

*Denying Intimacy:  
The Role of Reason and Institutional Order in the Lives of  
People with an Intellectual Disability*

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## **List of Persons**

### **Siblings**

Joseph (b. 4/5/1958)

Stephen (b. 11/7/1960)

Maryla (b. 10/11/1961)

Ursula (b. 1/10/1963)

Jani (b. 17/9/1965)

Tessa (b. 16/3/1968)

Peter (b. 29/6/1970)

### **Intellectually Disabled People at "Xanadu" (and place of residence)\***

**\* all names of people and places associated with my fieldwork have been changed to protect their privacy**

Cressida (Jeffrey Street)

Martin (Home)

Daniel (Home)

Patricia (Jeffrey Street)

Jacky (Corrie Street)

Polly (Jeffrey Street)

Joanne (Jeffrey Street)

Rachel (Home)

Kate (Corrie Street)

Sarah (Jeffrey Street)

Mary (Hervey Street)

Tony (Jeffrey Street)

### **Other Intellectually Disabled Persons Mentioned (and place of residence)**

Jane (Jeffrey Street)

Colin (Hervey Street)

Jill (Jeffrey Street)

Jim (Hervey Street)

Kerry (Jeffrey Street)

Sally (Hervey Street)

Shauna (Hervey Street)

## **Glossary of Terms and Places**

DOCS - Department of Community Services

DSA (1993) - Disability Services Act (1993)

ISPs - Individual Service Plans

IQ - Intelligence Quotient

MA - Mental Age

NSW - New South Wales

Grosvenor Diagnostic Centre - Formerly known as the Grosvenor Mental Deficiency Diagnostic Centre. Now known as the Department of Community Services Disability Specialist Unit.

Stockton Hospital - Now known as the Stockton Centre for Developmentally Disabled People.

"Corrie Street" - DOCS Community Group Home

"Huxley Street" - DOCS Community Group Home

"Jeffrey Street" - DOCS Community Group Home

"Keynton" - Paper Shredding Unit attached to Xanadu

"Xanadu" - Activities Centre

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*For Stephen, Maryla and Ursula*

**Denying Intimacy:  
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**Jani Klotz**

**Abstract**

This thesis explores differences in the ways that intellectually disabled people are perceived, interpreted and related to within a Western context. Through a comparison of familial and institutionalised forms of relatedness, it examines the interrelation between these differences and the consequences that they have for either denying or acknowledging severely intellectually disabled people's capacities for sociality. Drawing on Carrithers' (1992) concept of sociality and mutuality, and Wittgenstein's (1953) notion of language games, the thesis analyses the means by which a meaningful and shared existence with intellectually disabled people can be negotiated and developed. Although limited and restricted in their capacities for symbolic expression, such people do have modalities of symbolic life upon which sociality can be built. By analysing the symbolic practices utilised by my three profoundly intellectually disabled siblings, I seek to show how relationships across the difference of intellectual disability are able to be symbolically mediated and negotiated. I argue that it is necessary to engage in relations of mutual interdependence in order to even recognise and perceive these practices as purposeful and meaningful. The mutuality that ensues requires a level of intimacy, empathy and commitment that is not easily sustainable, but which is necessary for the maintenance of intellectually disabled people's existence as social beings.

These intimate relations are contrasted with clinical and institutional forms of relatedness, both of which have been informed and shaped by a symbolic scheme of

reason and normality. This symbolic scheme associates a capacity for reason with normal humanness, where reason is identified as particular abstract, linguistic, mental practices that are then deemed necessary for sociality. These are what intelligence tests measure, and it is through such assessments that intellectually disabled people are rendered asocial. The pathologising of intellectual disability as an abnormal embodiment, and the clinical tendency to search only for deficits in functioning and ability, has led to a denial or ignorance of intellectually disabled people's abilities to be the independent sustainers and authors of mutuality and sociality. I draw on my family's medical notes, records from the institution where two of my siblings were sent to live, as well as observations made during twelve months of fieldwork with a group of intellectually disabled people attending an activities centre, and either living in community group homes or with their families, to elucidate the ways in which such interpretations of intellectual disability become instituted into daily practice.

The instituting of training and management practices within day centres, group homes and institutions for the intellectually disabled are a consequence of the perception that intellectually disabled people have no capacity for sociality as they are. So too are the legal and structural obligations that inform the forms of relatedness that staff have with the intellectually disabled people with whom they work. These relations are based on separation and disengagement rather than mutuality and intimacy. The aim in these institutionalised environments is to instil in such people a range of normative social, domestic and vocational skills as though it is upon these that their capacity as social beings are dependent. As a result, the symbolic practices and dispositional behaviours through which intellectually disabled people express themselves are not recognised as such, nor are they engaged with. This undermines intellectually disabled people's capacity to be joint contributors to social life in a way which incorporates their differences rather than trying to transform them.



## Introduction

How is it that forms of sociality are generated and sustained with people who have severe and profound intellectual disabilities? And why is it that such people's capacities to create and engage in meaningful relations with others are so readily denied or ignored? These are two of the central questions that have motivated this thesis, and provide the underlying themes of the following seven chapters. Although limited and restricted in their capacities for symbolic expression, intellectually disabled people do have modalities of symbolic life upon which forms of sociality and mutuality can be built. Through an analysis of the symbolic practices and dispositional behaviours utilised by my three intellectually disabled siblings, I show how relationships across the difference of intellectual disability are able to be symbolically mediated and negotiated. I argue that it is necessary to engage in relations of mutual interdependence in order to even recognise and perceive these practices as purposeful and meaningful. The mutuality that ensues requires a level of intimacy, empathy and commitment that is not easily sustainable, but which is necessary for intellectually disabled people to exist as social beings as they are.

I juxtapose this social and symbolic milieu with that of an institutional life devoted to the normalisation, management and training of intellectually disabled people. These institutional environments include government-funded community activities centres, sheltered workshops, group homes, and large-scale institutions. In such environments, intellectually disabled people are trained to develop particular social skills deemed necessary for sociality. These include domestic and vocational skills, as well as specific communicational skills through which people are expected to express themselves and engage with one another. Such institutional practices have been informed by clinical

interpretations of intellectually disabled people as abnormal and deficient, asocial beings. They disregard the fact that what makes us persons, and allows for a multiplicity of persons, is our human capacity for mutuality and sociality, as well as our creative potential to produce different symbolic systems through which we engage, communicate and make meaningful the world to one another.

Despite a growing interest in the social experiences and perceptions of intellectually disabled people, the study of intellectual disability remains a relatively small field within the social sciences. Moreover, most of the sociocultural research that has been done has tended to focus on the social experiences of people with mild rather than severe or profound intellectual disabilities (Edgerton 1967; Bogdan & Taylor 1982). This is partly a consequence of the difficulties involved in using people who are severely intellectually disabled as informants. However, it is also a product of the perception that such people lack the capacity for symbolic expression. This view underpins clinical perceptions (Kanner 1944; Wing 1996) as much as it informs some sociocultural accounts of people with intellectual disabilities (MacAndrew & Edgerton 1970). The association of symbolic representation and expression with specific intellectual and linguistic competencies, and the notion that these are a necessary condition for cultural behaviour, has allotted those who lack such skills a place outside, or at best on the borders of, human encultured sociality. This thesis therefore involves a critique of the implicit or explicit denials of intellectually disabled people's capacities for sociality in a range of written studies and social environments, including historical documents, clinical and institutional records, and familial and institutional milieu.

In chapter one I provide a description of the forms of sociality and symbolic expression that my three intellectually disabled siblings created and utilised in their everyday lives within the intimate domain of our family life. Through an

analysis of their particular, highly contextualised and often embodied, symbolic and dispositional practices, I show how my siblings were capable of producing and sustaining mutual and intimate relations with one another and their non-intellectually disabled kin. Drawing on Carrithers' (1992) concepts of sociality and mutuality, Bernstein's restricted codes (1971; 1977), Geertz's (1993a [1973]) interpretation of culture, and Wittgenstein's (1998 [1953]) notion of language games, I analyse the means by which a meaningful and shared existence across the difference of intellectual disability is able to be developed and maintained. I show how my siblings' symbolic and dispositional practices were incorporated into and helped define my family's specific form of life, and how my siblings' existence as social beings ultimately depended upon levels of intimacy and interdependence that were generated within these familial relationships.

In chapter two, I explore some of the consequences of disrupting this familial intimacy. I examine the impact of social attitudes towards intellectually disabled people in general, and explore how these came to affect the ways in which I and my non-intellectually disabled siblings dealt with the stigma of having intellectually disabled kin. The chapter also includes an account of the tensions, difficulties and differences that were created when the intimacy of the home environment was replaced with the anonymity of institutionalised and clinical settings. In the second section of chapter two, I introduce my fieldwork, which was done with a group of intellectually disabled adults living in "the community" in government-funded group homes and attending an activities centre or sheltered workshop. I outline the forms of relatedness that exist within these "institutionalised" environments, and show how, despite recent changes in policies towards intellectually disabled people, these relationships are moulded and constrained by legal and institutional structures and obligations that continue to undermine intellectually disabled people's capacities to represent and express themselves as social beings.

Having introduced my two main "ethnographic sites", I then turn to analyse why it is that intellectually disabled people are perceived, interpreted and treated as asocial and abnormal beings within both clinical and institutional environments. I argue that the written documents that constitute the literature on intellectual disability—which includes historical, philosophical, religious, medical, psychological, welfare, educational and institutional records—embody shared and implicit assumptions about the nature of human nature. These can readily be interpreted as constituting a "symbolic scheme of reason and normality", where a "symbolic scheme" represents the taken-for granted ideas and values to which a cultural milieu conforms (Sahlins 1976). It is this scheme that orders and informs clinical interpretations of intellectual disability. It also informs the practices of training and management that have become the dominant modes of engaging with intellectually disabled people in institutionalised environments. Rather than merely being descriptions of intellectual disability, such material is also constitutive of the environments within which intellectually disabled people exist. As part of the discourse of reason and normality I have therefore incorporated what would normally be material for a literature review into my analysis of the ways in which intellectually disabled people are perceived, interpreted and treated. Throughout the thesis I make links between this material and my ethnographic notes and siblings' clinical records in order to describe and analyse the inter-related discursive forms drawn together by a symbolic scheme.

In chapter three I analyse the role that notions of normality play in this symbolic scheme by looking at the history of medical interpretations of intellectual disability. I explore the shift from religious interpretations of intellectual disability as a mark of sin to scientific medical views based upon a Cartesian view of the body. In distinguishing intellectual disability from insanity, I argue that medical practitioners have based their interpretation of

intellectual disability on notions of deficiency and abnormality. Although no longer explicitly connected with sin, these interpretations are thoroughly steeped in moral judgements that connect the continuing presence of "degeneracy" with concepts of heredity. Through an analysis of my siblings' medical records, I show how such notions of deficiency and abnormality become morally and pathologically embodied in contemporary medical interpretations and perceptions of people with intellectual disabilities.

In chapter four, I argue that a pervasive and implicit regime of reason underlies these medical interpretations of intellectual disability. By associating reason with specific intellectual and linguistic skills and capabilities, and assuming that these are necessary attributes for producing meaning and engaging with others socially, intellectually disabled people have been assessed, categorised and interpreted as lacking that which is deemed essential for both normal humanness and human sociality. Through an analysis of the role that intelligence tests have played in the diagnosis and assessment of intellectual disability, I show how such assumptions continue to pervade clinical interpretations of intellectually disabled people. Once again, I draw upon my siblings' records to elucidate the role that such assessments have played in rendering meaningless, bizarre, and irrelevant the practices that intellectually disabled people utilise to express themselves and engage with others socially. By not recognising or engaging with these symbolic practices, I argue that medical and psychological practitioners have consequently ignored or dismissed the capacities for mutuality and intimacy upon which such people's sociality depends.

In chapter five, I turn to the sociocultural literature on intellectual disability and show how it emerged as a direct criticism of the limitations of these medical and psychological interpretations. Through an analysis of the work of Robert Edgerton, Robert Bogdan, Steven Taylor, David Goode and John

Gleason, I separate the sociocultural study of intellectual disability into three distinct, though inter-related, "schools" of thought. Inspired by the seminal work of Robert Edgerton (1967), the majority of early sociocultural studies of intellectual disability tended to focus on the consequences of stigma, labelling and incompetence for intellectually disabled people. They also focused more exclusively on the social experiences and problems of mildly intellectually disabled people, particularly their adjustment to living in the community. More recently, there has been a shift towards analysing the experiences and perceptions of intellectual disability as a social construction (Bogdan & Taylor 1976, 1982; Manion & Bersani 1987). This second "school" extends into post-structural "discursive" analyses that seek to elucidate the connections between discourses of intellectual disability, institutional practices and identity (Branson & Miller 1989; Cocks & Allen 1996; Johnson 1998). Although different in their styles of analysis, the work of Goode (1980a; 1980b; 1990) and Gleason (1989; 1994) represents a third "school" within the sociocultural study of intellectual disability. By emphasising the centrality of relations and intimacy in encounters with severely intellectually disabled people, Goode and Gleason analyse the conditions that are necessary for such people to engage in meaningful interactions with others.

Despite their greater sensitivity to intellectually disabled people as social beings, constructionist accounts do not often allow for an interpretation of these people as more or other than just a product of these constructions. The studies therefore tend to mask the social and symbolic agency of intellectually disabled people and perpetuate the assumption that such people lack the capabilities to be the independent sustainers and authors of mutuality and sociality. Not all meaning is discursive meaning, and social life incorporates generational and transactional processes as much as it involves the reproduction of certain structural elements. While social and cultural factors

have been instrumental in producing an historically informed and socially constructed interpretation of what it means to be intellectually disabled, and while these have subsequently influenced the practices and forms of relating that exist in clinical and institutional encounters with intellectually disabled people, they do not in themselves capture the totality of what it is to be intellectually disabled, nor what is involved in engaging in social relations with such people. While my analysis of intellectual disability in terms of a symbolic scheme of reason and normality is similar to some of the post-structural and constructionist accounts, I have also been inspired by the interactional analyses of Goode and Gleason in my endeavour to analyse how intellectually disabled people actually express themselves and engage with others socially.

In chapter six I return to my fieldwork notes and the records of my siblings in order to examine the processes through which the symbolic scheme of reason and normality becomes instituted into daily practices and relationships in institutional environments. I also analyse this material with reference to contemporary policies towards intellectually disabled people. This includes normalisation and deinstitutionalisation policies, as well as the practices of behavioural management and individual domestic and vocational skills training. These policies and practices have been shaped by social and clinical interpretations of intellectual disability. They are also informed by legal and structural obligations that influence the ways in which staff are able to engage with their 'clients'. While these policies and practices acknowledged that intellectually disabled people are capable of learning, developing and changing, they also continued to render the intellectually disabled in terms of 'deficiencies'. Constructed as lacking or deficient in particular skills and competencies, intellectually disabled people are treated in institutionalised environments as though they need to be managed and trained to become social beings. As a consequence, very little attention is given to their own

modes of sociality and senses of intimacy; to any intimations that they may have of mutual sociality in everyday life.

