

Cambridge University Press

978-0-521-62569-2 - Deinstitutionalising Women: An Ethnographic Study of Institutional Closure

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Excerpt

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CHAPTER 1

Entry Points

I am not neutral, I am not distanced, for being an outsider does not mean to be cool and clinical; it must mean to burn with those fires which define you as the outsider.

(S. L. Gilman, 1991, p.17)

This book is about women and deinstitutionalisation. In particular it is about how deinstitutionalisation entered the lives of twenty-one women who were labelled as having intellectual disabilities and challenging behaviours. The book grew out of twenty months of field work with these women, who lived in a locked women's world at Hilltop, a large institution for people with intellectual disabilities. It describes their lives there prior to the decision to close the institution and it provides an account of the way deinstitutionalisation in process affected their lives and those of the people around them.

Essentially, this book is a collection of voices: those of the women who lived in the locked unit, their families, the women staff who worked with them and the people who were responsible for closing the institution. But these voices and stories are heard through my voice, and for this reason it is important at the beginning of the book that my biases, interests and limitations be made clear. This chapter, then, describes my reasons for undertaking the research, provides a brief account of the methodology used, and outlines the theoretical and personal perspectives which influenced my work as researcher.

Rationale for the Study

The study began with my questions and concerns about the impact of ten years of deinstitutionalisation policies on the lives of people with

intellectual disabilities who continued to live in large institutions. In order to explore this issue I gained access to Hilltop, an institution where 440 people were living. The study began with interviews with the staff and managers working there.

Within six weeks of entering the institution I had based myself within Unit N, a locked unit for women at the institution. My motives for selecting this unit for intensive study were personal, pragmatic and research based. The personal motives were complex and were not at all clear at the time, or even now. From my first sight of the women in the grounds of the institution I was fascinated by their loudness and the respect with which staff spoke of them. Perhaps I hoped to learn something from the women's experience which would help me understand my own position as a woman. Perhaps I was drawn to the unit because of the 'challenge' which these women and their lives appeared to pose for me as an individual. Once in the locked unit, I became enmeshed with the women in a complex set of relationships and emotions. I became committed not only to carrying out my research with them: I had a strong interest in ensuring that during deinstitutionalisation they were treated fairly and I very much wanted the quality of their lives to be improved following the closure of the institution. Further, I wanted to give them a voice: I wanted to be a witness to their experiences and to tell their stories.

More pragmatically, while I was regarded with suspicion by staff in other parts of the institution, staff in the locked unit welcomed my presence. They were ready to accommodate my demands for time and access. They saw my entry to the unit as a way of evaluating the work they were doing and as offering an opportunity for gaining knowledge about research and about the women who lived there.

There were also more traditional research-oriented reasons for my decision. The unit had a fearsome reputation in the institution. From my first day I was warned about the people living there, and staff outside the unit talked with anxiety about the possibility of being rostered to it. Consequently, I reasoned that if deinstitutionalisation had impacted positively on the institutional life of these women, who were regarded as the 'outcasts' within the institution, then perhaps generalisations about its impact could be applied to other, less stigmatised groups and individuals.

Finally, as a woman and a feminist, I was concerned that no previous studies had focused on the lives of women in institutions and I was interested in discovering in what ways institutional practices might be influenced by gender.

Four months after I started working in the locked unit, a decision was made to close the institution. My study instantly changed its focus, for

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here was deinstitutionalisation in practice. From this point on, my research was shaped and driven by the impetus of events. My contact with the women provided a focus for a study of how the ongoing process of deinstitutionalisation affected them and those around them. Because I had been in the institution for some time I was accepted by senior managers and so gained access to all levels of the closure process.

The Research Methodology

The research involved four stages. The first consisted of *going into* Hilltop and my initial meetings with the people living and working there. The second stage occurred *inside* the institution. During this stage I gained access to the locked unit, spent many hundreds of hours sharing the lives of the women who lived there, and was involved with the staff who worked with them and their families. The third stage involved *coming out* of the institution. During the closure of Hilltop I stayed with the women and watched how decisions were made about their lives. I was a participant observer in the consultations and meetings held to decide where the women would go after the institution closed, and I interviewed the managers and workers responsible for the closure process. In the final stage I moved *outside* the institution in order to reflect on the experience of deinstitutionalisation and to write this book.

Going In

The formal process of going into Hilltop was not very difficult. The Chief Executive Officer was enthusiastic about the idea of someone carrying out a long-term study there, and permission was readily obtained from the relevant government department. However, these formal requirements did not really 'get me in'.

