Chapter Six

Instituting Practices of Reason and Normality

We had better find out what is normal for you before we describe you as abnormal.

T. S. Elliot

The "historical bifurcation of the normal and the pathological", Gleason (1989: 7) argued, has had consequences for the way that intellectually disabled people have been treated, educated and managed. It has sanctioned staff attitudes towards intellectually disabled people, and set the parameters for the way their behaviour has been interpreted (Ryan & Thomas 1987: 67-82). On the basis of their supposed abnormality, intellectually disabled people have been perceived and treated as less than fully human. While this attitude has been challenged through recent changes in institutional practice and legal obligation, and through an increasing emphasis on the principles of normalisation and equal rights, the ambiguous and problematic status of intellectually disabled people remains a defining feature of the institutional world within which so many of them exist. This is so in part because contemporary practices in the field are informed and ordered according to the symbolic scheme of reason and normality.

In order to be integrated into society, intellectually disabled people must submit to an ongoing process of training and management. The policies of normalisation and deinstitutionalisation, combined with the principles of
equality and the right to an enhanced "quality of life"\(^1\), aim to transform the intellectually disabled into socially recognisable people in order for them to participate socially at all. The notions of humanness, normality and sociality that underpin this management and training are thoroughly steeped in notions of the rational and reasonable person, but with one further specification. Instituted practice underlines the value of reason embodied in work; not the moral and aesthetical dimensions of reason embodied in sociality itself, but the practical utility of tasks understood as productive. Intellectually disabled people are being trained to function in an impersonal, vocationally-oriented world, and the skills and competencies that are encouraged are based on this aim.

Individual service plans (ISPs), individual training days, and behavioural management practices are all geared towards aiding intellectually disabled people to assimilate the social skills of a rational, working being. While this may be an apt approach for the mildly intellectually disabled, it is a problematic course for the severely disabled who mostly are unable to assimilate the practices of a rational, working being. Indeed, in this context the practices designated as 'work', and differentiated from other practices, remain quite obscure to such people, while practices and socialities of interest to them become institutionally invisible.

In this chapter I use my fieldnotes to illustrate the way in which the symbolic scheme of reason and normality is instituted into training practices designated to cultivate a working being properly domesticated. The intrusion of these practices into the lives of intellectually disabled people will be

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\(^1\) There has been a recent emphasis in the services for intellectually disabled people on what is called "quality of life" (Atkins 1998; Rapley & Beyer 1996). This supposedly focuses on individual happiness and life enhancing activities rather than skills training and normalisation issues. Despite this change in emphasis, "quality of life" goals have effectively resulted in an additional qualitative assessment of service provision. They also tend to stress lifestyle, health, independence and safety issues rather than intimacy and social relatedness (Atkins 1998: 8, 150-157). As shall be argued later in the chapter, quality of life practices also continue to incorporate skills training as an essential attribute of an enhanced life. Therefore, quality of life is not an alternative to the principle of normalisation. It is, rather, an extension of it.
examined both in relation to Xanadu and to Stockton where my sister lives. The proliferation of record keeping and surveillance as a means for managing and training intellectually disabled people will also be examined with respect to the increasing rationalisation of their world. Such practices, however, are not just adhered to at the activities centre and sheltered workshops. They are expected to be continued, vigilantly, in the intimacy of the home as well. Policies of normalisation and integration provide a useful entry into these issues.

**Normalisation and Integration Policies**

The theory and practice of normalisation was influenced by post-WWII political concerns with human rights, civil rights, individualism, and social welfare in Europe and North America (Whitehead 1993: 47-51; cf. Ashton 1995; Burton 1996; Cocks 1989; Stella 1996 for accounts of the parallel situation in Australia). Such concerns included criticism of the conditions and treatment of intellectually disabled people in institutions and a call for the disbanding of these places of segregation and isolation and a return to community or "ordinary" living (Whitehead 1993: 56).² Some of the early proponents of the movement also utilised sociological theories of deviancy, labelling and symbolic interactionism. The specific application of these sociological theories to the world of intellectual disability came through the work of Wolf Wolfensberger, a clinical psychologist who had worked in institutions for the mentally retarded in the United States since the 1950s. Wolfensberger’s book, *The Principle of Normalization in Human Services*, which was first published in

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² James Trent (1995) has traced the history of the deinstitutionalisation movement in the United States back to World War II. In his book, *Inventing the Feeble Mind: A history of mental retardation in the United States*, Trent argues that conscientious objectors who ended up being employed as attendants in the wards of mental institutions were so appalled by the inhumane and barbarous conditions that they wrote and published accounts of these places that precipitated public discussion about the need for reform (Trent 1995: 227-30).
1972, had a major impact on the deinstitutionalisation movement, on the way in which intellectual disability was perceived, and on the delivery of social services to these people. Despite Wolfensberger's (1995: 366) claims to the contrary, the principles of normalisation have been widely instituted throughout the services for the intellectually disabled, at least in the United Kingdom (Digby 1996: 15-18) and Australia (Ashton 1995: 151-152).

Yet the movement known as normalisation actually began in Scandinavia and was more concerned with the right to an ordinary lifestyle than with a theoretical analysis of deviancy and the implementation of social service provision. Two of its foremost proponents were Bengt Nirje and Neils Bank-Mikkelsen, and their emphasis, and the original definition of normalisation, was "to let the mentally retarded obtain an existence as close to the normal as possible" (Bank-Mikkelsen; cited in Nirje 1976: 363; cf. Emerson 1993). Theirs was a concern for the rights, opportunities and conditions of existence of mentally retarded people, and the concept of normalisation proposed by them was based on a "normal respect for the integrity of the individual". Rather than relying on legislation to change conditions, Nirje believed that a new "ethical value theory" was needed and it was this that he called normalisation (Nirje 1985: 65-6; cf. Perrin & Nirje 1985). He argued that the mentally retarded should have available to them the same rhythms, patterns and conditions of life as those living in mainstream society. These should be based on a normal and normative rhythm of the day, week and year, on a normal lifestyle and developmental process, as well as access to the same sexual and familial relationships, economic standards and living arrangements (Nirje 1976: 364-7; Nirje 1980: 36-44; cf. Heshusius 1981). Nirje saw this new ideology as a cross-cultural, universal ideal and practice because it was based on the normative patterns of the society within which the mentally retarded person belonged. Interestingly, he was influenced by Ruth Benedict's (1934) argument in *Patterns*
of Culture that different cultural patterns affect the development of individuals and that a person needs culture in order to fulfil their potential as a cultural being (Nirje 1985: 66). Nirje and the Scandinavian movement in general concentrated on these "quality of life" aspects, whereby the cultural patterns within mainstream society were to be reproduced in the environments in which intellectually disabled people lived.

While there was a pedagogic and developmental element to Nirje's principles (Nirje 1976: 368), the development of normalisation and its implementation throughout the social services for the intellectually disabled ultimately took a different turn. Through the influence of Wolf Wolfensberger, the focus shifted to a concern with service provision, vocational and domestic skills training and the necessity of community integration (Wolfensberger 1977 [1972]: 45; cf. Emerson 1993). Wolfensberger developed his own definition of normalisation after witnessing the revolutionary treatment of mentally retarded people in Scandinavia in the late 1960s. He combined the aims of deinstitutionalisation and deviancy theory with these newly developed normalisation practices to produce a more sophisticated and arguably more influential theory of normalisation.

The trend towards community integration in the United States had gained momentum during the 1940s but Wolfensberger's analysis of the situation gave to the movement a theoretical and sociological basis from which to understand the social perception of mentally retarded people and the means to achieve their normal integration (Emerson 1993: 4). Wolfensberger explicitly based his theory of normalisation on the sociological theory of deviancy and labelling as well as on Goffman's analysis of the stigmatising effects of total institutions on self identity. As Wolfensberger argued:
A person can be said to be deviant if he is perceived as being significantly different from others in some aspect that is considered of relative importance, and if this difference is negatively valued. An overt and negatively valued characteristic that is associated with the deviancy is called a 'stigma' (Wolfensberger 1977 [1972]: 13).

According to Wolfensberger, mentally retarded people are regarded as deviants and this deviancy is both a stigma and a social construct. It is a product of ideology, of the beliefs, attitudes, interpretations and values associated with mental retardation. These in turn impact on the treatment of the mentally retarded. While Wolfensberger acknowledged the reality of mental retardation as an attribute of the person, he argued that it is social values and attitudes, combined with the lack of a normal lifestyle, that affects how we perceive and treat the mentally disabled. Rather than focusing on intellectual disability as an inherent attribute of the person, therefore, Wolfensberger was instrumental in shifting the emphasis to ideologies, beliefs, interpretations and attitudes (Cocks & Allen 1996: 284).

