against the wall and with his fists. When he was first transferred to the locked ward he was said to disrupt the 'entire ward': biting, throwing furniture and self-injuring. His mother stopped visiting him, and he has not seen her for many years. He now has no speech.

What happened to this cheerful, hyperactive four year old that turned him into the unhappy, doubly incontinent, severely disturbed adult that he is now, locked away in a secure unit and controlled by powerful antipsychotic drugs? Chapters 4 and 5 go some way towards answering this question with regard to the men and women in the locked wards.

It is now widely accepted that people who live in closed institutions, whose lives are socially and physically excluded from the community around them, are among the most vulnerable people in our society. Many have been isolated from society for most of their lives. Chapters 4 and 5 describe the perception, treatment and experience of men and women who live these segregated lives, and the effects that social invisibility, and living in materially and emotionally deprived environments, have had on people who have severe intellectual disabilities and mental health problems. These separate lives, and the treatment that such people have received over the years, have resulted in loss of individual identity. But they have lost more than this – they also have no social identity because they have not lived in society, they were not part of the community beyond the hospital, and had little or no contact with people living in other wards of the hospital. Most had also lost their familial identity, their last contact with any members of the family being many years ago. Yet, as Chapter 4 shows, the men still remembered their families, and their place within them, and wanted to still be part of a family – to 'belong'. There was no attempt by the people who worked with them to talk to the men or the women about their pasts. As Chapter 5 points out, when the women in the locked ward moved into their new homes, very little information about them went with them. Their pasts were not considered to be relevant, and their lives in this (and earlier institutions) were considered best forgotten, even though, for most of them, these had been home to them since childhood.

Knowledge of one's own personal history is integral to a sense of identity. For example, one of the most distressing results of a severe head injury can be the loss of past identity. It is bad enough for parents: 'It's like the son we had has died' (Hubert 1995: 37), but even worse for the people themselves, who may be aware that they have changed, but cannot remember who they were before, as one young woman said: 'I don't know my history, I have no history' (Hubert 1995: 93). She, like other young people in the project, tried desperately not only to regain the pasts that they had lost, but also to return to being the people that they had been before (Hubert 1995).

Challenging behaviour

The men and women who have grown up behind the locked doors of institutions of the kind described in this thesis are known to have suffered abuse of all kinds. They are particularly vulnerable to abuse, not only because they are unable to report what other people do to them, but also because others often see them as being quite different from themselves, without their own feelings and needs, and hence they are seen by some as 'acceptable' victims. Once people are thought of in this way they are no longer seen as human beings with their own individual and social identity. It seems that other people then feel free to disregard, or deny the existence of thoughts, emotions, hopes and fears, and even of pain.

Also, there is an imbalance of power in their relationships with other people, whether relatives, paid carers or other adults they come into contact with.

Sequeira *et al.* (2003), in a case-control study of 54 adults who had been sexually abused and 54 adults with no known history of abuse, living in residential care, found that sexual abuse was associated with increased rates of mental illness and behavioural problems, and with symptoms of post-traumatic stress. Furthermore, because people with severe intellectual disabilities cannot tell people when they have been abused (Murphy *et al.* 2007), it is natural that they become distressed and frustrated when the people around them do not acknowledge or react to what has happened to them. This may lead to ways of behaving that is then labelled 'challenging behaviour', without people trying to find out why someone is acting in this way. This makes people who are already very vulnerable even more so. The little freedom they have may be restricted even further, and they may be given more and stronger drugs, and become even more socially isolated. Thus the vicious circle of vulnerability and violence is continued.

It is relevant to the experiences of the men and women described in Chapters 4 and 5 that new approaches to challenging behaviour are now being proposed. A recent report from the Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists stresses that challenging behaviour is not a diagnostic entity but a socially determined concept (Royal College of Psychiatrists *et al.* 2007):

All behaviour has meaning or function and does not occur in isolation. There are likely to be a number of underlying causes of a behaviour that are a challenge to others. As well as functional determinants, precipitants and maintaining factors, aetiologies may include

- *physical: discomfort, pain, malaise, physiological disturbance (e.g. thyroid disorders)*

- *mental illness: mood disorders, psychosis, anxiety, obsessive–compulsive disorders*
- *neuropsychiatric disorders: epilepsy, Gilles de la Tourette syndrome, attention-deficit hyperactivity disorder (ADHD), dementia*
- *pervasive developmental disorders: autism*
- *phenotype-related behaviours: Prader-Willi syndrome, Lesch-Nyhan syndrome, Williams syndrome*
- *psychological trauma: reaction to abuse or loss*
- *communication difficulties: hearing loss, unclear communication, insufficient vocabulary or means of expression, difficulties understanding communication of others (Royal College of Psychiatrists et al. 2007: 13)*

The implications of this report for the men and women described in Chapters 4 and 5 could be profound. If those responsible for them took these guidelines on board, it would mean that instead of responding to episodes of challenging behaviour with increased dosages of psychotropic medication and other ‘restrictive’ practices, and simply accepting that the challenging behaviour was part of an individual’s intellectual disability, attention would be given to the underlying causes, at all levels, that make people behave in the ways that they do. In Chapters 4 and 5 it can be seen that participant observation in the ward, over time, revealed some identifiable justifications for the challenging behaviour displayed by some of the men and women, and work with all of them would doubtless reveal more. It might well be, however, that for some of the well-established patterns of behaviour it would be necessary to address them through general lowering of anxiety, and acknowledgement of the stress resulting from communication difficulties, aspects of the environment, and relationships within it, which are affecting individuals.

If, as the above report postulates, ‘Challenging behaviour is socially constructed and is a product of an interaction between the individual and their environment’ (Royal College of Psychiatrists *et al.* 2007: 9) then those responsible for the men and women would have had to, first, get to know them as individuals, second, find out more about them from whatever source of information was available, and third, re-examine the environment in which they lived.

However, few people who worked in the two wards seemed to want to get to know the men and women, and in this way both staff and professionals avoided getting into a situation where they would begin to understand why someone behaved as they did, and perhaps thereby be able to help them change the way they acted, and become less disliked, feared and socially excluded. It was obviously easier for many people not to understand, not to perceive them as social beings, so that it continued to be possible to treat them as they did. It is also relevant that the wards were locked wards, with very few people entering them who were not part of the hospital set-up. In the case of the men’s ward even visiting professionals tended to see the men in a side room, situated between the locked ward and the outer door (through which everyone, except the men, were able to escape into the outside world). This almost total segregation meant that the institutional culture that had persisted for so many years, in both wards, could continue to be condoned and changes need not be made, because no one outside really knew, or cared, about what happened from day to day.

Abuse

As stated above, the social ‘invisibility’ of these men and women inevitably exposed them to various kinds of abuse over the years. The white paper, ‘No Secrets’ (Department of Health 2000), defined abuse as ‘the violation of an individual’s human and civil rights by any other person or persons’, and identified six main categories of abuse:

- physical abuse, including hitting, slapping, pushing, kicking, misuse of medication, restraint, or inappropriate sanctions;
- sexual abuse, including rape and sexual assault or sexual acts to which the vulnerable adult has not consented, or could not consent or was pressured into consenting;
- psychological abuse, including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks;
- financial or material abuse, including theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits;
- neglect and acts of omission, including ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating; and
- discriminatory abuse, including racist, sexist, that based on a person’s disability, and other forms of harassment, slurs or similar treatment (Department of Health 2000: 9).

It is not now known what the extent of sexual and physical abuse has been in the past for the men and women described in Chapters 4 and 5, but it is generally accepted that this was the experience of many men and women living in closed institutions. As described in Chapters 4 and 5, it was possible to identify a range of ongoing abuse at various levels, and in most of the ‘No Secrets’ categories. ‘No Secrets’ also identifies ‘institutional abuse’ i.e. ‘poor care standards, lack of positive responses to complex needs, rigid routines, inadequate staffing and an insufficient knowledge base within the service’ (Department of Health 2000:10). All these were integral to the two wards, and underlay the other forms of abuse within them.

It is important to put these wards into some perspective. Although the men’s ward was considered to be the ‘worst’ ward in this hospital, evidence of abuse in other NHS Trusts is still coming to light. For example, in 2006, some six years after the publication of ‘No Secrets’, a Health Commission enquiry into intellectual disability services in an NHS Trust in Cornwall reported that in assessment and treatment centres physical restraint was being used illegally and there was excessive use of pro rata (PRN) medication to control unacceptable behaviour (Commission for Healthcare Audit and Inspection and Commission for Social Care Inspection 2006):

The service falls far short of the standards set out in the Valuing People strategy and, in some cases, it infringes human rights... It was clear to the investigation team that none of the trust managers responsible understood what a good model of care for people with learning disabilities should look like (CHAI and CSCI 2006: 60).

Another Health Commission report into services in a London NHS Trust reported a very similar situation (CHAI 2007). The recent Joint Committee on Human Rights report (JCHR 2008) stated, in the light of these Inquiries, that:

The extent to which the rights of adults with learning disabilities are currently being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: ., [and] also raises other important issues of substantive human rights law such as... the prohibitions on inhuman and degrading treatment... and unjustified discrimination. (JCHR 2008: 11)

The inhuman levels of treatment of the men in the locked ward have had inevitable adverse effects on them. Since childhood they have been labelled as having challenging behaviour, and there is little evidence that this was ever dealt with except through the use of psychotropic medication, the effectiveness of which is increasingly being questioned (Tyrer *et al.* 2008). An extension of this, and perhaps reflecting the need for others to place the men in the ward outside the margins of acceptability, was the added label of many of them as sexual abusers, thereby making them even more of outcasts than they already were. Their status as victims of abuse was rarely acknowledged. The threat, however misconceived, of potentially uncontrollable sexual activity, among people who are perceived as almost totally 'other', inevitably leads to further rejection and social exclusion.

Negative attitudes and perceptions

Another aspect of the men's and women's experience in the wards that has also affected them adversely, is that the attitude and perceptions held by the people who have been responsible for them, with a few notable exceptions, have been predominantly negative. In the case of the men's ward, it was considered to be a 'punishment block' for staff, and most tried not to work there. One example of the way the ward was perceived is in the attitude of one member of staff:

What [she said] could often be heard in the voices of other professionals, especially those who did not actually work directly with the men. There were clear undercurrents of fear, and prurience, in the way they spoke of them: fear of potentially uncontrollable sexual activity, of violence, ugliness, the unknown, and of the undefined power of people who are perceived as almost totally 'other' (Hubert 2000: 201).

By describing it in this way, the mythology that had grown up about this ward, which portrayed the men who lived there as sexually uncontrolled and unclean, was further fuelled. As Young (1990) wrote:

When the dominant culture defines some groups as different, as the Other, the members of those groups are imprisoned in their bodies. Dominant discourse defines them in terms of bodily characteristics, and constructs those bodies as ugly, dirty, defiled, impure, contaminated or sick (Young 1990: 123).

Communication

As seen in Chapters 4 and 5, where examples were given of responses to sympathetic approaches, little attention was paid to the constant desire of the men and women to communicate. De Waele and Van Hove (2005) highlight this issue in their ethnographic study of people with high support needs (including challenging behaviour) living in a large Flemish residential facility:

A lot of barriers and disturbances in the communication between residents and staff were noticed: unsuccessful messages and unheard shouts, being silenced (in very subtle and in very violent ways), and dependency on the ability and effort of others to understand you (De Waele and Van Hove 2005: 629-630).

Tuffrey-Wijne (2007), in her research to assess the Disability Distress Assessment Tool (DisDAT), states that one of the most striking findings was that people who were said to be unable to communicate were in fact able to communicate their distress.

Certainly, in the locked wards, communication was often subtle, but in those who have no speech such communication is very precious and should be nurtured, not ignored. One man, who was seen as someone with no useful means of communicating, nor desire to, was in fact, as were almost all the men and women, communicating almost continuously:

When I entered the ward he would often come up to me, take my hand, and smile. When I was standing around he would very gently touch my hair or shoulder as he passed. He would come and sit with me, and take my hand, and when I spoke to him would look very directly into my eyes, and sometimes he looked as though he understood what I was saying (JH fieldnotes).

Another example demonstrates the level of perception of the men by staff who preferred to focus on attributes which served to push the men further and further into the category of 'other':

When I told Marcus that I was going... he took my hand to take me back into the room... He sat on a chair and put my hand towards his back, then sat with his head down in his arms while I stroked his back. Later, as I was leaving, Staff B went up to Marcus and looked at his hands and said loudly... 'let's have a look at those nails, have they got faeces in them? Oh yes! They have'. I interpreted this as telling me that I would have faeces all over me. It was clear that our perceptions were quite different. I perceived Marcus's hand as a means of communication, whereby he could ask me not to leave the ward, and also ask me to rub his back. To Staff B, Marcus's hand had nothing to do with communication, but was something unclean, something not to be touched. Polluted and polluting (JH fieldnotes).

One of the ways that some members of staff rejected attempts to communicate was by attributing what they did to their autism. In this way autism, as with challenging behaviour, was used to define individuals. By attributing their actions to their autism they were denied their individuality. Many staff tried to ignore the fact that each individual had his own individual personal history, whereas each man was born as an individual and everything that

had happened to them since, every individual experience throughout their lives had made each one who they are now. Their individual experiences have led to their preferences and dislikes, to what gladdens, frightens, excites and saddens each one. Their autism may serve almost as a filter through which the world is experienced, but it is not *them*.

An example of this is one man's passion for music:

In the day centre Ralph made straight for the electronic keyboard, which he 'played' endlessly, and with great passion. When I said to a member of staff that Ralph liked music, she said 'Oh, he's just autistic'. To dismiss Ralph's desire to make music simply as 'autistic' was to deny him his individuality. It was also a way of avoiding seeing Ralph as a man who has potential, and has individual preferences and skills which could be developed. Five years earlier, a music therapist had written in Ralph's notes that his piano playing expressed 'internal anxiety and chaos'... and that: '[Ralph] has much more potential for understanding and learning than he seems to show' and that 'he really responds to praise and encouragement'. This therapist was obviously aware of Ralph's desire to communicate, but her words are obviously long forgotten (JH field-notes).

Another example of 'wasted' communication regards Joe. I had visited his father, and during the interview his father had broken down as he spoke of the family problems that had necessitated Joe going into a long-stay children's hospital:

This is a picturesque way of putting it but I say that if God strikes you in this way there has to be human sacrifice... sometimes it's the father, sometimes it's the mother, sometimes it's the sibling, but sometimes it's the child itself, and we took the last option [he begins to cry]. We made the last choice. In a sense we sacrificed Joe (JH parent interview).

The next time I went into the ward I told Joe about the visit, and told him that his father loved him. He took a loose lock of my hair and pressed it against first one of his eyelids and then the other; he did this a few times and smiled. I wondered whether talking about his father had conjured up some memory of childhood, perhaps of hair touching his face as he was kissed good night, who knows. I told a member of staff what he had done and she said 'oh yes, Joe likes to tidy your hair, he is very obsessional'. But this was not what he seemed to be doing, although of course I was not sure what his response meant or was trying to communicate. This incident, like many other things that happened on the ward, tended to be dismissed simply as 'autism' or as 'compulsive behaviour', and so on. There were so many occasions when a communication was ignored, because it fell somewhere outside the shared perceptions of the men, i.e. on deaf ears.

In the case of one member of staff, his hostility to the men was palpable. Far from responding to communication he would deliberately misinterpret the efforts of the men:

When the jelly was put in front of Larry so that he could help himself, he made a movement which Staff S immediately interpreted, or deliberately misinterpreted, as

meaning that Larry did not want any jelly, and took his bowl away, saying 'well if you don't want any, don't have it'. A bit later Larry held up his water mug; I interpreted this as meaning he wanted some water, but again Staff S snatched the mug away saying 'oh well if you don't want any water' (JH fieldnotes).

Few staff behaved in this deliberately cruel way towards the men and women, but there is no doubt that attempts to communicate were often ignored. By treating them in this way, as non-social and non-communicating beings, it made it possible - for those members of staff who wanted it that way - to perceive the men as quite unlike themselves, i.e., as the unknowable 'other'. This was very clear in the way that staff perceived and treated Jed (see Chapter 4), who was labelled as a sexual abuser, and much disliked. The staff who worked with him seemed unable to perceive him as someone who was crying out for reassurance and comfort.

Perhaps this was the only way the staff could survive in this bleak environment. When I first entered the ward I wrote in my notes:

I am struck by the sadness and anxiety that I see on so many faces there. It is no place for anyone to live. I must not get accustomed to it. I must continue to see the unhappiness, and the barren environment in which these people have to live (JH fieldnotes).