Staff at the institution had been under frequent attack from the media because of conditions in the institution and were defensive and resistant to the idea of my research. Consequently, each interview with a staff member was an exercise in careful negotiation. My decision during this time to base myself in the locked unit assisted the process of 'getting in'. Unit N was perceived as one of the most difficult to work in and staff from other units respected those who worked there. My commitment to undertake long-term work in the unit led to a more positive attitude towards my research: I was seen as less of a threat to other staff since most of my time was spent confined within one unit. In their view I was effectively locked away.

To get into the locked unit I negotiated a contract with the staff in the unit which involved assisting them with evaluations of some innovative

work which they were carrying out. In return they gave me access to the unit and were willing to allow me to be part of its life. Negotiations about access to the unit with the women who lived there occurred only on an informal basis and this was a constant source of concern to me.

Inside

My time in Unit N consisted of making detailed observations of the lives of the women living and working there. The emotional impact of living and working in a large 'total institution' was profound. I was shocked at the lives which the women lived in the locked unit. They were confined behind locked doors with little access to the institutional grounds and even less to the wider community.

Within the unit there was nothing to do and the monotony of the days was broken for some women only by short periods of occupational therapy or by irregular visits from family. Violence was a constant part of life within the unit. Some women were aggressive to each other or to staff; others sought to injure themselves or attacked the building in which they were locked. I watched this in helpless pain and, as a participant observer in the unit, became part of the means of controlling the women. It was not possible to be in the unit and not be active. At times I was afraid of being attacked or of not being able to 'manage' an incident. At other times I was shocked at the speed with which I became institutionalised.

L. [staff member] was trying to get Brigid to leave the couch and go for a bath. Brigid seized her by the hair and refused to let go. L. tried to remove Brigid's hand. I saw this happening as I came through the door into the day room. I asked L. if she wanted some help and she asked me to hold Brigid's hand while she freed herself. She then asked me to help her lift Brigid off the couch. I started to do so, then realised that I was actually 'manhandling' someone. I stopped. (Field notes)

Through incidents such as this, I became aware of the strength of the staff pressure to conform to the culture in the unit. Without staff support I would not be able to retain my place there. I also experienced at first hand the powerlessness of staff and families in attempting to change the situation for the women.

I spent much time sitting in the day room observing what was happening around me. I talked with the women and took part in their day-to-day activities. These included going for walks, watching television and looking at magazines or cards. I was also part of the unit's routines. At meal times I assisted people who had difficulty in eating, and I helped people go to the toilet or have a bath. I scrubbed floors and mopped up

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urine and vomit. The work was physically exhausting and emotionally tiring. The unit was noisy, women screamed and shouted, the television (when it worked) was on, the phone rang loudly and there was the constant threat (or reality) of physical aggression.

As time went on, my knowledge of the women living in the unit increased. It was not possible to hold 'formal' interviews even with the women who could speak, but I did hold many informal discussions and conversations with them. In addition to the time spent with the women in the locked unit I spent long hours reading yellowing files which documented their lives in the institution, and also read their General Service Plans (GSPs).

During my twenty months of field work I formally interviewed all members of staff in the unit at least twice. In addition, my field notes included many hundreds of conversations and discussions. Throughout the research process I kept detailed field notes, slipping away from the unit at lunch times and during breaks to write them up before later transcribing them.

Coming Out

With the decision to close Hilltop, the complexity of the study increased. I obtained permission to be an observer at all management meetings concerned with institutional closure and also of the decision-making processes about the future of the women carried out during that closure.

I interviewed the six managers responsible for the closure of the institution three times throughout the research and carried out individual interviews with their staff who were directly involved with the women. In addition I facilitated group consultations with all project team staff. During this time I continued to spend time with the women living and working in the unit.

I contacted and interviewed eighteen members of the women's families, or their advocates. The time I spent with the families was extremely painful. None of them had been given any opportunity previously to discuss their daughter/sister. Each told stories filled with the pain and grief of their life with the woman before she went to the institution. These stories gave me a different view of individual women. Sometimes the views a family had of their relative were completely contradictory to my experiences with her. Listening to the families' stories, I came to understand the need some had to distance themselves from their relative, and some of the resistance they felt about deinstitutionalisation. I was forced to re-examine my previous assumptions and beliefs about the role of families and the views I held about deinstitutionalisation.

I found the gap between my encounters with closure team members and life in the unit enormous. This increased the stress involved in the field work. Further, because of industrial disputes resulting from the closure decision, I found myself privy to information from groups in conflict with each other. Much of this information could not be shared with anyone. Paradoxically, therefore, as my relationships with people at the institution became closer over time, as we worked, ate and talked together I was conscious of an increasing estrangement.