Another important contribution of Wolfensberger to the history and treatment of intellectually disabled people lies in his reformulation of the issues in terms of social roles and the negative value attributed to difference. Wolfensberger's definition of normalisation was based on the utilisation of "means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (Wolfensberger 1977 [1972]: 28). By adopting culturally normative means such as familiar techniques and tools to create a normative life based on culturally positive options Wolfensberger argued that one can support a person's behaviour, skills, competencies, experiences and appearance such that they become more socially accepted and valued (Wolfensberger
The instituting of these practices through deinstitutionalisation policies, combined with the training of normative skills and competencies, will, according to Wolfensberger, precipitate normal behaviours. Consequently, the means by which these are achieved are as important as the goal (Wolfensberger 1980b: 106; cf. Johnson 1998: 157). Just as Séguin had done more than 100 years earlier, the treatment for intellectually disabled people's difference became their socialisation, management and training based on the development of normative social skills and competencies. Only this time it included the right to live in the community as well.

Wolfensberger's expansion and systematisation of the normalisation theory stressed the need for mainstreaming services for the disabled as part of their community integration. He devoted much of his work to the application and management of normalisation principles in the human services and developed a method called Program Analysis of Service Systems (PASS or PASSING)\(^3\) by which organisations could be assessed according to their compliance with his normalisation standards (Wolfensberger 1980b: 79; Emerson 1993: 9). However, it was not just the intellectually disabled who were to be integrated and normalised; the services that dealt with intellectually disabled people were to be normalised and integrated with one another as well (Wolfensberger 1977 [1972]: 45-54; McCord 1982: 249). Within a relatively short period of time this theory became the fundamental guiding principle for the treatment of intellectually disabled people in the United States, Europe and Australia. It became a "paradigm for human services" as Flynn and Nitsch (1980: 3) claim, or a "meta-theory" as Wolfensberger himself writes (Wolfensberger 1980a: 7). As Wolfensberger put it: "Today, [normalization] is a captivating watchword

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\(^3\) Program Analysis of Service Systems Implementation of Normalizing Goals.
standing for a whole new ideology of human management” (Wolfensberger 1977 [1972]: 27).4

Wolfensberger’s theory of normalisation has been widely criticised for many reasons, including its inherent conservatism, assimilationist undertones, and emphasis on individualism. It has also been criticised for its social and structural homogenisation, moral authoritarianism, and internal inconsistency, as well as its lack of comprehension and theorisation of the real difference that is intellectual disability (Ashton 1995; Branson & Miller 1989, 1992; Brown & Smith 1989, 1993a, 1993b; Dalley 1993; Digby 1996; Emerson 1993; Ferns 1993; Jenkins 1998b; Johnson 1998; McGill & Emerson 1993; Ramon 1991; Rose-Ackerman 1982; Szivos 1993; Ward 1993; Whitehead 1993; cf. Wolfensberger & Thomas 1994 for a response to some of these criticisms). British critics in particular have focused on the ahistorical, idealistic and functional nature of normalisation, arguing that it denies the structural and material inequalities inherent in relationships between disabled and non-disabled people (Bleasdale 1996; Chappell 1992; Fullagar & Hardaker 1993; Oliver 1990; Stone 1984). Others have argued that acceptance of the difference that is mental retardation is paradoxical if this difference continues to be perceived as a state which must be changed (Branson & Miller 1989, 1992; Szivos 1993).

Contemporary practices in the field of intellectual disability, which includes normalisation, deinstitutionalisation, special education, disability legislation, and training and management practices, reinforce the pathological

4 Wolfensberger changed the name of normalisation to Social Role Valorisation (SRV) in response to criticisms, and what he saw as misinterpretations of the meaning, of normalisation (Wolfensberger 1983). As he wrote, “Social Role Valorisation is the "establishment, enhancement, or defence of the social role(s) of a person or group, via the enhancement of people’s social images and personal competencies” (Wolfensberger 1983: 234). People need to be seen to be living valued lives and they do so through developing their social skills and leading as normal a life as possible.
interpretations that the clinical model espouses (cf. Gleason 1989: 51-64). In doing so, they reproduce and perpetuate the implicit values and practices embodied in the symbolic scheme of reason and normality. Rather than acknowledging, supporting and incorporating intellectually disabled people as social beings, these institutional and social practices end up perpetuating the deep division that separates intellectually disabled people as abnormal and asocial others in relation to a normal social self. Proponents of normalisation, and the practices associated with it, do not recognise that sociality is a product of mutual relatedness and interdependence. Although Nirje (1976: 364-367) stressed the need for access to familial and sexual relationships, and while relationships in general are becoming an important issue in the field of intellectual disability (Bigby 2000; McVilly 2000), these have tended to be regarded as necessary features of a normal social life rather than encounters through which sociality is developed and sustained.5

The problematic issue of normalcy has been central to much of the literature on intellectual disability (Branson & Miller 1989, 1992; Jenkins 1998a, 1998b; Ryan & Thomas 1987; Szivos 1993). It has, as Richard Jenkins points out, a descriptive and prescriptive aspect, elaborating on that which is normal as the most typical, but then asserting "that this is also the way things ought to be" (Jenkins 1998b: 17; author's emphasis). The processes of normalisation and socialisation to which intellectually disabled people are subjected are a consequence of this normalising tendency. They accept only certain ways of being human as normal and then enforce this norm upon those who deviate from it. The norm thus becomes the status quo based on a cultural and historical specificity of reason as personhood, as well as standardised notions of productivity, literacy, numeracy, time management, and behaviour; the domesticated individual as worker (Branson & Miller 1989; 1992: 24-25; cf.

5 This issue of relationships is a central feature of my final chapter.
Chappell 1992; Jenkins 1998b; Oliver 1990; Stone 1984). It also emphasises such attributes and competencies as independence, self-reliance, individualism, mobility and reflexivity (Davies 1998: 116; Devlieger 1998: 56-58; Lundgren 1998: 217). These are the principles and aims that inform the institutional practices of training and management. Although such practices may be appropriate for those with mild intellectual disabilities, for people who lead relatively independent or autonomous lives and have the necessary capabilities to participate in the workforce, it is highly questionable whether they serve any legitimate purpose for those with more severe forms of disabilities. The people with whom I worked did not aspire to become "workers", and while a "quality of life" was emphasised as a component of Xanadu's services, this still existed within a dominant ethos of vocational and domestic skills training. Their quality of life was seen to depend upon becoming skilled in normative social practices.

Training and Socialising the Intellectually Disabled

Despite Wolfensberger's argument that social attitudes and values need to be altered, the primary focus of the practice of normalisation has been on changing the intellectually disabled individual and the services that provide for him or her. Although Wolfensberger stated that "deviancy is in the eye of the beholder", he argued that it is primarily the "deviant obstacle" that needs to be eliminated. In this sense, integration practices need to be based on the dispersal of "deviant" individuals so that they become less noticeable (Wolfensberger 1977 [1972]: 53-54). In order for intellectually disabled people to be socially acceptable, in order for them to become integrated into society, Wolfensberger also stressed the need for such people to develop normative behaviour and goals (Wolfensberger 1977 [1972]: 31-33; 1980b: 89-90). Intellectually disabled
people are therefore worked upon so that their behaviours and social skills conform more closely to the expected norm (Ashton 1995: 152). And, as Leonie Stella has argued in her account of the setting up of hostel accommodation for the intellectually disabled in Western Australia, "people were expected to learn, develop and earn their way to a better quality of life and ultimately into the community" (Stella 1996: 132).

The principles and practice of normalisation are still very much a part of contemporary ideology and policy with regards to the treatment of intellectually disabled people in NSW. Individual Service Plans (ISPs) are the most recent form through which the skills and competencies associated with normalisation are implemented, and, indeed, it is part of government policy that all consumers have regular ISP updates. The emphasis in these individual plans is on what goals the person should be working towards. These goals are based on an assessment of the person's abilities, strengths and needs by relevant staff in consultation with the intellectually disabled person and their guardian or advocate. As noted in the transition plan for Xanadu, the aim of the ISP is to provide a "written plan that outlines a set of goals that [the person] can work towards. It . . . also describe[s] ways in which he or she will get help to achieve these goals". These goals include vocational and domestic skills training, as well as community integration and recreation.

An Individual Service Plan (ISP) outlines the expectations, activities and aspirations of all concerned. It stipulates what each consumer should be working towards, as well as providing guidelines for how staff should go about their duty of socialising, training and managing the intellectually disabled.

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6 Leonie Stella (1996: 132) also argues that there has been a change from a "total focus on training" to a concern with rights, relationships, responsibilities and a 'normal' lifestyle. She sees this reflected in changes in accommodation for intellectually disabled people. In the situations that I observed, however, there was a continuing emphasis on normalisation, behaviour modification and training as guiding principles in the delivery of services to the intellectually disabled.
person. As the ISP notes for my sister commented: "After the goals are set and the appropriate people sign the master plan, it is then the relevant staffs' job to ensure that we will all work towards them" (Stockton ISP Notes). Each person at the group home where I worked also had an "ITD", an individual training day, during which a staff person worked one to one with a consumer to help develop their social skills and encourage appropriate behaviour. This was especially so in relation to domestic skills such as cleaning, cooking, hygiene, banking and shopping.