In my final chapter, I examine the connection between mutuality, sociality and meaning, and the link between these and the different ways in which intellectually disabled people are perceived and related to. In institutional environments, staff relate to intellectually disabled people on the basis of training and management practices. These reflect legal and institutional requirements of maintaining professional levels of distance, separation and disengagement. As a result, the range of symbolic practices and dispositional behaviours that intellectually disabled people utilise to express themselves are not recognised as such, nor are they engaged with. Consequently, as part of their social training, the people with whom I did my fieldwork have been encouraged to develop particular normative communicational skills. This training occurred specifically during the weekly meetings that took place at the activities centre and group homes, although it was also an aspect of the general ethos of training and management that dominated most aspects of both environments. These practices excluded any requirement that intellectually disabled people relate to and engage with the staff.

In order to perceive the intent and meaning of intellectually disabled people's symbolic practices and behaviours, however, I argue that it is necessary to engage with them on the basis of intimacy and mutuality. It is through relations founded on intimate mutuality that differences are able to be symbolically mediated. It is also through such relationships that mutual forms of sociality emerge and upon which intellectually disabled people's existence as social beings depends. To ignore or deny the pre-existing capacities of intellectually disabled people to generate and sustain modes of mutual sociality and symbolic expression is therefore to undermine their existence as social beings. By juxtaposing modes of sociality within a familial and institutional

domain, it is possible to elucidate the consequences of forms of relatedness based on either intimate mutuality or training and management practices. While chapters one, two and seven conceptually frame this thesis and provide a description of familial and institutional modes of sociality and relatedness, chapters three to six provide an analysis of how notions of deficiency founded on a symbolic scheme of reason and normality have become embodied in clinical interpretations and institutional life.

## Chapter One

### Ethnographic Encounters I:

#### Growing up in a world of intellectual disability

My older sister Ursula and I were playing in the main bedroom at the home of some friends of our parents. It was a large and luxurious room. A bay window dominated one wall, with loosely draped curtains letting in the afternoon sun. Textured rugs covered the floor, paintings adorned the walls, and an antique dressing table stood in one corner, laden with boxes, bottles and brushes. We were both drawn to this corner, and climbed up onto a stool to get a closer look at ourselves in the large gilt mirror. The sound of adults talking drifted up from the downstairs drawing room, and other children's voices could be heard outside in the garden. Yet we were in our own secluded world, in this hidden and forbidden room. We knew full well we were not supposed to be there but nonetheless we were both enticed by the beauty, colours and scents of the place. We drew open the drawers of the dressing table, pulled out lipsticks, powder, and bottles of perfume and watched ourselves intently in the mirror as we applied garish colour to our faces, to lips, eyes and cheeks alike. I cannot remember whether we went downstairs to show ourselves off, or were discovered in the act itself, but the consequences differed none. We were soundly punished for our transgressions and scrubbed to a colour just as bright as the pinks and reds of the lipsticks we had used.

This is one of my earliest memories, and like nearly all the memories I have up until the age of three and a half, it involves me playing with my sister Ursula. She was a beautiful, gentle child, with soft brown curly hair, olive skin and brown eyes. We were close in age; two years separated us, with three older siblings making five children in all at the time. Consequently, Ursula and I

spent a lot of time together, climbing fences on country picnics, playing on the swings in the back garden, drawing pictures, looking at books, playing with toys and having morning tea together as we watched Playschool<sup>1</sup>. Being older, she was the leader and I dutifully followed her quiet but definite lead as we moved through the daily activities and games of childhood. I do not remember us ever talking with one another, or playing anything highly organised, but we understood and communicated in the way that siblings close in age often do. We existed in each other's world, and within the wider world of our family. When Ursula went to preschool I was devastated to be left alone at home, packing my school bag each morning in the hope that one day I too would follow her and my other older siblings into a larger world. The only difference was that the world I would one day enter was profoundly different to the one that three of my siblings experienced.

Three of the four older children in my family are intellectually disabled.<sup>2</sup> In addition, my eldest brother Joseph has had to deal with enduring problems due to contracting encephalitis as a 20 month old baby.<sup>3</sup> All four children were

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<sup>1</sup> Playschool is a popular children's television programme that has been running in Australia since the 1960s.

<sup>2</sup> The range of people, and their social and linguistic skills, who are considered to be intellectually disabled varies considerably. The definitions of the American Association on Mental Retardation and the World Health Organisation includes all those with "subaverage intellectual functioning", or an IQ below 70, where the disability is manifest before maturation and includes functional limitations in at least two areas of independent living, mobility and language ability (Bullock & Trombley 1999: 519-520; Schalock *et al.* 1994: 182). The majority of research on the social lives of people with intellectual disabilities has been done with those in the upper functional range, those with an IQ above 50, or the mildly mentally retarded using the old terminology. Two of my siblings were considered to be severely mentally retarded, and when using the term intellectually disabled it is to such people that I am more specifically referring.

<sup>3</sup> In a psychological assessment done in 1977 it was considered that Joseph had "a residual organic impairment" related to the encephalitis, resulting in physical, intellectual and psychological developmental problems. His problems were thought to be related to the "familial disorder" that Maryla, Stephen and Ursula were seen to exhibit (30/9/77). Joseph was included in all the early medical records from 1961 to 1967 but apart from this single psychological assessment, done when he was nineteen years of age in 1977, he does not appear in any other records relating to intellectual disability in the family. He was not

epileptic, three went to special schools, and two were on lifetime medication. My sister Ursula died of pneumonia in 1969 when she was five years old, and my brother Stephen died at the age of seventeen in 1978 following an epileptic seizure. Stephen was five years older than me and had an open, friendly face that often looked out on the world with a mixture of curiosity and amusement. Although labelled autistic he was a very affectionate person who loved to be cuddled, tickled and teased, and would always reach out to one of the family to let us know what he wanted.<sup>4</sup> Maryla is four years older than me, the third

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assessed at the Grosvenor Diagnostic Clinic in Sydney, and, unlike our other three intellectually disabled siblings, he attended a normal school. Due to his obvious abilities in relation to our other siblings, his high IQ, and the fact that he ceased having convulsions at seven years of age, my parents did not pursue assessments and a diagnosis in relation to his problems. However, these continue to cause difficulties for him, especially in the areas of employment, independence, financial management, domestic responsibilities and relationships. He has been on a Disability Pension since 1995 due to his Obsessive Compulsive Disorder, and now has an advocate provided for by the Citizen Advocacy NSW Association to help him with domestic, financial and other social issues. In this thesis I do not include Joseph as one of my intellectually disabled siblings, mainly because none of my family, including Joseph, have thought of him in this way. My other siblings were far more disabled than he is, and it is relationships with people who have more severe forms of intellectual disability that I am concerned with here.

<sup>4</sup> Like many terms that try to characterise and define a category of persons, autism is a controversial and contradictory concept. First coined by Leo Kanner in 1943 to describe what he called "early infantile autism", the term was used to define a particular group of children who from birth (or up to 30 months of age) did not fit the contemporary category of feeble-mindedness due to their cognitive potential (Kanner 1944). Kanner argued that autistic children exhibited similar patterns of unusual behaviour, including extreme aloneness or social aloofness, delayed echolalia, and the need for obsessive repetitive routines (Kanner 1944; L. Wing 1996). More recently it has been argued that autism presents as a spectrum of disorders with similar clinical symptoms rather than being a singular isolated disorder (Gray 1995; L. Wing 1996). According to Lorna Wing, these include "Asperger's syndrome, a condition characterised by borderline or normal IQ; social isolation or naive, inappropriate social interaction; intensive interest in only one or two subjects; a narrow, repetitive life style; limited or inappropriate intonation and body language; and poor motor coordination" (L. Wing 1996: 327). David Gray argues, however, that despite occasional media assertions that autistic people are savants, displaying extraordinary powers of mathematical calculation or musical memory, up to four-fifths of all autistic people are profoundly mentally handicapped (Gray 1995: 102). Autism was originally thought to be a social condition caused by what was termed Refrigerator Mother Syndrome. More recent arguments claim that it is a neurological condition due to

child born into our family. She is very Polish in appearance, taking after my father, with olive skin, blue eyes, wide cheekbones and straight dark hair. Like Stephen and Ursula, she hasn't any particular physical features that mark her as disabled and yet her physical presence is strikingly different. It is the way she holds herself, the way she walks, how she uses her hands; it is the way she is in the world. She lacks any of the self-consciousness, and indeed capabilities, that compel most people to act in accordance with accepted social norms.

When I was born into this family my intellectually disabled siblings were already there, were already a part of the familial environment. I knew no other world. I accepted it and sought to understand and relate to my siblings as they were; not seeking to change them but to engage with them, play with them, be with them, and, as I grew older, to help them if need be. The story that I am about to tell concerns the different ways in which intellectually disabled people are responded to. It concerns the ways in which these differences are conceptualised, and the consequences that these various responses have for either denying or accepting such people's capacity for sociality and mutual relatedness. It is also the story of my family. It focuses on the difference that having a severely intellectually disabled brother and two sisters made to our family life. It interprets what this difference involved within a familial domain, and contrasts it with other historical and social interpretations of intellectual disability. My argument will be that living intimately with disability brings its own, quite crucial perspective.

### **Meaning, Mutuality and Sociality**

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metabolic or genetic disorders, pre or post natal brain injury or viral infections (Leser 1996: 45). However, as Gray points out, there is still no agreement as to what causes autism (Gray 1995: 99).

Far from being isolated, meaningless, non-symbolic, abnormal, or asocial, as the behaviour of intellectually disabled people is so often described (Connors & Donnellan 1993: 269; Goode 1990: 30; Kanner 1944: 211-4; Lea 1988; Leser 1996: 45; MacAndrew & Edgerton 1970: 28; Rose 1985: 37; Ryan & Thomas 1987: 47-8; L. Wing 1996: 327; cf. Taylor & Bogdan 1998: 198-199; Gleason 1989: 62; for similar criticisms of such interpretations), my siblings were continuously creating meaningful lives for themselves. They were also intricately engaged in the complex patterns of sociality and mutuality that constituted our family life. The issue of meaning and its relation to sociality is a central dimension of this thesis. Although I expand more fully on this in my final chapter, it is important to introduce what I mean by "meaningless" and "meaningful" behaviour when it comes to social perceptions of intellectually disabled people. In anthropological terms I take the expression of meaningful behaviour and interaction with others as forms of sociality, as that which is symbolic, structured and purposeful, which exists within an interpretable and predictable social context, and is open to change and transformation (Austin-Broos 1987: 142-5; Carrithers 1992; Geertz 1993a [1973]: 99; Kuper 1999; Parsons 1970 [1951]: 3-11; Sahlins 1976: 58-67). Sociality does not just mean becoming recognisably encultured, nor is it merely related to social structures and institutions (Carrithers 1999: 1033). It refers instead to the "intensity of social life", with the recognition that human existence and experience is fundamentally shared and social (Carrithers 1999: 1033; 1992: 1).

Sociality refers to shared existence within a meaningful world and as such is based on mutuality and interrelations between people. In this sense mutuality is, as Michael Carrithers (1992: 11) has put it, a view "which stresses that people are so deeply engaged with each other that we can only properly understand them if we understand even their apparently private notions and attitudes as interpersonal ones". The contextual environment, and ultimately the form of

relatedness across the difference of intellectual disability, influences the way intellectually disabled people's expressions, behaviour and experiences are perceived and interpreted. Different persons are constituted differently in different environments (Carrithers *et al.* 1985). The *joint* constitution of social life as a product of relations and degrees of mutuality across this difference only occurs if intellectually disabled people's contributions to the social world are accepted on their own terms. However, without many of the predictable dispositions that act as the usual markers of sociality, intellectually disabled people are often presumed to lack any form of meaningful social existence at all. The idea that their sociality can constitute a mutuality with the intellectually able is largely dismissed.

Focusing on forms of relatedness that do not seek to change an intellectually disabled person into someone socially more 'normal' but rather accepts their expressions of difference as interpretable, allows for an awareness of meaning and sociality as inherent in their actions and interactions (cf. Gleason 1994: 247-249). Meaningful patterns of structured and purposeful behaviour are both created within the context of relatedness and produce the very form that this context takes on; it is both the product and producer of a social environment (Geertz 1993a [1973]: 93-4). The context or "form of life" (Radcliffe-Brown 1965 [1952]: 6; cf. Wittgenstein 1998 [1953]: §19) that can be experienced, perceived and created through particular types of relatedness—such as those of mutuality embedded in kin relations—thus raises issues as to the public and shared nature of this form of life, of the symbolic and purposive nature of it as a system or "language game", and hence the capacity for it to be analysed and interpreted (Geertz 1993a [1973]: 95-6; Wittgenstein 1998 [1953]: §7; cf. Bourdieu 1999 [1972]: 97; Jackson 1998: 8-10).<sup>5</sup> My use of "language games" to connote such

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<sup>5</sup> While I use Wittgenstein's "language games" in conjunction with Radcliffe-Brown's "form of life" I do so by incorporating an enriched analytical content derived from symbolic anthropology and Carrithers' concept of mutuality. This combination allows me to analyse the forms of engagement and symbolic

forms of interaction is deliberately paradoxical. Rather than referring simply to Language writ large, I use the term in the broadest sense as a system of communication that mediates and interprets the intentions and experiences of those involved. The term is also useful because it connotes a domain of sociality and symbolic exchange that, although confined and limited in its nature, is also open to possibilities.<sup>6</sup>

This interpretation raises serious questions about the ways in which intellectually disabled people traditionally have been treated and perceived; a perception that is embodied in Tredgold's 1956 statement that "they have eyes but they see not; ears but they hear not; they have no consciousness of pleasure or pain; in fact, their mental state is one of entire negation" (cited in Bogdan & Taylor 1982: 15). It also raises problems for some contemporary policies within the field of intellectual disability, including the practices of normalisation, deinstitutionalisation, and community integration, and the push for equal rights and a quality of life. While these have been introduced as positive alternatives to the older practices of segregation and isolation, and are an attempt to protect intellectually disabled people from real and potential abuse, I argue later in the thesis that the forms of relatedness that exist in group homes and activities centres often preclude the possibility and the legitimacy of developing long-term relations of mutual engagement. The mode of sociality that constitutes such institutional environments (for, despite no longer being an institution, they are still institutional) is not conducive to producing a genuinely shared social milieu. Instead, these places are founded on the principles and

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mediation that exist in encounters with intellectually disabled people without entering into phenomenological interpretations of their lived experiences. I do this because I am not fully able to apprehend the experiences of my siblings from their perspectives.

<sup>6</sup> Although I introduce Basil Bernstein's concept of "restricted codes" later in the thesis, a concept which suggests deficits and limitations in communication and social interaction, I wish to emphasise that intellectually disabled people do utilise a range of symbolic systems. In fact, these symbolic practices become the vehicles of mutuality and sociality, and are open to mediation through engagement, imagination and use.

practices of management, control, training and assimilation. These practices are themselves built upon the interpretation that intellectually disabled people are inherently abnormal and asocial, and that they are in need of being normalised and socialised in order to be meaningfully engaged with.