During this time I watched the dismantling of the women's world. It was an extremely intense experience which evoked strong feelings. At different stages I was angry, joyous, grieving, fearful and outraged. Some of my research data suggest that these feelings were experienced by many others involved in the closure process.

My role with the women changed over time. From being a participant and intruder into their lives in the unit, I became an advocate for some of them during consultations to decide their futures. With staff in the unit I tried to provide some support in the transition time before they left the institution. And I held their stories.

Outside

The research concluded as the institution closed. As the final months went by I became increasingly a receptacle for the grief and the stories of others. 'You'll tell the story' was a refrain I heard from different people. Others began to plan their futures, new jobs, new homes, a new way of life. I was left symbolically holding the institution and the thousands of stories which form the basis of this book, for while the institution came to an end for those working and living there, I relived the experience through writing about it. There was a trust from those with whom I had been involved that I would tell 'their story' and tell it as they would want it told. Yet this was a trust that in some instances I was forced to betray, for I had to choose the stories and to make of them a new one.

Nor did I finally get outside. I had formed close links with the women who lived in the locked unit and I spent time in following them up after they left the institution. I became an informant to whom others would come to find out how the women's lives had changed. I also kept in contact with the closure team and with the staff with whom I had worked in the unit.

Sharing information gained during my field work with those with whom I had been involved proved difficult. During the field work I had written a series of reviews of the processes of deinstitutionalisation which had been given back to those managing the closure. There had

been acceptance of these 'working papers' by those involved and they had proved to be a useful source of information. However, accounts of life in the unit proved confronting for staff who had worked there. Reading draft chapters they relived the sense of powerlessness and the relationships which were broken by the institution's closure. One staff member commented: 'I don't want to read any more. I just want to forget the whole thing.' There have been times, as I struggled with reliving the experiences of my twenty months with the women, that I too have wanted to forget the whole thing.

The Positions of the Researcher

At different times during this research I held different positions in relation to those with whom I worked and in relation to the data I collected. I deliberately entered the field with the intention of remaining as open as possible to the experience with which I was engaging, and I eschewed adopting a particular theoretical position into which my data might fit. However, I did take particular theoretical frameworks with me into the field work. These provided themes which influenced the conduct of the research.

As the study developed, further themes emerged from my experiences, from involvement with the data and from reflection and reading. In this chapter these two sets of themes are somewhat artificially divided into 'entering' and 'emerging' themes, and while the latter are introduced in this chapter, they receive much greater discussion later in the book. These themes were not always equally important or relevant to me throughout my field work, but they did influence the positions I held during the research process.

Entering' Themes

It is precisely the encounter between the social scientist's own beliefs and practices and those of the people he or she is studying which makes up whatever understanding we can have of another social reality. (Outhwaite, 1985, p.29)

The experience and theoretical positions I brought with me to the study influenced the way it was carried out, and some became influential too in the way the data were later interpreted.

Knowledge of Intellectual Disability

Although I had no previous experience of living or working in a total institution, I had worked as a researcher with people with intellectual

disabilities in a variety of community settings (Johnson, Andrew and Topp, 1987; O'Brien and Johnson, 1987; O'Brien and Johnson, 1988; Johnson and O'Brien, 1989; O'Brien and Johnson, 1993). I had a firm commitment to the value of deinstitutionalisation and a concern for the fate of those I saw as unnecessarily segregated from the community.

I was interested in exploring 'the personal, subjective experiences of people with developmental (intellectual) disabilities and those around them' (Taylor, Bogdan and Lutfiyya, 1995, p.1) in order to understand better the meaning their lives had for them. From past research and reading I had learned the research skills of clear, straightforward written and spoken expression, the need to share ideas, to provide a relatively informal environment in which to talk to people, and to listen with care and attention (Bogdan and Taylor, 1976; Munro, 1977; Bogdan and Taylor, 1982; Bogdan and Taylor, 1989a; Potts and Fido, 1991; Ferguson, Ferguson and Taylor, 1992a; Booth, 1996).

I had not worked very much with people who were unable to speak directly with me, but I was aware that participant observation, taking time to be with someone and watching my own reactions to their behaviour and feelings would provide guides to communication (Edgerton, 1984a; Biklen and Moseley, 1988; Gleason, 1989; Goode, 1989; Wilkinson, 1989; Sinason, 1992).

Qualitative Research

I began this study with a view that a qualitative methodology was the one most suited to my purposes. This view was quickly confirmed as the focus of the research became the lives of the women. Adopting this perspective in order to research did not just mean a focus on qualitative methods, but involved the adoption of a research paradigm described by Ferguson, Ferguson and Taylor (1992b) as 'interpretative qualitative research'. The consequences of using this paradigm profoundly influenced the goal of the research, the way it was carried out and the assumptions on which it was based.