After months of 'living' in the ward I also became inured, at one level, to the suffering. I began to understand why the members of staff, many of them young and inexperienced, had to close their hearts, if not their minds, to what was happening to the people around them. It was clear that at least some of the staff who worked on the ward were affected by it. One member of staff, now working in a different ward, said of the men's ward:

People sitting in their offices don't know what it's like, the stresses, and that. When you go home you can't think properly. When you're working there you can't think - you've got to stop it getting into your head.

Another member of staff (who I only saw on the ward once) said that to see people like this, to see them suffering and not be able to do anything for them: 'hurts my heart'. For others, in order to be able to stay on the ward day after day, it was perhaps necessary not to let it 'get into' their heads and hearts.

The effects of total institutions

Chapters 4 and 5 describe locked wards in one category of institution, i.e. a long-stay hospital for people with intellectual disabilities, but it is relevant here to widen the discussion to other types of institution, and discuss the nature of 'total' institutions of other kinds, and the reported effects that these can have on the people who are incarcerated in them. To what extent are the experiences similar in any closed institution? Is the 'mad' behaviour of the men in the ward the result of, or part of, their intellectual disability, or are they behaving in ways that other people might behave in the same circumstances?

Goffman (1966) wrote about the nature of the total institution, and about the enormous gulf between life inside and outside:

A basic social arrangement in modern society is that the individual tends to sleep, play and work in different places, with different co-participants, under different authorities, and without an overall rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life (Goffman 1966: 17).

People who live in a total institution do everything in the same place, under a single authority, in the company of a group of people who are all treated alike, and do things together. There are rigid schedules, with one pre-arranged activity leading to the next at an allotted time, and everything is dictated by one authority, and under one 'rational plan' (Goffman 1966).

As a result of these differences between home life and institutional life, when people enter an institution, not only does their life change fundamentally, but so too do the attitudes and perspectives of other people towards them. They are at once perceived as 'different' and 'other'.

Sibley (1995), in his discussion of difference in a range of contexts, writes:

The social self [can] be seen as a place-related self, and this applies also to stereotypes of the other which assume negative or positive qualities according to whether the stereotyped individual or group is 'in place' or 'out of place' (Sibley 1995: 19).

Douglas writes about the effects of moving into an institution - people move into a marginal state and are, from that moment on, 'left out in the patterning of society' (Douglas 1966: 95). She writes:

So long as they stay at home their peculiar behaviour is accepted. Once they have been formally classified as abnormal, the very same behaviour is counted intolerable (Douglas 1966: 97-98).

Douglas cites a Canadian report on attitudes to mental illness that also suggests that there is a threshold of tolerance marked by entry to a mental hospital. When someone lives 'in society':

His eccentricities are comfortably tolerated by his neighbours. Behaviour which a psychologist would class as pathological is commonly dismissed as 'Just a quirk', or 'He'll get over it, or 'It takes all sorts to make a world'. But once a patient is admitted to a mental hospital, tolerance is withdrawn (Douglas 1966: 97).

This is not only true of mental institutions, but also of other types of institutions where people are held for quite different reasons. It is clear that the effects of life in any kind of total institution are profound. For example, Primo Levi (1987) writes about his experiences as a prisoner in a German prison camp during World War II, and the effects that entering an institution has on individuals:

Imagine now a man who is deprived of everyone he loves, at the same time of his house, his clothes, in short, of everything he possesses: he will be a hollow man, reduced to suffering and needs, forgetful of dignity and restraint, for he who loses all often easily loses himself (Levi 1987: 33).

Primo Levi again:

For living men, the units of time have a value... but for us, hours, days, months spilled out sluggishly from the future into the past... the future stood in front of us, grey and inarticulate, like an invisible barrier. For us, history had stopped (Levi 1987: 123).

This timelessness and isolation was also apparent in the locked ward, even to a researcher, who was free to leave at any time:

This early period, after they have got up and before it is time to get dressed and washed, is one of the times in the ward when there is no time. There is an unreality about it, and yet also an awful reality, a turmoil and yet a kind of peace. There is no other world, no other life outside. Just this (JH fieldnotes).

Fyodor Dostoevsky wrote about the effects of living in an institution in his book 'The House of the Dead' (Dostoevsky [1860] 1955), on the basis of his years as a political prisoner in the 1850s. He describes his reactions to living day and night in a closed environment with other prisoners: 'Besides the loss of freedom, besides the forced labour, there is another torture in prison life, almost more terrible than any other - that is, *compulsory life in common*' (Dostoevsky [1860] 1955: 20).

In a letter to his brother he also wrote:

To be alone is a necessity of normal existence... otherwise, in this forced communal life, you become a hater of mankind. The society of people acts like a poison or an infection, and from this insufferable torment I have suffered more than anything' (Quoted in Carr 1931: 60).

Dostoevsky also observed the powerful effects of the institution on the others around him:

All the convicts lived in prison not as though they were at home there, but as though they were... at some temporary halt. Even men sentenced for their whole life were restless or miserable... This everlasting uneasiness... sometimes found involuntary utterance, at times so wild as to be almost like delirium, and what was most striking of all, often persisted in men of apparently the greatest common sense (Dostoevsky [1860] 1955: 232-233).

And later:

When he has lost all hope, all object in life, man often becomes a monster in his misery (Dostoevsky [1860] 1955: 234).

These examples of the effects of segregation in closed institutions on people who do not have intellectual disabilities are significant. It is not surprising, perhaps, that young children

with intellectual disabilities who were locked away at a very early age became restless and miserable, even, perhaps, 'haters of mankind', and began to give voice to wild, involuntary utterances. It is clear that the transformation of the men, most of whom were institutionalised before the age of eight, into what Chapter 4 describes as 'the popular stereotype of 'mad' people in institutions' may be as much the result of 30 or 40 years incarceration in the institution, as it is of their individual disabilities and characteristics.

It is hard to believe that wards like the ones in Chapters 4 and 5 actually survived until the late 1990s, in spite of generations of professionals, managers and care staff coming and going over the years. Certainly, things were better than they had been when Joan Bicknell (who set up the Department of Mental Handicap at St George's) first went into the wards in 1980. But it cannot be denied that the neglect of the conspicuous physical, emotional and psychological suffering of the men and women had, over many years, become an integral part of the ethos of the wards, and to the succession of changing staff over the years this was simply part and parcel of life on the wards. When the men's ward was about to close, and the men were moving to various different health and social service organizations, the future managers and staff began to spend time in the ward. There was an outcry about the conditions they found there, and a confidential report was written detailing the low standards of care in the ward, followed by the suspension of a number of care staff.

The managers in the NHS Trust responsible for the ward claimed to have had no idea what was happening. Is that really possible?

Primo Levi, in his 'Afterword' to 'If this is a man' and 'The Truce' (Levi 1987), tries to answer the question: Did the German people know what was happening in the concentration camps? His answer is that they must have known of their existence, but perhaps not the 'most atrocious details'. He suggests that the reason that most people did not know was:

... because they didn't want to know. Because, indeed, they wanted not to know... [the ordinary citizen] built for himself the illusion of not knowing, hence not being an accomplice to the things taking place in front of his very door' (Levi 1987: 384).

3 Are there gender-related differences in the way men and women are perceived and treated in the single-sex wards of the institution? (Chapters 4 and 5)

The separate projects carried out in the two single sex locked wards (in the same hospital) yielded significant material on the disparity between the treatment of men and women, and the perception of them by the staff who worked with them.

'Gender' refers to the culturally and socially determined characteristics of women and men. There are expectations of different roles, ways of behaving, rights and responsibilities for men and women in the society they live in. As Swann (2002) writes, gender is 'experienced and understood through a complex system of sociocultural concepts, representations and constructions.... bodies are gendered - fixed within the confines of beliefs and representations about men and women in our culture' (Swann 2002: 197).

In the society in which we live, there are fundamental inequalities between women and men, with men tending to have greater access to power, influence and status. In these locked wards, however, neither the men nor the women could be said to have power,

influence or status, and it is the women who were given marginally more respect, and whose lives, on a very superficial level, echo women's lives in the outside world.

In order to understand the experiences of the men and the women, and people's perceptions of them, it is necessary to first look at what was common to them both, i.e. segregation in locked wards in a large old 'mental handicap' hospital. It is important to tease out what pertains to the women, as women, and to the men, as men, in the context of a total institution, and to see what is simply integral to the institution itself, and to the process of institutionalisation. If they are treated differently is it *because* they are men, or women, or is it partly because they have different pasts and abilities? To what extent have any different attitudes and ways of behaving towards them shaped and/or reflected the lived realities of the men and women? Have the perceptions of them created, or are they the result of, the surroundings in which they live, and the degree of stigma that attaches to them?

Living in a physically and emotionally deprived environment they are, as adults, and as women and men, perceived to be beyond the pale, and their needs are met even less adequately than other people with intellectual disabilities. In these settings their individual preferences and needs tend to be largely ignored, and since many of them have little or no speech they can only be understood by people who know them well, and make the effort to 'listen'. They are also neglected because the people who care for them perceive them as being innately different from themselves, having only minimal 'ordinary' human attributes and desires and, significantly, without any meaningful 'gendered' feelings and needs.

They are not seen as women or men with a past, present and future; they are not remembered as children, as adolescent boys and girls, growing into manhood or womanhood.

The women

Staff working with the women in the locked ward found it easier to treat the women as children, enabling them to withhold power and autonomy from them, but the denial of their true identity as women went beyond this. The existence of their adult sexuality was acknowledged, but was mocked and stifled, rather than nurtured. They were denied any meaningful expression of their identity and role as women. In spite of this, the women felt themselves to be women, and expressed themselves as such. They saw themselves as adult, sexual women, and clearly showed their need to be acknowledged as women. However, other people did not see them in this way. Although on a superficial level they were seen as women, and were given clothes to wear that reflected this, they were not considered to have a right to womanhood, with all that that encompasses.

To the extent that the staff did acknowledge the women as sexual beings, this aspect of them was seen as problematic and something to be controlled or eliminated. Some of the women were said to display 'sexualised behaviour', but their actions were not seen as natural behaviour of women living in these deprived circumstances, but as 'attention seeking', and so would be punished. Furthermore, expressions of sexual longings were often made into a joke, because it was easier for staff to believe that the women's desires and longings were different from the ones that are common to us all. It was probably made harder for staff because if they had acknowledged the depth of the women's sexual desires, and the similarity of these to their own, they would have had to confront the cruel

fact that the women lived in a segregated and deprived environment in which there was no hope of fulfilment of their dreams.

In spite of these attitudes towards them, the women were treated with more respect than the men, at least at on the surface. Two psychotherapists, on visiting the women, wrote:

We were impressed by the physical care provided to the women and the environment. Given the extreme levels of institutionalisation we observed it was important to note how dedicated nurses had made an impact in recent years in providing a sense of physical self-esteem. There was also a strong sense of individual clothes style and individual style in the separate sleeping areas.

The sitting room approximated to a 'normal' sitting room. In material terms, the contrast with the men's ward was astounding. It was relatively small and homely, it was carpeted and curtained, there were lamps and ornaments. The very 'normality' of the environment, and smaller size of the rooms, meant that the women had to, in a sense, 'fit' within it. They wore what appeared to be their own clothes, and feminine shoes; some even carried handbags. Overall there seemed to be a very different atmosphere. Compared with the harshness of the men's ward this was more like home. Entering the ward for the first time one could be lulled into believing that the women's lives were also fundamentally different - it was full of women, and appeared to reflect the softness and caring of women. However, this apparent ordinariness was only skin deep. As shown in Chapter 5, the lives of the women were emotionally deprived, and were regimented and institutionalised, just as the lives of the men were.

The men

Physically there is no doubt that the women's ward was quite different from the huge bare rooms - more like community halls than a home - that the men lived in. There was no attempt to make the men's rooms homely. There were no carpets or curtains or anything that could be thrown or destroyed. The men themselves were dressed in a variety of unmatched clothes, often too big or too small for them. One man wore no clothes at all, others wore bits of clothing, which they often pulled down and then stood, bare-bottomed, unnoticed and uncorrected.

As described in Chapter 4, the men were represented as physically and sexually dangerous. They were not treated as wayward children, as the women were, but as dangerous adults. Many were considered to be active sexual predators, and the common description of the men was that they were 'motivated by sex', and were sexually uncontrolled. The men's medical notes reflected these labels.

An example of the effects of this label on staff attitudes and perceptions is the experience of Kevin, who was said to be a sexual abuser. This was constantly reinforced by staff, and the label shaped his life in many fundamental ways. At a case meeting, one of the health professionals said that he was 'totally motivated by sex', and the others round the table agreed. This perception of Kevin seriously affected how care staff responded to him, and restricted his autonomy within the ward. He was not allowed to approach other residents, and however unthreatening his approach may have been, members of staff would shout at him to move away. This was also the response to a number of other men in the

ward. This response was very isolating for the men labelled in this way. Not only did it deprive the individual of contact with anyone else, but it is possible that it also made them feel, at some level, and whether fully comprehended or not, that they were in some way unclean. Furthermore, in Kevin's case, it seemed to be counterproductive for a man who was said to be autistic to be prevented from initiating contact or communication with anyone else.

The men's gender and sexuality were constantly mocked. Attempts to put clothes on the man who was naked had long been abandoned, which meant that he continued to be excluded, as others were, from the social category of an adult man (see Chapter 4). Perceptions of the men were contradictory in that at one level their sexuality and gender were denied, but at the same time, as alleged sexual predators, their sexuality was acknowledged and feared.

Perceptions of the women were also contradictory, but in a different way. Johnson (1998), with regard to a group of women living in a locked unit of a large institution in Australia, reveals a similar situation:

The women's sexuality was thus constructed by others in terms of either the threat of pregnancy or exploitation. It was not perceived as an expression of individual desire and an internal fantasy life (Johnson 1998: 65).

The denial of normal sexual feelings and desires was true in relation to both the men and the women, but how it was achieved in each case was different. The women tended to be treated as wayward children, not as adult sexual women. The men, on the other hand, were considered to be dangerous adults, sexually uncontrolled, and in some cases labelled as active sexual predators. In both cases the refusal to accept that they had normal sexual feelings and desires was yet another means by which the people caring for them could reinforce the perception of difference between the men and women they cared for, and themselves.

4 When institutions close, do those who move out now live different lives, approximating to the 'normal' lives led by the majority population? Are they still physically and socially excluded? Do they regain their lost identities? Are they still subject to stigma and prejudice? (Chapters 5 and 6)

It had been hoped, even assumed, that the men and women who had lived in institutions in Britain and who were now moving out into some other kind of residential care in the 'community', would have the opportunity to live quite different lives. It was anticipated that they would have a greatly improved quality of life in their new homes, approximating more closely to the lives of the wider population (Ericsson and Mansell 1996). Chapters 5 and 6 reveal that although the men and women live in improved environments, and in smaller groups, many fundamental aspects of their lives have changed little, or not at all.

There have been many studies comparing life in the community and institutional life. Many of these have been summarised in two major reviews (Emerson and Hatton 1994; Kozma *et al.* 2009). The research has shown that on most counts community based services are better than institutions. However, it is significant in the context of the people described

in this thesis that in the areas of challenging behaviour and psychotropic medication there were 'mixed or worse results' (IASSID Special Interest Group on Comparative Policy and Practice 2009: 4). Kozma *et al.* (2009) note that in 13 studies which compared individual challenging behaviour while in the institution with behaviour after the move into community provision, most studies reported no significant changes in challenging behaviour. On the contrary, some found that there was deterioration in some behaviours (Kozma *et al.* 2009). Overall, this research review found that:

Positive outcomes are generally associated with better adaptive skills and abilities, and people with high or complex support needs, including challenging behaviors, are at greater risk of experiencing poorer outcomes in community services. The provision of ordinary environments is not enough to achieve quality and positive outcomes in community services (Kozma et al 2009: 213).

This supports Mansell's claims (2006) that people with higher support needs 'whether because of the nature of their intellectual and physical disabilities, their challenging behaviour or social impairment' tend to have worse outcomes than those with fewer support needs (Mansell 2006: 4-5).

Thus it can be seen that the experiences of people who are the subject of this thesis, those with severe and profound intellectual disabilities and challenging behaviour, are at the greatest disadvantage on all counts in the formation of their new lives in the community.

In the context of the two studies described in Chapters 4, 5 and 6 the outcomes are mixed, but to a great extent it is only the environments that have changed to any great extent. In Chapter 6 it was seen that:

The men's lives were better in material terms in their new homes, but there seemed to be limited possibilities of making other significant changes in their lives. To a great extent they still lived within the old paradigm of social exclusion and denial of individual identity and autonomy. There appeared to be few fundamental changes in professional and social attitudes, and as a result men such as these continue to live socially excluded and forgotten lives.

Similarly, in Chapter 5, with regard to the women:

Material surroundings may be improved, but institutional practices, stigma, social exclusion and lack of autonomy continue.