I too never came to know the people I did my fieldwork with as intimately as I know my siblings. This was partly due to the shortness of the time I spent with them—twelve months in all. It was also because of the fact that, structurally, I was inhibited from developing close relationships with the intellectually disabled people with whom I worked. This prescription conformed to the newly instigated Standards of Practice based on the NSW Disabilities Services Act (1993).<sup>7</sup> Consequently, although I observed similar forms of meaningful behaviour, interaction and creativity in their daily lives with one another, I do not feel able to rely on material from my fieldwork in the way that I can on knowledge of my siblings. The boundary that had been created, and to which I had to respond, meant that there was little possibility of negotiating a shared social milieu out of which such interpretations and perceptions might emerge. Without denying the difficulties that exist in relating to people with limited modes of mutuality and dispositional behaviour, the fact that they do exist, and that it is possible to develop a shared form of life across

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<sup>7</sup> The NSW (New South Wales) Disability Service Standards and the NSW Disability Services Act (1993) were passed by the NSW Legislative Assembly in accordance with the Commonwealth State Disability Agreement of 1991. Throughout the 1980s there had been agitation for changes to the treatment of intellectually disabled people in Australia. This resulted in the Richmond Report (1983) which examined conditions in NSW institutions and emphasised the ideologies of deinstitutionalisation and normalisation as an alternative social policy. The Commonwealth Disability Services Act was established in 1986 due to the recommendations of the Richmond Report and other similar reports and submissions. Each of the States agreed to pass a complementary Act to the Commonwealth Disability Services Act so as to uphold the Principles, Standards and Objectives of the 1986 Act. Under the present arrangements, the Commonwealth Government takes responsibility for employment services for all people with disabilities, while each of the States are responsible for all other services, including accommodation, activities centres and community programmes (NSW Department of Community Services 1996).

these differences, means that the institutional response to intellectual disability perpetrates a violence against the disabled. Being trained to conform to normative social practices and skills does not produce a social and cultural person. It is a procedure that attempts to transform someone who has already been constituted as "radically other" into a simulacrum of normality. Much of this thesis is concerned with analysing just what this process involves, and how it has come about.

### **The Intimacy of Living with Disabled Kin**

We were a large family by contemporary standards, seven children in all by the time my younger siblings, Tessa and Peter, were born. My parents were a union of Irish and Polish Catholic migrants who met at university in England in the 1950s. We emigrated from northern England in the winter of 1966 to Perth, where my father had been offered a position at the University of Western Australia as a Lecturer in Applied Mathematics. It was in Perth that my parents first connected with other families like our own. For five years they had been going backwards and forwards to different specialists in England trying to get a diagnosis and some advice on my siblings' epilepsy, slow development and unusual behaviour. Neither of my parents remember being given any helpful information, or a diagnosis of "mental retardation". Notwithstanding this, the records at the Alder Hay Children's Hospital in Liverpool show that the paediatricians had certainly come to this conclusion with regards to two of my siblings (30/4/65; 7/7/65).<sup>8</sup> In Perth, my parents were introduced to a physician at the University who took over the family concerns. She initiated further tests which confirmed deficits in intellectual capability in three of my four older siblings. However the causes of these conditions remained a

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<sup>8</sup> Throughout the thesis I draw on the medical records for my family dating back to 1962. The dates refer to these notes, reports and letters.

mystery. Instead, it was the viewing of a film on autism brought to Australia by the English child psychiatrist and specialist on autism, Doctor Mildred Creak, that gave my parents their first inkling that Stephen might be autistic. For the first time they recognised his behaviour in another, and saw that he could be understood in terms of this recently defined "syndrome".<sup>9</sup> They realised that they were not alone, and that there were special schools being set up that could provide for at least one of their children.

The mixed emotions that this raised, and that my parents have had to deal with since their older children were infants, is one that is familiar to many parents of intellectually disabled children (Booth 1978: 218; Kearney 1993a, 1993b, 1996).<sup>10</sup> Theirs is the responsibility, the expectations, hopes, fears and disappointments. Yet, as Penny Kearney has pointed out, the common assumption that parents only ever experience their handicapped child as a burden and tragedy denies the depth of joy and pleasure that often accompanies such a relationship (Kearney 1996: 56-8). Being born into this world as a sibling of intellectually disabled people, however, has made my perceptions and experiences somewhat different. I had no immediate

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<sup>9</sup> After an assessment in Perth it was considered that Stephen displayed autistic tendencies, particularly due to his repetitive and obsessive behaviour and fascination with spatial patterns. The interpretation of these as simply characteristic of a deficiency and abnormality, rather than as potentially socially and symbolically meaningful expressions of his own experience of the world, is something that I analyse throughout this thesis.

<sup>10</sup> The majority of the literature that examines familial attitudes to intellectually disabled people tends to focus on the experiences and perceptions of parents, or else utilises the parent-child relationship as a source for interpreting an intellectually disabled person's actions and intentions (Booth 1978; Goode 1980a, 1980b; Gray 1995; Jacobs 1980; Kearney 1993a, 1993b, 1996). Much of the autobiographical and biographical literature on intellectual disability has also focused on the relationship of parents with their intellectually disabled child (O'Halloran 1993; Vohs 1993). While there are an increasing number of studies focusing on sibling attitudes to intellectual disability, these often tend to emphasise the difficulties or consequences of such a situation for the non-disabled sibling (Cleveland & Miller 1977). There is also a tendency to focus on the issue of service provision, and the role that the family should have in negotiations on their kin's behalf with such services (Bigby & Johnson 1995; Krupinski *et al.* 1983).

expectations, hopes, or disappointments. This was the world as I knew it, and these were my brothers and sisters, the people with whom I most closely associated. Although I became aware as I grew older that my siblings were different, it was quite some time before I was affected by the view that this difference was something of which to be ashamed.

Memories of those early years for me are filled with the bliss and melancholy that colour childhood recollections. The difficulties were real enough for all of us but the immediacy of the familial environment made those difficulties seem natural and just a part of everyday life. That everyday life was filled with activities, adventures and journeys, most of which I remember as day trips from Sydney to the Blue Mountains and Hawkesbury River for picnics, excursions to the northern beaches on hot summer days, visits to my grandparents after church on Sundays, or else fooling around at home enjoying a world of childhood games and family activities.

The almost weekly picnics during the cooler months of the year remain for me the most special, enjoyable and easy time that my family experienced. The Holden<sup>11</sup> station wagon would be packed to overflowing with all the children, including a collection of blankets to sit on, warm clothes for later in the day, an 'Esky'<sup>12</sup> that was filled with sandwiches, biscuits and cordial, and a box loaded with plastic cups and plates, plus a thermos of hot tea or coffee. My father would take his place behind the wheel, my mother in the front seat beside him, and we would drive out of the suburbs into the wild dry scrubby bush that surrounds the fringe of Sydney. Once out on these open country roads we would search for a spot to unload, lay out the blankets in a place that caught the afternoon sun, and open up the Esky for a long and lazy lunch. We often whiled away the afternoon hours climbing trees or fences. We walked through

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<sup>11</sup> A Holden is an Australian car made by General Motors.

<sup>12</sup> The word Esky is a trademark term that refers to a portable insulated icebox used for keeping food and drink cold.

the long paddock grass, or lay in the sun until it disappeared behind some trees. Finally we would pack up all our things and crowd back into the car.

The journey home as evening fell was often quiet with children dozing off to sleep after a long day, curled up against one another in the back seat. For part of each trip, however, my parents would strike up a tune that was familiar to us all, and those of us who could sing would join in the chorus or repeat the refrains led by my father in the front. Stephen in particular loved some of these songs, and the words were sometimes changed around to include him in them. He would squeal with pleasure and catch hold of my mother or brother Joseph, or whoever was sitting next to him, to indicate his comprehension and participation.

These outings were happy times, and the boxes of slides attest to this, showing images of my family relaxing and enjoying ourselves; brothers and sisters holding hands with one another as we walked through the paddocks, or sitting side by side on the blankets eating sandwiches and cake. My mother also remembers these occasions with fondness:

I really loved those picnics. I think it was because we always went to an isolated spot, a safe spot, a spot where we wouldn't come into contact with other people. And we always had a good time. And just as you were talking I was picturing Stephen as a younger child. One of the things that he really liked was beakers. We used to bring plastic beakers, or glass-plastic beakers, and he would just love to play with those. And he would pour liquid from one to the other—because of course we didn't bring jigsaws on the picnic, thank goodness, so we had to find some other occupation. And he would sit for hours just playing with them, or sometimes filling them up with soil and just pouring from one to the other . . .

sometimes stacking the beakers up. He really could be quite occupied with that. The picnics were very enjoyable; they were peaceful.

Looking back on those journeys to the countryside evokes memories of my family happy in its separation from the wider, conventional, social world; a world within which my siblings' differences became noticeable, incomprehensible, problematic and socially unacceptable. I realise now that they provided moments of relief from situations that forced interaction with the wider society. A natural environment provided us with a peace and freedom that society never could; a freedom to be ourselves without the endless stares, judgement and apprehension of other people.

I experienced a similar sense of calm and easy association during the bus journeys that were a regular part of each day of my fieldwork with intellectually disabled adults. Although the separateness of the staff set up a counterpoint to the dynamics of the group, the atmosphere of those journeys was tinged with familiarity. The bus provided a space away from social expectations. It was a liminal space representing moments of transition between one activity and the next (V. Turner 1967: 93).<sup>13</sup> As such it allowed

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<sup>13</sup> I use the word liminal in accordance with Victor Turner's use of Arnold van Gennep's concept of "the liminal phase" as a transitional and transformative phase that exists between two other social states (V. Turner 1967; 1969: 94). Robert Murphy has also used liminality as an explanatory concept to describe the social state that physically disabled people find themselves in (Murphy 1990: 131). Rather than being transformed into a new social role, as van Gennep's liminal stage implies, Murphy argues that the disabled are unable to recompose themselves within the social world and therefore permanently exist at the threshold of, and oftentimes outside, the formal social system (Murphy 1990: 45, 131). Being neither sick nor well, disabled people remain ambiguous persons whose social and human status is in doubt. They are forever "betwixt and between" in the words of Victor Turner (V. Turner 1969: 95; Murphy 1990: 131). Interestingly, for Turner, there is a "certain homology" between people whose social status is inferior or marginal and liminality as a state of "weakness" and "passivity" (V. Turner 1969: 99). Turner also argues that many of the ritualised transitional qualities of liminality in tribal societies have become permanent institutionalised states in more complex societies (V. Turner 1969: 107). In my use of the term, liminality incorporates these dual aspects. It

people to just be in the present, to be themselves, their presence justified by the momentary movement that demanded nothing other than that they be in that bus.

During the picnics we too were separated from some of the often antagonistic demands, judgements and expectations of the social world. My siblings were protected from pressures to conform to social expectations of normality, to socially prescribed ways of being, behaving and interacting. However, rather than being a liminal and transitional space, a space in-between, the picnics (and family life in general) were constituted of a mutuality and interdependence that permanently embodied my siblings' social presence. The relief from demands to conform may have been similar, but the form of sociality was entirely different. Within an institutional environment intellectually disabled people are not considered potential contributors to the social milieu. They are not considered to be the authors of their own social lives. Instead, they become recipients of practices of assimilation and normalisation and are constantly subject to an ethos of training and management. As a family we incorporated my siblings' differences rather than trying to erase them. We acknowledged my siblings' capacities to create independently and sustain a form of mutuality and sociality. We had our own internally produced and externally inherited social and cultural mores, and operated according to our own complex and shared mutuality and sociality.

Despite the tensions and difficulties experienced within my family there has always been an underlying mutuality, intimacy and love, an "enduring, diffuse solidarity" (Schneider 1968: 52), upon which our relations with one another and

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refers to the institutionalised interpretation of intellectually disabled people as abnormal and asocial beings. It also refers to the bus journeys or moments of inactivity that represent a transitional phase between socially accepted activities.

our sociality was built. As Schneider elaborates, family in the United States, as a cultural category, is based on the principle of solidarity:

. . . because the relationship is supportive, helpful and cooperative; it rests on trust and the other can be trusted. [It is] *diffuse* because it is not narrowly confined to a specific goal or a specific kind of behaviour . . . Two members of the family cannot be indifferent to one another, and since their cooperation does not have a specific goal or a specific limited time in mind, it is *enduring* (Schneider 1968: 52; author's emphasis).

In this sense of shared experience the notion of a shared substance develops upon which relations are established and around which they oscillate. While such a notion of a shared substance can exist beyond the intimacy of kin to include all those who are human, the humanness of intellectually disabled people is often denied by categorising and marking their differences as abnormal and asocial.

The mutualism and relatedness across difference upon which my familial environment was built acknowledged and incorporated in an unspoken way the fundamental need to find a means for interaction and understanding through which we could exist as a social entity. My siblings' humanness, and their capacity to participate in this mutual and intersubjective engagement, albeit in a limited and often opaque way, was entirely taken for granted. For, although my family may have been unconventional in its make-up and in the way we communicated and existed with one another, it was conventional for us. It was the way we were, and outings such as the picnics where we remained separate from other people allowed us to act and exist as though this difference was unimportant.<sup>14</sup>

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<sup>14</sup> Whereas my parents may have perceived their disabled children differently to this, my childhood perception of my siblings has allowed me to underline

Like the picnics, home life also provided us with a socially enclosed world. Here, the routine of daily domestic life gave an order and structure to the world within which we all operated. This order and structure was in part a cultural manifestation. It incorporated within it the values, attitudes and lifestyle of a European-Australian, middle class, educated family. This order and structure, however, also developed in response to the particular differences that my siblings presented. Their presence, and the response of all of us to this difference, produced another, different, way of being a family, of communicating, being with, and relating to one another. It produced a unique form of mutuality and sociality that was a product of the interdependence and interrelatedness of my family members.

We spent many long hours together as children with all the accoutrements of middle class life around us; books, toys, jigsaw puzzles, games, crayons, television, a swimming pool, swings, sandpit, a table tennis table, as well as a large garden with trees to climb and plenty of room to run around in. The difference was that my intellectually disabled siblings often played and used these objects in ways that were socially different and unexpected. These were ways that did not conform to normal and predictable dispositions that generally act as markers of sociality—although as a child I accepted their engagement with these things as ordinary and everyday. In fact, I was drawn into their world just as much as they were drawn into the wider world of the family. Their way of utilising objects and engaging with us gave shape to the world that we all lived in. Through such mutual encounters "we progressively developed common schemes of communication, congruent practical relevancies, mutually defined things to do in the world, and so forth" (Goode 1980b: 204-205)—as Goode has described it in reflecting on his own interactions with a severely intellectually disabled person. These engagements therefore

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and interpret an often ignored potentiality in social relations with profoundly intellectually disabled people.

produced a specific form of life, "a certain set of actions and interactions amongst persons which are . . . interconnected in such a way that we can give a general analytical description of them as constituting a system" (Radcliffe-Brown 1965 [1952]: 6).