It was not just staff at the institution, group home or activities centre who were supposed to provide such training and maintain these aspirations. It is also suggested that families sustain these practices when the intellectually disabled person is at home. Ann Shearer (1982: 36) argues that if the principles of normalisation are to be fully implemented in Australia they need to include "specific education for parents" alongside the coordination of service provision. Norman Megahey (1996b: 270) also comments on the role of social workers in "normalising client relationships with family and community", while Kiernan (1978: 419) argues that behaviour modification techniques will be more rapid and effective if parents, teachers and all those involved with the person implement the same practices.7

Through coordinating the individual service plans that exist in the sheltered workshops, activities centre and group homes, as well as extending them into the familial environment, the ISP aims to provide a uniform plan within which training and management can take place. As a document it seeks to provide a total environment for the way in which staff and family interact with an intellectually disabled person such that training becomes a part of their

7 Roy Brown (1982) argues that the goals of independence and integration will only be achieved through the development of integrated vocational, educational, domestic and leisure services combined with individual training programmes. These programmes require the precise assessment and measurement of behaviour through such tests as the Gunzburg Progress Assessment Test (PAC) and the Marlett Adaptive Functioning Index (FAI).
everyday life rather than just a part of their programming period. As acknowledged in the notes on ISPs for a similar activities centre: "the process ensures that a consistent plan of action for staff interaction with each individual client is implemented" ("Ballimore" Adult Education Centre).

The value, importance and, indeed, necessity of work lies at the heart of these institutional practices of training and management. Work and "vocational success" are seen as essential attributes of normalisation and adaptation to the community (Edgerton & Bercovici 1976: 491; Wolfensberger 1977 [1972]: 51-52; Woods 1983: 38-44). As Simon Olshanky (1977) has emphasised, the aim of normalisation is to change the behaviour of intellectually disabled people so that they become better functioning, self-determining, self-directional beings with opportunities to develop and fulfil their own potential. The value of work, he claimed, "continues as one of the central facets of their lives. Without work they feel they are nothing. They feel useless, abnormal, childish, and unwanted" (Olshanky 1977: 159; cf. Baron et al. 1998; Edgerton 1967). While Olshanky stressed the importance of work for intellectually disabled people's sense of themselves as worthwhile beings, he also argued that it is through the experience of work as a normal aspect of social life that the intellectually disabled learn to develop into socially accepted and acceptable people (Olshanky 1977: 157).

This positive valuation of work has a long history in Western societies, connected as it is with the development of capitalism and the Protestant work ethic (Weber 1978 [1930]; Giddens 1978). The value, and indeed necessity, of labour as a natural aspect of human nature can be observed in the writings of Rousseau (Foucault 1995 [1961]: 192). Marx built upon Rousseau's philosophical proposition and argued that the value of human identity lies in our capacity to labour. As an aspect of human nature it is therefore perceived as natural, normal and necessary for people to engage in some form of paid employment.
And, as Baron et al. (1998: 94) have argued, the attainment of adult status is dependent on participation in the labour market. These social values are used as a justification for normalising intellectually disabled people into the workforce so that they are now expected to become "productive and useful members of their society" (Shearer 1982: 38). If intellectually disabled people are to be accepted as normal human beings they must engage in socially recognisable and vocationally oriented activities. Consequently, an emphasis on work and the development of vocational skills has become a central component of training practices for intellectually disabled people.

The majority of the intellectually disabled adults in the area where I did my fieldwork were employed doing light industrial factory work at local sheltered workshops. A few were integrated into mainstream working environments as kitchen hands or office workers, while a number of others were involved in a post-school options programme that provided a range of activities focused on developing work related skills and attitudes. Those with whom I spent most of my time at the activities centre were too old to participate in the post-school options programme and were generally considered incapable of working in sheltered employment. However, the staff at the homes often commented that those going to the activities centre were, like those employed at the sheltered workshop or in open employment, also "going to work". When Jane left the activities centre because of her age and increasing frailty, it was said of her that she had "retired".

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8 Due to an increasing dependence on, and movement towards, “economies of signs” in the workplace, as well as the changeable nature and the speed with which the workplace now operates, Baron et al. argue that people with learning difficulties are becoming increasingly marginalised as their capacity to learn and adapt to new skills quickly, and indeed to utilise a wide range of symbolic patterns, is often severely compromised (Baron et al. 1998: 100-103).

9 Deborah Stone (1984) argues that people were administratively categorised by the welfare state as disabled or non-disabled according to their capacity to work. Those who could not work were categorised as disabled, as being in need of support, and this legitimised their position within society. These days, however, in conjunction with changes to welfare ideology and the principles of normalisation, intellectually disabled are encouraged and expected to work.
There was most definitely a hierarchy between the activities centre, sheltered workshops and open employment, and people moved between them according to their age, abilities and aspirations. The activities centre took the least capable and independent consumers in the region, while those who were most competent participated in supervised open employment positions. The aim was to encourage people upwards, to provide them with the skills and motivations required to do the more lucrative and lowly paid menial tasks that took place at the sheltered workshop. From there it was hoped that a few would move into some form of open employment.

When I first arrived at Xanadu I was told by the co-ordinator that the purpose of the activities centre was to provide "life enhancing" activities for adults from the local community group houses and private homes. The stress, he claimed, was on "quality of life" rather than life skills or task training. However, the emphasis was clearly on providing productive and meaningful activities and work opportunities and encouraging the attitudes and skills necessary to move up to the sheltered workshop. Consequently, attached to the activities centre was a small sheltered workshop where four people were employed to shred paper for a local business. At the activities centre itself a paper shredder also stood in a corner of the main room. It was turned on each day so that someone could have their turn at learning how to do this purposeful, socially valued, work. However, most of the consumers found this work tedious, uninteresting and, above all, dirty. Joanne was the only exception. She spent all her spare time at the centre tearing up newspaper in preparation for shredding. This was a closely guarded and solitary operation, and one which never extended to operating the shredding machine as well. The staff were constantly encouraging other consumers who were considered potentially capable of sheltered workshop activities to spend time operating the shredding machine or engaging in other work-related activities.
For a number of weeks a group of women from Xanadu spent each morning tying bits of string to cardboard tags for a local industrial company. This work was being paid for, and it was valued by the staff as meaningful and important for the consumers to participate in. I sat with the consumers and helped to thread these strings. Two of the other women, Sarah and Kate, wanted to sit with us and watch as we performed this task but did not want to participate. A staff member came in and told them they should be helping us. Neither were interested in doing this work. Both were happily engaged in other activities; Kate rocking in her chair and singing, and Sarah watching what we were doing.

Sarah was told by the staff person that she either had to help us thread the strings or do some paper shredding on the machine. Sarah told the staff person that she wanted to thread her beads instead. These large wooden beads were a favourite object of hers, and most mornings she would ask me to collect them from the cupboard so that she could thread them onto a piece of plastic string. When Sarah finished threading them, she would pull them all off and start all over again. This enterprise of Sarah’s reminded me of my sister's collection of bits and pieces, and her love of jigsaw puzzles. To an outsider both seem to be meaningless, purposeless and never-ending tasks, though engaged in with absolute dedication and ceaseless interest by the person concerned. Threading pieces of string onto cardboard did not seem all that different to the skill required for threading the beads onto string but Sarah would not have anything to do with the paid work, and kept insisting that she be able to do her beads instead. The staff person told Sarah that she could do her beads, but only after she had done her work, and that if she didn't help us or shred some paper she would not get her beads at all, nor have any make-up put on later in the day. The staff member wheeled Sarah over to the paper shredding machine and told her to stop being difficult and to do some work. She stood over Sarah,
handing her sheets of newspaper to feed into the machine piece by piece. Although Sarah acquiesced at first, she was very annoyed, and demonstrated her resistance by folding her arms across her chest and leaning back in her wheelchair with a dark and angry scowl across her face. At this point, the staff person gave up. Consequently, Sarah did neither the work nor her beads and eventually went into a trance like state and fell asleep.

I was later told that Sarah must only be given the beads as a reward; that it is hard to get her to "do anything" and if she's given the beads whenever she wants them then she'll "do nothing". This separation of only certain forms of activity as "doing something", as productive and meaningful practice in comparison to the meaningless and purposeless act of threading beads, was a constant source of tension at the centre. Interestingly, it was the activities that the consumers initiated themselves that were considered empty of purpose and meaning. Those that the staff instigated, such as shredding paper, tying string to cardboard, painting and potting plants, were considered socially meaningful, purposeful and worthy of spending time on. There were numerous occasions when I observed such tensions.