The findings in the two studies show that all the men, and almost all the women, still lived predominantly institutionalised lives, and continued to be physically and socially excluded from the social world around them. Their new homes were pleasanter and they had more choices from day to day than they had had before, but they were still excluded from decision-making at a more fundamental level. They had not chosen where they would live, nor with whom they would live. In the women's house, particularly, there was obvious hostility and dislike between some of the women, who nevertheless faced living the rest of their lives together in the same house.

It is perhaps unsurprising that these men and women, who have severe intellectual disabilities and challenging behaviour, have greater difficulties integrating in, and being accepted by local communities than people who can talk and who blend in more easily with other people. However, there is more to it than that. Being institutionalised not only changes the individuals themselves, as seen earlier, but also changes other people's perception of them. Even the staff who worked with them in the institution continued to treat them in the same way when they moved out - partly because they themselves had become 'institutionalised' as well. As stressed in Chapter 5:

There is a vital need for the development of training programmes for staff, and also for them to receive the supervision and support necessary to deliver care in accordance with the principles of the 'Valuing People' strategy.

The tenacity of negative attitudes to people in the community who have been moved out of an institution is also true of other kinds of institution.

Douglas (1966), with regard to prisoners and patients in 'mental' hospitals, writes: 'A man who has spent any time 'inside' is put permanently 'outside' the ordinary social system. With no rite of aggregation which can definitively assign him to a new position he remains in the margins' (Douglas 1966: 97).

In the research described in Chapter 7, with families who have a son or daughter with severe or profound intellectual disabilities and challenging behaviour living at home, their perceptions of people who had moved out of the old institutions was still very negative.

The men who lived in the locked ward (Chapter 4) were perceived, as seen earlier, as unclean, polluted and as barely human. Is it possible for marginalised groups who are perceived in this way to be reabsorbed into the community?

Among the most visible groups of marginalised people have been people with leprosy, and the term 'leper' has become a metaphor for any person whose behaviour or moral status leads to his or her social exclusion. One definition of 'leper' in the Concise Oxford Dictionary is, in fact, 'a person who is shunned for moral or social reasons'. The perception of people with leprosy as unclean goes back a long way. In the Old Testament someone with leprosy was physically excluded and was expected to make a guilt offering (Leviticus 14: 18, 21) and a sin offering (Leviticus: 14: 22, 30-31), although the 'sin' to be expiated was not identified (Douglas 1999: 182). It is significant that, in the New Testament, Jesus is said to have 'healed' the deaf and the blind, but to have 'cleansed' the lepers (e.g. Matthew 8; Mark 1; Luke 5 and 14).

Leprosy, which is perhaps the epitome of conditions that carry with them the negative connotations of uncleanness and pollution, is a prime example of the resistance to more positive perceptions, even when the supposed negative aspects are removed. Hyland (2000) wrote that, after a public health education programme in Nepal, which informed the population that leprosy was a medical condition which could now be cured, it had been hoped that beliefs that resulted in social exclusion and expulsion from the village would be reduced - but this did not happen. Hyland's research showed that even after someone was cured of leprosy, they continued to be perceived as ritually polluted and were still socially ostracized. She questioned whether there could ever be a return to social health, or social integration, after someone had been cured. Even those people who did understand that

leprosy could be medically cured still believed that if people knew that they had leprosy they would be socially isolated, i.e. that the disease was still both ritually polluting and socially ostracizing. Hyland asks: 'What would the mechanism be, if any, that would bring people with leprosy back from social death?' (Hyland 2000: 178).

Similarly, it is clear from the study of the men in the locked ward, in the material from interviews with parents, that for some parents it is as though their child also died a social death when they entered the children's hospital many years ago. This contributes to the resistance of some families to the closure of the ward, and the opportunity for a new life for their son or daughter in the community.

Once a child, or adult, has been committed to a long-term institution, to this marginal, socially and physically excluded existence, how can they years later be brought back into society without indicting the family, the wider kinship and social group, and society as a whole? Such a move must carry with it the uncomfortable, and perhaps for some the unbearable implication that this person was not, and thus had really never been beyond the social pale, was not too morally, emotionally or physically dangerous to be incorporated into the social group... Parents, even some thirty or forty years after their child went to live in an institution, still have strong and unresolved emotions... Their young children, when they entered the institution, died a social death. For the parents who remain, this may sometimes be harder than a real death. There is an incompleteness: there has been no burial, no closure to the mourning of the parents who let them go. Even those who never visit their children mourn them still. One mother said that she thinks about her son every day, and has done so for thirty years... Her son is lost to her, but there is no relief from her bereavement. She has never told her neighbours or friends that she has a son. It is as though he is dead, a child to remember and mourn - but not to lay to rest. She, and many other parents, now oppose the closure of the institution; they would prefer that their adult children remain segregated, because the alternative, to bring them back into the social world, is too painful to contemplate. No one really wants to resurrect their dead (Hubert 2000: 377-378).

Similarly, when the 'Colony of the Mentally Ill', on the Greek island of Leros, was to be closed down, following an international scandal about the appalling conditions of the colony, the closure was initially opposed by doctors, staff and families of residents (Tsiantis *et al.* 1995). The reasons why the families did not want them back, or even living in or near their communities, were said to include powerful concepts of stigma and 'bad blood'. It is also relevant to this discussion that, in spite of improvements in the quality of life of the Leros residents who moved to residential homes, the attitudes of staff who had worked with them before were said not to have substantially changed (Kourdoutis *et al.* 1995).

Concepts of stigma and pollution are not easily thrown off by people who have lived in institutions, wherever they go next. In the French town of Ainay-le-Chateau, the local mental institution was transformed in the 1970s into a 'Family Colony'. This remained administratively and medically responsible for the patients, but they actually lived outside the Colony, with some 500 families in the area. Research carried out with these families some 20 years later (Jodelet 1991) revealed that, even after living so many years in the household, the majority of lodgers were kept separate from the family, and used separate en-

trances. Some were only communicated with through a 'spy-hole'. In only 12% of families did the lodger eat with them as a regular arrangement. They were also given separate cutlery to use, and their washing-up was done in a separate bowl:

'I wash their things when my own are finished and I add some disinfectant as well'
(woman quoted in Jodelet 1991: 246).

Clothes were generally washed separately as well. There was a strong belief among the families that the lodgers from the Colony could pollute the water. Some were not allowed to touch anything in the house except in their own rooms. Thus, in spite of twenty odd years of living under the same roof, the families continued to believe that they could be polluted by their lodgers, people who had formerly been patients in the local mental institution (Jodelet 1991).

In the 1980s, blood taken from residents in Normansfield for pathology tests was carried in plastic bags marked 'dirty blood' and kept separately in the lab (Sheila Hollins *pers com.*).

It can be hard to separate out concepts of pollution from a natural reluctance to be covered in, and carry the smell of other people's bodily waste. The locked men's ward described in Chapter 4 was dominated by the smell of urine, faeces, disinfectant and drug-laden breath. It was inevitable that contact with the men, and with their physical environment, would result in one's own hands, at least, smelling of bodily excretions. But the sense of pollution and uncleanness that seemed to be held by people who worked within the ward, and by those outside it, was not limited to these tangible, physical things. The men were defined, as Young wrote (above), in terms of these bodily characteristics 'as ugly, dirty, defiled, impure, contaminated or sick' (Young 1990: 123).

However unprejudiced one believes oneself to be, it is hard, deep down, to be sure that one is totally free from these concepts of pollution and contamination:

When I come out of the ward I usually wash my hands. I do it to get rid of the smell of faeces. I am entitled to do that because many of the men spread faeces with their hands, or manually evacuate their bowels. But sometimes I wonder whether that is the only reason I do it. And why have I never complained about the ward practice of different mugs for staff and for residents? Can I be sure, in spite of what I want to believe I feel, that I am not still afraid, somewhere deep inside, of contamination? Or am I simply ritually cleansing myself of the institution, before I enter the outside world? (JH field-notes).

5 How different are the experiences of people with severe intellectual disabilities and mental health problems who were not institutionalised, but have lived all their lives at home with their families? Are they perceived differently from people who live in institutions? (Chapters 7 and 8)

The nature of the experiences of men and women who have lived their lives in institutions are very different from those of people who seemingly started out with similar disabilities, but who have lived with their families all their lives.

As seen in Chapter 7, although those who live at home may not always be fully integrated into the community in which they live, they are perceived as social beings, with individual, social and familial identities. They have reciprocal relationships, at least within the family, with people who love them, and who do everything they can to understand their various ways of communicating, not only in order to be able to fulfil their needs but also to respond to their wishes, preferences, dislikes and fears. The people who live with their families have pasts and presents and futures; they live in the memory of those around them, are an interactive part of the present, and are included in the futures of their immediate families.

All the mothers (and many of the fathers) who had their adult children still living with them accepted them fully, and perceived them quite differently from the way they perceived people who lived in long-term institutions, even though to others they may appear to be similar in their abilities and ways of behaving (Hubert 2000). In an important sense the families accepted as 'normal' the way their own children looked and behaved, but tended to consider the same kinds of appearance and behaviour of institutionalized people as bizarre and dangerous (and see Hubert 1991: 26).

There are many differences between the experiences of those who live in institutions and those who live at home. As shown in Chapter 7, the people who live at home:

- Are not physically and socially segregated
- They do not live in physically deprived environments
- They are not emotionally deprived
- They are socially visible
- They are not dehumanised
- There are likely to be less opportunities for sexual and physical abuse because of the constant presence of their mothers
- Their little (or no) speech and non-verbal communication is interpreted and understood as far as possible
- As children they are allowed and encouraged to develop into adolescents and adult men and women
- Their challenging behaviour is generally interpreted in terms of their individual likes and dislikes, or discomfort
- They do not 'die a social death'
- They have individual, family, gender and social identities
- They are loved by their mothers, and usually by other members of the family as well
- They are perceived and treated as sons and daughters, siblings, and usually (see below) as grandchildren, cousins and aunts or uncles, i.e. they 'belong' in their families
- They have a remembered individual past and are part of the familial memory
- They are mourned when they die and will be remembered in the future.

One experience those at home did share with the people who live in the institution was that they were on a similar range and dosage of psychotropic drugs, prescribed by the psychiatrists in the community teams (Hubert 1992). As in the institution, psychotropic medication was the accepted response to challenging behaviour. The young men and women at home certainly exhibited challenging behaviour, but there were differences in

the way they behaved as compared with the institutionalised men and women. They were, to some extent, socialised by their parents, who constantly 'controlled' their behaviour so that it could be tolerated in the family home, both by others in the family, and be acceptable within the domestic environment. It could be said that these young people who lived at home with their parents were not allowed to develop the kinds of behaviour that characterised many of the men (and, less so, the women) in the locked wards.

Looking at the dissimilarities listed above it can be seen that the experiences of children growing up at home are quite unlike those who were institutionalised as children. They are also perceived very differently.

Because of the strength of the relationship between mothers and their adult children living at home, it was possible for a mother of an adult son with profound intellectual disabilities to say, as reported in Chapter 7:

I never really think of Tony as being a handicapped person until someone asks me to speak about it. He's just Tony, I don't know how else to put it (From parent interviews).

Whereas, with regard to similarly disabled people living in the local institution, she said: 'They're awful, they are so different, my son isn't like them' (From parent interviews).

The views that parents have of institutions, and of the people who live in them, make many of them adamant that their sons and daughters will not go into any sort of residential care, and attempts by professionals to plan for the future are often met with hostility. Three quarters of the mothers described in Chapter 7 would prefer their adult child to die before they did themselves, to ensure that they never had to go into a long-term institution. Their lives have been devoted to their disabled child, and in a very important sense they perceive them simply as ordinary people with extraordinary needs. This is very far from their attitudes and preconceptions about people who live in institutions.

The mothers quoted in Chapter 7 and 8 reveal the nature and strength of their relationships with their adult sons and daughters who have severe and profound intellectual disabilities. The mother who said of her son: 'he doesn't look like a monster from outer space... he's beautiful' was fully aware of other people's perceptions of her son, but at the same time she demonstrates the strength of her relationship with him, which makes it possible for her to perceive him as 'beautiful'.

Although it is parents who have the most positive perceptions of their children, other people's attitudes to people with severe intellectual disabilities who live at home are tempered by the fact that they have not been physically excluded. The families themselves may often feel socially isolated, and sometimes even cut off from their wider family, but to some extent, at least, their adult children are seen by others as sons or daughters, siblings, grandchildren, and so on, and thus have retained some degree of social identity. It may not always be easy, however, for parents to ensure that their adult children are always recognised by other people as individuals in their own right.

The communication that exists between parent and adult child demonstrates a crucial difference from those who live in an institution. Parents struggle to understand what their adult children are trying to say, and know them so well that they are able to respond to the small individual signs of distress or pleasure. They also see them as adolescents and young adults, who have the same feelings and emotions as other young people. Unlike the atti-

tudes to the men in the locked ward, parents are also aware that their young adult children can in fact be both adult and child, allowing them to hold their childish toys, but at the same time ensuring that, for example, a young man will always be shaved, and dressed as an adult, and is never left in wet or soiled clothes.

Another difference is the parents' attitude to their challenging behaviour. This has been illustrated by the story of Eddie in Chapter 7. However violent their behaviour may be, the parents continue to love them, and want them to live at home with them. This is where they belong. This is illustrated by another mother:

All of a sudden she flew at me - I'd done nothing. You're standing there in your nightie... and she's thumping at you, and you're putting up your hands to protect your head, and across your chest, everywhere, and she gets through it - so I ran out and locked the door on her, and she ended up by wrenching the door knob off, pulling the screws right out, and she screamed... I thought I was going to have a heart attack, I was taking great gulps of air and shaking, I was in the most dreadful state. She becomes so unbelievably vicious and absolutely unrecognisable (From parent interviews).

Yet in spite of this, when her daughter goes in to respite care for the weekend:

We get a break but we don't actually enjoy it all that much. We just feel awful when she goes away, we can't seem to adjust to it. When she is away the place is empty, because she is our life, she is our family (From parent interviews).

Her mother hopes that the decision will never actually have to be made to put her daughter into long-term residential care:

In an ideal situation I would live to a sprightly old age, and then when Lisa went I would pop my clogs almost immediately afterwards, because I would hate the thought of losing Lisa... I often hope, you know, that she dies before I do, whilst I'm still able to look after her (From parent interviews).

Her husband says the same thing (though it is unclear whether they know this of each other):

I would say most definitely that I would hope to outlive her. And it'll be a tragedy if she goes, because she's been part of the fabric, part of the thinking and everything since she's been born (From parent interviews).

These attitudes can be found among the majority of mothers in the research described in Chapter 7, and some of the fathers. What shines through these quotations is the love and acceptance they have for their children, however difficult and even violent they may be. They also illustrate the remarkable resilience that the mothers, particularly, demonstrate in their constant struggle to care for their disabled son or daughter, manage the rest of the family, and battle with the services to get the help they need (Grant *et al.* 2007).

The Black and ethnic minority carers in Chapter 8 are in most cases more socially isolated from the community, and have less satisfactory access to health and social services, than those carers described in Chapter 7, but they have the same close bond with their disabled adult children, and are also afraid of what would happen to their adult child if he or she had

to go into residential care. With ageing carers there was sometimes, in the case of a son or daughter with less severe intellectual disabilities, the comfort and help they were able to give their elderly parent. But those whose adult children had severe or profound intellectual disabilities were also determined, in many cases, not to let their son or daughter go, because of their communication difficulties and their extreme vulnerability. In this group of carers there were a number who were elderly and suffering from a severe illness. One mother would not tell anyone how ill she was, and even lied to her other adult children about the severity of her illness, in case her son, whom she had cared for over the last 40 years, should be taken away from her and put into long-term residential care. Another mother, whose son has multiple disabilities, said:

Who is going to take him, if something happens to me... Who is going to look after my son? I am praying every single day, I say, take him before I go... I am really hoping... because he can't say anything. He'll just get hurt. I don't want him to go into residential care.

And another, who is in very poor health:

In my prayer I say, let her go before me... Definitely, definitely, definitely – then I would have done my last bit for her, instead of me having to leave her. I would have been at peace.

These attitudes contrast with the attitudes to the men and women in the locked wards, who mostly have no one who really cares about them at all, let alone someone who gives them the love and understanding that the young people at home receive.

6 How are adolescent boys with intellectual disabilities who have been labelled as 'sexual abusers' perceived? Does the label affect how they are perceived and treated by the professionals who work with them (as it does in the locked ward)? How does it affect the way their futures are projected? (Chapter 9)

Chapter 9 documents a different group of people with intellectual disabilities, adolescent boys who were sexually abused as children, and who are now abusing others. As Hollins and Sinason (2000) have written, this is a cycle of abuse that is now recognised:

We know that sexual abuse of children and adults with learning disabilities is more common than it is in the rest of the population... , and that some of the 'victims' later become perpetrators of abuse. If spoken language skills are limited, it may be difficult to communicate the emotional feelings of emerging sexuality or those associated with sexual experience or sexual abuse (Hollins and Sinason 2000).