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Maryla and Stephen both loved playing with jigsaw puzzles. In fact the whole family partook in this rainy day activity, enjoying the satisfaction of completing a picture by fitting the last piece of the puzzle into place. For Maryla and Stephen, however, the process was always somewhat different, and the interest went way beyond rainy days to become an almost permanent preoccupation. Stephen had a special knack for finding pieces by sight alone. He worked not with the picture, nor the emerging image, but with the shapes themselves. His task was to work from one end of the puzzle to the other, putting each piece into place one after the other in rows, rarely picking up the wrong piece that was next in line. He would sometimes do these puzzles picture side down as if to prove that it was the satisfaction and pleasure of recognising shapes that motivated him. Stephen's sounds of delight and satisfaction whenever he found a particularly difficult piece seemed proof of this. Often he would get up in the middle of the night to continue with his jigsaw puzzle and Joseph or I would try to get him back to bed before he was discovered by our father. At other times, if Stephen lost a piece down the back of the skirting-board as he sometimes did, he would come up to my mother with a large knife in his hand to let her know he needed help retrieving it. Doing jigsaws was one of Stephen's primary pleasures in life and I will forever have memories of him and Maryla half lying side by side on the rugs in the living room, the pieces spread out on the floor around them, as they did their respective puzzles.

Maryla is both more elaborate in her approach to the jigsaw puzzles but also less capable. She begins each new puzzle by spending hours laying out the pieces in a snake-like domino pattern across the floor, picture side down. When she has completed this she then turns each piece over and replaces it in another snake-like domino pattern picture side up. Having done this, and talking to herself at the completion of each stage in a sort of incantation that comments on what she has just done and is about to do, Maryla then begins the slow task of putting together the puzzle in the same way that Stephen did, beginning at one end and working her way across the board to the other side. Sometimes she would have to call on Stephen to help her with a piece, and he would respond with delight at being able to do it better than she could. Rarely would she let anyone else help her. If we ever came too close to where Maryla was sitting she would get distressed and want us to move away. It didn't help that we were mostly younger than her and as babies had a habit of wanting to eat the pieces. Her memory of this, and the potential threat to her ordered world that our intrusions represented, were reasons enough to keep us at bay no matter how much we wanted to participate. It was all right to be close by if we were involved in some other activity but not if it was clear we were trying to intrude on her enterprise.

These days Maryla is much more amenable to shared work on a puzzle, although this still has to take place on her own terms. When she comes to stay at my parents' places for the weekend it does not take her long to go to the drawer where the puzzles are kept, pull them out and begin the endless task of doing the jigsaws over and over again. If Maryla feels that there is respect for the fact that this is her puzzle then she is quite happy for someone to sit beside her, even allowing them to point out the next piece in the sequence if she is having difficulty finding it. This entering of her space is very special. It is quiet, concentrated and occupied. There is no conversation other than about the

pieces, and when the puzzle is complete Maryla finishes off with an incantation before pulling out the next one and starting all over again.

The incantations that Maryla repeats involve referring to herself in the third person, and are not confined to jigsaw puzzles. They also take place when we are waiting at traffic lights, at the completion of each meal, when she has questioned someone about plans for the rest of the day, after putting down her 'bits and pieces'<sup>15</sup>, or when she has observed and asked questions about what somebody else is doing. The incantations go something like this: "Maryla just putting your bit (sic) and pieces down, just putting your bit and pieces down. Yes." Or: "Mummy just going back to the Kirribilli house, she just going back to the Kirribilli house, yes. Mummy not staying at the Chatswood house. No. Not staying at the Chatswood house. Just going to the Kirribilli house. Yes."<sup>16</sup> She repeats such comments over and over to herself, rocking backwards and forwards as she recites the relevant phrase, and then finishes off with another incantation before ending with "Ooha. Ooha. Ooha" as though satisfied that all is as it should be. Try as I might, however, I still have not been able to fully interpret what it is that she says to herself in this final incantation. They do not appear to be recognisable words and yet when I listen closely she is definitely saying the same thing each time in relation to each particular situation.

The same interest in ordering and patterns displayed by Maryla in her approach to doing jigsaws was also expressed in her relationship with books. When Maryla was living at home the books from one or other of the bookcases in the house would be systematically pulled out onto the floor and layed out in a snake-like domino pattern similar to the jigsaw pieces. She would then begin at the end of the line and flick through each book, page by page from front to back, laying them back on the floor, cover side down, in a similar

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<sup>15</sup> A collection of small objects which will be elaborated upon later in the chapter.

<sup>16</sup> Kirribilli and Chatswood are Sydney suburbs.

pattern. Maryla would make her way through the books in this fashion, transferring them one by one to the new line. When she had come to the end she would then go through the books from back to front in the same way and replace them in their original order.<sup>17</sup> This procedure would take days, and the rest of us were obliged to tread carefully around her closely guarded pattern lest we disturb its order. Sometimes the collection would include a book that one of us was reading but the effort required to recover it was often not worth the trauma and trouble that it caused. Even if done in secret at the end of the day Maryla would invariably know that a book had been taken from the pile.

One of Maryla's most enduring and absorbing activities involves her collection of 'bits and pieces', as it is described by the family. She spends most of her time searching for these bits and pieces to add to her collection; a collection of small objects that until recently she always held in her hands. This occupation causes her to spend much of the time with her face to the ground as she calmly and methodically peruses the space she is in for these valuable objects (although when one of us tries to stop her the calmness can quickly turn to frustration and anger). Yet not everything is collected. Sometimes she will pick something up and discard it as rubbish while other objects are meaningful treasures to be guarded and possessed.

Once, on Maryla's birthday, I went around the house collecting such things in a tin for her. They included bits of foil, broken coloured pieces of plastic, small bits of metal, safety pins, paper clips, some nails, a butterfly clasp off an earring, a rubber band and other such small household objects. Maryla was excited when I gave her the present, hearing that it contained small objects moving around inside my father's old tobacco tin. After opening the present

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<sup>17</sup> When Maryla was a child she also had the habit of circling letters and numbers in books. She usually did this with a pen and still to this day some of my father's precious mathematics texts have the tell-tale signs of Maryla's interventions in them.

she pulled out each piece one by one, adding some to her collection while discarding others over the side of the chair as rubbish. She even said that it was rubbish. I was unable to see what the determining feature was that separated these objects. Those that I would have considered rubbish, such as the broken bits of plastic or metal, were quickly coveted and added to her collection, while others such as the earring or rubber band were thrown away. While she obviously appreciated the gift of bits and pieces, I hadn't quite understood their meaning and value to her.

The fact that her collection has varied slightly over the past ten years adds to this difficulty. More recently she has taken up an interest in bits of fluff and loose cotton threads off clothing, as well as off-cuts of material, yet I am never absolutely certain what will catch her attention. On one birthday when she was given some new clothes she quickly pulled the shop labels off and added the plastic tags to her collection, pushing the clothes to one side. Her excitement at being given quite a number of plastic tags was palpable. On another occasion she became fascinated with a metal ring on my car stereo and spent much of the five hour journey from my home back to Stockton (the institution where she now lives) trying to pull it off, much to our shared frustration and my annoyance.

In the past Maryla always held these bits and pieces tightly in her fist for most of the day, but there were times when she carefully and methodically laid them out on the floor. This would generally be every meal or bath-time, or when she went to bed, as this was when her hands had to be free. Like the jigsaws and books, the laying out of these bits and pieces has always had a very particular and repetitive aspect to it. It is done with complete dedication, concentration and seriousness, and follows the same basic pattern each time. Maryla repeats over and over to herself what she is about to do in a similar incantation to the ones that she uses at traffic lights or when doing the books

and jigsaw puzzles. After going through this for up to five minutes, Maryla then proceeds to lay the pieces out on the floor in a spatial pattern so that each piece is equidistant from others. This is done in a precise order; usually the reverse order in which she collected them. After doing this she leaves them there on the ground but always has one eye out making sure that no-one goes near them. Of course, this is the only chance the rest of us have to reclaim some personal or necessary item, such as the screws and plastic pieces from the toilet that she snatched up while it was being fixed, some jewellery she might have found in a drawer, or a collection of paper clips from on top of a desk. These moments are usually laden with anxiety and tension as we dispute the nature, value, meaning and ownership of these objects. At times there is also humour involved, especially when family members tease Maryla about wanting something from her collection. Unless it is absolutely imperative that we reclaim an object, the tendency has been to allow Maryla to keep it, allowing her meaning, value and significance of the items to supersede our own.

At Stockton, Maryla has recently been trained to keep her bits and pieces in a purse so that her hands are not always clenched. She had been working in the craft room and was collecting bits of off-cut cotton and other pieces of fabric and the sweating that this caused in her palms was damaging her skin. Although this was given as the reason for initiating the change in habit it is clear from Maryla's case notes that her collection also caused a fair amount of frustration for the staff. Too much time was involved in convincing Maryla to put the pieces down, and too much time was taken up in her actually doing so. This has now been altered due to the whole purse being picked up and put down in one go. Yet Maryla still spends much of her time searching for objects to add to this collection, and now that the items are hidden away it is much harder to see and reclaim a lost possession.

Every evening, the staff at Stockton lock Maryla's purse in the locker that stands beside her bed. This is to prevent Maryla from spending much of the night arranging her bits and pieces. We are supposed to do this as well when she comes home for a weekend. The first time this happened, however, my mother and I decided to let Maryla have the purse as we both agreed that her bits and pieces are her primary love in life. Despite recommendations to the contrary, coming home should be a special time rather than merely a continuation of institutional practices.<sup>18</sup> I shared the room with Maryla that evening and watched as she spent half the night laying out the pieces on top of the sheets before finally falling asleep with them beside her.

While Maryla is absorbed in what she is doing she is also constantly alert to what is going on around her. She is fascinated by and totally aware of what everyone is doing, and will sometimes ask after others in the family who are not there, including our siblings who have died. We tell her that they have gone to heaven and this seems to be satisfactory, not that she ever asks what or where heaven is. It is enough for her just to be reassured that they are somewhere else, and that this somewhere else has a name and is a place. In an attempt to appease her distress over lost bits and pieces my mother used to tell Maryla that they had gone to the moon, a procedure that usually eventually worked to calm her down.

Maryla also keeps up an intermittent commentary on everything that happens around her; who is eating what, going where, or doing this or that. If my stepfather takes off his glasses at the table she will comment on this to my mother, saying, "Oooh, Mummy, Tony's taken off his glasses". If someone uses a different piece of cutlery to her or has something different to eat then this will be commented on. She directs these statements to one person in particular, usually my mother, or step-mother Wendy, and if not them then to the next

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<sup>18</sup> I discuss this issue further in chapter six.

person in line. We have all learnt how to play these conversation games, and can easily get Maryla upset if we do not respond to her appropriately.

Maryla needs to know exactly what is happening throughout the day; when she will be eating lunch and dinner, where she will be going, and when she will return to Stockton. Life isn't always predictable, however, and there are times when the unforeseen transpires. These are always tense moments as we all try in our various ways to appease Maryla and convince her of the new order to her schedule. Until she receives a satisfactory explanation, Maryla will not retreat from her line of questioning. This usually requires repeating the new order of events a number of times and then agreeing with Maryla when she repeats it back. Nowadays, the staff at the institution where Maryla lives have a behaviour modification programme in place to try and wean her off this form of communication. The staff have been instructed to answer Maryla only once and then ignore her questioning, arguing that this form of communication represents her obsessive compulsive nature, and that it dominates too much of their time. It hasn't worked though. Maryla still continues to ask questions over and over, just as she always has, as this is the pattern in her way of communicating. Only now she is ignored for the most part by those with whom she spends most of her time.

I noticed this on a recent visit to see Maryla. She was coming out with my husband and I for lunch and wanted to check with the residential care worker that she was coming home to the ward rather than going to Sydney. He told Maryla she was just going for lunch and then told her to stop talking. She became quite agitated and upset. As we walked out to the car I fell into my usual relationship with her and answered her questions, explaining over and over again exactly what we were doing until she was happy and quiet. It took a good ten minutes but finally she was satisfied and sat peacefully in the car until we came to the river and unpacked the lunch. This is her way of

communicating and to ignore it is to cut her off from interacting and engaging with others.

As a child and adolescent, Maryla was often the most difficult of my three intellectually disabled siblings to engage with. This was not so much to do with her having less of a capacity or desire to communicate than Stephen or Ursula, but because she was more emotional and highly strung. If plans were changed or things did not go her way she would often get intensely annoyed and upset. If we interfered in her ordering of books or jigsaw puzzles she would get very angry and annoyed. Sometimes when Maryla came home from school she would repeatedly slam her school case on the kitchen floor, grind her teeth, and scream in a high pitched and angry voice because she had lost a miniscule piece of foil or plastic from her collection of bits and pieces that she had put in her case for the journey home.

Stephen, on the other hand, was a far happier and easier person to spend time with. He was particularly curious and inventive and often his different observations and ways of engaging with the world drew me into a milieu that I otherwise may not have noticed: the sound of everyday objects being rhythmically hit against one another; the observation of patterns in sand; the enigma of light and the play of shadows; the freedom of climbing up high and balancing in the swaying branches of trees; the pride of finding the next jigsaw piece of a puzzle by sight alone. Whenever he heard an aeroplane going overhead he would grasp someone's arm, usually my mother's, take her into the garden, point up to the sky and say with utter joy, "Oooh, there's another aeroplane up in the blue sky!"

As a girl, I adored Stephen, and was often in awe of him. He had a talent and humour that still brings a smile to my face when I think of him. One of his favourite occupations was building precariously balanced towers using such

objects as milk bottles, playing cards and children's blocks. My brother Joseph remembers playing with Stephen as a young child and commented that:

As far as the blocks were concerned, well, we would build. We had all these blocks with letters on them, you may remember, and we used to build with them and make words. I'd make words with them. [Stephen] didn't do that. He'd put them on top of each other and build towers. And we used to do that a lot, and I think he enjoyed that. He was happy. He liked playing with these.

Stephen's delight at climbing on top of the rickety wardrobe in the bedroom that he shared with Joseph, and later Peter too, pulling out the crayons and drawing coloured circles on the ceiling was amusing to us all, except of course my parents. Stephen knew that this was a punishable offence but he continued to do it with pleasure and amusement. Upon hearing my father coming down the hallway we would all try to get him down as quickly as possible so that at least he would not be caught in the act. The tell-tale marks up on the ceiling were proof enough of his deviancy, however, and the expected punishment would usually be meted out.

When I asked Joseph about his memories of those early years he recalled that he related to Maryla and Stephen through play rather than verbal communication. Joseph was aware of the difference that this made to their relationship, especially when he saw how other siblings related to one another, but he still remembers those times as fun and loving despite their difficulties. When I asked him whether his relationship with Stephen was affectionate, Joseph responded emphatically, saying: "Oh yes, yes, we certainly did [have affection]. We got on very well on the whole . . . It was fun. He certainly was fun and it was nice having him around and I believe I loved him".