Kate, the young woman who had also been watching us tie pieces of string to the cardboard, spent much of her time at Xanadu sitting in the same place, under the high window in the front room, rocking and singing to herself, and flapping her hands in front of her face. She would quite happily remain there all day if allowed. On this particular occasion the staff member also tried to get Kate to join the rest of us in threading the pieces of string onto the cardboard. She patiently showed Kate how to do it and gave her the board and string to copy, whereupon Kate promptly threaded the cardboard in her own way. The staff person gave up in despair, told her not to worry about it, and left the room. I went out to get more string and when I came back, Kate and Cressida were sitting at the table laughing. I was unsure what they were laughing about.
although it seemed to have something to do with the scenario that had just been played out. They were clearly engaged in a matter of mutual concern.

When Martin drew all over a sheet of paper in thick dark lines, rather than tracing over the dotted "M's" that covered the page, he was reprimanded for not doing his prescribed activity. Teaching Martin to write his name was one of his ISP goals, and Martin was given these sheets most mornings as a form of training to develop this skill. Martin was 30 at the time, and lived with his parents on a dairy farm that his family still operates. He did not read or write, nor did he show any interest in learning to do so. Despite his illiteracy, Martin was actively engaged in the world around him, always observing and commenting on what was going on at home, with the staff, or with his fellow consumers. Like Sarah—a strong-minded woman who, once she had been taught her rights, believed she had the right to do nothing if she so pleased—Martin also had a difficult relationship with the staff. The staff treated him with some disdain because he sometimes talked back at them and even went so far as to tease staff members on occasion. Martin would sit at the table and painstakingly trace over the dotted "M's" while a staff member was around, but as soon as they left the room he would start to draw on the page; not a picture as such, but dark heavy lines in the same direction so that the paper eventually tore. His scribbling was perceived by the staff as nonsensical and deviant; his tracing of the letter "M" an achievement. Seen from another perspective, scribbling was an activity Martin enjoyed and engaged in spontaneously; tracing the letter "M" a meaningless chore that had to be performed for someone else's gratification. Martin knew that he was writing the letter "M" but there appeared to be no meaning or purpose in it for him.

Another person who came to Xanadu was a particularly quiet man called Tony. He was in his late 30s and was confined to a wheelchair in which he was usually slumped over, giving the appearance of being half asleep and unaware
of what was going on around him. Tony was severely multiply impaired, incontinent, and did not speak, although at times he made noises to affirm whether he wanted to eat what was in front of him or not. Tony was also epileptic, his body very frail, and often spent the afternoons lying on a mattess resting rather than joining in the activities. He did not appear to engage with anyone at the centre although over time I came to realise that Tony was acutely aware of what was going on around him and could get easily distressed by the more vigorous and aggressive behaviour of some of the other consumers. They too were quite aware of him, and a number of times it was one of the consumers who looked after him, holding him at the shoulders or patting his head, before informing the staff that Tony had just had a seizure or had wet himself.

One of the things that Tony enjoyed was playing with a box of yellow glass bulbs. He would take them from the plastic container that they were kept in and drop them into a glass jar, delighting in the noise of glass hitting glass. The bulbs were sometimes given to him during those moments of "inactivity", when people were filling in time between activities. Tony would be captivated by these bulbs and could be occupied with them for quite some time. They were one of the few objects that he was given to "play" with at the activities centre. At the group home where Tony lived he was sometimes strapped into a special chair with a table attached to it. Some wooden puzzles or paper and crayons would be placed on his table. This was to aid Tony's posture, to give him some physical therapy and also teach him tactile skills.

On one occasion at Xanadu I noticed Tony taking an interest in the brightly coloured nail polish jars that were sitting on the table. As I noted in my field notes for that day:
I'd been painting nails and he [Tony] was interested in the nail polish jars. I gave them to him and he arranged all six of them in a triangular pattern, each jar equidistant from the other. When I gave him the one that I'd been using he placed it in the very centre. I'd never seen him so alert. He also did a colour coded puzzle, fitting the cylinders into holes around a wooden block. He did this quite happily, at times seeming to follow the colour scheme but then randomly inserting the pieces seemingly any old way. When I gave him the domino blocks he just began to put them back in the box rather than match the animals. All of them have done this with the domino puzzle. He was bored with the jigsaw wooden blocks but when given the light bulbs and clear bottle he became animated again and began to fill up the bottle with the bulbs, but only with a few, before putting them back in the box and going back and forth like this.

I was interested in the purposefulness of Tony's actions, and his interest in the objects around him. He definitely had a sense of what he was doing and the order in which he wanted to do them, and was conscious of the patterns and sounds that he could make with these objects. It reminded me of Maryla and Stephen, who also liked to order the pieces of a jigsaw puzzle, arrange objects in an ordered spatial pattern, and make rhythmic echoing sounds by hitting objects against one another. I wondered what meaning these actions had for Tony and whether he approached these objects in the same way each time. I watched him over the twelve months on those occasions when he came to the centre and saw him continue to repeat this process with the bulbs and puzzles. Rather than an arbitrary and aimless procedure, Tony's actions had a level of intensity, order and engagement that Maryla and Stephen also showed with
their respective activities. They were patterned and symbolic expressions upon which mutuality could be built.

Jacky was another person who regularly came to Xanadu from the group home that she shared with four other people. She was a young woman who, although physically independent, was unable to speak clearly or comprehensibly. Jacky used various high pitched noises and squeals to get people’s attention and had a tendency to grab someone’s arm and drag them around when she wanted to show them something. Jacky was one of the least popular of the consumers, with both staff and the other consumers, and was considered to be extremely difficult to "manage". She was also somewhat of a loner. One of her interests was to keep everything in order in the main room. To do this required that Jacky constantly rearrange the furniture so that the chairs and tables were aligned and in their correct positions. It also meant putting away anything that had been taken out of the cupboards, including the cups for morning tea, a cloth to wipe the tables down, or the box of makeup or toys. It caused Jacky great distress when the room was out of order, which it often was with twelve other people sharing it. Consequently, Jacky spent much of the day sitting in a corner squealing and crying, tearing at her clothes and hair, or chewing her fists and hitting herself, much to everyone's distress and frustration. The staff labelled Jacky’s behaviour as obsessive-compulsive and tried to stop her. Rather than using these expressions of order as possibilities for negotiating mutual sociality they were categorised as abnormal.

One day when a group of us were at the local nursery doing some weeding, the staff person complained that there was little point doing these activities as the consumers spend their time "doing nothing while the staff do all the work". Yet despite this comment, the consumers were doing all sorts of things. Kate often sat in the tin shed stacking and unstacking a pile of plastic plant pots, building a teetering tower out of them and watching as they swayed and then
collapsed. Cressida would sit on a stool poking at the grass with a garden fork, while Mary would sit under the awning of the shed smoking a cigarette as she watched the rest of us. None of this was considered acceptable behaviour; it was not the doing of productive work and was thus constituted as inactivity, as doing nothing. I was told that the consumers would get bored if they were doing nothing so their days were filled up with activities. Just as the staff now have something "to do" in training and managing the consumers to make them conform to normal social behaviours, so too must the consumers work; not only towards becoming more normal, but by participating in socially productive and meaningful activities as well. In fact, they must be normalised through training and management procedures in order to be meaningfully engaged with at all.

The interesting aspect about these observations is not so much that the staff labelled the consumers' own actions as meaningless and abnormal, but that they rarely, if ever, engaged with the consumers through these acts. As Goode (1980b: 192-193; Goode 1984: 234-235) has argued, the behaviour of intellectually disabled people is often interpreted as faulty and in need of remedial training. It is this training, and the management of behaviour, that is at the heart of institutional practices. By not observing behaviour as meaningful, argues Gleason (1994: 256), staff "impose another order of behaviour as therapy". Both Goode (1980b) and Gleason (1989) have also pointed out, however, that it is possible to observe purpose and meaning in the actions and interactions of severely disabled people.

While agreeing with both Goode and Gleason, I argue that what is central to these institutional relationships is the lack of engagement of staff with consumers on the basis of the consumers' own actions and behaviours. While this lack of engagement also exists in relation to social skills training (as I argue in the following chapter) there is a significant difference. Socially recognised
activities are encouraged and enforced, while these other activities are rendered "meaningless" and an expression of abnormality. This is an extension of the clinical perception that interprets intellectually disabled people as deficient in the core human attribute of reason, an attribute that supposedly makes social life possible and meaningful. Consequently, there is no attempt by staff at symbolic mediation, at negotiating the value and meaning of such activities as the threading of beads, the rocking, the stacking of pots, or the ordering of furniture. These activities are not seen as meaningful for the consumers, nor as potentially meaningful for those who engage with the consumers. Like my sister's bits and pieces, they are interpreted as obsessive, compulsive, bizarre, and abnormal. It is as though meaning only exists in the socially prescribed use of objects, rather than being an emergent entity that exists through shared encounters with various objects. By not engaging with the consumers on the basis of their own behaviours and expressions, the capacity for creating and sustaining a genuine and mutual sociality has been rendered impossible. By not recognising these dispositions as expressions of degrees of mutuality and sociality there is no negotiation of different ways of being within a shared social world.