The boys in this research project lived at home, at least most of the time, and at the time of the research project they were receiving group psychotherapy together. The original aim of the research was to find out the outcomes of psychotherapy for these abused and abusing adolescents, but material was also gathered from interviews with the boys, their parents, school and residential care workers, and the therapists themselves, revealing a range of attitudes and perspectives that augured badly for the futures of the boys.

It was clear from the mothers' accounts that the majority of the original episodes of abuse were not investigated or taken seriously. This has also been described by others, (e.g. Peckham 2007; Brown 2007). As Brown wrote:

Research has demonstrated that people with learning disabilities are at risk of abuse and exploitation both within services and in their families and communities and that when people with learning disabilities are victims of crime they are often not taken seriously and nor are the offences which have been committed against them (Brown 2007: 3).

Because professionals had tended not to believe the mothers, they had had to deal with both the short-term and long-term emotional and behavioural effects of the abuse on their sons alone (none of the fathers of the boys were still resident with them). Chapter 9 presents the mothers' perspectives on their sons, and on the support, or lack of it, that they have received over the years and currently, i.e., since their sons had been labelled as sexual abusers.

When their sons became abusers themselves, the mothers were told that the earlier abuse was the 'cause' of their current behaviour. At this point, when 'normal' life had probably become unachievable for both sons and mothers, there was belated acknowledgement of the past abuse, and its consequences in the present.

Thus at the ages of 14 to 16, the boys were labelled as sexual abusers. They were not thought of, or treated as victims, by anyone other than their families. In this regard their experience was similar to the men in the locked ward, who were labelled as abusers, while their own experiences as victims were forgotten or ignored (Chapter 4). The mothers of these boys realised that the label would never leave them, as one mother said:

That stigma is going to follow him... I mean, he may pose a threat, a risk, but does it have to be labelled in black and white the way it is, to give him that stigma?

The service professionals involved with the adolescent boys saw residential placement away from home as inevitable. The mothers, on the other hand, were asking for help and support so that their sons could continue to stay with them. They saw their sons as young people who were struggling to become adult in an impossible situation, and who were held back in life by their intellectual disabilities and communication difficulties. They had seen what had happened to them as young children, and were aware of the traumatic effects that early abuse had had on them. As a result they were predominantly protective and sympathetic towards their sons, as they coped with the wet beds, the screaming in the night, and sometimes with physical violence. Nevertheless, some admitted that it was quite difficult at times to feel positive towards a son who was said to be assaulting younger children: 'You never want to believe that your own children could be abusers'. Overall, however, the difference between how the mothers saw the boys and how the professionals perceived them reflects the situation described earlier in this thesis, where attitudes of parents who care for someone at home are seen to contrast with the attitudes of care workers and professionals towards the men and women they care for.

Although living at home, the boys were already socially excluded, living a life under constant surveillance. Their mothers tried not to allow them out of their sight, not only in

case they tried to abuse other children, but also because they were afraid that their sons might be led into an abusive situation which would then be blamed on them. The mothers were aware that their sons would be held to blame if they were involved in any sexual encounter that their sons were involved in, because they were labelled as sexual abusers. The 'blaming' that was evident in the locked ward was also apparent here. The mothers were painfully aware of the dangerous situations that their sons could get into, because of their intellectual disabilities and communication difficulties, and were afraid that they might become unwilling, or even acquiescent, victims in encounters with older and more dominant abusive men.

As with the men and women in the locked ward, the boys were highly vulnerable to abuse from others, and at the same time they carried with them the stigma that the label 'sexual abuser' brought upon them – a label that was seen as a justification, in the case of the men in the ward, for segregation in a locked environment. Although the young boys in this study were currently unconfined - though almost always under surveillance - it is hard not to come to the conclusion that, probably sooner rather than later, they would be placed in residential specialist units away from home, as foreseen, and apparently approved, by the professionals who currently worked with them.

Conclusion

The future for people with severe and profound intellectual disabilities and challenging behaviour.

In the UK, in 2009, it would be true to say that children who cannot be managed at home by their parents are not subjected to the level of institutionalisation that the men and women in this research were at a young age. However, many still live away from home. The government white paper 'Valuing People' stated that disabled children were still being placed in residential schools and residential homes, which resulted in their isolation from 'normal childhood support' (Department of Health 2001: 37). It also drew attention to the fact that children living in residential care are particularly vulnerable to abuse (Department of Health 2001: 37). The aim in 2001 was to identify how many disabled children were in residential homes, and to 'create better linkages between children living in residential placements and their family, and ensure they are properly supported and protected by key agencies' (Department of Health 2001). The Care Standards Act 2000 was said to have strengthened the safeguards for children living away from home.

However, in 2003, Lindsey wrote that:

The shift of service provision in the UK from health provision... to community care in the last 30 years has not led to all young people with intellectual disabilities living in the community. There has been a growth in residential homes and residential schools, not always with good access to healthcare (Lindsey 2003).

The more recent Department of Health document: 'Aiming high for disabled children: better support for families' (HM Treasury and DES 2007) stresses the need for early family interventions:

Early support for disabled children and their families is essential to prevent problems such as deteriorating health, family stress and breakdown, children potentially being placed in care, and deteriorating emotional and social development for disabled children and their siblings (HM Treasury and DES 2007: 35).

This must be taken seriously and implemented for those children today who have similar disabilities to the men and women described in this thesis. We must make certain that their experiences are in no way the same, and ensure that they and their families get the support and encouragement they need 'to retain their individual, social and gender identities, and to develop as socially included and emotionally healthy men and women' (Chapter 4).

In 'Valuing People' (Department of Health 2001) it is stated that:

The principles of rights, independence, choice and inclusion we put forward are challenging... Enabling people with learning disabilities to have their voices heard and have wider opportunities for a fulfilling life as part of the local community is central to our message (Department of Health 2001: 119).

It can be seen from this thesis that these challenges are very far from being met for men and women with severe and profound intellectual disabilities and challenging behaviour (and see Grant and Ramcharan 2009).

The United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006) came into force in 2008, and set a legal framework for the rights of people with intellectual disabilities to live in the community (IASSID Special Interest Group on Comparative Policy and Practice 2009). In Article 3 of the Convention, the 'General Principles' state that:

The principles of the present Convention shall be:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- b. Non-discrimination
- c. Full and effective participation and inclusion in society
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e. Equality of opportunity
- f. Accessibility
- g. Equality between men and women
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (United Nations 2006: 5)

If these principles were accepted as the basis for action and the development of services it would make a huge difference to the lives of people with intellectual disabilities.

This thesis has shown that for people with severe and profound intellectual disabilities who also have challenging behaviour and mental health problems, the real change that is necessary is in the attitudes that people have towards them, not only people in the wider community, but also the care staff, professionals and others who work with them.

As long as these men and women remain physically and socially excluded, those who work with them can continue to treat them as the 'other', even as barely human - and as long as they are perceived and treated in this way, they will continue to live physically and socially excluded lives. It is a vicious circle that must, finally, be broken.

References

- Brown, B. (2007) *Valuing People Learning Disabilities Strategy Document: abuse and protection issues*. Canterbury: Salomons Centre for Applied Social and Psychological Development.
- Care Standards Act 2000. London: The Stationery Office.
- Carr, E.H. (1931) *Dostoevsky: 1821 – 1881*. London: George Allen and Unwin.
- Commission for Healthcare Audit and Inspection & Commission for Social Care Inspection (2006) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*. London: Commission for Healthcare Audit and Inspection.
- Commission for Healthcare Audit and Inspection (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London: Commission for Healthcare Audit and Inspection.
- Cummins, R. A. (2005a) Issues in the systematic assessment of quality of life. In *Assessing Adults With Intellectual Disability: a service provider's guide*, Hogg, J. and Langa, A. (eds). Oxford: Blackwell Publishing Ltd. 9-22.
- Cummins, R. A. (2005b) Instruments assessing quality of life. In *Assessing Adults With Intellectual Disability: a service provider's guide*, Hogg, J. and Langa, A. (eds). Oxford: Blackwell Publishing Ltd. 119-137.
- Department of Health (2000) *No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: Department of Health.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the Twenty-first Century*. London: The Stationery Office.
- De Waele, I. and Van Hove, G. (2005) *Modern times: an ethnographic study on the quality of life of people with a high support need in a Flemish residential facility* *Disability & Society* 20 (6): 625-639.
- Dewalt, K. M. and Dewalt, B. R. (2002) *Participant Observation: A Guide for Fieldworkers*. Alta Mira, CA: Alta Mira Press.
- Dostoevsky, F. [1860] (1955) *The House of the Dead*. (Trans. Constance Garnett) London: William Heinemann Ltd.
- Douglas, M. (1966) *Purity and danger: an analysis of the concepts of pollution and taboo*. London: Ark Paperbacks.
- Douglas, M. (1999) *Leviticus as Literature*. Oxford: Oxford University Press.
- Economic and Social Research Council (2005) *Research Ethics Framework*. Swindon: ESRC.
- Emerson, E. (2003) *An Analysis of NHS Long-Stay Beds and Residential Places for Adults with Learning Disabilities*. London: Department of Health.
- Emerson, E. and Hatton, C. (1994) *Moving out: relocation from hospital to community*. London: HMSO.
- Ericsson, K. and Mansell, J. (1996) Introduction: towards deinstitutionalisation. In *Deinstitutionalisation and community living: intellectual disability services in Britain, Scandinavia and the USA*, Mansell, J. and Ericsson, R. (eds). London: Chapman and Hall.
- Goffman, E. (1966) *Asylums: essays on the social situation of mental patients and other inmates*. London: Penguin Books.
- Grant, G. and Ramcharan, P. (2009) Valuing People and research: outcomes of the Learning Disability Research Initiative. *Tizard Learning Disability Review* 14 (2): 25-34.
- Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: tracing elements of a psycho-social model. *Journal of Applied Research in Intellectual Disabilities* 20 (6): 563-575.

- HM Treasury and the Department for Education and Skills (2007) *Aiming high for disabled children: better support for families*. London: Department for Children, Schools and Families/Department of Health.
- Hollins, S. and Sinason, V. (2000) Psychotherapy, learning disabilities and trauma: new perspectives. *The British Journal of Psychiatry* 176: 32-36.
- Hubert, J. (1991) *Home-bound: crisis in the care of young people with severe learning difficulties: a story of twenty families*. London: King's Fund.
- Hubert, J. (1992) *Too Many Drugs, Too Little Care: parents' perceptions of the administration and side-effects of drugs prescribed for young people with severe learning difficulties*. London: Values Into Action.
- Hubert, J. (1995) *Life After Head Injury: the experiences of twenty young people and their families*. Aldershot: Avebury.
- Hubert, J. (2000) The social, individual and moral consequences of life in long-stay institutions. In *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*, Hubert, J. (Ed.). London: Routledge. 196-207.
- Hyland, J. (2000) Leprosy and social exclusion in Nepal: the continuing conflict between medical and socio-cultural beliefs and practices. In *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*, Hubert, J. (Ed.). London: Routledge. 168-179.
- IASSID Special Interest Group on Comparative Policy and Practice (2009) Proposed position statement on deinstitutionalisation and community living. Unpublished Report.
- Jodelet, D. (1991) *Madness and Social Representations: living with the mad in one French community*. California: University of California Press.
- Johnson, K. (1998) *Deinstitutionalizing Women: an ethnographic study of institutional closure*. Cambridge: Cambridge University Press.
- Joint Committee on Human Rights (2008) *A life like any other? Human rights of adults with learning disabilities*. London: The Stationery Office.
- Kourdoutis, P., G. Kolaitis, A. Perakis, P. Papanikolopoulou and J. Tsiantis (1995) Change in care staff's attitudes towards people with learning disabilities following intervention at the Leros PIKPA asylum. *British Journal of Psychiatry – Supplement*. 56-69.
- Kozma, A., Mansell, J. and Beadle-Brown, J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual Disabilities and Developmental Disabilities* 114 (3): 193-222.
- Levi, P. (1987) *If this is a man and The Truce*. London: Abacus.
- Lindsey, M. (2003) Overview of learning disability in children. *Psychiatry* 2 (9). Or: http://www.intellectualdisability.info/families/ldchildren_ml.htm (Accessed June 9 2009).
- Mansell, J. (2006) Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability*, 31(2): 65-76.
- Murphy, G. H., O'Callaghan, A. C. and Clare, I. C. H. (2007) The impact of alleged abuse on behaviour in adults with severe intellectual disabilities. *Journal of Intellectual Disability Research*, 51 (10): 741-749.
- Owen, K., Hubert, J. and Hollins, S. (2008) Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities* 36 (4): 220-226.
- Peckham, N. G. (2007) The vulnerability and sexual abuse of people with learning disabilities. *British Journal of Learning Disabilities* 35 (2) 131-137.
- Royal College of Psychiatrists (2004) *Psychotherapy and Learning Disability*. RCPsych Report CR116. London: Royal College of Psychiatrists.
- Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists. (2007) *Challenging Behaviour: a unified approach. Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*. RCPsych Report CR144. London: Royal College of Psychiatrists.
- Sequeira, H., Howlin, P. and Hollins, S. (2003) Psychological disturbance associated with sexual abuse in people with learning disabilities. Case-control study. *British Journal of Psychiatry* 183: 451-456.
- Sibley, D. (1995) *Geographies of Exclusion: society and difference in the west*. London: Routledge.
- Tsiantis, J., P. Kourdoutis, G. Kolaitis, A. Perakis and H. Assimopoulos (1995) The psychosocial dynamics of change at Leros PIKPA asylum. *British Journal of Psychiatry – Supplement*. 46-55.

- Tuffrey-Wijne, I. (2007) *Palliative Care for People with Intellectual disabilities*. PhD dissertation, Maastricht University.
- Tyrer, P. and Bajaj, P. (2005) Nidothrapy: making the environment do the therapeutic work. *Advances in Psychiatric Treatment* 11: 232–238.
- Tyrer, P., Oliver-Africano, P. C., Ahmed, Z., Bouras, N., Cooray, S., Deb, S., Murphy, D. *et al.* (2008) Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *Lancet* 371: 57–63.
- United Nations (2006) *Convention on the Rights of Persons with Disabilities and Optional Protocol*. Geneva: United Nations.
- Young, I. M. (1990) *Justice and the politics of difference*. Princeton: University of Princeton Press.

Summary

Chapter 1

Introduction

People with severe or profound intellectual disabilities who also have mental health problems and challenging behaviour are among the most vulnerable people in our society. Those who live segregated lives in locked wards or residential homes are perhaps the most vulnerable of all. This thesis focuses on the experiences of men and women who have lived their lives in locked wards, and also those who live at home with their families. A number of questions are addressed:

1. What can the use of ethnographic methods offer in the field of research with very vulnerable people? Are there specific ethical issues that arise?
2. What is the nature of life in a locked ward? What effect do social and physical exclusion have on the mental state of those confined, and on their identities?
3. Are there gender-related differences in the way men and women are perceived and treated in the single-sex wards of the institution?
4. When institutions close, do those who move out now live socially included lives, approximating to the 'normal' lives led by the majority population?
5. How different are the experiences of people with severe intellectual disabilities who have lived all their lives at home with their families?
6. How are adolescent boys with intellectual disabilities who have been labelled as 'sexual abusers' perceived? Does it affect the way that their futures are projected?

Chapter 2

The use of ethnographic research methods with people who have severe or profound intellectual disabilities

Ethnographic methods of research (consisting mainly of intensive interviewing and participant observation over time) were traditionally used by social anthropologists doing fieldwork in small-scale societies in distant parts of the world. Qualitative approaches, especially ethnographic research, have been viewed with suspicion by health professionals, who are more used to quantitative methods traditionally used in clinical research. However

qualitative methods are now popular in health research, and projects using these methods are now reported in mainstream medical journals.

Ethnography is concerned with the meaning of people's actions and words. In the context of health research it can provide answers to questions about why people act as they do in relation to their health and well-being, and what their beliefs are about health and ill-health. Participant observation is particularly useful in research with people with severe and profound intellectual disabilities who have little or no speech.

Chapter 3

Ethics of research

This paper discusses a number of ethical issues that arise in the context of ethnographic research with people with severe intellectual disabilities and mental health problems living in closed institutions. These men and women have tended to live emotionally and physically deprived lives in segregated and bleak environments, and because they cannot communicate through speech, and often have seriously challenging behaviour, they have tended to become socially and physically isolated from society.