Often Joseph was the only one who could influence Stephen. Consequently he was put in charge of Stephen whenever we went out on picnics or to the beach. Stephen had a habit of running away as soon as the car doors were opened and Joseph was invariably the one to chase after him and encourage him back. Mealtimes were another occasion that required careful intervention, either in terms of getting Stephen away from his puzzles and to the table, or enticing him to eat his meal long after the rest of us had finished. Joseph sat next to him at the table and it seemed that Stephen would respond to what Joseph said more than anyone else. My mother commented that even when Stephen was very young he "was absolutely devoted to Joe; followed him around with his eyes, if not with his body. [He] just adored Joe and would light up the minute he saw Joe . . ." When Joseph left to go to boarding school I took over his role in relation to Stephen. My memories of this time are very special because Stephen would often turn to me if he wanted something done, or for acknowledgment that he'd finished his meal or jigsaw puzzle, and that interaction made me feel very close to him. There were few words involved, if any, but the interaction was conscious, affectionate, and purposeful.

### **Symbolic Mediation, Language Games and Restricted Codes**

It is more an object relationship that my siblings have with the world, rather than a conceptual one, and yet on one occasion Maryla quietly removed the laundry clothes from the baby's bassinet and replaced them with a photograph of my new nephew while no-one was around. In her world certain objects are for specific uses; sometimes this is in accordance with the rest of us, at other times it is use of her own determination. This relationship to the world, while also involving long and repetitive explanations and affirmations in Maryla's case, partly replaces other forms of sociality that usually exist between people. Rather than engaging through complex verbal communication and normative social interactions, my intellectually disabled siblings often related to each other

and the rest of the family through objects. All of us were drawn into this world due to our relationships with one another and our shared engagement with the objects that surrounded us. These objects symbolically mediated our worlds (see Comaroff 1985: 1-6). They accommodated our differences. Their ability to be vehicles for more than one system of meaning, and for systems of different orders, was crucial in the maintenance of our mutuality (cf. Geertz 1993a [1973]).

The jigsaw puzzles, books, blocks, and bits and pieces were all such objects. They came to operate and exist within the family both as our means for interaction with one another and as expressions of our particular form of life or sociality. In the daily, though not necessarily entirely utilitarian, uses to which they were put, these objects played the role of "language games" (Wittgenstein 1998 [1953]: §7).<sup>19</sup> They existed between us as the entity through which we related to one another. While sounds may be the most readily acknowledged vehicles for conceptualising and communicating meaning, objects too, and the dispositions associated with them, come to operate as public manifestations of meaning. In fact, as Wittgenstein has argued, sounds are also related to the dispositions of shared objects (Wittgenstein 1998 [1953]: §7-18, §23, §47). Rather than existing within the mind or being singularly attached to an object, as has been a traditional philosophical and anthropological interpretation of meaning,

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<sup>19</sup> By use I do not mean something that exists purely for utilitarian purposes (cf. Sahlins 1976), as if it were concerned only with some purposeful application towards a specific objective. Use here takes on a more ephemeral aspect, implying both the purposeful action and utilisation of objects as well as the outcome of a desire to relate to another person. For, if the meaning of things, and indeed the meaning of language, lies in its use, it must first operate as something which exists between people. It exists in the very act of communicating and engaging with others. It is the outcome of being in the world with others and making sense of this world as a negotiated and potentially shared phenomenon. It is meaningful action and practice that constitutes the social world. This communication, and the sharing of such language-games, constitutes a life form, existing as it does within the immediacy of a social context which is itself a product of the specificity of those who give life to its form.

meaning itself exists as the public expression and manifestation of use and practice (cf. Austin 1975 [1962]; Geertz 1993b [1973]). As such, meaning is shared, and generates shared experience, but is also constantly open to negotiation (Austin-Broos 1997: 8-11; Bourdieu 1999 [1972]).

Symbolic mediation exists as a fundamental aspect of mutuality. It operates as a means through which relationships across difference are negotiated. Even when the meanings of these objects are opaque—such as my inability to get quite right the significance of Maryla's bits and pieces when I collected some as a birthday present—the very fact that my family respect that these objects have meaning and value for my siblings means that we enter into a committed process of negotiation and symbolic mediation. It was primarily through objects that Maryla and Stephen expressed their form of sociality, and it was through our intimate mutuality that their expressions became purposeful, meaningful and interpretable. They become the very substance of our shared sociality and mutual interdependence. Although the meanings we attributed to these objects differed, their capacity to be vehicles for more than one meaning allowed them to accommodate these differences. Our shared engagement with these objects meant that we participated in the joint construction of our social life. The particular and meaningful social lives that my siblings were capable of were represented and articulated through these objects. The point of articulation of these interpenetrating systems of meaning existed as an aspect of our mutual sociality.

Therefore, not only are intellectually disabled people such as my siblings fundamentally able to engender forms of sociality, mutuality and intimacy, but their ways of doing so involve an engagement with the world. By virtue of our coexistence, and the degrees of mutuality and intimacy that we shared, this world became significant for all of my family. While to some degree the rest of us were kept outside my siblings' specific modes of engagement with these

objects, we were also invariably drawn into and affected by their consequences. My family provided the space within which this articulation was acknowledged and engaged with. It came to be a cultural environment all of its own, and those of us within it developed ways of acting and interacting through the objects that surrounded us. These objects became sites for the mediation and negotiation of differently articulated but symbolically meaningful systems.

Within any particular shared social milieu behaviour has meaning and value (Bourdieu 1999 [1972]). It is what someone does, and each person, each sibling, did so in their own particular ways such that we all knew who they were and could interpret what was going on without the need for words or explanation. Yet, until I began this account, I was convinced that Stephen had always communicated through speech. I distinctly remember him talking about the aeroplanes because this was a phrase he used often, but I was sure that he had always spoken to us about other things as well. It was only when my step-mother pointed out that he never spoke that I began to question my own memories and realised that he did not use language conventionally. When I spoke to my mother about this she remembered the speech therapists at the Autistic School trying to encourage Stephen to talk. As she commented:

. . . they did want me to insist that he spoke, or tried to speak, before he got what he wanted, before he, for instance, got a glass of water. And I found this very time consuming and irritating because, I mean, he knew I knew what he wanted. He knew that I would get it for him, and it just seemed to be a stupid thing to hang around waiting for this word to come which I knew he wouldn't say. Because if he wasn't going to say the word there was no way in the world he would say it. And you just couldn't force him.

Going back to Steve talking. If we were walking in the street [in England] and a car passed by, he might say grey car, or just grey, and I'd be so thrilled because he knew his colours and I'd be so thrilled that he'd said grey car. But if another car went past which was grey and I'd say "what colour's that Steve?", he would absolutely refuse to answer. We both knew that he knew but he wasn't going to say it. Why should he?

And it was the same with asking for water. If he really was desperate to get the water and I wouldn't give him the water until he said the word, all he had to do was to get his stool, stand up, or he didn't even need a stool then, get to the tap, turn the tap on, and fill the glass of water. He was quite capable of doing that. But he wanted this interaction with me which of course he got because, why not? Why shouldn't I do that . . . with him? What's the point of him talking? I mean conversation didn't mean anything much to him. So I just told the teachers at the school that, for one thing, I didn't have time to hang around, and I didn't want Steve to get frustrated and upset and me upset with it. I just didn't think it was worth it. So I didn't go along with it. I mean, I tried maybe for the first week and then gave it up as a bad job.

This issue of communicating and "knowing" without words is not in itself unusual. We all experience the world and interact with one another through a myriad of forms and expressions, including sensation, body language, intonation, eye contact and touch.<sup>20</sup> However, a competency in language as

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<sup>20</sup> Part of Merleau-Ponty's (1962) phenomenological enterprise was an explicit critique of the overtly cognitive rendering of human nature and understanding, and an argument for knowledge as attainable through both the senses and the intellect. It is interesting that many writers on intellectual disability turn to phenomenology as a tool for interpreting the life experiences of such people (Atkins 1998; Bogdan & Taylor 1976, 1982; Goode 1980a, 1980b, 1990), although they tend to draw their inspiration from Alfred Schutz (1972 [1967]) rather than

speech (and literacy) is one of the primary cultural markers of normality in our society (Jenkins 1998b: 19). Definitions of intellectual disability have traditionally and consistently incorporated references to deficiencies in language ability and comprehension (Binet & Simon 1976 [1905]: 336-7; Connors & Donnellan 1993: 269; Howe 1976 [1848]: 45; Kanner 1944: 214; MacAndrew & Edgerton 1970; Pinel 1962 [1801]: 172; L. Wing 1996: 327). Language is considered to be that which connects ideas, knowledge, meaning and creativity. The mind is seen as the necessary tool for humans to convey meaning. Its capabilities are what define us as human and separate from animals. However, language is often conceived as if it were solely a vehicle for communicating preexisting notions and ideas, as though these exist as specific and identifiable entities in the world. Those who are perceived to be deficient in mental ability and linguistic competency are therefore often considered unable to communicate meaningfully at all.

In this way, language as a system of communication often becomes Language, to the exclusion of other symbolic systems. It becomes the singular mode of communication and the primary criterion for humanness. As Merleau-Ponty argued: "To treat communication as essentially linguistic is to fall victim to the 'ruse of language'" (cited in Goode 1990: 30). Because intellectually disabled people are often lacking in linguistic competencies, it is assumed that they do not develop and share any meaningfully articulated symbolic systems at all. In the process their capacity for mutuality and sociality is undermined, as is their human status. While the issue of language is important, and will be explored more fully in the following chapters, what is important at this point is the recognition that intellectually disabled people utilise and develop other systems of symbols, such as the use of objects, as their means of communication, interaction, mutuality and sociality; as attributes of culture.

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Maurice Merleau-Ponty (1962). In chapter five I outline some of these phenomenological analyses of intellectual disability.

However, it is not solely through the mediation of symbolic objects that my siblings attempted some form of communication and interaction with others. When Maryla is introduced to someone new she goes right up to them, looks them in the eye, and grabs hold of their arm as she says "hello", turning back to the person she is with to get some affirmation of her actions. While this is Maryla's familiar way of communicating and acknowledging another person's presence, it can often be responded to with apprehension and confusion by those who do not know her. Their lack of recognition of the meaning and intention in Maryla's actions and dispositions, and her inability to utilise accepted social modes of interaction, both linguistically and behaviourally, means that people often respond by not seeking any form of interaction and engagement at all.

Other intellectually disabled people I know will smell, stroke the skin, or touch the face of someone they meet. Sometimes they will avoid any contact whatsoever, while others will hit out or make noises from a distance (cf. D. Williams 1996: 45). For many intellectually disabled people such forms become their primary means of interacting with others. To engage with the world in such a way makes interaction and mutuality highly contextual. The symbolic systems that my siblings used were highly dependent on particular persons, objects and places. In this way they represent what Basil Bernstein has termed a "restricted code", a mode of communicating that is implicit, shared, general and contextual, and whose reference points are not transferable (Bernstein 1971: 143-148). As Bernstein elaborates: "The principles and meanings [of restricted codes] are embedded in local contexts, in local social relationships, practices, activities. To this extent they are relatively strongly related to a *specific* material base (Bernstein 1977: 193-194; author's emphasis).<sup>21</sup>

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<sup>21</sup> Bernstein was interested to discover the means through which different social/class relations become embedded in social identity and social roles. He argued that different forms of social relations produce different communicative or linguistic codes, and that the capacity of individuals to utilise these codes was

Stephen and Maryla had no need or capacity for communication in the form that we are socially accustomed to. While this limited their range of sociality within the wider social world, it did not prevent other forms of sociality emerging and existing within the confines of family life. It did not prevent us articulating a degree of mutuality and sociality across shared and mediated symbolic systems such as the jigsaw puzzles, books, blocks, and bits and pieces. This capacity for sociality means that forms of mutuality are able to be transferred to other social domains provided certain conditions are upheld.<sup>22</sup> This requires acknowledging that there is a modality of symbolic life upon which sociality and mutuality can be built. It also requires the inclusion of objects and behaviours that are not normally utilised as means of engaging with others. Therefore, it is not a lack of desire or the capacity to communicate that necessarily marks one's relationship with intellectually disabled people, but a very different way of doing so. When I was a child it never occurred to me that Maryla, Stephen or Ursula should communicate with me in any other way. Growing up with them meant that I absorbed and assimilated their systems of signs and dispositional behaviours. Their dispositions carried a specific and interpretable valency due to their shared and intimate nature, and were accepted as meaningful and purposeful. They, and their actions, were an integral part of our mutual interdependence and shared sociality.

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culturally rather than genetically determined (Bernstein 1971: 143-152). In the situation that I am describing, these restricted codes are a consequence of forms of difference associated with the disability rather than a product of social relations. However, the form of the restricted code—its local, situational nature whereby communication "goes forward against a backcloth of closely shared identifications and affective empathy" with a dependence on "extra verbal" rather than complex verbal articulation—is essentially the same. In fact, Bernstein argues that restricted codes do not correlate with linguistic competency *per se*, but with types of social relationships that are marked by a sense of the "we" over the "I", including kin relations, peer group relations, institutional bonds, and close friendships (Bernstein 1971: 146-147).

<sup>22</sup> Much of the thesis will involve looking at the conditions that either support or undermine this capacity.

## **Shame, Incomprehension and Distance**

My perception of my family began to shift as I grew older and became more aware of how others responded to the differences that my siblings presented. While those who are familiar with the idiosyncrasies of an intellectually disabled person are more likely to predict what it is that they are communicating, strangers often respond with apprehension, uncertainty and fear. Despite my own experiences, I am still cautious when meeting someone new who is intellectually disabled because I cannot initially predict or understand their way of being in the world. This creates an uncertainty, and it is this that so often isolates the intellectually disabled in their own world, beyond the reach or desire of social interaction and intimacy from others. Intellectually disabled people's social limitations, their non-normative dispositions, and the institutionalised perception of them as asocial and abnormal, creates a barrier between them and the wider society. It is difficult for others to transcend these attitudes, in addition to the very real differences and limitations that intellectually disabled people present.

It is not just strangers, however, who respond with uncertainty. When I interviewed my mother's sister, Christine,—who came out from Tanzania and stayed with my family for a few months in 1970—she told me that she remembered Maryla as "a very strange being" and added that: "As somebody who only meets her occasionally you can't get through at all." My mother commented that Peter, the youngest child in our family, was terrified of Maryla and Stephen when we came back from spending a year in Europe in 1973. Maryla and Stephen had lived in an institution for the 14 months that we were away and Peter was only two when we left. These responses make me realise how much of our wariness of intellectually disabled people, and an inability to relate to them, is due to unfamiliarity, and the difference that separates them

from others. Rather than being an attribute of non-kin relatedness, this separation and incomprehension is the consequence of a lack of mutual interdependence, interrelatedness and intimacy. It is the product of forms of relatedness that do not seek symbolic mediation and negotiation through a shared and highly particular environment. It is, moreover, the consequence of attributing to intellectually disabled people an incapacity for symbolic representation, mutuality and sociality; of assuming that their modes of articulation and engagement are inherently meaningless and asocial.

Despite the fact that such attitudes and their associated lack of engagement and relatedness can exist between kin, it is generally through encounters with strangers and within a clinical and institutional environment that these become more noticeable. For my family, the occasions when this became most obvious were when we ventured out into public spaces such as the beach or local shops. It also occurred through our contact with medical and psychological specialists, as well as at the institution where my siblings went to live. Whereas I generally remember the picnics and time spent at home with happiness and a certain ease, these other occasions evoke memories of anxiety, apprehension and shame. For the remainder of this chapter I describe some of these encounters with strangers before turning to examine institutional engagements with intellectually disabled people in the following chapter.