The activities that are encouraged emphasise the development of decontextualised capabilities based upon an elaborated code. Like the decontextualised mental skills of intelligence tests, these skills have become measurements of humanness, normalcy and the capacity for human sociality. They ostensibly allow a person to develop transferable and utilitarian skills so that they can function in the social world and work place. These include such things as operating machinery, packing boxes, potting plants, and putting nails and similar objects into plastic bags. They rely on tactile, numerate and sometimes literate skills, and are based on the recognition of such activities as meaningful, relevant and purposeful. The restricted and contextualised codes
that many intellectually disabled people inherently utilise are considered meaningless and, because of this, such people are denied the capacity to contribute to the social milieu as they are. This denial of their pre-existing capacity for sociality and mutuality disregards the fact that none of us actually lives entirely according to such paradigmatic principles, as Michael Carrithers (1992: 113-114) has also pointed out. We all exist within culture and society according to the dynamics of our interactions with others. It is upon these that our sociality depends and is, indeed, built (Carrithers 1992: 57).

Owing to the inherent contradiction between the interpretation of intellectually disabled people as abnormal and asocial beings yet who are in need of normalising and socialising, the practices that exist in contemporary institutional environments have ended up producing a permanent state of liminality. The ideal of transformation can never be achieved. The constant movement from one activity to another at the activities centre reflected this paradoxical and liminal state. There was nowhere to go, so the journeys that constantly took place between one activity and the next became the defining moments of each day. The consumers were locked within a bus that had no possibility of ever really reaching its destination. Everyone, including the staff, waited around for these moments of mobility, for these journeys that legitimised their place within society. Being still and silent and doing nothing but being in one another's presence was illegitimate; to be on the move towards socially recognised activities was the only legitimate form of practice. The bus journeys metaphorically represented this continual process of training, socialisation and transformation that intellectually disabled people must undertake in order to move towards becoming socially legitimate beings.

Managing the Intellectually Disabled
The training of vocational and domestic skills are not the only institutional practices that affect the lives of intellectually disabled people. Behaviour modification is also utilised as a means to change and ameliorate what are considered to be undesirable and asocial behaviours (Cuvo 1976). With the recent emphasis on deinstitutionalisation and community integration it became increasingly necessary to reassure the community that behaviour could and would be managed and changed to conform to socially acceptable standards and norms (Johnson 1995: 213; Johnson 1998). This is what behaviour modification practices attempt to do.

The practice of behaviour modification was in part influenced by Séguin's belief that intellectually disabled people could be trained. It has also been influenced by recent developments in cognitive and behavioural psychology (Kiernan 1978; Megahey 1996a: 20). The successful use of training programs such as those that were developed by Jack Tizard in the 1950s and 1960s—who, like Wolfensberger, combined the insights of behavioural and developmental psychology with an emphasis on social causes of the problem of intellectual disability—characterised the shift in emphasis from incarceration and custody back to training and treatment (O'Connor & Tizard 1956; Megahey 1996b: 249-50; cf. Sinson 1993: 57-8). As Phillip Roos puts it: "all behaviour manifests the same basic principles, and is the product of the organism's interaction with the environment . . . therefore behaviour is modified according to the principles of

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10 Carman-Brown and Fox (1996: 229) argue that the success and influence of behaviourism for the treatment of intellectually disabled people in Australia in the 1960s and 1970s was in part due to the post WWIl emphasis on efficiency, progress and empirical science.
11 The emphasis in some 18th century asylums, such as The Retreat run by William Tuke at York, was on moral treatment. Rather than solely utilising physical treatments such as purging, blood letting and cold showers, Tuke also incorporated intellectual, social and behavioural methods of treatment. These included an emphasis on constant activity, recreation, reading, diet, hygiene, religious devotion, diversion from morbid thoughts, socialisation through mimicry, and the encouragement of rational discussion between physician and patient (Kraft 1961: 400-403; Rose 1985: 24-25). In Madness and Civilisation (1995 [1961]) Foucault argues that this new method, and the reforms instigated by Pinel in France in the early 19th century, reflected a change in political attitudes as well as to ideas of responsibility and guilt. Morality replaced punishment in what became a more subtle form of control and exclusion (cf. B. Turner 1987: 64).
learning” (Roos 1977: 140). Consequently, behaviour modification techniques aim to "free individuals from crippling behaviour, enabling them to interact more meaningfully with their environment and thereby enhancing their opportunities to develop their human qualities" (Roos 1977: 146).

Although used in combination, behaviour modification stands in contrast to the principles of normalisation. The principle of normalisation provides the theoretical and practical tools for understanding and transforming the position and treatment of intellectually disabled people in society. Behaviour modification provides the techniques by which these can be attained (McGill & Emmerson 1993: 60; cf. Rose-Ackerman 1982). Normalisation tends to emphasise environmental factors and their affects on behaviour, arguing for a change in practices, services and lifestyle, whereas behavioural modification techniques focus exclusively on how to alter the individual. Normalisation became an ideology, behaviour modification became the means by which this ideal could be achieved.¹²

In the case of those with whom I did my fieldwork, these practices were incorporated into the individual service plans which were regularly referred to during the course of each day. On my first day at the activities centre I was informed by the coordinator that as part of their obligations to the consumers, each person had an individual programme that was used by staff as a guide to daily activities. Not only was this programme used for training and skills development, but the ways that staff engaged with and managed the

¹² Despite their different emphases, both normalisation and behaviour modification embody the aim of changing individual behaviour so that the person functions normally, conforms socially, and "fulfils" their own potential. Like clinical interpretations, normalisation and behavioural management practices are based on the perception that intellectually disabled people lack the capacity for sociality as they are. They blame the intellectually disabled for not fitting in and pathologise their behaviour and experience (Brown & Smith 1989: 107; cf. Goffman 1990 [1961]; Johnson 1998; Mehan 1988). They also force intellectually disabled people to be participants in their own normalisation. As Gerben de Jong (1982: 53) argues, contemporary practices of behavioural management are akin to the Parsonian concept of the sick role in that the person must be seen to be working towards their own improvement.
consumers were also based on the information in these plans. The details of the ISPs were not available to me. However, there were numerous occasions when I was able to observe the role that these plans, and the behaviour modification practices enshrined in them, played in the daily lives of the consumers.

The staff constantly reminded me that Patricia was to be positively redirected whenever she became irritable. This included getting her to tear up paper for the shredding machine or sweep the floors. Patricia was one of the more social of the consumers, and often came into the staff room to engage with the staff. The staff used this practice of positive redirection to get rid of Patricia when they’d had enough of her alternating aggressive and affectionate behaviour. Within Patricia’s ISP there were guidelines as to the progressive measures to be taken if this was unsuccessful, ending in solitary confinement as a last resort. Patricia often did not follow staff instructions and when in a bad mood would continue to shout and squeal and shake her head, walking around the room hitting out at people and creating a tense atmosphere for all those in her presence. These scenes sometimes ended with her being shut in the small broom cupboard near the toilets.

Similarly, others at the activities centre were also engaged with on the basis of their ISP guidelines. Kate loved to play with her hands and could often be found rocking in her chair flapping her hands rhythmically in front of her face. The staff were supposed to distract Kate from this by giving her an alternative activity to do and throughout the day she was constantly being reprimanded for her behaviour. Daniel enjoyed going up close to people and staring them in the face, often wanting the other person to scratch his head. The staff all told him to keep his distance and would not engage with him in this way even though his way of communicating was through touch rather than spoken words. Halfway through the year a young intellectually disabled man and
woman from a nearby town joined the group from Xanadu for activities once a week. The woman was very social and went around the room saying "hello" to everyone and giving them a hug. The regular staff were unsure if this was all right and checked with the staff person who came with her to see how they should interact with her.

Another woman, Kerry, who lived a semi-independent life in the flat attached to the larger group home, was very curious about what was going on around her and always asked numerous questions of the staff on duty. When I first met her she wanted to know about my car, my family, why I wore odd earrings and why I was "working" at the home. We had quite a long conversation about these and other things but I was informed by a staff person when I entered the house that I was not to have personal conversations with Kerry and that I should make sure she knew nothing about my life. I was informed that as a volunteer I too had to comply with these management practices whether I liked them or not.