Ethnographic research involves spending long periods of participant observation with people in their 'natural' settings, providing intensely qualitative material, in order to present data as far as possible from each individual's perspective. Such research provides rich and emotionally powerful material which is often distressing and even shocking. This raises a number of ethical issues in relation to the conduct of such research, including questions regarding consent - who can give consent for someone who does not have the capacity to give consent themselves? The ethics of publication of such research are also discussed. This paper outlines the reasons why such research, and its publication, is vital for the futures of institutionalized men and women with severe intellectual disabilities.

Chapter 4

Men with severe learning disabilities and challenging behaviour in long-stay hospital care

The aim of the study was to gain a greater understanding of the experiences and needs of men who were living in a locked ward, in order to contribute to a significant improvement in their lives after closure of the institution. Community-based health and social care professionals have little knowledge of the past experiences of people with severe intellectual disabilities and challenging behaviour who have lived all their lives in institutions.

The study sample consisted of 20 men living in a locked ward of a long-stay institution. Ethnographic methods of research were used, involving participant observation (about 250 hours) on the ward. All traceable families were interviewed. The analysis used grounded theory, and the results were fed back to those involved in the resettlement process.

The study found that the men's lives were emotionally, socially and physically deprived. Their individual, gender and social identities were not recognised, and their general health and mental healthcare needs were inadequately addressed. This complicates the presenta-

tion of mental health and behavioural problems, and raises important adult protection issues.

Chapter 5

Women with severe intellectual disabilities and challenging behaviour in long-stay hospital care

This research aimed first to understand how women with severe intellectual disabilities experienced transition from a locked ward of an old long-stay hospital into other homes, and second, to determine the extent to which their lives changed in their new homes. Ethnographic methods were used, including participant observation, interviews and document analysis, in order to get to know the eleven women and the nature of their daily lives.

The study found that the experience of the move was largely negative for all the women: they were not involved in the process of their move, little information was transferred to their new homes and they were insufficiently supported.

The study also found that for the majority of the women little changed in their lives in their new homes. Most of them continued to lead lives restricted by rigid routines, strict rules, few daily activities, and few opportunities for relationships beyond the staff team. A few women had more opportunities to make choices and learn new skills. In general, the women continued to be unacknowledged as unique individuals, or as adult women.

Chapter 6

A follow-up of men with severe intellectual disabilities and challenging behaviour leaving the long-stay hospital

The closure of the old 'mental handicap' hospitals has opened up opportunities to improve the lives of institutionalised people moving to campus homes and homes in the community. This chapter describes the lives of 20 men (see Chapter 4) who are moved out of a locked ward, to determine the extent and nature of changes in their lives when they move 'into the community'.

The research found that when the men moved their lives were better in material terms in their new homes, but there were still limited possibilities of making other significant changes in their lives. To a great extent they still lived within the old paradigm of social exclusion and denial of individual identity and autonomy. There appeared to be few fundamental changes in professional and social attitudes, and as a result the men continued to live socially excluded and forgotten lives in a locked environment. .

Despite wide acknowledgement of the unacceptable treatment of people living in institutions, there is evidence that the individual human and civil rights of men such as these continue to be ignored in spite of the closure of the institutions.

Chapter 7

Perspectives of mothers of young people with severe learning disabilities and challenging behaviour living at home

This chapter describes a study carried out with families in which a young adult son or daughter with severe intellectual disabilities and challenging behaviour is living at home. The main aim of this research was to gain understanding of the experiences and perspectives of families, especially the mothers, who were the main carers.

Ethnographic methods were used, consisting of intensive interviews, mainly with mothers, over two to three years, and participant observation.

The mothers' main focus was on their disabled son or daughter, which sometimes contributed to marital tensions. Most of the mothers had become socially isolated, but in spite of this, unlike the men and women in the locked wards, their sons and daughters retained their individual and social identities, and had significant reciprocal relationships with their parents and siblings, and often with others.

The parents' negative attitudes to institutions, and fears for the safety and well-being of their son or daughter, led to determination not to put them into long-term care. The lack of effective services, especially around transition to adulthood, increased parents' protectiveness.

Chapter 8

Family carers from Black and minority ethnic groups caring for an adult son or daughter with intellectual disabilities at home

In 2001, the UK Government identified the widespread neglect of the needs of people with intellectual disabilities from Black and minority ethnic communities. This chapter describes a qualitative study carried out with 30 family carers of adults with intellectual disabilities from Black and minority ethnic communities. Their views were sought regarding the services they received, the services that they felt they needed, and any cultural or communication barriers they encountered in accessing appropriate services.

The study showed that although carers were largely satisfied with the few services they actually received, service provision was highly inadequate and ineffective. Even very elderly and ill carers and those caring for people with severe disabilities received little support. Social worker support was negligible, and future planning rare. It is clear that the needs of carers from Black and minority ethnic communities are not being met. The situation would be considerably eased by adequate social worker support. Stereotypes of supportive family networks, (especially regarding south Asian families) proved to be unfounded.

Chapter 9

The perspectives of mothers whose adolescent sons with learning disabilities sexually offend

The subject of sexual abuse is a major focus of professional and public concern.

The project described in this chapter had three aims: (1) to determine whether group psychotherapy produced effective outcomes for six adolescent boys with intellectual disabilities who had been sexually abused as children and who were now exhibiting sexually abusive behaviour themselves, (2) to explore the perspectives of parents and other caregivers, (3) to document the nature and extent of service support to families.

The study used both quantitative and qualitative methods. Clinical measures were used to track changes throughout the course of psychotherapy. Semi-structured interviews (taped and transcribed) were held (separately) with the boys, their parents, paid caregivers, and the therapists.

This paper focuses solely on the mothers' perspectives. The mothers tried hard to make sense of, and come to terms with what was happening to their sons and to themselves, and often struggled to reconcile their own confused and often conflicting emotions. They felt almost totally unsupported by the services, both in the context of the past abuse of their sons, and in the present, and could see little hope for the future.

There is an urgent need for development of effective and sympathetic services for the parents of boys with intellectual disabilities who have been abused, and who are now showing abusive behaviour.

Chapter 10

Discussion

This final chapter discusses the findings of this thesis. It also places the findings in a wider context, drawing on other academic and literary sources. Answers are put forward to the questions posed in the Introduction. The choice of ethnographic methods of research is justified by the richness of the material, and the hypotheses and insights it produces. The second question, which forms the heart of the thesis, regards the effects of life in a locked ward. It shows that the men and women have lived emotionally and physically deprived lives. Having been institutionalised since childhood, their challenging behaviour has increased over the years. They are vulnerable to abuse of all kinds. Moving into the community has not brought many changes to their lives – they remain socially and physically excluded. Differences were found in the way men and women in the locked wards were perceived and treated, but in neither case were they treated as gendered men or women with normal sexual desires.

Other forms of institution are discussed, and the severe effects that incarceration can have on people without intellectual disabilities, such as political prisoners and prisoners of war, demonstrating that it is not only people with intellectual disabilities who are driven to bizarre and even 'mad' behaviour.

The experiences of the men and women in the locked wards were compared with those of people living at home, and were found to be very different. The men and women at home retained their individual and social identity, and they were very much part of the family. Members of the family 'listened' to their various, usually non-verbal, methods of communication. Parents were adamant that they would not let them go into long-term care.

The final question relates to adolescent boys who were abused as children and are now abusing others. The mothers felt neglected by the services, and were confused and anxious about what was happening to their sons. The professionals saw residential care as the only solution, whereas the mothers wanted support to keep them at home.

'Valuing People', published in 2001, put forward a number of principles: rights, independence, choice and inclusion. These worthy principles are still well out of the reach of these men and women. Negative attitudes are entrenched in the wider community, and among many of the people who work with them.

Accessible summary

CHAPTER 1

Introduction

- This book is about the lives of people with very severe intellectual disabilities. Most of them cannot speak. They can't wash, bath or dress themselves. They can't go to the toilet on their own. They need other people to help them.
- Most of them also have challenging behaviour. They hurt themselves or they hurt other people, or try to break the things around them, or try to run away.
- Some of them live at home. Some lived in locked wards in long-stay hospitals for a long time. They now live in homes in the community.

What we wanted to find out

1. Is the way we do this research a good way or not? Spending a lot of time with people means that we learn a lot about them. The people in our studies couldn't tell us if they wanted to be in the study or not. Does that matter?
2. What is it like to live in a locked ward the whole time? Does being shut away make a difference to how people think and feel? Does it change the way they act?
3. Are men living in locked wards together treated differently from women living in locked wards together?
4. The long-stay hospitals closed and the people moved out. Do they now live normal lives in the community?

5. Some people with severe intellectual disabilities live at home with their families. Are their lives different from the lives of people in a locked ward?
6. What do others think about young boys with intellectual disabilities who hurt people in a sexual way? What will happen to these boys when they grow up?

CHAPTER 2

Doing research by spending a long time with people, in the place where they live

- This sort of research doesn't have questions written down that you answer yes or no to.
- The researcher wants to find out about people's lives. If people can talk, then the researcher will have long talks with them.
- The researcher asks them about their life. She asks them how they feel and what they would like to happen. She also asks them about the things they don't like.
- The researcher will visit many times. Perhaps every week, for a year or longer. She gets to know the place they live in very well.
- If someone can't talk then the researcher will still spend time with them. She tries to understand how they show her what they mean, without talking.
- This sort of research tries to understand:
 - why people say things
 - why they act the way they do
 - what it means to them

CHAPTER 3

Problems that may come up when we find out about the lives of people with severe intellectual disabilities

What we wanted to find out

- We want to do research with people who can't give their consent. This means that they can't tell us whether they want us to spend time with them or not. Does this cause problems?
- This sort of research means:
 - trying to get to know people
 - trying to understand what they feel about their lives

Is such research useful?

- The things we find out about people should be kept private (for example, their names). Can we still write about our research?
- Some things we found out are very shocking. It upsets people to hear about it. Does it matter if we still write about it?
- Bad things that happened to people in the long-stay hospitals. Those hospitals have now closed down. Why is it still important to write about it?

What we did

- We looked carefully at our research in the long-stay hospital.
- We looked again at what we found, and what we had written about it.

- We read what some other people had written. They wrote about what you should and should not do in research with people who can't give their consent.

What we found

- Some people can't give their consent when the research starts. But the researcher can look at what the person does, each time she visits. That way, she can tell if the person wants to be in the study on that particular day.
- People don't get upset by research where the researcher spends time with them. Most people like to have someone who is interested in them.
- It is important that we write about what life was like for these men and women. Others should hear about it. We shouldn't make the same mistakes in the future.
- People who have moved out of the hospitals now have new carers. It is important that the new carers know what has happened to the people in the past.

CHAPTER 4

The lives of men who live in a locked ward, who have severe learning disabilities and challenging behaviour.

What we wanted to find out

- There were 20 men who lived in a locked ward of an old long-stay hospital. We wanted to get to know each of them very well.
- What was life like?
- What did they need? What did they like? What didn't they like?

What we did

- We spent a long time with the men in the locked ward. We visited them for nearly 3 years. We wrote everything down about the visits.
- Some men still had families somewhere. We talked to their families.
- We wrote about the lives of each man. We gave these detailed stories to their future carers.

What we found

- The ward was some very large empty rooms. They were more like community halls than a home.
- Most of the men had been in an institution since they were small children, less than 8 years old.
- They were not treated like individuals or as adult men.
- Other people thought they were dangerous. Or that they hurt people in a sexual way.

- They were always on the ward. They had no life outside the ward. They were hidden from the outside world.
- It seemed that no one cared how they felt, even when they were sad or upset.
- Their difficult behaviour was treated with drugs. No one tried to find out why they were so unhappy.

CHAPTER 5

Women with severe intellectual disabilities, who moved out of a locked ward

What we wanted to find out

- There were 11 women who had lived most of their lives in a locked ward of an old long-stay hospital.
- What was their life like?
- What was it like for the women to move into the community when the ward was closed?
- Do they now live more like other people in the community, or do they still live lives shut away from everyone else?
- Do their carers treat them more like equals now that they are not living in the hospital?

What we did

- We spent long periods of time with the women while they were living in the locked ward, and then in their new homes.
- We kept detailed notes on the visits.
- Some women still had families somewhere. We talked to their families.

What we found

- Moving home was very hard for the women.
- They were not told what was going to happen.

- They had no choice about where they would move to, or who they would live with.
- The people looking after them in their new homes had not been told much about them. The new carers didn't know about the women's lives. The carers didn't know what the women liked and didn't like.
- For most of the women, life in their new homes was very like their old life. It was still full of rules. They were still told what to do. They were not given chances to make new friends. There was little for them to do all day.
- For three women, life was different. They had more choices and a fuller life.

CHAPTER 6

Moving out of the long-stay hospital into new homes

What we wanted to find out

- 20 Men with severe intellectual disabilities moved to a new home. They had spent most of their lives in a big locked ward.
- What was it like for them to move out of the ward?
- Did they now start to live more like other people in the community?
- Did their carers treat them more like equals now?

What we did

- We visited the men often in their new homes. We talked to them (although most men couldn't talk themselves).
- We found out what sort of lives they were living now.
- We joined in with things that were happening in the new homes.

What we found

- Compared with the ward, the men's new houses were more like other people's homes in the community.
- The men now had more freedom inside their house. But they were still locked in. They had little to do.
- Most things didn't change for most of the men.
- They didn't have much of a life outside their homes. They didn't meet many other people, or make new friends.

- The attitudes of their carers were very important. If the people in charge don't really care about the people who live there, then a nice home in the community can still feel like a hospital ward.

CHAPTER 7

Talking to mothers of young people with severe intellectual disabilities living at home

What we wanted to find out

- How do parents feel about caring at home for a son or daughter with severe intellectual disabilities and very difficult behaviour?
 - A mother may have to spend almost all her time looking after one person. Does this upset other people in the family?
 - Do families get enough help from the services?
- What do parents think will happen in the future?
- Would they let their son or daughter go into long-term care?

What we did

- We visited 20 families for 3 years.
- We talked with the mothers most of the time. But we also interviewed fathers and sisters and brothers.

What we found

- The mothers spent most of the time looking after their disabled son or daughter. This son or daughter who was very much part of the family.
- Sometimes the mothers had hardly any time for their husbands.
- Some families became cut off from friends and family outside the household.

- The local services were not very good. The families needed much more help and support than they could get.
- The mothers didn't have good things to say about the local long-term residential units, and the people who lived there.
- They were devoted to their disabled child. They were determined that their child should never have to live in those residential units.

CHAPTER 8

Talking to family carers of people with intellectual disabilities from Black and ethnic minority groups.

What we wanted to find out

- We already know that some people get a poorer service than other people. There is a poorer service for:
 - Black families (e.g. from Africa and the Caribbean)
 - ethnic minority families (e.g. from India, Pakistan and China)
- Do these families feel that their needs are met? Do they get a service that is right for them?
- Do they ever feel that that people treat them unfairly?

What we did

- We talked to 30 families who were caring for an adult with intellectual disabilities at home.

What we found

- They were not getting enough help from the services.
- Only 8 of the 30 families thought they had a social worker. Only 3 of these felt that the social worker had been useful to them.
- Very few families thought that because they were Black or from other ethnic groups, services were unfair to them.
- More than half the carers were over 60 years old, and a quarter over 70. Some of these were very frail and ill.

- They felt that no one was helping them plan ahead for the time when they were too weak to go on caring, or when they died.
- Few of them had wider families who could support them.
- Families caring for someone who was very dependent on them had the most difficult time.
- Most parents did not want their son or daughter to go into long-term care. They felt that their son or daughter would not get enough love and care away from home. No thought that one would protect them against harm and abuse.

CHAPTER 9

Talking to mothers whose young sons with intellectual disabilities are sexually abusing other children.

What we wanted to find out

- Some young men with intellectual disabilities were abused as children, and were now abusing other children themselves.
- What do their mothers feel about them?
- Were the mothers getting the help and support they needed? Were their sons getting help?
- Did they understand what was happening to their sons?

What we did

- The young men were having psychotherapy with a group of other young men. During this time, we talked their mothers. The research took 3 years.
- This chapter is about the mothers. But we also talked to the boys themselves.
- We also talked to people who were looking after them at school or in residential care.

What we found

- The mothers felt that they had been given very little help and support over the years.
- They were very sad about what had happened to their sons in the past. They were upset by some of the things that their sons were doing now.

- Because their sons had intellectual disabilities, it was harder for them to talk to people about what had happened to them.
- The mothers said that it was hard for their sons to deal with the fact that they had been abused. Other people didn't understand how hard it was. The mothers also thought it was difficult for their sons to understand what was happening to them now.
- The mothers were trying to do their best for their sons. They were very worried about what was going to happen to them in the future.
- The mothers felt that people only saw their sons as sexual abusers, and not as young people who had been abused themselves.