On hot summer days we would often follow the path of many other Sydney families and head to the coast, joining the snake-like crawl of traffic up Mona Vale Road to the northern beaches, or eastwards to Queenscliff. The smell of hot bitumen and exhaust fumes would add to the already oppressive heat of the day as we children squirmed in frustration in the back seat of the car. On arrival at the beach we would open up the doors to let in the cool ocean breeze and out would leap Stephen, understanding this as his moment to run free. He would take off in any direction, and even if there were other cars around

would always manage to expertly weave his way through them without seemingly being aware that the cars were even there. My mother would stay with the rest of us, my baby brother or sister on her hip, and my older brother would take off after Stephen, anxious to catch him before he disappeared from sight. My mother later told me that Stephen and Maryla would often both leap out of the car and take off, and that my father and Joseph would head after them, my brother chasing Stephen while my father pursued Maryla.

With the family all regrouped, we would make our way with towels, buckets and spades down to the beach. Weaving our way amongst other families spread out across the hot sand I remember being acutely aware of the responses of other people. Children would stare in wonder as my brother or sister walked along in their unique way; Stephen with his joyful lurch and Maryla stopping constantly to check out everything on the ground as she searched for that obscure object to add to her collection of bits and pieces. Stephen would often approach other people and initiate some form of interaction with them that was incoherent to all other than those who knew him well. It seemed to me that some parents would unconsciously pull their own children closer as if to protect them from possible contagion by the obvious difference that Maryla and Stephen presented. They could not understand my siblings' ways of behaving and appeared to be threatened by their seemingly unpredictable and incomprehensible natures. I found these momentary interactions difficult to the point of being almost unmanageable. My self-consciousness made me extremely aware of how others responded to us as a family. I wanted to melt into the crowd but on most occasions was unable to; we were different, my family stood out, and there was no escaping it. And somehow, by being connected to Maryla and Stephen, I also felt tainted.

But we would press on, and find ourselves our own place in the sun, as far removed from the other families as possible. From there we would go

swimming in the cool ocean water or play in the sand. Stephen would make loud squeals of delight as the water rushed up his shins, joining the rest of us as we played in the waves. Maryla, on the other hand, would run screaming from the waters edge, unable to appreciate or enjoy the luxury of the ocean. We would spend all afternoon at the beach and as the day cooled would pack back into the car and join the homeward traffic, arriving back with sodden towels, sandy costumes and pierced ear drums as Maryla would invariably have screamed most of the way home. She had learnt that when the traffic lights are red the car has to stop, and still to this day repeats to herself an incantation to do with the orange, green and red lights whenever she is waiting at lights. Yet a traffic 'jam' opened up a whole different problem as there was no obvious reason why we should be stopped. It was impossible to convey to her the concept of congested traffic. A red light in front of her was all right but not a long unbroken line of traffic. She would scream and scream, grabbing hold of my mother or father in the front to demand an acceptable explanation. I would be hiding in the back seat, imagining all the people in the neighbouring cars looking over to see what was going on in our car.

The other less regular foray that we made out into the world as a family was to the shops. People would move away from us as we walked around the shopping centre, or tell their children not to stare and be rude as they firmly pushed them on and away from possible contact with us. Often my mother would ask me to stay in the car with Maryla and Stephen because it was easier for her to go into the shopping centre by herself. We would wait in the car but it would not be long before boredom and frustration set in. Stephen would try to open the car door to run off, and if successful could often be found running along the footpath towards our home almost two kilometres away.<sup>23</sup> Maryla,

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<sup>23</sup> Stephen's ability to know the way home and to understand directions was with him from early childhood. My mother often tells the story of the time in England when she was at a local park with the four oldest children and Joseph walked into the metal ear of a play horse and cut his head open. A woman who

on the other hand, would start asking where my mother was. I remember now that these comments were not so much questions as statements. It would be more like: "Mummy coming back soon," or "Mummy just doing the shopping now, she just doing the shopping. Yes." Yet these statements were always said with the need for affirmation. If met with a negation there was likely to be uproar. The scenes emanating from our car were enough to keep most people at bay, as they either pretended to ignore what was going on or else looked over at us disapprovingly.

Going to church was a different matter. We were regular parishioners in those days and the other families were familiar with our presence. Despite their acceptance of us within the service, however, we were never included as part of the parish, nor did any of the other parishioners offer my parents any, much needed, support. Generally, my parents found that they felt most comfortable in the presence of other families who had intellectually disabled children. Through the special schools that my siblings attended, and the various organisations that my parents became involved in, we came to know quite a few families with intellectually disabled relatives.

The need for appropriate schools for Maryla and Stephen had caused problems for my parents and siblings in Perth. Stephen had been accepted into the Spastic School but was asked to leave after one year because his mobility, and inclination to climb anything in sight—the higher and more unstable the better—caused problems for the teachers. Maryla attended the University kindergarten but was considered to be a "great trial" and a drain on the time and energy of the staff (15/2/66; 7/4/66). The psychologist who observed and tested my siblings in Perth suggested that they needed forms of special

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was at the park offered to help and while my mother took Joseph to the doctor Stephen directed the woman to our home by leading the way without words. It was over a kilometre away and involved numerous road crossings and turns up different streets, but he got her to our place without any hesitation.

schooling that were unavailable in Perth at that time. The specialists whom we saw in May 1967 at the Mental Deficiency Diagnostic Centre at Grosvenor Hospital in Sydney had also emphasised the need to find "appropriate educational facilities" (12/7/67). Access to an Autistic School in Sydney, and to the Grosvenor specialists, were what brought us east across the Nullarbor Plain in our Holden station wagon in the summer of 1967-8.

## Chapter Two

### Ethnographic Encounters II:

#### The world of intellectual disability from the other side

A few months after arriving in Sydney, my siblings were all enrolled at various schools: Stephen at the Autistic School in Belrose; Maryla at Inala, a Steiner school for handicapped children; Joseph at the local primary school; and Ursula at a nearby pre-school. Fifteen months later, Maryla moved to the Sunshine School for Children for one year before finally enrolling at Crowle Home Special School. She was joined there by Stephen in 1973. I couldn't wait to start at the local pre-school and join my older siblings in the morning hustle and bustle. The fact that they all went to different schools each morning was not at all unusual to me; it was just a part of the differences that existed between us.

I knew that my intellectually disabled siblings were different, and that they required more attention than the rest of us, but at this stage their difference caused little more than momentary anxiety. I distinctly remember, however, the occasion when this anxiety became cemented in my mind as an intense and seemingly intransigent shame. I was walking to school one morning behind some older kids when the Spastic bus went past. The children ahead of me started making fun of the occupants of the bus, pulling faces, mimicking their physical movements, and calling out "spastic", "retard", "dumb", "idiot" . . . The words still echo around in my head as I picture myself rooted to the spot, mortified, not so much by their behaviour, but by the fact that this bus was on its way to my home to pick up my brother and sister and take them to school. This was 1975 and I was nine years old. I was devastated at the reaction of my peers and realised only too well what it implied: that my brother and sister

were something to be ashamed of; that their difference was not all right; it was wrong, bad, disgusting, fearful, laughable; anything but acceptable.

My younger sister Tessa<sup>1</sup> had a similar experience at around the same age. As she told me when I asked her about her memories of growing up:

I think I was in 3rd grade, or 4th grade, and I took a friend . . . home on a Friday afternoon, and Maryla and Stephen were there. And I'm not sure whether I sensed, no I did sense that she was a bit, obviously hadn't come across people like Stephen and Maryla before, and was a bit reserved, maybe a bit frightened. But I don't remember feeling that it was a huge deal. We just went on with the afternoon. I can't remember how long she stayed, but we played and she left, and I didn't think any more about it.

When I got to school on the Monday I felt everyone was looking at me and talking about something that had to do with me, or about me, but it was like whispers and gossip, and I remember feeling very self-conscious. And then I remember somebody told me, 'oh you've got a spastic sister and brother' and I remember feeling . . . very mixed up inside. And I'm not sure if I was ashamed. I was definitely embarrassed. I felt perhaps that I'd been found out, or there was something wrong. Maybe I did know that there was something wrong, but because the family, we acted like there wasn't anything [wrong], I sort of carried that on. I was very very upset. That's my first memory of really realising that they were different.

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<sup>1</sup> Tessa (b. 16/3/68) was born three months after we moved from Perth to Sydney. My youngest sibling, Peter (b. 29/6/70), was also born in Sydney. Neither of them were intellectually disabled.

I then asked Tessa whether she ever denied that Maryla and Stephen existed and she responded by saying:

Yeah, I wouldn't tell anyone about [my intellectually disabled siblings] actually. I don't feel that I was hiding; I don't know whether I was hiding them or whether it just got so involved. If you started to say there were seven children in the family and then you were asked what they did, then it was, you couldn't just sort of end that in a couple of minutes. Yes, I wouldn't tell people because I didn't like to be the centre of questions. I didn't want to have to go into the whole detail of, you know, that Ursula had died, that Stephen and Maryla are autistic, that they lived in a hospital, or they were still living with us, and it was much easier to just say that there was the four of us. And I don't know whether I was denying it or whether I didn't want to go into it. I guess a part of it was denial.

I too went on to deny that I had older brothers and sisters. Despite my love for them I would tell people that I only had two or three other siblings. When the odd friend did come over to play I would be deeply embarrassed at the presence of Maryla and Stephen doing their jigsaw puzzles on the living room floor. I would be even more embarrassed if Stephen emerged from the bathroom with his pants around his ankles as he sometimes did. I found a history assignment I had written when I was twelve in which we were asked to write an autobiographical account of our lives. There is no mention of any other siblings besides Tessa and Peter. We were then asked to get a friend to write a description, and my best friend at the time wrote that I had "a younger brother and sister. There [sic] names are Peter who is eight and is in third grade and Tessa who is ten and is in fifth grade". When I went to my year twelve school reunion a few years ago people asked me what I was doing with myself

these days. I told them I was doing research on intellectual disability and when they pressed me further about why I was interested in the topic I mentioned that it was because I had three older siblings who were intellectually disabled. What surprised me more than anything else was that so few of these old friends knew about this. The success of denying my siblings' existence disturbed me. Only those friends with whom I was very close ever came to know or meet Maryla and Stephen. Despite having gone to the same school as some of these classmates for 12 years, very few knew the true extent of my family.

### **Becoming Institutionalised . . .**

In August 1975, eighteen months after returning from a year in Europe for my father's sabbatical, Maryla and Stephen were admitted to an institution as minor-voluntary patients under the Mental Health Act (1958), amended section 21(b). The medical, welfare, educational and psychological specialists at the Grosvenor Diagnostic Centre had been encouraging my parents since 1967 to send my intellectually disabled siblings to an institution. They were of the opinion that it would be better for all of us: that we other children needed to have a normal family life, and Maryla and Stephen the opportunity to be cared for and "managed" professionally. While Maryla and Stephen had spent 14 months in a psychiatric institution the year we were overseas, this move was different. There was a finality to it that affected us all. This would be forever. Never again would Maryla and Stephen live with us as a family; playing with jigsaws on the living room floor, pulling down books, drawing on the ceiling, taking hours to eat their dinner; making us laugh, cry, despair and fill with joy at different times throughout the day.

I remember our last day together living as a whole family. We all dressed up in our good clothes and went down to the local park to take some photographs and play on the swings and roundabout. I was in my favourite burgundy and white summer dress with large flowers printed all over it. My hair was tied back and I had my good white buckle shoes on. We all looked really smart and formal, as though it were Christmas and we were having photographs taken to send to my grandparents in England. The sadness in everyone's faces in the photographs, however, is palpable. We knew that the family was breaking up and that Maryla and Stephen were leaving to go to an institution, a mental hospital, a "madhouse".

Over the previous months we had visited a number of institutions as a family to find one that was appropriate, and one that would take both Maryla and Stephen so they would not be separated. The first available place for both of them to live was Morisset Hospital, an hour's drive north of Sydney. As well as an institution for the intellectually disabled, it was also a prison for the criminally insane. The buildings reminded me of a nineteenth century Dickensian nightmare; concrete yards, dilapidated stone buildings, barbed wire, and grills on the windows. After being at Morisset for only a few weeks Maryla and Stephen were transferred to Stockton Hospital, north of Newcastle. By comparison it was beautiful. A former naval base, the Hospital was situated on a large property backing onto Stockton beach, with red brick and 'fibro'<sup>2</sup> buildings scattered around the grounds, separated by pine trees, ovals and grassland. But as I very quickly discovered, the surface appearance of Stockton was deceptive. Although it had no associated prison facilities, it concealed practices and attitudes that made my siblings inmates rather than kin in their new home. Furthermore, they were now three hours distant from their family.

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<sup>2</sup> Cheap and common house cladding made of asbestos fibres and cement.

Six months after Maryla and Stephen left to live at Stockton my parents separated. My eldest brother went to live with my father, which left my mother, younger sister and brother, and myself at home, a situation which made it easier to claim that there were only three children in the family. Weekends alternated between seeing my father and catching a bus up to Stockton to spend the day with Stephen and Maryla. It was a strange time. We would meet up with other families early in the morning at Hornsby railway station and travel the long journey by bus to visit our respective intellectually disabled relatives. It was like going to a gaol. There was that same sense of furtiveness, of strangers being bound together by a shared secret and shame. On arrival we would collect Maryla and Stephen from the ward (as it was then called) and sit in the grounds under the Norfolk pines with all the other families. We would unpack a picnic lunch and eat our sandwiches looking out at all the other people in this same situation. Not only were Maryla and Stephen now just two amongst hundreds of similarly intellectually disabled people, but the distance between us grew wider. They were no longer just my brother and sister, different, of course, but part of the family. They were now officially institutionalised along with others similarly classified as mentally retarded.

Without the intimacy, mutuality and familiarity of the home environment it was difficult to relax and enjoy each other's company. Maryla would continually ask when she was going back to the ward, and Stephen would seem distant and preoccupied. There were no books to pull down off shelves, no jigsaws to spread out on the ground, no crayons to draw on the ceiling with. The means through which we had previously mediated and negotiated our differences were almost entirely absent. The activities through which we had socially engaged with one another, and through which my siblings had expressed themselves, were no longer central to our interactions. It was just us,

a small group of kin amongst a large group of strangers, trying to make something of this new situation, and not really succeeding.

The sadness at saying goodbye always seemed to be ours. Maryla and Stephen appeared to be quite happy to return to the wards at the end of lunch. I read in their records, however, that they absconded together not long after being admitted, and that they constantly asked after the family and wanted to know when they were going home. Perhaps they weren't so happy after all. Perhaps it was us who wanted and needed to believe that they were settled in order to alleviate the guilt and sadness at sending them away. Yet it is hard to imagine how anyone could be happy in such an environment. These were locked-up buildings: sterile, clinical and bare, each with an enclosed concrete courtyard, dormitories lined with single beds, and staff in uniform. It was a mental institution, and the residents were treated as both sick and in need of treatment and training. Most of them were drugged and would wander around the recreation room, or curl up in one of the old plastic chairs in a corner, some screaming, some crying, many still in their pyjamas, some sitting in a puddle of urine, others lost in their own withdrawn world. The never-ending blare of a television dominated the environment. I remember standing outside the locked and barred door looking in to where my brother and sister now lived. The scene horrified me. To this day the journey past the BHP<sup>3</sup> steelworks near Stockton still brings memories of dread and fear to my mind.