Jill—who also lived at Jeffrey Street on semi-permanent respite, was more independent and worked in a local 'take-away'—was very affectionate and friendly and we had become quite good friends during my time at the house. One afternoon when I arrived at Jeffrey Street she rushed over to give me a hug but was reprimanded by a staff person and told to shake my hand instead as this was the socially appropriate way of engaging with others. This was part of Jill's ISP and it was enforced as a means of protecting her from potential abuse by others. It was also enforced as a way of engaging with Jill generally.\footnote{The ethical dilemmas that can arise when relationships with intellectually disabled consumers blur the distinction between professional care and friendship will be discussed in the following chapter.}

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Cressida, whom I had come to know at the activities centre and who lived permanently at Jeffrey Street, was always wanting affection of some sort, be it a pat on the back, holding hands, or just sitting side by side on the couch. She had apparently been violent when living in one of the other houses a number of years ago and I was told that, according to her ISP guidelines, staff were never to turn their back on her. They were to refrain from maintaining eye contact with Cressida and should always stay over a metre away from her. One day when I arrived at Jeffrey Street I found Cressida sitting alone in the television room. There was nobody else around inside the house. She was in a bad mood, with her arms folded across her chest and her head hanging down. She told me not to talk to her as she was very angry, and then told me that "they" were talking about her, meaning the staff who were sitting smoking at the outside table. Cressida hates the thought of anyone talking about her, or even looking at her sometimes. She often says that someone or other is pulling faces at her, including both the staff and other consumers. I told her I had only heard them talking about Sarah and how she had been taken to hospital that afternoon after a series of epileptic seizures. When I came out of the TV room one of the staff members was in the hall and she asked what Cressida had said to me. She wanted to know whether or not Cressida had been "whingeing". I said she had complained a bit but that otherwise we were just talking. I was then told that I was not to let Cressida whinge and that if she ever did I was to change the topic to something else, to something positive, as this was part of her ISP guidelines.

The same procedure was used with one of the other women who came to the activities centre, although the consequences of her behavioural and mood changes were essentially more serious. Mary was far more vocal than most about her dislike of the activities centre, and often told disturbing stories about her family and former life in an institution. She would tell stories about when
she was taken away from her mother and sister as a child and sent to an institution, about being locked in solitary confinement when she misbehaved, given injections against her will, and forced to have an abortion. Mary often complained about her fellow residents and those at the activities centre, saying that they were nasty to her and that she didn't like them. These comments, however, were to be ignored. They were interpreted as signs of regressive behaviour rather than legitimate complaints about her life or specific problems she was having with the centre or group home. This ideal of constant behaviour and uniform emotional expression denied to Mary any possible "normal" variation in mood and behaviour. It also imprisoned Mary in a world within which her intellectual disability was used as the sole interpretation of her behaviour and subsequent treatment.

This interpretation of behaviour in terms of the disability is similar to that which Lynne Hannan observed in her ethnographic study of people with a mental illness living in hostel accommodation. Hannan argued that the absolute stigma attached to the status of mental illness meant that all behaviour was immediately attributed to the "illness" (Hannan 1990). Kelley Johnson (1998) also notes this in her account of intellectually disabled women living in an institution. She argues that the discourses of intellectual disability "constituted the women as the problem" so that their behaviour was always interpreted within the terms of this discourse (Johnson 1998: 77). This was very much the case for the people with whom I worked. In Mary's case the consequences of it were that she was periodically sent back to the institution where she once lived for intensive drug therapy. Drugs such as Valium, Risperidone or Largactil were sometimes used by the staff to control behaviour or calm someone down, especially when they were "going off", although this was only done if a person's ISP allowed and if permission had been granted by
the guardian or advocate. On one occasion I was shocked to hear Mary tell one of the other women to "stop mucking up otherwise you'll get the needle too!" In fact, there were numerous occasions when the consumers would discipline one another, repeating verbatim staff instructions as to how someone was to behave. Their reproduction of the attitudes of staff towards one another highlights the pervasive influence of these practices of management and training in intellectually disabled people's lives.

One of the ways that Mary's house manager dealt with Mary's behavioural "problems", which at their height included physical aggression towards one of the other residents, was to call in a "programmer". This was a professionally trained behavioural therapist who worked for the Department of Community Services. Although they spend no regular time with the consumers, the programmers are called in to intervene and work on a one to one basis with a consumer when there are "severe and challenging behavioural problems" that are disrupting the general atmosphere at the group home and/or the workplace. The programmer observes people's behaviour and interprets from this what it is saying about them, and whether it can be attributed to a lifestyle, medical, or communication problem. The programmer will then develop a uniform management plan to be implemented by staff at the group home and the workplace or activity centre in an attempt to alter and ameliorate the problem.

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14 In the institution where Johnson did her fieldwork drug therapy was regularly used as a legitimate form of behavioural management. Despite the implementation of service plans for the women, staff had little opportunity to develop programmes for dealing with forms of "challenging behaviour" and saw the administration of drugs such as Largactil and Melleril as the basic means for managing these "problems" (Johnson 1998: 76). The use of drugs to manage behaviour, however, is not confined to those who are intellectually disabled. There is a growing trend in the United States and Australia in the use of drugs such as Ritalin to treat children who have been diagnosed with Attention Deficit Disorder. As Mark Riley points out, at the heart of the legal battles now ensuing over the use of these drugs is the issue of defining what constitutes "normal" behaviour (Riley 2001: 10).
As well as instituting these training and behavioural management practices, the staff were also involved in the administrative management of consumers. One staff person was responsible for between three and five consumers as their case manager. Part of the responsibility in being a case manager involved attending ISP meetings and keeping an up to date record of each consumer’s behaviour, mood, communication and participation in activities. These records were used as references whenever issues concerning particular individuals arose, such as behavioural problems. They became the (im)personal diaries for the consumers, written about them, and for them, but not by them (cf. Bogdan & Taylor 1976: 49; Bogdan & Taylor 1982: 217; Goffman 1990 [1961]: 7; Johnson 1998: 114-126; Ryan & Thomas 1987: 36 for similar accounts of the role that records and reports play in the lives of intellectually disabled people).

When I began chairing the weekly meetings at Hervey Street, the smaller group home around the corner from Jeffrey Street, I was accompanied on my first day by the new house manager for Jeffrey Street. Kevin introduced himself to the people living in the house and shook hands with all of them. Mary was particularly put out by the fact that he already knew her name and seemed to know all about her even though she had never met him before. Kevin had heard about Mary, and indeed all the consumers, from other staff members and through their record books, but Mary had no knowledge of who he was. Nor was she ever likely to. Mary was especially conscious of the power that staff wielded over her and did not like having things written down at the house meetings because she could not read them.

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15 During the deinstitutionalisation process that Johnson (1998) observed it was the impressions, assessments and observations of staff that had influence and were used in the final decisions as to who would live in what form of accommodation. The women were effectively excluded from the process due to this power differential despite officially being a part of the consultation process. Kathryn Pyne Addelson (1991) also comments on the power of professionals in her analysis of pregnant teenagers in the USA. As Addelson states: "what we call 'truth' is based on the authority of someone or other . . . [and] in professionalized fields, the confirmation or falsification of truths is handled by professionals. What is relevant here is the authority the social workers had in constructing the explanations of the young women's pasts . . ." (Addelson 1991: 102).
It is the staff person's assessment and perception of consumers that is being recorded. These are based on the underlying interpretation that intellectually disabled people are abnormal, that they essentially lead aberrant lives, and that they need to be both trained and managed in order to become part of society. Whenever a particularly unusual or difficult situation arose an incident report had to be filled in and signed by staff. A communication book passed between the houses and the activity centre and it was through this and all the other reports, minutes, and progress records that information about the consumers was circulated. This included staff from the DOCS office, and it was through such information and their conversations with one another, that staff became uniformly informed as to how they were to engage with, manage and train those who were in their care.

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This ideal of integrated behavioural management, although different in that it is combined with the contemporary ideology of normalisation and community integration, is not entirely new. Even before my brother and sister went to live at Stockton Hospital in 1975 the staff at the Grosvenor Diagnostic Centre were suggesting to my parents ways in which my siblings’ behaviour could be better managed. In fact, the people at Grosvenor, as well as other professionals in the field, saw advice on management as one of their primary roles and duties towards my parents (19/5/67; 19/2/69; 12/5/69). In a letter to my father in April 1967 the then Director for the Mentally Handicapped in NSW suggested that: "the first stage in discussing the problem of your three children would be for them to be examined at the Mental Deficiency Diagnostic Centre at Grosvenor Hospital, Summer Hill. After the appropriate diagnostic work-up, we could then discuss the best possible avenues for management" (26/4/67).