CHAPTER 10

Discussion

This final chapter talks about all the things we found out.

- The way we did the research was a good way to find out. We got to know people very well.
- The men and women in the locked wards lived very empty lives. They didn't have friends outside the ward. They spent almost all the time in the ward, doing nothing.
- The men were treated differently from the women. Staff thought the men were violent, but they treated the women like children.
- When they moved out of the hospital they lived in nicer houses. But their lives didn't change much. They were still locked in. They didn't have much to do at home. They didn't make any more friends.
- We compared the lives of the men and women in the hospital wards with the lives of people living at home with their families. We found that their lives were very different. The people at home were loved by their families. They lived lives much more like other people in the community.
- The mothers of the young boys who had been abused and were now abusing other children, needed much more help and support. They felt that no one cared what happened to them. The people who worked with the boys thought they should go into residential care. Their mothers wanted help to keep them at home.
- 'Valuing People' is a report from the government in 2001. It said that things would get better. But not much has changed for peo-

ple with severe intellectual disabilities who have mental health problems. People's attitudes to them don't seem to have changed very much.

Samenvatting

Hoofdstuk 1

Inleiding

Mensen met zeer ernstige tot diepe verstandelijke beperkingen, die eveneens geestelijke gezondheidsproblemen hebben en problematisch gedrag laten zien, behoren tot de meest kwetsbare groepen in onze samenleving.

Degenen die in afzondering leven in gesloten instellingen of tehuizen zijn wellicht het meest kwetsbaar van allen. Onderwerp van dit proefschrift zijn de ervaringen van mannen en vrouwen, die in deze gesloten afdelingen hebben geleefd en ook de ervaringen van degenen, die thuis bij hun familie wonen. Een aantal onderzoeksvragen komt aan de orde:

- Wat kan het gebruik van etnografische onderzoeksmethoden betekenen voor het onderzoek naar zeer ernstige kwetsbare mensen? Zijn er specifieke ethische zaken waar rekening mee moet worden gehouden?
- Hoe ziet het leven eruit op een gesloten afdeling? Wat is de invloed van sociale en fysieke uitsluiting op de geestelijke gesteldheid van hen die opgesloten zijn en wat betekent dit voor hun identiteit?
- Zijn er genderverschillen in de wijze waarop mannen en vrouwen worden gezien en bejegend in de voor mannen en vrouwen gescheiden instellingsafdelingen?
- Wanneer instellingen sluiten, zijn dan degenen die de instelling hebben verlaten geïntegreerd in de samenleving en leiden zij een leven dat bij benadering overeenstemt met het leven van de meeste mensen in de maatschappij?
- Hoe verschillend zijn de ervaringen van mensen met zeer ernstige verstandelijke beperkingen, die altijd thuis hebben gewoond binnen het gezin?
- Hoe worden adolescenten jongens gezien, die het etiket opgeplakt kregen van 'seksuele misdader'? Beïnvloedt dit de wijze waarop naar hun toekomstig leven wordt gekeken?

Hoofdstuk 2

Etnografisch onderzoek bij mensen met zeer ernstige tot diepe verstandelijke beperkingen

Etnografische onderzoeksmethoden (meestal bestaande uit diepgaande interviews en participerende observatie gedurende een langere periode) werden van ouds gebruikt door sociaal antropologen, die veldwerk verrichtten in kleine gemeenschappen in afgelegen delen

van de wereld. Kwalitatieve benaderingen, vooral etnografisch onderzoek, werden argwauwend bekeken door gezondheidswetenschappers die meer gewend waren aan de gebruikelijke kwantitatieve methoden van onderzoek voor de klinische praktijk. Nu zijn echter kwalitatieve onderzoeksmethoden populair in gezondheidsonderzoek. Projecten waarin gebruik wordt gemaakt van deze methoden van onderzoek zijn nu te vinden in de gangbare medische tijdschriften.

De etnografie is gericht op de betekenis van de handelingen en woorden van mensen. In de context van gezondheidsonderzoek kan het antwoord geven op vragen waarom mensen zich gedragen zoals zij doen in relatie tot hun gezondheid en welzijn, en wat hun opvattingen zijn over gezondheid en ziekte. Participerende observatie is bijzonder goed bruikbaar in onderzoek naar mensen met ernstige tot diepe verstandelijke beperkingen, die niet of bijna niet kunnen praten.

Hoofdstuk 3

Ethiek van onderzoek

In dit hoofdstuk komt een aantal ethische zaken aan de orde, gerelateerd aan etnografisch onderzoek bij mensen met zeer ernstige verstandelijke beperkingen en geestelijke gezondheidsproblemen die in gesloten instellingen leven.

Deze mannen en vrouwen hebben over het algemeen emotioneel en fysiek gedepriveerde levens geleid, afgezonderd in een troosteloze omgeving. Daar zij niet kunnen communiceren met behulp van spraak en vaak zeer moeilijk gedrag laten zien ontstaat een tendens tot sociale en fysieke uitsluiting van de maatschappij.

Bij etnografisch onderzoek worden lange perioden van participerende observatie doorgebracht bij mensen in hun natuurlijke leefomgeving. Hierdoor komen veel kwalitatieve gegevens beschikbaar en kunnen de data zoveel mogelijk vanuit ieders individueel perspectief worden gepresenteerd.

Dergelijk onderzoek levert een schat aan gegevens en emotioneel krachtig materiaal op, veelal ongemakkelijk en zelfs schokkend.

Dit roept een aantal ethische kwesties op in relatie tot het verrichten van dergelijk onderzoek, met inbegrip van vragen voor toestemming – wie kan toestemming verlenen voor iemand die dit zelf niet kan?

De ethiek rond het publiceren van dergelijk onderzoek wordt ook besproken.

In dit hoofdstuk komt naar voren waarom dergelijk onderzoek en het publiceren hierover van wezenlijk belang is voor de toekomst van geïnstitutionaliseerde mannen en vrouwen met zeer ernstige verstandelijke beperkingen.

Hoofdstuk 4

Mannen met zeer ernstige verstandelijke beperkingen en moeilijk gedrag, die in residentiële instellingen voor langdurend verblijf wonen

Het doel van het onderzoek was meer zicht te krijgen op de ervaringen en behoeften van mannen, die op een gesloten afdeling verbleven, om op deze wijze een wezenlijke bijdrage

te leveren aan het verbeteren van hun kwaliteit van leven na het sluiten van de instelling. Hulpverleners in de ambulante setting hebben bijna geen weet van de ervaringen uit het verleden van mensen met zeer ernstige verstandelijke beperkingen en moeilijk gedrag, die hun hele leven lang in instellingen hebben gewoond.

De steekproef bestond uit 20 mannen, die op een gesloten afdeling van een instelling voor langdurig verblijf wonen. Er werden etnografische methoden gebruikt, bestaande uit participerende observatie (ongeveer 250 uur) op de afdeling. Alle families die konden worden opgespoord zijn geïnterviewd. Tijdens de analyse werd gebruik gemaakt van de 'grounded theory'. De gegevens werden voortdurend teruggekoppeld tijdens het proces van herhuisvesting.

Uit het onderzoek komt naar voren dat het leven van de mannen emotioneel, sociaal en fysiek gedepriveerd was. Hun individuele, seksuele en sociale identiteiten werden niet herkend en aan hun somatische en geestelijke gezondheidsbehoeften werd niet adequaat tegemoet gekomen. Dit bemoeilijkt de manier waarop geestelijke gezondheids- en gedragsproblemen naar buiten komen, en roept belangrijke vragen op rond het beschermen van de volwassenen.

Hoofdstuk 5

Vrouwen met zeer ernstige verstandelijke beperkingen en moeilijk gedrag, die in residentiële instellingen voor langdurend verblijf wonen

In dit onderzoek wordt allereerst gepoogd te begrijpen op welke wijze vrouwen met zeer ernstige verstandelijke beperkingen de overgang ervaren van een gesloten afdeling in een oude instelling voor langdurend verblijf naar nieuwe woonvormen. Vervolgens wordt gekeken naar de mate van verandering in hun leven in de nieuwe woonomgeving.

Voor het leren kennen van de deelnemende 11 vrouwen werd gebruik gemaakt van etnografische onderzoeksmethoden, met inbegrip van participerende observatie, interviews en analyses van documenten.

In het onderzoek werd aangetoond dat de ervaring van verhuizen grotendeels negatief was voor alle vrouwen: zij werden niet betrokken bij het proces van de verhuizing, slechts weinig informatie werd doorgegeven aan hun nieuwe woonomgeving en zij kregen onvoldoende ondersteuning.

In het onderzoek werd ook gevonden dat voor de meerderheid van de vrouwen slechts weinig veranderde in hun leven in de nieuwe woonomgeving. De meesten van hen continueerden een leven beperkt door rigide routines, strikte regels, weinig dagbesteding en weinig mogelijkheden voor het ontwikkelen van sociale contacten buiten de begeleiders om. Een beperkt aantal vrouwen had meer mogelijkheden voor het maken van keuzen en het leren van nieuwe vaardigheden. Over het algemeen werden de vrouwen nog steeds niet erkend als unieke individuen of volwassen vrouwen.

Hoofdstuk 6

Een vervolgstudie naar mannen met zeer ernstige verstandelijke beperkingen en moeilijk gedrag, die de residentiële instelling voor langdurend verblijf verlaten

Het sluiten van de ouderwetse ‘zwakzinnigenzorginstellingen’ biedt mogelijkheden voor het verbeteren van het leven van geïnstitutionaliseerde mensen, die naar kleinschalige woonvormen binnen of buiten een instellingsterrein verhuizen. In dit hoofdstuk wordt het leven van 20 mannen (zie hoofdstuk 4) beschreven, die overgeplaatst werden van een gesloten afdeling naar woonvormen in de buurt. Dit voor het in beeld brengen van de aard en de mate van veranderingen in hun leven.

Het onderzoek laat zien dat door de verhuizing hun leven in materieel opzicht verbeterde, maar de mogelijkheden in hun leven voor het maken van andere wezenlijke veranderingen waren nog steeds beperkt. Zij leefden voornamelijk nog steeds binnen het oude paradigma van sociale exclusie en ontkenning van individuele identiteit en autonomie. Fundamenteel veranderde er slechts weinig in professionele en sociale houdingen, met als gevolg dat de mannen hun leven van sociale exclusie en vergeten levens in een gesloten afdeling continueerden.

Over de niet acceptabele behandeling van mensen, die in residentiële instellingen wonen bestaat algemene overeenstemming, ondanks dit is er bewijs dat na het sluiten van de instellingen de mensenrechten van deze burgers nog steeds worden geschonden.

Hoofdstuk 7

Perspectieven van moeders van thuiswonende jonge mensen met zeer ernstige verstandelijke beperkingen en moeilijk gedrag

In dit hoofdstuk wordt een onderzoek beschreven dat werd uitgevoerd bij gezinnen met thuiswonende jong volwassen mannen of vrouwen met zeer ernstige verstandelijke beperkingen en moeilijk gedrag. Het belangrijke doel van deze studie was het verkrijgen van inzicht in de ervaringen en perspectieven van de gezinnen, met name van de moeders die de belangrijkste verzorgers waren.

Gebruik werd gemaakt van etnografische onderzoeksmethoden, bestaande uit participerende observatie en diepgaande interviews, voornamelijk met moeders over een periode van twee tot drie jaar.

De aandacht van de moeders ging met name uit naar de gehandicapte zoon of dochter, hetgeen soms aanleiding gaf tot spanningen binnen het huwelijk. De meeste moeders raakten sociaal geïsoleerd, maar ondanks dit en in tegenstelling tot de mannen en vrouwen van de gesloten afdelingen, behielden de zoons en dochters hun individuele en sociale identiteit. Zij onderhielden belangrijke en wederkerige relaties met hun ouders en broers en zussen, en vaak met anderen. De negatieve opvattingen van ouders over de instellingen en de angst voor de veiligheid en welzijn van hun zoon of dochter, resulteerden in vastbeslotenheid om het kind niet in een verblijf voor langdurende zorg te plaatsen. Door het

gebrek aan adequate hulpverleningsmogelijkheden, met name rond de overgang naar volwassenheid, nam de beschermende houding van de ouders toe.

Hoofdstuk 8

Verzorgers uit gezinnen van gekleurde en etnische minderheidsgroeperingen, die in de thuissituatie zorg dragen voor een volwassen zoon of dochter met een verstandelijke beperking

Het op grote schaal negeren van de behoeften van mensen met verstandelijke beperkingen van gekleurde en etnische minderheidsgroeperingen werd in 2001 erkend door de regering van Engeland. In dit hoofdstuk wordt een kwalitatief onderzoek beschreven verricht bij 30 gezinsleden, die zorg dragen voor volwassenen met een verstandelijke beperking afkomstig uit gekleurde en etnische minderheidsgroeperingen. Onderzocht werden hun zienswijzen met betrekking tot de geboden en de gewenst geachte hulpverlening. Gevraagd werd naar mogelijke culturele en communicatie barrières, die de gezinnen ondervonden bij het zoeken naar passende hulp.

Uit het onderzoek kwam naar voren dat de geboden hulp zeer inadequaat en ineffectief was, hoewel de verzorgers veelal tevreden waren over de weinige hulp die zij feitelijk kregen. Zelfs zeer oude en zieke verzorgers, of zij die voor mensen met ernstige beperkingen zorgden, ontvingen weinig hulp. De hulpverlening van sociaal werkers was verwaarloosbaar en het maken van plannen voor de toekomst uitzonderlijk. Het is duidelijk dat niet aan de behoeften wordt voldaan van verzorgers afkomstig uit gekleurde en etnische minderheidsgroeperingen. De situatie zou aanzienlijk verbeterd kunnen worden met doeltreffende ondersteuning vanuit sociaal maatschappelijk werk. Stereotype opvattingen over ondersteunende familienetwerken (met name met betrekking tot zuid Aziatische families) werden gelogenstraft.

Hoofdstuk 9

De perspectieven van moeders wiens adolescente zonen met verstandelijke beperking plegers zijn van seksueel grensoverschrijdend gedrag

Het onderwerp van seksueel misbruik staat sterk in de belangstelling van hulpverleners en publiek.

Het in dit hoofdstuk beschreven project heeft drie doelen: (1) het nagaan of groepspsychotherapie een positief effect heeft bij zes als kind seksueel misbruikte adolescente jongens met een verstandelijke beperking en die nu zelf plegers zijn van seksueel grensoverschrijdend gedrag, (2) het nader verkennen van de perspectieven van ouders en andere zorgverleners, (3) het in kaart brengen van de aard en mate van geboden hulp aan de gezinnen.

In het onderzoek werd gebruik gemaakt van kwantitatieve en kwalitatieve onderzoeksmethoden. Klinische metingen werden gebruikt voor het vaststellen van veranderingen tijdens de therapie. Semi-gestructureerde interviews (op band opgenomen en vervol-

gens uitgeschreven) werden (afzonderlijk) gehouden met de jongens, hun ouders, betaalde zorgverleners en therapeuten.

Het hier gerapporteerde onderzoek is gericht op het perspectief van de moeders. De moeders deden veel moeite om de situatie te begrijpen en in het gerede te komen met hetgeen met hun zonen was gebeurd en wat hen zelf is overkomen. Zij trachtten met moeite in het reine te komen met hun verwarde en vaak conflicterende emoties. Zij voelden zich vrijwel totaal in de steek gelaten door de hulpverleners, zowel in de context van het misbruik in het verleden van hun zonen als het heden. Zij hadden weinig vertrouwen in de toekomst.

Er is grote behoefte aan het ontwikkelen van doeltreffende en cliëntvriendelijke hulpverleningsmethodieken voor de ouders van jongens met een verstandelijke beperking, die zijn misbruikt en nu zelf dader zijn.

Hoofdstuk 10

Discussie

In dit laatste hoofdstuk wordt nader ingegaan op de bevindingen uit dit proefschrift. De resultaten worden in een bredere context geplaatst met gebruikmaking van andere academische en literaire bronnen. Antwoord wordt gegeven op de in de inleiding gestelde vragen. De keuze van de etnografische onderzoeksmethoden wordt gerechtvaardigd door de rijkheid van het materiaal en de hieruit voortvloeiende hypothesen en inzichten. De tweede vraag, dit is de kern van het proefschrift, heeft betrekking op wat leven in een gesloten afdeling betekent. Aangetoond wordt dat het leven van mannen en vrouwen emotioneel en fysiek gedepriveerd is. Door institutionalisering van kindsaf aan is het probleemgedrag met de jaren toegenomen. Zij zijn kwetsbaar voor allerlei vormen van misbruik. De verhuizing naar de maatschappij heeft voor hun leven niet veel verandering meegebracht, zij blijven sociaal en fysiek uitgesloten. Verschillen werden gevonden in de wijze waarop mannen en vrouwen op de gesloten afdelingen werden gezien en bejegend, maar in geen van de gevallen werden zij behandeld als mannen en vrouwen met normale seksuele behoeften.