Despite the many changes that have taken place at Stockton since my brother and sister first went to live there, and despite the fact that Maryla is generally well cared for by the staff at Stockton, it is still a strange place. Entering the grounds of the Centre, as it is now called, is to enter another world. Maryla lives in Unit 13 (the new name for the same ward she has always

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<sup>3</sup> Broken Hill Proprietary Ltd. One of Australia's largest companies involved in mining and the manufacturing of steel.

lived in) with forty other men and women. She shares a dormitory with three women, the locker beside her single bed the only "private" space that she has. Even this is locked by staff at night to prevent her having her bits and pieces. She attends an activities centre during the week that is located in the same grounds. These days, in accordance with community integration guidelines, Maryla also goes on occasional visits to the local shops, attends community activities such as girl guides, and participates in TAFE<sup>4</sup> courses to learn domestic skills. She eats her meals at one of the child size tables in the open recreation/dining area with a bib around her neck. The TV is still blaring, the kitchen still locked, the internal courtyard a concrete desolate space. The other doors are no longer locked, and people can wander in and out more freely, but the institutional smell and feel of the place is pervasive. Beneath it all this is still a place of management, control and training. When I was going through the records at Stockton as part of the research for this thesis, I could hear Maryla's voice as she came and went from the Unit, still asking questions and getting frustrated. Hers was just another voice among the many different ones I could hear but it resonated with me. I felt separate, cut off, an outsider. She too, however, was also an outsider in her own home.

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The year that my parents and non-intellectually disabled siblings had spent in Europe in 1973 had given us an inkling of how different life could be without Maryla and Stephen living at home.<sup>5</sup> While there, we had the opportunity to visit museums and castles, to wander around art galleries, and go to the theatre and cinema. My mother had time to spend with me, making sure I kept up with my school studies by making me write a story each afternoon about what

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<sup>4</sup> Technical and Further Education, a form of tertiary trade training college in Australia.

<sup>5</sup> Maryla and Stephen spent the 14 months that we were overseas living at Ryde Psychiatric Hospital in Sydney.

we had done that day. She would mark my spelling and grammar, began to teach me French, and during the evening we would discuss the day's events and plan our next exciting outing without interruption. I was so unused to all these possibilities that I associated them with Europe, being unaware at the time that museums, galleries and theatres also existed in Sydney.

When we returned to Sydney it became obvious that the whole family, reintegrated with Maryla and Stephen, was feeling the tension and strain. For thirteen years my parents had looked after their children at home, dealing with regular epileptic fits, daily medication, a vast array of professionals, the difficulties of finding appropriate schools, and many other problems associated with having three of their seven children seriously affected by an intellectual disability of unknown cause. When Ursula died in 1969 my parents had all but given up. This seemed the final blow to their already exhausted and emotionally drained lives. They continued to insist that we remain together as a family but were aware that as all of us grew older, my parents included, the harder and more isolating life would become.

My mother remembers that while people were supportive and sympathetic when Maryla, Stephen and Ursula were young, they were less tolerant as my siblings grew older. It was also becoming increasingly difficult to sustain the family as a distinct and separate social unit. We occasionally had friends over, and my parents always organised birthday parties for us, but Tessa, Peter and myself were wanting to move beyond the confines of family life through our involvement in social activities, weekend sport, friendships and school. The fact that government regulations required that my parents have their childrens' names on a waiting list before they were 15 years of age in order that they even be considered for permanent residential placement in an institution only added to the pressure. Within a matter of weeks of making the decision, and having been told that it would take at least two years, Maryla and Stephen

were offered the places at Morisset. Despite my awareness that life was definitely far simpler and easier without Maryla and Stephen living at home, that the institution provided my family with a way out, and that at the time this was one of the few options available to us, I was disturbed by the difference between how we as a family related to and love our retarded kin, and the ways in which socially instituted practices affect intellectually disabled people's lives.

### **. . . and Scrutinised**

Three years after he moved to Stockton, and four weeks before his eighteenth birthday, Stephen had a grand mal seizure in his sleep and died. His medical certificate reads that he died of an "Anoxia Cerebri due to Antecedent causes with mental retardation as a contributing cause". He died partly because he was retarded is the implication of this report, as though retardation is necessarily connected with demise.

My family have been subjected to numerous medical, psychiatric, psychological and genetic tests since 1962. These tests are still going on as medical researchers try to uncover what it is that made my family so different. As new tests are discovered, so they are performed, and each new piece of information on the family is duly added to the files in the hope of one day making sense of my family's circumstances. When my youngest brother died in January 1994 of a brain tumour Maryla was sent off for more tests. The doctors wrote that ". . . this girl, indeed the family, still poses a diagnostic puzzle. The most recent information is that the youngest son, Peter (13/6/70) (sic) died just a few weeks ago from a brain tumour. This leaves 2 out of 7 who are apparently normal." My brother actually died from a secondary cancerous tumour as a result of a melanoma that had been removed from his shoulder five years earlier. He had just completed the exams for his Bachelor of Arts

degree, was highly intelligent, articulate, quick and witty, and there was absolutely no evidence that he was anything other than "normal". The report echoed my own earlier conclusion on the beach with my family: that we had all been tainted by a potential abnormality.

When my younger sister was pregnant in 1996 with her first child, and the first child of the next generation, the doctors at The Greater Ormond Hospital for Children in London strongly recommended that she have genetic counselling before making a decision to continue with the pregnancy. She was worried about having a disabled child herself and had told the staff at the hospital our family history of intellectual disability. Tessa had tests which showed a potential "fragile-X chromosome disorder"<sup>6</sup> and the geneticists in London suggested that the same tests be carried out on Maryla and our mother. They thought, hopefully, that this was finally the answer. Tests confirmed that Maryla definitely does not have Fragile-X syndrome, and that this condition is not the cause of our family history of intellectual disability. It was back to the "unknown" file.

My siblings have had an extensive history of being scrutinised. Being epileptic they were put under medical observation from infancy and treated with medication.<sup>7</sup> This led to investigations about what was causing the

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<sup>6</sup> Fragile-X syndrome is considered to be the most common form of a genetically based intellectual disability (Dykens 1995: 522). The syndrome is marked by an unusually large number of FMR-1 repeats on the X chromosome (4/4/96) occurring as a "visible fragile site on the end of the long arm of the X chromosome" (Scheerenberger 1987: 43; cf. Dykens 1995). A repeat of over 55 sequences of the nucleotides that make up the DNA on either of the X chromosomes puts the foetus at risk of inheriting the disorder at 10% or more (Dykens 1995: 522; Scheerenberger 1987: 43). My sister had less than this amount on one of her X chromosomes. Because it was borderline, however, and due to the family history, the Senior Registrar in Clinical Genetics at The Greater Ormond Hospital recommended further tests and sought other expert opinions, both of which concluded that the possibility of having a child with Fragile-X syndrome was "extremely unlikely" (18/4/96).

<sup>7</sup> Epilepsy is a neurological disease generally associated with convulsions and loss of consciousness. Some of the drugs that have been given to my siblings over the years include Phenobarbitone, Mysoline, Dilantin, Phemitone, Epilim,

epilepsy, and why Maryla, Stephen and Ursula were so much slower than average in starting to walk and talk. Why were they not learning to read, write or count? Why were they so different? And underneath it all, what was causing this difference? My parents were wondering what was wrong with their children and sought advice from numerous specialists who occasionally sent them away telling them their children would grow out of it.<sup>8</sup> Much of their desire to know was a need to interpret and give meaning to their children's differences. Part of it was externally motivated by the pressure to find my brother and sisters schools that would accept them.<sup>9</sup> Yet this desire to know, this will to knowledge, is bound to some degree by the environment in which a family is embedded. My parents sought professional help because that is the background from which they came. My siblings were sent to special schools because this was how society dealt with their difference. Other parents might have chosen a different path, seeking alternative forms of assistance and knowledge. Other cultures often interpret the causes and meaning of

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Tegratol, and Ospolot. Phenobarbitone was later found to have unexpected side effects such as behavioural problems and hyperactivity, and also damaged Maryla and Stephen's teeth. Chris Atkins points out that these and other drugs for epilepsy cause further impairments beyond those that the person is born with (Atkins 1998: 22).

<sup>8</sup> It was not until 1965, after three years of regular contact with the specialists, that the records include a diagnosis of retardation, although both my parents claim that they were never given this diagnosis, and that if they had they would never have come to Australia. There is only one mention of retardation earlier than this and that refers to my oldest brother, who in 1962 was thought to have "some mental retardation" associated with his epilepsy, irritability, slow walking and spasticity, as a result of his earlier encephalitic illness. However, by 1965 the records indicate that he no longer presented with any abnormal features.

<sup>9</sup> In a study of Mexican-American parents of disabled children, Marilyn Mardiros noted that parents acknowledged the pragmatic necessity of a label for their child's disability. As one parent comments: "You can call it whatever you want. He's disabled and he'll have problems the rest of his life. We need that label to get us help" (Mardiros 1989: 57). The need to find "appropriate schooling" was what finally brought my family to Sydney in 1968. Having been labelled autistic, Stephen was able to enrol at the Autistic School that had recently been established in Sydney. Maryla, however, who in many ways has far more "autistic" tendencies, was not considered autistic and therefore my parents had to find her a different school.

intellectual disability in entirely different ways (Connors & Donnellan 1993; Edgerton 1984a; Manion & Bersani 1987; Mardiros 1989; Miles 1992; Peters 1980; Westermeyer 1979; Whyte 1998).

The cross-cultural study of intellectual disabilities and mental disorders has brought to light differences in the ways that cultures interpret and diagnose disabilities (Mardiros 1989; Miles 1992; Whyte 1998). Westermeyer argues that while "folk concepts" incorporate references to witchcraft, magic and religious taboos, they generally conform to universal conceptual interpretations and experiences of mental disorder (Westermeyer 1979: 315). Others argue that the cultural interpretation of illness and well-being profoundly affects the diverse ways in which intellectually disabled people are perceived and the extent to which they are incorporated within the community as competent and social beings (Connors & Donnellan 1993; Nuttall 1998).

According to Marilyn Mardiros, Mexican-American parents believe that problems within a marriage are a potential cause of a child's physical and/or mental disability, as are past transgressions and divine intervention (Mardiros 1989: 60-62). These include such things as "breaking culture taboos, going against the teachings of the Catholic church, conducting oneself in a way that would disgrace the family, and mistreating family members" (Mardiros 1989: 61). Interpretations of disability have also been based on a belief in witchcraft, or the evil eye, and culturally appropriate healing practices are consequently sought as remedies (Mardiros 1989: 62-4).<sup>10</sup> Similarly, in Pakistan, the cause has been variously attributed to "exposure of a pregnant woman to the rays of an eclipse or to the shadow of a corpse; parental sins; [or] possession by evil spirits through passing under a haunted tree or place" (Miles 1992: 243). Miles has also

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<sup>10</sup> The Mexican-American parents that Mardiros studied utilised both the dominant Western biomedical model and Mexican-American cultural models to interpret the cause of their child's disability. They also used a combination of both as sources of possible treatment (Mardiros 1989: 60-67).

documented cases showing that retardation is believed to be the manifestation of God's will, an inherited illness, the result of inadequate maternal nutrition or the product of consanguineous marriages (Miles 1992: 243).<sup>11</sup>

Consequently, interpretations of intellectual disability, and the subsequent social attitudes towards such people, must be understood within the context of particular sociocultural and historical milieux. Such constructions, interpretations and perceptions are often complex and multifaceted. As Miles (1992: 242) has noted, they incorporate ideas and concepts from many different historical and cultural sources. These perceptions also perpetuate a particular construction and classification of the world as normal, normative and true. In Western cultures, intellectually disabled children are slotted into such a scheme, and their parents are consequently caught up in a world of medical, psychological and educational professionalism that renders their child abnormal, asocial and deficient. However, this can often contradict parents own interpretations and perceptions (Goode 1984).

This gulf between ways of relating to and perceiving intellectual disability is highlighted in the early reports that I examined from the Grosvenor Diagnostic Centre in Sydney. The doctors often commented on how difficult my parents could be, suggesting that they had an inbuilt defensiveness which prevented them from accepting that their children were profoundly retarded (7/4/66; 9/5/66; 17/7/67). There was never any suggestion, however, that this difficulty might be due to the fact that my parents understood and related to their children, albeit imperfectly, very differently. That they, and all of us, could

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<sup>11</sup> Gray (1995) has shown that this pattern of drawing from diverse sources in attempting to understand and interpret a child's disability also exists in parental explanations of autism in Western cultures. At times, my parents sought a religious interpretation of their children's disabilities. While this is an interesting issue, to pursue this line of research was not my aim. I am interested in analysing how my family came to understand and relate to my siblings as encultured and social beings, and how this compares to the dominant sociocultural and institutional interpretation of them as abnormal and asocial.

do so according to the negotiation of various symbolic systems centred mostly around object use, building mutuality over the course of years. Judgements on their children framed in stark terms of normalcy and pathology were therefore confronting.