In July 1967, after my siblings’ second assessment at Grosvenor, it was surmised that: "only the passage of time and the further evolution of the condition will make the
definite diagnosis clear and assist the parents in accepting fully the implications of the situation with regard to management, training and placement. . . We recommended that Stephen and Maryla needed an educational or training program for the retarded, geared to their intellectual level and possibly in a residential setting, although such placement may not be easy to find in view of their added behaviour disorder” (12/7/67). On finding Maryla, Stephen and Ursula “extremely difficult to examine” the doctors gained an impression of them as “almost UNMANAGED and UNMANAGEABLE” (25/5/67; capitalised in original). They blamed this on my parents “inappropriately permissive techniques of child handling”, acknowledging, however, that this “seems to have been forced upon them by the exigencies of the situation—aside from their own personality tendencies” (25/5/67). As they wrote: “We gave an interpretation that the disturbed behaviour shown by the children had an organic rather than a Psychotic basis and needed firmer control, fixed limits and expectations, and minimisation of external stimuli rather than overpermissiveness (I feel this advice may have fallen on deaf ears). We also recommended domestic or Mothercraft help for Mrs. Klotz in the home, to assist in organising a routine for the children’s medication, habit-training etc.” (12/7/67). There was little further elaboration in the records on just what this management and training should include. It was consistently alluded to as an essential requirement for my siblings’ progress and development but rarely expanded upon. More often than not, the advice from Grosvenor took the form of drug therapy for controlling my siblings’ epileptic seizures and “managing their difficult behaviour” (9/5/66; 19/2/69; 24/2/75).

In February 1975, when my parents sought advice from the staff at Grosvenor “regarding the possibility of residential placement”, the attending Senior Medical Officer commented that: “although devoted to their two handicapped children, [the parents] realise that little progress has been made of recent years and that the demands of home life are causing difficulties for both Stephen and Maryla, and for the rest of the family . . . They now function in the severely mentally retarded range of intelligence
and because of increased difficulties in home management and their limited abilities in self-care, performance and communication, residential placement in a State institution for the mentally retarded is being sought (eg. Stockton Hospital)” (24/2/75). The principal at Maryla and Stephen’s school supported this recommendation, noting that “Both children fall within the moderately retarded level & if in a better living situation a better performance would be seen” (7/8/75).

Although the staff at Grosvenor tried to encourage management of my siblings’ behaviour in the home, outside of an institutional environment this is difficult to implement. Families have a different way of engaging with and perceiving their retarded kin, and the dynamics of an intimate home environment do not easily lend themselves to managed training. This was one of the reasons why my parents were encouraged to consider placement in an institution. It was believed that this would alleviate pressure on the rest of the family. It was also thought that an institutional environment would provide my brother and sister with what those at Grosvenor perceived to be the necessary care and management for their progress and development. It was at the institution that very specific programs for changing my siblings behaviour were put in place, although this only began in earnest in the early 1990s.16

In Maryla’s early ISPs the main aim seemed to be controlling and stabilising her epilepsy. Prior to these plans the general focus in the wards had been on toilet training and hygiene. It was not until 1994 that the emphasis shifted to normalisation and community integration. This change was primarily due to the recently instituted NSW Disability Services Act (1993) which legalised the principles of community integration and normalisation in all NSW government services and institutions. By 1996 Maryla’s "Lifestyle Management Plan" included the aims of "effectively managing her

16 The general tendency at the institution is for patients to be segregated according to their different abilities. In this way the staff would work on the group as a whole rather than focusing on individual skills and training, and people would be moved from ward to ward according to developments in their abilities.
challenging behaviours in the least restrictive manner possible. To improve her independence and living skills . . . [and her capacity to] socialise in an appropriate manner”. This combination of normalisation, training and behavioural management was seen as a positive way of improving my sister’s social acceptability, independence and lifestyle. While these included such things as joining the local girl guides and going to cooking classes, there was a definite bias towards managing her behaviour.

In 1991, one of the staff on Maryla’s ward used her as a case study for an assignment on reducing compulsive behaviour. The “problem” they were having with Maryla was “compulsive pacing of dormitories, corridor and bathroom for hours after retiring at night” (Chadban 1991: 2). Over a period of time this “disruptive” and “inappropriate compulsive behaviour” was decreased and replaced by a “contextually relevant alternative”. This involved Maryla listening to a recording of a children’s story each night before going to sleep. Maryla was thirty years old at the time. It was considered that this constituted a change in her environment “more in keeping with the principles of normalisation” (Chadban 1991: 9).

Another consistent “problem” that the staff at Stockton have with Maryla is her constant collecting of bits and pieces. This too is labelled as obsessive-compulsive ritualistic behaviour, as it interferes with Maryla’s other activities such as the crafts and living skills lessons that are part of her social training (Chadban 1991: 5; 15/11/94). In April 1994 a Management Plan was drawn up with the aim of teaching Maryla to carry her bits and pieces in a box. Due to the craft work Maryla was engaged in at the time she had begun collecting bits of off-cut material and cotton thread which caused her palms to sweat and the skin to peel. The strategy was to get Maryla to take a box with her and when it got too full she was to dispose of the cotton in the dispensary. As the plan noted: “It is important that Maryla is able to keep the box with her all day, except for a few times when she will be encouraged to put the box down (meal times, hygiene time, shower time, dressing etc). THE BOX WILL NOT BE USED AS A PUNISHER OR A REINFORCER. THAT IS, SHE IS TO HAVE THE BOX
 REGARDLESS OF HOW HER BEHAVIOUR HAS BEEN. Using the box allows her ritualistic and obsessive behaviours to be managed and allows her hands time to heal” (29/4/94; capitalised in original).

As I remarked in chapter two, Maryla now carries her bits and pieces around in a purse which is locked up at night to prevent her arranging them as she likes to do. We were asked to do this as well when Maryla came home for visits. However, my family view Maryla’s collection of bits and pieces as an integral component of her sociality, and it is through our engagements with her over these objects that our particular form of relating to one another has evolved. Ongoing discussions as to what is happening are also a part of our interactions with Maryla. She needs to know exactly what is happening, and this has to be regularly repeated and reinforced in order for Maryla to be satisfied. In the past Maryla always directed these questions to one person in particular, and it was from them that she elicited the information and affirmation required. The staff at Stockton have been informed that this form of interaction with Maryla must be changed. According to her ISP guidelines, Maryla is now responded to once and then told to stop asking questions. This has led to Maryla being mostly ignored by those with whom she spends the majority of her time. However, another change has also occurred. Instead of directing her questions to only one person, Maryla now includes the names of everyone who is present before asking a question, a procedure that can take quite a long time at family gatherings. This is a somewhat poignant attempt by Maryla to maximise communication as the institutional forms work to minimise it.

The Rationalisation of Daily Life

The interconnection between clinical interpretations and assessments, training and management practices, and daily reports and updates on behaviour, has created an environment in which intellectually disabled people are constantly
under surveillance. Intellectually disabled people constitute a problem that has to be worked on. Their beingness is not acceptable. It is asocial and abnormal, and as such it has to be trained and managed to conform to normative social skills and behaviour. This is what the staff are employed to do. Their work is predicated on the notion that they be "doing something", as Shaddock et al. (1993: 49-50) and Ryan and Thomas (1987) have also noted. This ethos of training and management becomes an ongoing and ceaseless attempt to continually redress the situation that is intellectually disabled people's reality. Since they are not expected to procure this state of self regulation and control themselves, the management and disciplining of this state is maintained in the hands of those who work with, or on, them. As Murray Simpson puts it: "it was a lack of ability to practice normality as a self-discipline which became the primary pathological feature of mental retardation" (Simpson 1996: 103; author's emphasis). Underlying this feature, however, is the implicit assumption that human sociality rests on the capacity for reason, where reason is identified with certain abstract skills and practices embodied in productive work.

The implementation of coordinated individual service plans and behavioural management practices in the group home, institution, work-place, activities centre and, ideally, in the family home as well, has produced an environment in which the surveillance and management of intellectually disabled individuals has become increasingly vigilant. This "total environment" is one which is now filled with reports, records, programmes, plans and meetings. The term was coined by Goffman (1990 [1961]) to refer to the enclosed and totalising regime of asylums. However, the contemporary practices of training and managing intellectually disabled people in accordance with normalisation principles has produced what I would argue is an even more totalised environment,
especially for those who live in government-funded group homes. The walls of the institutions may have been removed but they have been replaced by an interconnected and reinforcing network of services, reports and plans that now imprison each consumer.

Wolfensberger's legacy of integrating services according to the principles and practice of normalisation has inadvertently locked intellectually disabled people into a system that reproduces their identity as abnormal, deficient and asocial beings. These services produce a uniform institutionalised response to intellectually disabled people. They inform the ways that staff must engage with consumers, and provide an outline of desired behaviours and skills to be worked towards. Such a monolithic approach to services has produced what Burton Blatt has called a "closed no-option system" (Blatt 1981: 10-11). Rather than resulting in greater freedom and community integration, the contemporary practices in the field of intellectual disability have therefore created an environment of increasing institutional bureaucratisation and rationalisation.