Andere vormen van inrichtingen komen ter sprake en de ernstige invloed die opsluiting kan hebben op mensen zonder verstandelijke beperkingen, zoals politieke gevangenen en krijgsgevangenen. Dit om te laten zien dat het niet slechts mensen met verstandelijke beperkingen zijn, die gedreven worden tot bizar en zelfs 'waanzinnig' gedrag.

De ervaringen van mannen en vrouwen op de gesloten afdelingen werden vergeleken met die van mensen, die thuis wonen. Aangetoond werd dat deze zeer verschillen. De mannen en vrouwen, die thuis woonden behielden hun individuele en sociale identiteit en maakten echt deel uit van het gezin. De gezinsleden 'luisterden' naar hun uiteenlopende, meestal niet-verbale, manieren van communiceren. Ouders waren vastbesloten om hen niet in instellingen te laten opbergen.

De laatste vraag heeft betrekking op adolescente jongens, die als kind misbruikt werden en nu zelf daders zijn. De moeders vonden dat zij geen gehoor kregen bij de hulpverlenende instellingen. Zij waren verward en angstig voor hetgeen met hun zonen aan het

gebeuren was. De professionele hulpverleners zagen residentiële hulpverlening als enige mogelijkheid voor een oplossing, terwijl de moeders hulp wilden om hen thuis te kunnen houden.

Het in 2001 gepubliceerde rapport 'Valuing People' brengt een aantal principes naar voren: rechten, onafhankelijkheid, keuze en inclusie. Deze belangrijke uitgangspunten liggen nog steeds ver buiten bereik van deze mannen en vrouwen. Negatieve houdingen zijn nog steeds in de samenleving aanwezig en bij veel van de mensen die met ze werken.

Eenvoudige samenvatting

HOOFDSTUK 1

Inleiding

- Dit boek gaat over de levens van mensen met een ernstige verstandelijke beperking. De meesten van hen kunnen niet praten. Ze kunnen zichzelf niet wassen of aankleden. Ze kunnen niet zelf naar de wc. Ze hebben andere mensen nodig om hen te helpen.
- De meesten van hen hebben ook moeilijk gedrag. Ze doen zichzelf pijn, of ze doen andere mensen pijn, of ze proberen dingen stuk te maken, of weg te lopen.
- Sommigen van hen wonen thuis. Sommigen hebben heel lang op een gesloten afdeling gewoond, in een groot instituut. Zij wonen nu in gewone huizen in de buurt.

Wat wij te weten wilden komen

- Is onze manier van onderzoeken een goede manier of niet? Als wij veel tijd met mensen doorbrengen, komen wij veel over hen te weten. De mensen in ons onderzoek konden ons niet vertellen of ze wel met het onderzoek mee wilden doen. Is dat erg?
- Hoe is het om de hele tijd op een gesloten afdeling te wonen? Gaan mensen anders denken of voelen als ze opgesloten zijn? Gaan ze zich anders gedragen?
- Worden mannen, die samen op een gesloten afdeling wonen anders benaderd dan vrouwen, die samen op een gesloten afdeling wonen?

- De instituten zijn gesloten en de mensen die er woonden zijn verhuisd. Leiden zij nu een normaal leven in de maatschappij?
- Sommige mensen met een ernstige verstandelijke beperking wonen thuis bij hun familie. Zijn hun levens anders dan de levens van mensen op een gesloten afdeling?
- Hoe denken andere mensen over jongemannen met een verstandelijke beperking die seksueel misbruik plegen? Wat zal er met deze jongemannen gebeuren als zij ouder worden?

HOOFDSTUK 2

Onderzoek doen door veel tijd bij mensen door te brengen waar zij wonen

- Bij dit soort onderzoek heb je geen vragen opgeschreven waar je ja of nee op moet antwoorden.
- De onderzoeker probeert het leven van andere mensen te begrijpen. Als mensen kunnen praten, gaat de onderzoeker lang met hen praten.
- De onderzoeker vraagt hen naar hun leven. De onderzoeker vraagt hoe zij zich voelen en wat zij graag willen. De onderzoeker vraagt hen ook waar zij niet van houden.
- De onderzoeker komt vaak op bezoek. Bijvoorbeeld iedere week, gedurende een jaar of nog langer. De onderzoeker leert hun leefomgeving goed kennen.
- Als iemand niet kan praten, brengt de onderzoeker veel tijd met hem of haar door. De onderzoeker probeert te begrijpen wat iemand bedoelt, die niet kan praten.
- Met dit soort onderzoek probeert de onderzoeker te begrijpen:
 - waarom mensen dingen zeggen
 - waarom mensen zich op een bepaalde manier gedragen
 - wat het voor hen betekent

HOOFDSTUK 3

Problemen die wij tegen kunnen komen als wij dingen te weten komen over de levens van mensen met een ernstige verstandelijke beperking

Wat wij te weten wilden komen

- Wij wilden onderzoek doen met mensen, die geen toestemming kunnen geven. Dit betekent dat zij ons niet kunnen vertellen of zij wel willen dat wij tijd met hen doorbrengen. Geeft dit problemen?
- Dit soort onderzoek houdt in:
 - proberen mensen te leren kennen
 - proberen te begrijpen hoe zij zich voelen over hun leven

Is dit soort onderzoek nuttig?

- De dingen die we over mensen te weten komen moeten privé blijven (bijvoorbeeld hun naam). Kunnen wij toch over het onderzoek schrijven?
- Sommige dingen die wij te weten zijn gekomen zijn erg schokkend. Mensen kunnen ervan in de war raken als ze het horen. Is het belangrijk dat wij er toch over schrijven?
- Er zijn erge dingen gebeurd met mensen die in grote instituten woonden. Die instituten zijn nu gesloten. Waarom is het toch belangrijk om erover te schrijven?

Wat wij gedaan hebben

- Wij keken heel zorgvuldig naar ons onderzoek in het instituut.

- Wij keken nog eens naar wat we te weten zijn gekomen en wat wij erover hadden geschreven.
- Wij lazen wat andere mensen hebben geschreven. Zij schreven over wat je wel en niet moet doen als je onderzoek doet met mensen die geen toestemming kunnen geven.

Wat wij te weten zijn gekomen

- Sommige mensen kunnen geen toestemming geven als het onderzoek begint. Maar de onderzoeker kan kijken wat de persoon doet, telkens als de onderzoeker op bezoek komt. Op die manier kan de onderzoeker zien of de persoon op die bepaalde dag wel mee wil doen aan het onderzoek.
- Mensen vinden het niet erg om mee te doen aan onderzoek als de onderzoeker tijd aan hen besteedt. De meeste mensen houden ervan als iemand in hen is geïnteresseerd.
- Het is belangrijk dat we over de levens van deze mannen en vrouwen schrijven. Andere mensen moeten het te weten komen. Wij moeten in de toekomst niet dezelfde fouten maken.
- Mensen die uit de instituten zijn verhuisd hebben nu nieuwe verzorgers. Het is belangrijk dat deze verzorgers weten wat er in het verleden met de mensen is gebeurd.

HOOFDSTUK 4

Het leven van mannen met een verstandelijke beperking, die op een gesloten afdeling wonen en moeilijk gedrag laten zien

Wat wij te weten wilden komen

- Er woonden 20 mannen op een gesloten afdeling in een oud instituut. Wij wilden ieder van hen goed leren kennen.
- Wat hadden zij voor een leven?
- Wat hadden ze nodig? Waar hielden ze van? Waar hadden ze een hekel aan?

Wat wij gedaan hebben

- Wij hebben veel tijd doorgebracht met de mannen op de gesloten afdeling. Wij bezochten hen bijna 3 jaar lang. We schreven alles op over deze bezoeken.
- Sommige mannen hadden nog ergens familie. Wij hebben met hun familie gepraat.
- Wij hebben over iedere man geschreven. Wij gaven deze gegevens over hun verhalen aan hun toekomstige verzorgers.

Wat wij te weten zijn gekomen

- De afdeling was troosteloos . Het leek meer op een hal of zaal dan op een huis.
- De meeste mannen woonden al van kindsaf aan in het instituut, soms waren zij nog geen 8 jaar oud.
- Ze werden niet als individuen behandeld, of als volwassen mannen.

- Andere mensen dachten dat zij gevaarlijk waren. Of dat ze anderen pijn deden op een seksuele manier.
- Zij waren altijd op de afdeling. Ze deden niks buiten de afdeling. Ze waren weggestopt van de buitenwereld.
- Het leek alsof het niemand iets kon schelen hoe zij zich voelden, zelfs niet als zij verdrietig of overstuur waren.
- Hun moeilijke gedrag werd met medicijnen behandeld. Niemand probeerde erachter te komen waarom zij zo ongelukkig waren.

HOOFDSTUK 5

Vrouwen met een ernstige verstandelijke beperking, die verhuisd zijn van een gesloten afdeling

Wat wij te weten wilden komen

- Er waren 11 vrouwen, die vrijwel hun hele leven op een gesloten afdeling hadden gewoond in een oud en groot instituut.
- Wat voor leven hadden zij?
- Hoe was het voor de vrouwen om in de maatschappij te komen wonen toen de afdeling gesloten werd?
- Lijkt hun leven nu meer op het leven van andere mensen in de maatschappij, of zijn zij nog steeds buitengesloten?
- Worden zij meer als gelijke behandeld door hun verzorgers, nu zij niet meer in het instituut wonen?

Wat wij gedaan hebben

- We hebben veel tijd doorgebracht met de vrouwen toen zij nog op de gesloten afdeling woonden en daarna in hun nieuwe woningen.
- We hebben alles opgeschreven over onze bezoeken.
- Sommige vrouwen hadden nog ergens familie wonen. Wij hebben met hun familie gepraat.

Wat wij te weten zijn gekomen

- Het was vaak erg moeilijk voor de vrouwen om te verhuizen.
- Niemand vertelde hen wat er gebeurde.

- Ze hadden weinig keuze over waar zij naartoe verhuisden of met wie zij samen gingen wonen.
- De mensen die voor hen zorgden in hun nieuwe huis wisten niet veel over hen. De nieuwe verzorgers wisten niets over het leven van de vrouwen. De verzorgers wisten niet waar de vrouwen wel en niet van hielden.
- Voor de meeste vrouwen leek het leven in hun nieuwe tehuis erg veel op hun oude leven. Er waren nog steeds veel regels. Ze kregen nog steeds te horen wat ze moesten doen. Ze kregen geen gelegenheid om nieuwe vrienden te maken. Overdag was er bijna niets te doen.
- Het was voor 3 vrouwen anders. Zij konden nu meer keuzes maken. Zij hadden een beter leven.

HOOFDSTUK 6

Verhuizen van een instituut naar een nieuwe woning

Wat wij te weten wilden komen

- 20 Mannen met een ernstige verstandelijke beperking zijn verhuisd naar een nieuwe woning. Zij hadden vrijwel hun levenlang op een grote, gesloten afdeling gewoond.
- Hoe was het voor hen om weg te gaan van de afdeling?
- Begon hun leven nu meer te lijken op het leven van andere mensen in de samenleving?
- Behandelden hun verzorgers hen nu meer als gelijke?

Wat wij gedaan hebben

- Wij gingen vaak bij de mannen op bezoek in hun nieuwe tehuis. Wij praatten met hen (hoewel de meeste mannen niet zelf konden praten).
- Wij kwamen erachter wat voor levens zij nu leidden.
- Wij deden mee met de dingen, die nu in hun nieuwe tehuizen gebeurden.

Wat wij te weten zijn gekomen

- Vergeleken met de afdeling, leken de nieuwe tehuizen van de mannen meer op de huizen van andere mensen in de samenleving.
- De mannen hadden meer vrijheid binnen hun huis, maar zij zaten nog steeds opgesloten. Ze hadden bijna niks te doen.
- Voor de meeste mannen veranderde er bijna niks.

- Ze hadden vrijwel geen leven buitenshuis. Ze leerden geen andere mensen kennen en maakten geen vrienden.
- De houding van hun verzorgers was erg belangrijk. Als de mensen die de baas waren zich niet veel van de bewoners aantrokken, dan leek het mooie nieuwe tehuis in de buurt nog steeds op een afdeling in een instituut.

HOOFDSTUK 7

Praten met moeders van thuiswonende jonge mensen met een ernstige verstandelijke beperking

Wat wij te weten wilden komen

- Hoe voelen ouders zich over de verzorging van een zoon of dochter met een ernstige verstandelijke beperking, die zeer moeilijk gedrag vertoont?
- Een moeder zorgt misschien wel de hele tijd voor één persoon. Vinden de andere gezinsleden dit erg?
- Krijgen gezinnen genoeg hulp van de instanties?
- Hoe kijken ouders tegen de toekomst aan?
- Zouden zij hun zoon of dochter laten opnemen in een tehuis?

Wat wij gedaan hebben

- We hebben 20 gezinnen 3 jaar lang bezocht.
- We praatten meestal met de moeders. Maar we praatten ook met de vaders, broers en zussen.

Wat wij te weten zijn gekomen

- De moeders besteedden bijna al hun tijd aan het verzorgen van hun zoon of dochter met een beperking. Deze zoon of dochter maakte echt deel uit van het gezin.
- Soms hadden de moeders bijna helemaal geen tijd voor hun man.
- Sommige gezinnen raakten geïsoleerd van vrienden en familie buiten het gezin.

- De plaatselijke hulpverlening was slecht. De gezinnen hadden veel meer hulp en steun nodig dan zij kregen.
- De moeders hadden niet veel goede woorden over voor de instellingen of tehuizen in de buurt en voor de mensen die daar woonden.
- Zij deden alles voor hun kind. Ze wilden beslist niet dat hun kind ooit in zo'n instelling of tehuis zou moeten wonen.

HOOFDSTUK 8

Praten met mensen uit gezinnen van gekleurde- en minderheids-groeperingen, die thuis voor een gezinslid met een verstandelijke beperking zorgen

Wat wij te weten wilden komen

- We weten al dat sommige mensen slechtere hulp krijgen dan anderen. Er is slechtere hulp voor:
 - Families met een andere huidskleur (zoals Afrika en de Caribische eilanden)
 - Etnische minderheidsgroeperingen (zoals mensen uit India, Pakistan en China)
- Vinden deze mensen dat zij goed worden geholpen? Krijgen zij de juiste hulp?
- Denken zij dat mensen hen soms oneerlijk behandelen?

Wat wij gedaan hebben

- We praatten met mensen uit 30 gezinnen, die thuis zorgden voor een volwassen gezinslid met een verstandelijke beperking.

Wat wij te weten zijn gekomen

- De gezinnen kregen niet genoeg hulp van buitenaf.
- Slechts 8 van de 30 gezinnen had een maatschappelijk werker. Slechts 3 van hen vond dat die maatschappelijk werker nuttig was.
- Heel weinig gezinnen vonden dat zij oneerlijk behandeld werden omdat zij tot een minderheidsgroepering behoorden.

- Meer dan de helft van de verzorgenden was ouder dan 60 jaar. Een kwart was ouder dan 70 jaar. Sommigen waren erg ziek of hulpbehoevend.
- De ouders vonden dat niemand hen hielp om vooruit te plannen, voor als zij niet meer voor iemand konden zorgen of voor als zij zelf dood gingen.
- Slechts weinig gezinnen hadden grotere families, die hen steun konden bieden.
- Het was het moeilijkst voor de gezinnen, die zorgden voor iemand die heel erg veel hulp van hen nodig had.
- De meeste ouders wilden niet dat hun zoon of dochter naar een tehuis of inrichting ging. Ze dachten niet dat hun zoon of dochter daar genoeg liefde en zorg zou kunnen krijgen. Ze waren bang dat niemand hun zoon of dochter daar kon beschermen tegen misbruik.

HOOFDSTUK 9

Jonge mannen met een verstandelijke beperking, die andere kinderen seksueel misbruiken: Praten met hun moeders

Wat we te weten wilden komen

- Sommige jongemannen met een verstandelijke beperking zijn seksueel misbruikt toen ze klein waren en misbruiken nu zelf andere kinderen.
- Hoe kijken hun moeders tegen hen aan? Hoe voelen hun moeders zich?
- Kregen de moeders de hulp en steun die zij nodig hadden? Kregen hun zonen hulp?
- Begrepen zij wat er aan de hand was met hun zonen?

Wat we gedaan hebben

- De jongemannen kregen psychotherapie met een groep andere jongemannen. Wij praatten gedurende die tijd met hun moeders. Het onderzoek duurde 3 jaar.
- Dit hoofdstuk gaat over de moeders. Maar we praatten ook met de jongens zelf.
- We praatten ook met de mensen, die voor hen zorgden op school of in een tehuis.