The goal of this study was essentially to 'describe, interpret and to understand' (Ferguson *et al.*, 1992b, p.7) the processes which were impinging on the lives of the women and to explore reactions to them. The major method used to achieve this goal was participant observation. This included active ongoing involvement in the life of the unit over an extended period, discussions with the women who lived there, and interviews with families, advocates, staff and managers. It also included the documentation of meetings and the analysis of documents and files (Edgerton, 1971; Estroff, 1981; Frankenberg, 1982; Gans, 1982; Burgess, 1984; Jorgensen, 1989; Weiner, 1990; Edgerton, 1991; Richardson, 1991).

The study was based on a number of assumptions about the nature of research ‘reality’ outlined by Ferguson *et al.* (1992b). In particular I held firmly to the view that reality is created and social, and that ‘people as social actors construct the reality or truth of a situation’ (Ferguson *et al.*, 1992b, p.5). I also believed that the division, promulgated in much empirical research, between the researcher as an objective observer and the subjects to be studied was artificial and that the experiences, values and ideas which I brought to the study were an important part of the data which had to be acknowledged openly as part of the research process (Rose, 1990). Finally, I believed that the data I obtained during the research would be value laden.

The utilisation of a qualitative interpretative methodology meant that rich data were accumulated from field notes, transcribed interviews and texts which were made available during the research (for example ‘client files’). It was an open-ended, interactive form of research which sought to ‘bridge the gap between stories and research’ (Taylor *et al.*, 1995, p.1) .

Action Research

My past experience in research had been that carried out from an action research position. There are differing views about the nature of action research (Sanford, 1970; P. A. Clark, 1972; A. W. Clark, 1976; Susman and Evered, 1978; Brown and Tandon, 1983; Carr and Kemmis, 1986; Kemmis, 1990; Chein, Cook and Harding, 1990; McTaggart, 1991; Schratz and Walker, 1995; Jennings, 1996; Stringer, 1997). These views reflect a spectrum ranging from minimal participation by those taking part in the research, to the integral involvement of all those engaged in it. Within the context of this research I used the following definition of action research:

[Action research] aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework. (Rapoport, 1970, p.499)

I believed that this approach was ethically necessary in working with people who were disadvantaged and from whom I was seeking information. It was a means of establishing some form of reciprocity.

I saw action research as involving the following characteristics. First, it is collaborative (Rapoport, 1970; Cherns, 1976), involving the development of relationships with others at the research site. Second, it is participatory, with people involved in the research taking part in its design and implementation (Cunningham, 1976). Inevitably, this means

that it must problematise the relationship between researcher and participants (Finger, 1990). Third, it is change oriented and aims to alter conditions or behaviour. Finally it involves a focus on group interactions and relationships (Susman and Evered, 1978).

The nature of the people and the organisation involved in this research precluded a full commitment to a participatory action research approach, however the research was shaped and influenced by a commitment to that underlying philosophy. In practice, action research became an integral part of the research in the following ways. A number of different forums were developed which involved people in the research process. These included a group of senior managers at the institution who met to talk about work concerns relevant to my study and who provided advice and information. I also participated in staff seminars and joined a planning group which organised a three-day seminar to conclude the closure project.

An informal group of staff at the locked unit initiated and then participated with me in designing an evaluation of an innovation being developed in the unit. In addition to its usefulness to them, this work was helpful in developing my own study.

Later I worked with managers of the deinstitutionalisation process to provide two policy papers about it. These were then fed back to staff and were used to assist in the programme of closure.

Developing Theory from the Research Experience

The study was essentially ethnographic in nature. It involved me in twenty months of participant observation and in a study of actions and activities as they occurred (Burgess, 1982; Hammersley and Atkinson, 1992). It was open-ended and flexible in nature and it involved a detailed collection of rich descriptive data obtained from many different sources (Bogdan and Biklen, 1992). It also involved a reflexive approach in which my experiences and reactions to them became part of the research data (N. Rose, 1990).

Although I began with a particular focus and a plan of action for the study, the research design developed largely as a result of reflecting on the experiences in which I was involved at the institution. From such reflections arose questions for which I sought answers. For these reasons it was important to keep the collected data as broad and rich as possible. However, my intention was not purely descriptive: I was also concerned to develop from my experiences theories which seemed to best fit them.

Reflexivity

There are many voices in this study, but inevitably they are all heard through my voice. For this reason, if for no other, it was important that