The production and categorisation of an intellectually disabled identity which is then processed and ordered through the rationalised institutions of society reflects these very processes. As an "administrative category" (Stone 1984: 233; Rose 1985: 106) intellectually disabled people are positioned within these interlocking services as "serviceable objects" (Goffman 1990[1961]: 374; cf. Foucault 1978; Handelman 1981), as people who are to be provided services for the purpose of transforming their place within society. There are two aspects to this process; one is the structure of services and their underlying

The continuation of institutionalised attitudes and practices within smaller residential services in the community has been well documented (Halpen et al. 1980; Rapley & Hopgood 1997; Szivos 1993). As Johnson notes: "The women in the locked unit remained locked into the discourse of intellectual disability within which they had lived at the institution. In fact the process of deinstitutionalisation itself was conducted within that discourse, and it's implementation served to develop the discourse further" (Johnson 1998: 146; cf. Branson & Miller 1992: 19).
interconnectedness; the other is the role these services play in the daily lives of intellectually disabled people.

Gunnar Dybwad (1976 [1969])—a Professor of Human Development and longtime President of the International League of Societies for Persons with a Mental Handicap—argued that there is a strong correlation between the prevention of mental handicap, its early diagnosis, intervention and treatment, and the coordination of services and policies. Ann Shearer (1982) supported this view and, adopting Wolfensberger's service oriented approach to normalisation, argued that the Australian government and voluntary organisations for the intellectually disabled required proper planning and coordination otherwise they faced the problem of providing duplicate services with different standards. The Commonwealth Disability Services Act (1986), along with state legislation including the NSW Disability Services Act (1993), fulfilled this criteria by legislating uniform standards for service provision throughout Australia.

While the standardising and rationalising of services through such mechanisms was supposed to aid intellectually disabled people's access to adequate services, the outcome has more often been that such people experience being trapped within them. The people with whom I worked experienced this meta-institutional reality in their daily lives. Some of the people with whom I worked, such as Martin, Daniel and Sarah, either lived at home or had family in the area who were able to support them. They had people who provided alternative environments and relationships to those that marked the institutional nature of the group homes, sheltered workshops and activities centre. Despite this, their families were still under pressure to adopt the aims and stipulations of individual training programmes. The majority of the consumers whom I came to know, however, lived in a group home, went daily to the activities centre or workshop, and had little or no contact with
relatives, or indeed anyone outside the service. They were permanently under the auspices of the Department of Community Services and were constantly subject to institutional practices of training and management.

The link between legislation and the instituting of practices of reason and normality can be seen in the effects of the NSW Disability Services Act and the Standards of Practice that aim to fulfil these obligations under the Act. Staff were bound and limited in their interactions and relations with consumers by their duties and responsibilities as employees of the NSW government. Normal and intimate relationships were made difficult through legal requirements as set out in this legislation and departmental policies. Despite the ideal of extending to the intellectually disabled the same rights and opportunities that the rest of the community enjoys, the Disability Services Act and government policies end up legislating and instituting the form the relationship between intellectually disabled people and staff must take. They also highlight and reinforce differences between the staff and consumers, and trap consumers within a legal definition of intellectual disability, as Angrosino (1998a: 27) has argued. Institutional forms of relating are based upon the assumption that intellectually disabled people are abnormal, deficient and asocial beings who

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18 Johnson (1995) has analysed the clash between normalisation principles and legislative practices that exist in the field of intellectual disability. She argues that problems arise between conflicts over rights and responsibilities or between contradictory rights such as a "duty of care" to the consumer and their right to a "dignity of risk". Johnson argues that while power has shifted away from the medical profession, intellectually disabled people are still caught within power relations wielded by other "knowledge-holders" in society. As she puts it in her Foucauldian analysis of institutional practices: "while no longer regarded as sick and in need of medical treatment, people with intellectual disabilities are now subjected much more than previously to the power of the 'lawyer-judge' and the 'advocate-judge'" (1995: 210). Johnson (1995: 222-3) accepts that there is still a "collision of two powerful discourses—medical and legal" and that this adds to the confusion experienced by staff and the intellectually disabled in the process of deinstitutionalisation. Consequently, the legal discourse has shaped the process of deinstitutionalisation but it also "governs relationships and shapes the ways in which people with intellectual disabilities are viewed by those around them" (1995: 222). Although such an analysis is useful for exposing the interrelationship of power and knowledge in institutional and clinical encounters with intellectually disabled people, it does not allow us to explore the mutuality, sociality, subjectivity and intersubjectivity of these people as anything other than objects or "others", as anything other than the products of these discourses.
need to be trained to become social. They are based upon managing intellectually disabled people’s behaviour and also instilling in them forms of communication and behavioural expression that conform to normative standards of social action and expression.

Section Nine of the NSW Disability Service Standards states the obligation that "Each person with a disability receives a service which . . . is sensitive to their cultural and linguistic environments" (NSWDOCS 1996). While this acknowledgment of different cultural backgrounds is important, it is done within the broader framework of erasing and ignoring the differences that are integral to people’s actual intellectual disabilities. Stressing equality as a right places an emphasis on treating the intellectually disabled as though they are the same as everyone else. However, this ultimately ends up in a denial of who they are, as they are, while at the same time making their differences the reason for implementing programmes designed to incorporate intellectually disabled people into normative social practices.

Owing to the institutionalised nature of the relationship between the staff and consumers, and the time spent updating reports, designing management plans and doing other paperwork, there was no such thing as time for "normal" interaction. During my year at the activities centre the coordinator wrote a letter to the assistant manager at DOCS who was responsible for Disability Services in the region. He asked her if the staff could have a consumer-free day each fortnight so that they could catch up on their paperwork. The staff often complained about the proliferation of paperwork and how it interfered with their "hands on" responsibilities but these did not involve just being with those whose care they were responsible for. They were employed to work, and this meant working on the consumers, guiding them towards a "normal" life and providing them with training to develop social and vocational skills (cf. Ryan & Thomas 1987: 48 for a similar account of this practice of "working on" mentally
handicapped clients). It did not involve partaking in this life themselves or engaging with consumers through their own symbolic systems. It did not involve creating an environment within which a genuinely shared mutual sociality could emerge through the negotiation and mediation of different symbolic systems. The emphasis was always on forcing conformity to normative social skills and behaviours as though this was what constituted human sociality.

If, as Kelley Johnson (1998) has argued, there is no change in the underlying ideology or discourse of intellectual disability, then there is no possibility for real change in the way that intellectually disabled people are treated (cf. Branson & Miller 1989, 1992; Cocks & Allen 1996; Simpson 1996). As Don Handelman puts it:

. . . administrative-frameworks may be affected by deeper, less visible, structural ambiguities and disjunctions, whether within the organisation itself or within the larger social order in which it is embedded. In general, organisation adjustments to the surface contradictions generated by such deep disjunctions fail to resolve the latter, thus creating the conditions for the generation of further dilemmas whose causes remain unrecognized (Handelman 1981: 19).

The attitudes and practices that existed in large-scale institutions will continue to structure and inform the lives of intellectually disabled people wherever they live. Introducing, instituting and legislating practices such as normalisation, deinstitutionalisation, quality of life and equal rights ends up being counter-productive when they implicitly reinforce the symbolic scheme of reason and normality that constitutes intellectually disabled people as abnormal, deficient and asocial beings. The fact that they must be trained and
managed to become socially normal and integrated means that intellectually disabled people are still not accepted as social and encultured beings on their own terms. Their capacities for meaningful sociality and mutuality have still not been acknowledged; they must be brought into being.

The "deep disjunctions" that exist between the practices and aspirations of institutionalised environments perpetuate ongoing contradictions in the ways that intellectually disabled people are dealt with. Informed as they are by the association of reason with normal humanness, and by the value of reason embodied in productive work, the forms of sociality and relatedness that institutional environments precipitate are ultimately based on the requirement that intellectually disabled people master particular domestic and vocational skills. The contextualised, immediate, embodied, and often highly specific symbolic systems that many intellectually disabled people actually utilise are not recognised as potential mediums for developing and sustaining mutual sociality. Having already been separated as radically other, intellectually disabled people are subsequently reintegrated into the "socially normal" carrying the total burden of their supposed deficient and asocial "otherness". As such, intellectually disabled people only ever live a simulacra of sociality in institutional environments, one which has all the trappings of normality but none of the actual substance of mutual sociality. Branson and Miller argue that the administration and rationalisation of contemporary practices of integration and normalisation represent a "symbolic violence of humanism" (Branson & Miller 1992: 17). The violence that is being perpetrated rests on the denial of intellectually disabled people's inherent capacities for creating and sustaining forms of sociality and mutuality.