Wat we te weten zijn gekomen

- De moeders vonden dat zij erg weinig hulp en steun hadden gekregen de afgelopen jaren.

- Zij waren erg verdrietig over wat er in het verleden met hun zonen is gebeurd. Ze waren van streek over sommige dingen, die hun zonen nu deden.
- Het was moeilijker voor hun zonen om te praten over wat er met hen was gebeurd, omdat zij een verstandelijke beperking hadden.
- De moeders zeiden dat het moeilijk voor hun zonen was om met het feit om te gaan dat zij misbruikt waren. Andere mensen begrepen niet hoe moeilijk dat was. De moeders dachten ook dat het moeilijk was voor hun zonen om te begrijpen wat er nu met hen aan de hand was.
- De moeders probeerden het allerbeste te doen voor hun zonen. Zij waren erg bezorgd over wat er in de toekomst met hen zou gebeuren.
- De moeders dachten dat andere mensen hun zonen alleen maar als seksuele misbruikers zagen en niet als jonge mensen die zelf misbruikt waren.

HOOFDSTUK 10

Discussie

- Dit laatste hoofdstuk gaat over wat we allemaal te weten zijn gekomen.
- De manier waarop wij onderzoek deden was een goede manier om dingen te weten te komen. Wij leerden mensen heel goed kennen.
- De mannen en vrouwen op gesloten afdelingen hadden helemaal geen goed leven. Zij hadden geen vrienden buiten de afdeling. Ze brachten vrijwel al hun tijd op de afdeling door. Ze hadden daar niks te doen.
- De mannen werden anders benaderd dan de vrouwen. Het personeel vond dat de mannen agressief waren en behandelden de vrouwen alsof het kinderen waren.
- Na de verhuizing uit het instituut wonen zij in mooiere huizen. Maar hun leven veranderde niet veel. Ze zaten nog steeds opgesloten. Ze hadden thuis niet veel te doen. Ze maakten geen nieuwe vrienden.
- Wij vergeleken het leven van de mannen en vrouwen in de instituten met het leven van mensen, die thuis woonden met hun familie. We kwamen erachter dat hun leven heel anders was. De gezinnen hielden veel van de mensen die thuis woonden. Hun leven leek meer op dat van andere mensen in de samenleving.
- De moeders van jongemannen, die misbruikt waren en die nu zelf andere kinderen misbruikten, hadden veel meer hulp en steun nodig. Zij dachten dat het niemand kon schelen wat er met hen gebeurde. De mensen, die met deze jongens werkten vonden dat zij maar in een inrichting of tehuis moesten gaan wonen. Maar hun moeders wilden hen thuis houden.

- De Engelse regering heeft een rapport geschreven over hoe het moet worden voor mensen met een verstandelijke beperking. Daarin staat dat zaken moeten worden verbeterd. Maar er is niet veel veranderd voor mensen met een ernstige verstandelijke beperking met moeilijk gedrag. De houding van mensen tegenover hen is niet veranderd.

Acknowledgements

First and foremost I want to thank Sheila Hollins for her enduring encouragement and support over the last 15 years, and for her faith in the strange mind and method of a social anthropologist swimming in a sea of psychiatrists.

I am also grateful to my colleagues at St George's, past and present, for their friendship and support.

This thesis is one of the outcomes of the ongoing collaboration between Maastricht University (Netherlands) and St George's, University of London (UK). I am very grateful to Leopold Curfs for giving me this unique opportunity to look back at my work over the years at St George's, and bring it together in this PhD thesis.

Thank you, Tom and Emma, Olivia and Chris, Jess Toby and little Barnaby, for always being there, and for the joy that you bring into my life.

And Peter, I have missed you throughout this whole exercise. You were my greatest support, and sternest critic.

Curriculum Vitae

Jane Hubert

Education

BA (Hons.Oxon.) Psychology and Philosophy (P.P.P.); Postgraduate Diploma in Anthropology (Oxon.); Graduate studies, Department of Anthropology, London School of Economics and Political Science, London.

Current Appointment

- 1994 - Senior Research Fellow and Honorary Senior Lecturer in Social Anthropology, Division of Mental Health, St. George's, University of London.
- [2008 - Honorary Senior Research Associate, Institute of Archaeology, University College London]

Current and recent research at St George's

Social anthropological study of 20 men with severe learning disabilities and challenging behaviour living in a locked ward of an old 'mental handicap' institution, and their transition to smaller homes.

Senior Researcher on qualitative project 'Understanding and addressing the needs of 11 women with severe learning disabilities in transition from a locked ward'.

Supervisor of qualitative project: 'Helping adults with learning disabilities to survive bereavement and move on'

Supervisor of mixed methodology project: 'The effectiveness of group therapy for adolescent boys with learning disabilities who have been sexually abused and who now present with sexualised behaviour'.

Qualitative study: 'People with learning disabilities in families from Black and ethnic minority groups: the accessibility and appropriateness of existing services in an inner London borough'.

- Qualitative study: ‘Listening to the voices of people with learning disabilities and their carers from marginalised groups in a London borough’.
- Research advisor on ethnographic study: ‘The experiences of people with learning disabilities who have cancer’
- Research advisor on qualitative project: ‘Reaching the isolated: improving access to families (women with children under 5) with limited English’
- Research advisor on project ‘Health information and advocacy for people with learning disabilities’.

Previous Appointments

- 1991-1994 Senior Research Fellow, Department of Psychology, University of Southampton. Qualitative study with families who have a young adult who has recently suffered a severe head injury; individual/social effects on the young people, and on their families (funded by the Joseph Rowntree Foundation).
- 1986-1990 Senior Research Fellow (as above). Social anthropological study of twenty families who have, living at home, an adolescent or young adult with severe or profound learning disabilities and challenging behaviour (funded by the Joseph Rowntree Foundation).
- 1984-1986 Researcher, HCERT, Department of Community Medicine, University of Southampton: project to develop procedures to help parents with young adults with profound learning disabilities and severe challenging behaviours.
- 1976-1981 Resources Co-ordinator, Australian Institute of Aboriginal Studies, Canberra, Australia: to collect and document photographic, film and taped Aboriginal material. Direction of research staff (in ethnomusicology, linguistics and anthropology); liaison with Aboriginal communities. Executive Officer: AIAS Psychology Academic Advisory Committee.
- 1974-1976 Research Officer, Cape York Project, AIAS (as above): evaluation of research needs and priorities (social anthropology and psychology).
- 1972-1973 Fieldwork in Bali, Indonesia. Preliminary research on family and kinship relationships.
- 1970-1972 Library research: cross-cultural beliefs and practices in the context of conception, contraception, abortion, pregnancy and birth.
- 1965-1969 Senior Research Officer, Department of Anthropology, London School of Economics. Ethnographic research project on the social factors, beliefs and practices involved in conception, contraception, pregnancy and birth (in first pregnancies).

1960-1965 Research Officer/Senior Research Officer (as above). Team Leader on the North London Kinship Project (with Chicago University), an ethnographic study: 'Extra-familial kinship among middle-class families in London'.

Membership of Professional Societies

Royal Anthropological Institute (Fellow)

Association of Social Anthropologists

Research interests

Familial, social and cultural aspects of learning disability, especially with regard to people with severe learning disabilities and mental health problems; the experience and effects of institutionalization and deinstitutionalization on social, individual and gender identity; cultural attitudes, beliefs and practices; social exclusion; indigenous claims for the return of human remains from museums; oral history and cultural heritage in the context of institutionalization; concepts of ethnic and social identity.

Publications

Hubert, J. (1965) Kinship and geographical mobility in a sample from a London middle-class area. *International Journal of Comparative Sociology* 4 (1): 61-79.

Hubert, J. (1965) Kinship and geographical mobility in a sample from a London middle-class area. In *Kinship and Geographical Mobility*, Piddington, R. (ed.) Leiden: Brill.

Hubert, J., Forge, A. and Firth, R. (1968) *Methods of Study of Middle-class Kinship in London: a working paper on the history of an anthropological project*. London: Department of Anthropology, London School of Economics and Political Science.

Firth, R., Hubert, J. and Forge, A. (1970) *Families and their Relatives*. London: Routledge and Kegan Paul.

Hubert, J. (1974) Belief and reality: social factors in pregnancy and childbirth. In *The Integration of a Child into a Social World*, Richards, M. P. M. (ed.). Cambridge: Cambridge University Press. 37-51.

Barwick, D., Forge (Hubert), J. and Urry, J. (1979) The Australian Institute of Aboriginal Studies. In *Handbook for Aboriginal and Islander history*, Barwick, D. et. al. (eds). Canberra: AIAS. 16-20.

Kushlick, A., Hubert, J. and Smith, J. (1987) An intervention package to teach parents, residential care staff and teachers of children with severe learning difficulties and seriously self defeating behaviours. In *Extending and Developing Portage*, Hedderly, R. and Jennings, K. (eds). Windsor: NFER-Nelson. 104-124.

- Hubert, J. (1988) The disposition of the dead. *World Archaeological Bulletin* 2: 12-39.
- Hubert, J. (1989) A proper place for the dead: a critical review of the "reburial issue". In *Conflict in the Archaeology of Living Traditions*, Layton, R. (ed.). London: Unwin Hyman. 131-166.
- Hubert, J. (1990) At home and alone. In *Better Lives: changing services for people with learning difficulties*, Booth, T. (ed.). Sheffield: Community Care/Joint Unit for Social Services Research, University of Sheffield. 105-114.
- Hubert, J. (1990) The first World Archaeological Congress Inter-Congress, Vermillion, S.D. USA. *World Archaeological Bulletin* 4: 14-19.
- Hubert, J. (1990) A proper place for the dead: a critical review of the 'reburial issue' *Journal of Indigenous Studies* 1: 27- 62.
- Hubert, J. (1991) After the Vermillion Accord: developments in the "reburial issue". *World Archaeological Bulletin* 5: 113-118.
- Hubert, J. (1991) A mixed blessing: twenty families' experience of short term residential care. *Community Care* 853: 18-19.
- Hubert, J. (1991) Dissatisfaction with essential respite care. *Social Care Research Findings*. York: Joseph Rowntree Foundation.
- Hubert, J. (1991) *Home-bound: crisis in the care of young people with severe learning difficulties: a story of twenty families*. London: King's Fund.
- Hubert, J. (1992) *Too Many Drugs, Too Little Care: parents' perceptions of the administration and side-effects of drugs prescribed for young people with severe learning difficulties*. London: Values Into Action.
- Hubert, J. (1992) Administering drugs to young people with severe learning difficulties. *Social Care Research Findings*. York: Joseph Rowntree Foundation.
- Hubert, J. (1992) A spoonful of sugar. *Community Care* 902: 16-17.
- Hubert, J. (1992) Dry bones or living ancestors? Conflicting perceptions of life, death and the universe. *International Journal of Cultural Property* 1: 105-127.
- Hubert, J. (1992) Poisonous solutions to complex problems. *Community Living* 6: 2.
- Hubert, J. (1992) Slightly fewer drugs, a little more care? *VIA Newsletter* 69: 4.
- Hubert, J. (1993) Human options: the spirit, the body and the disposal of the dead. In *Kun-aitupii: coming together on native sacred sites: their sacredness, conservation and interpretation*, Reeves, B. and Kennedy, M. A. (eds). Calgary: Archaeological Society of Alberta. 25-37.
- Ucko, P. and Hubert, J. (1993) The basketry experience: a 70-minute re-definition of 'self'. *Journal of Museum Ethnography* 2: 157 - 162.

- Carmichael, D., Hubert, J., Reeves, B. and Schanche, A. (eds) (1994) *Sacred Sites, Sacred Places*. London: Routledge.
- Hubert, J. (1994) Sacred beliefs and beliefs of sacredness. In *Sacred Sites, Sacred Places*, Carmichael, D., Hubert, J., Reeves, B. and Schanche, A. (eds). London: Routledge. 9-19.
- Carmichael, D., Hubert, J. and Reeves, B. (1994) Introduction. In *Sacred Sites, Sacred Places*, Carmichael, D., Hubert, J., Reeves, B. and Schanche, A. (eds). London: Routledge. 1-8.
- Hubert, J. (1995) *Life After Head Injury: the experiences of twenty young people and their families*. Aldershot: Avebury.
- Hubert, J. (1995) The social repercussions of severe head injury. *Social Care Research Findings*. York: Joseph Rowntree Foundation.
- Hubert, J. (1996) Confronting the realities: dilemmas facing parents of young people with severe learning disabilities and challenging behaviour. Proceedings of Conference: *Rights of Passage: the transition to adulthood for people with learning disabilities*. 21-27.
- Hubert, J. (1996) A severe blow. *Community Care* 1147: 32-33.
- Bonell-Pascual, E., Huline-Dickens, S., Hollins, S., Esterhuyzen, A. Sedgwick, P., Abdelnoor, A. and Hubert, J. (1999) Bereavement and grief in adults with learning disabilities: a follow-up study. *British Journal of Psychiatry* 175: 348-350.
- Hubert, J. (ed.) (2000) *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*. London: Routledge.
- Hubert, J. (2000) Introduction: the complexity of boundedness and exclusion. In *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*, Hubert, J. (ed.). London: Routledge. 196-207.
- Hubert, J. (2000) The social, individual and moral consequences of life in long-stay institutions. In *Madness, Disability and Social Exclusion: the archaeology and anthropology of 'difference'*, Hubert, J. (ed.). London: Routledge. 1-8.
- Hubert, J. and Hollins, S. (2000) Working with elderly carers of people with learning disabilities and planning for the future. *Advances in Psychiatric Practice* 6: 41-48.
- Hubert, J. and Hollins, S. (2000) Special needs of adolescents and elderly people with mental retardation. In *The New Oxford Textbook of Psychiatry*. Oxford: Oxford University Press. 1995-1999.
- Fforde, C., Hubert, J. and Turnbull, P. (eds.) (2001) *The Dead and Their Possessions: repatriation in principle, policy and practice*. London: Routledge.
- Hubert, J. and Fforde, C. (2001) Introduction: the reburial issue in the twenty-first century. In *The Dead and Their Possessions: repatriation in principle, policy and practice*, Fforde, C., Hubert, J. and Turnbull, P. (eds). London: Routledge. 1-16.

- Dowling, S., Hubert, J. and Hollins, S. (2003) Bereavement interventions for people with learning disabilities: 'My mother's name was Marjorie'. *Bereavement Care* 22 (2): 19-21.
- Hubert, J. (2004) *Services for people with learning disabilities from Black and ethnic minority groups: a qualitative study of 30 families in a South London Borough*. Research Report. London: St George's, University of London.
- Dowling, S., Hubert, J., White, S. and Hollins, S. (2006) Bereaved adults with intellectual disabilities: a combined randomized controlled trial and qualitative study of two community-based interventions. *Journal of Intellectual Disability Research* 50 (4): 277-287.
- Fforde, C. and Hubert, J. (2006) Indigenous human remains and changing museum ideology. In *A future for archaeology: the past in the present*, R. Layton, S. Shennan and P. Stone (eds). London: UCL Press. 83-96.
- Hubert, J and Hollins, S. (2006) Men with severe learning disabilities and challenging behaviour in long-stay NHS hospital care: qualitative study. *British Journal of Psychiatry* 188: 70-74.
- Hubert, J. (2006) Family carers' views of services for people with learning disabilities from Black and ethnic minority groups: a qualitative study of 30 families in a south London borough. *Disability & Society* 21 (3): 259-272.
- Hubert, J., Flynn, M., Nicholls, L. and Hollins, S. (2007) 'I don't want to be the mother of a paedophile': the perspectives of mothers whose adolescent sons with learning disabilities sexually offend. *Journal of Child Psychotherapy* 33 (3): 263-376.
- Hubert, J. and Hollins, S. (2007) Ethnographic research in closed institutions: ethical issues. *Research Ethics Review* 3 (4): 122-126.
- Ucko, P., Qin L. and Hubert, J. (eds) 2007 *From concepts of the past to practical strategies: the teaching of archaeological field techniques*. London: Saffron Press.
- Owen, K., Hubert, J. and Hollins, S. (2008) Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities* 36 (4): 220-226.
- Hubert, J. and Hollins, S. (2008) Special needs of adolescents and elderly people with intellectual disability. In *The New Oxford Textbook of Psychiatry* (2nd edition), Gelder, M. (Ed). Oxford: Oxford University Press. 1878-1882.
- Tuffrey-Wijne, I., Bernal, J., Hubert, J., Butler, G. and Hollins, S. (2009) People with learning disabilities who have cancer: an ethnographic study. *British Journal of General Practice* 59: 503-509.