The files at the Grosvenor Diagnostic Centre also contained a series of photographs of myself and my siblings that had been taken each time we were assessed. These images of the family are interesting for a number of reasons. Firstly, it is clear from the early photographs (25/5/67) in particular that all of us were extremely uncomfortable and distressed at being examined and photographed in the nude. Stephen is being held in place at his wrist by someone whose arm appears at the edge of the image, his face a picture of distress and fear. The blank surface of a door frames him. My mother sits stiffly in a chair with me naked on her lap, both of us looking with uncertainty, fear and anxiety at the camera lens. Maryla also looks unhappy and distracted. Only Ursula appears to be calm and happy as she stands against an examining table. Secondly, each of the images—except one final one in 1975 of Maryla and Stephen seated at a table together clothed in their school uniforms, and the one of me being held by my mother—is of each child alone and naked, in a bare clinical room.<sup>12</sup>

In contrast to the photographs of us as a family, engaging with one another and surrounded by the paraphernalia of family life, these images separate my siblings out as medical anomalies, as objects to be examined, observed and analysed. They were being stripped bare and de-contextualised. For people

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<sup>12</sup> The same sort of images can be found in textbooks on mental retardation (see Berry & Gordon 1931). These images show individuals looking uncomfortable and isolated, with no distinctive background or context within which to place and interpret them. They exist not as social beings but as examples of different levels of idiocy, imbecility, or mental defectiveness (as levels of intellectual disability were termed in the early twentieth century). Each image is accompanied by a description of the person's chronological age, mental age, phrenology, stature, weight, grip, "vital capacity", and a description of their capabilities, habits and appearance.

whose communicative and social abilities rest on a high degree of contextualisation, such a process creates and perpetuates an isolating, abnormal and asocial perception.<sup>13</sup> It is also a process that highlights a profound refusal to negotiate and communicate, to look for the possibilities of symbolic systems through which mutual sociality exists and can be built. The development of institutional practices based on such perceptions and interpretations have had an enormous effect on intellectually disabled people's lives. By associating deficits in reasoning and intelligence with the capacity for sociality, such interpretations and practices have denied intellectually disabled people their ability to be the authors of their own social lives. When I visited the Grosvenor Centre in 1997 I spoke with the medical director. She was interested in my research and wanted to know what had happened to the family. She helped me as I looked through the files and as I was leaving said to me in a wistful and perplexed tone: "You really love them don't you". It was as though the lens through which she interpreted people like my intellectually disabled siblings somehow precluded the possibility of true love, affection, intimacy and relatedness. The scientific imagination upon which her assessments were based

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<sup>13</sup> The images at the end of Diane Arbus' (1972) collection of photographs also emphasise this separation. Arbus had an interest in marginal, urban people, particularly freaks and social outcasts such as midgets, giants, transvestites and nudists. She preferred to photograph these people in the intimacy of their own homes and each of the images in this collection is a vividly rich portrayal of the uniqueness and diversity of such people's lives. Hers is not a medical gaze, nor does it attempt to be objective. Arbus identified with her subjects and sought to portray them in a sympathetic, compassionate, albeit awestruck, manner. In contrast, however, the seven images at the end of the monograph are an untitled collection of photographs of intellectually disabled people wandering around in an unidentified landscape, a blurred, park-like space with trees in the distance. The people have no names, there is no descriptive title, nothing to define their subjectivity, location and specificity. They are photographed as though they exist in a world outside this world, an unidentified and unidentifiable world, finding pleasure and sociality only in relation to one another. Such estrangement from the wider social world can be related to the isolation of this institutional environment (the bare details of which are revealed in a later monograph, titled *Untitled* (1995), that deals exclusively with this series of photographs). However, there is also an underlying sense in these images that Arbus had been unable to transcend the difference between herself and the people she was photographing. That, unlike the other marginal people, she was unable to engage with and relate to them.

appeared to be entirely unfamiliar with the ways in which mutuality might be built.<sup>14</sup>

My parents spent many long hours at the Grosvenor Diagnostic Centre waiting as their children were assessed by paediatricians, psychiatrists and psychologists, frustrated and distressed by the attitudes of these professionals towards themselves and their children. We were being judged, my parents criticised, my siblings categorised, and none of us, in particular Maryla and Stephen, were willing to cooperate with the demands being placed upon them to respond to these tests. My mother eventually challenged the doctors to come and visit the family at home, to see for themselves that the threatening environment of the Clinic produced a limited picture of the family, my siblings, and the way we related to one another. I could find no reference to this visit in the reports. As my mother commented when I interviewed her:

I didn't find the doctors, I mean they were sympathetic in the end, but not much help. I mean they didn't seem to really understand what I was going through or how the family coped with these manifestations of retardation.

One of the classic things was after Tessa was born in 1968. Before 1968, we came over to Sydney in 1967 from Perth and we went to the Grosvenor Diagnostic Centre where all the children were examined from head to toe; brain scans, blood tests, urine samples, measurements, you name it. And we spent I think three days from memory . . . The first day wasn't so bad, but when we had to go back the second day, Stephen and Maryla saw these men and

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<sup>14</sup> Of course there are exceptions to this, as is shown by Chris Atkins (1998) in her analysis of nurse's perceptions of people with severe multiple impairments. Rather than denying their difference, or attempting to change these people, Atkins claims that the nurses she interviewed mostly sought to relate to the people they worked with based on an acceptance of them as humans in need of support, intimacy, and "situated belonging" (Atkins 1998: 132).

women in white coats at the reception and so on, and they just freaked out because they knew what they'd undergone the day before, and they just ran off . . . But of course they had the tests done. And they hated it of course. They hated all this pummelling with their bodies. They had to have x-rays done and all sorts of things. And when we had to go at the end of the week for the summing up of these tests the three doctors who we spoke to [said] they didn't know what had caused the retardation. Ursula wasn't so bad. Although she was upset too, she wasn't quite so difficult to deal with. But they said they didn't know, with all these tests done, what had caused the retardation, and in fact they put them in the 'not known' draw.

. . . And because the children, . . . especially Maryla, had been so difficult to control, this one doctor, Dr M was her name, I remember [her] well, [she] said to me 'I don't know how you cope with these screaming children'. She was an Irish woman and rather gruff. And I was very angry with her because she was quite sort of obnoxious to me. And I said, 'do you think that these children behave like this all the time? I wouldn't be here. I would have done myself in long before this if I had children that screamed day in day out, day in day out'. I said 'no, they're like this because they're scared stiff of these white coats, these stethoscopes and knowing what's going to be done to them'. I said 'if you really want to know what the children are like, you should come to the house'.

I was expecting Tess at the time, and I said 'why don't you come to the house one afternoon and see what the children are like?' I threw out this challenge to them and after Tessa was born, we'd already moved to Sydney, they took me up on the offer. I think

Tessa was perhaps two months old at the time, [or] three months old, and they came for afternoon tea. And Stephen and Maryla were playing with their jigsaws and it was a reasonably peaceful household. Okay, Stephen had a little scream and Maryla probably had hers, and we sorted that out. But I think they saw for themselves, right, it wasn't a normal family, but we coped.

A few months before moving to Sydney we were visited by a psychiatrist in Perth who was interested in autism. She wrote to her colleague in Sydney saying that she thought it was a good idea that the family be kept together rather than sending my siblings to an institution (as those at Grosvenor had recommended). As she commented:

You see, this family have never known intimately any other children but their own and all their children are queer. Within the confines of this queer family there is no doubt whatever that the children play in a family way. They love each other, they help one another, particularly the eldest and the youngest, who have at present by far the highest ability. All their play is socially oriented within, of course, their limitations, and both parents are obviously very fond indeed of this queer collection of little oddities that they have brought into the world. I would think that as long as the family can get along as well as I saw them doing yesterday there is more to be gained by family life than they would probably get with treatment and training in a hospital school (30/10/67).

Both this psychiatrist and the staff at Grosvenor (according to my mother's account) acknowledged the integration of my siblings into family life. Yet this

acknowledgment seemed to have little impact on the diagnosis, treatment and care of my siblings. Why?<sup>15</sup>

### **Scrutinising the Scrutinisers**

David Goode (1984), David Gray (1995) and Timothy Booth (1978) have explored the relationship between clinical and parental perceptions of mentally retarded people, albeit in different ways. Where Goode and Gray both emphasise differences in perception and interpretation, Booth explores the process by which parents are drawn into the dominant medical interpretation of subnormality. Through an analysis of parent's experiences Booth shows how the medical diagnosis and degraded social status accorded a handicapped child is one which evolves over time. He argues that this label and status is part of a process of social construction based upon the social meaning attributed to the handicap rather than being an inherent attribute of the child (Booth 1978: 204-6). Parents come to make sense of their child's differences based on this diagnosis, and this in turn folds back on itself by influencing the everyday social world of how parents interact with and relate to their child (Booth 1978). Consequently, Booth argues, the construction of subnormality as a social status is a medicalisation of difference that is dependent on "the network of relationships which constitute the social world" (Booth 1978: 208).

David Gray, on the other hand, draws on Arthur Kleinman's notion of explanatory models as a way of exploring different ways in which autism (as a very particular form of intellectual disability) is conceptualised by physicians,

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<sup>15</sup> This does not mean that all families accept their intellectually disabled kin, nor that society responds to intellectually disabled people in a uniform way. Some parents abandon their children entirely, and some people who have never had retarded kin absorb these people into their social world with acceptance and love. However, what I have perceived and experienced in my observations and relationships with my siblings stands in stark contrast to the way society generally perceives and treats them.

patients and families. Gray argues that parents develop significantly different explanations to medical professionals as to the causes and consequences of autism (Gray 1995). They do this as a way of coping with and making sense of their child's problems. As such their models are "characterized by an eclectic borrowing from biomedical and other explanations, the use of metaphor and symbolic logic, and a lack of clear boundaries between conceptual categories" (Gray 1995: 116). Some of the reasons for these differences are due to the fact that the classification of autism is diagnostically blurred, lacking as it does some of the genetic or biological markers that other forms of intellectual disability portray. Moreover, these children do not develop in a uniform manner, and parents tend to deny the seriousness of the problem due to their desire to have "normal offspring" (Gray 1995: 108). Gray argues, however, that in attempting to make sense of these difficulties parents do develop meaningful explanatory models that help them cope.

David Goode (1984) also analyses the consequences of "socially produced identities". He does so, however, in a way that highlights the tensions and differences that exist between clinical and parental perceptions of retardation. Goode argues that these differences are based on different types of social interaction, and that while parents are often perceived by the medical profession as delusional or uncooperative, their knowledge of their retarded kin is based on an intimacy that allows them to perceive their child in other ways (Goode 1984). Goode argues that clinical assessments are based on "etic"—external, abstract and indifferent—interpretations that assess the child according to normative standards and criteria. Familial perceptions, on the other hand, are "emic", implying that they are "intrinsic to the actions of the cultural members". They are one's own way of existing within and making sense of intimate relationships that constitute the familial environment (Goode 1984: 233). Based on these different ways of relating, parents, clinicians and care

givers grant "radically different identities" to retarded individuals such that there is often profound disagreement over the person's potential, competencies, behaviour and identity (Goode 1984: 229).<sup>16</sup>

Goode (1984) argues that parents develop an identity for their retarded kin on the basis of intimacy. For him, intimacy is an aspect of social relations, and different types of relationships produce different interpretations of a retarded person's identity. In this sense, intimacy is an attribute of affect, and refers to the sentiment of being one "substance", of "unity" or "oneness" (Schneider 1968: 52). It is also related to love, to a diffuse and enduring solidarity (Schneider 1968: 52). But intimate relationships with people who are intellectually disabled are also a product of complex patterns of mutuality and sociality. This form of relatedness is based on the symbolic mediation of shared objects through which overlapping systems of meaning are negotiated. It involves particular and locally generated "social idioms" (such as the jigsaw puzzles and bits and pieces that my siblings used) that, although potentially "considered a source of external embarrassment . . . nevertheless provide insiders with their assurance of common sociality" (Herzfeld 1997: 3). Intimacy is a product of shared language games through which a specific sociality or form of life emerges; a sociality that fundamentally acknowledges the implicit mutuality of the intellectually disabled participants. It is a sociality that recognises the ability of intellectually disabled people to generate and sustain systems of symbolic representation despite their limited and restricted codes of behaviour and communication. These are the practices that build compatibility and solidarity.

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<sup>16</sup> Rather than utilising Goode's etic/emic distinction I prefer to use Sahlins' (1976) concept of a "symbolic scheme" which I describe in the following chapter. The problem with the etic/emic distinction is that it separates these two domains as though they are somehow distinct, whereas the emic always carries with it an etic dimension, and vice-versa. However, despite this difference between my work and Goode's, his analysis, and especially his emphasis on intimacy, is an important contribution to the study of intellectual disability. As such Goode's work will be analysed in greater detail in chapter five when I outline some of the sociocultural interpretations of intellectual disability.

Without them, intimacy is difficult to sustain. However, when combined with institutionalised forms of relatedness based upon separation, training and management, intimacy and shared mutuality is almost impossible to attain.<sup>17</sup>

Goode, Gray and Booth all focus on the relationship of medicine to retardation and adopt a social constructionist position. Whereas Booth explores how parents reproduce medical interpretations, and Gray acknowledges the complex mix of medical and familial constructions in the production of an intellectually disabled identity, Goode sets them apart according to whether the relationship is clinical or intimate. In doing so he acknowledges the difference between intimacy and objectivity, and explores the consequences of both in terms of how an intellectually disabled person is perceived and related to (Goode 1984: 231). Despite their differences, however, each of these writers has focused on the issue of a constructed identity, and does so by contrasting and/or assimilating the interpretations of parents with those of the medical profession.

While it is obviously an intrinsic part of the social experience of intellectual disability, this constructionism does not provide a full picture of the complexity of relating to intellectually disabled people (cf. Bogdan & Taylor 1976, 1982, 1989; Branson & Miller 1989; Cocks & Allen 1996; Ferguson 1987; Gerber 1990; Lea 1988; Manion & Bersani 1987 for other social constructionist interpretations of intellectual disability). It does not allow for an analysis of who these people are, as human beings who live within and also produce specific forms of sociality. Neither does it acknowledge that sociality and meaning is something which is created through mutuality and the symbolic mediation of shared objects. Constructionism interprets meaning as something projected onto the intellectually disabled, but not as something that is integral to them.

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<sup>17</sup> My concept of 'intimacy' and 'deficit' (see below p. 74) has evolved in discussions with Diane Austin-Broos.

Constructionism thereby fails to make an adequate assessment of the modes of relatedness and symbolic expression that intellectually disabled people participate in, develop and sustain.<sup>18</sup>

To further this argument I propose to present field data I collected in an activities centre and two group homes for intellectually disabled adults. While the setting for these places was ostensibly a community environment, I refer to them as institutional for they were characterised by institutionalised practices. While institutions also have a form of mutuality and relatedness it is one that is pervaded by notions of deficit.<sup>19</sup> Within this environment intellectually disabled people are implicitly characterised as abnormal and lacking in sociality. Affect and solidarity are largely absent and therefore so too are modes of mutuality focused on the sociality of intellectually disabled people as whole persons capable of participating in the joint constitution of social life. Rather than engaging with intellectually disabled people through the negotiation and mediation of symbolic systems, the institutional environment assumes that intellectually disabled people have little capacity either to articulate or negotiate symbolically meaningful systems. The assumption that intelligence and reason are the necessary competencies for sociality and symbolic expression underpins this attitude. By inference, the form of relatedness that exists in institutional environments is based upon management and training; on making intellectually disabled people more socially normal; on making up the deficit. In the process, the meaning, sociality and selfhood implicit in intellectually disabled people's actions and interactions goes largely unnoticed (cf. Gleason 1994). Many factors both personal and organisational contribute to this situation. My objective will be to compare and contrast forms of sociality and mutuality in an intimate and institutional milieu.

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<sup>18</sup> I explore these issues in more detail in chapter five.

<sup>19</sup> See footnote 17 above. Mary Howard (1990: 167) also argues that institutional practices are influenced by a "deficiency view" of mental retardation.

## Being Managed and Trained

The activities centre where I began my fieldwork was funded by the New South Wales Department of Community Services (DOCS), a government department responsible for family, community and disability services. As a state body DOCS handled all residential and community access services for disabled people in the area. The Commonwealth government was responsible for employment services throughout Australia.<sup>20</sup> The activities centre was officially called the "Xanadu"<sup>21</sup> Community Access and Support Service. Xanadu was "a day programme centre for adults with a developmental disability". Its aim was to "provide a service to the consumers in accordance with their individual service plans", which included such things as recreation, community support services and access, living skills, and some pre-vocational training.<sup>22</sup> In accordance with the aims of the NSW Disability Services Act (1993) the emphasis at Xanadu was on community integration, equal rights and an enhanced lifestyle. Through the services that the centre provided, and each person's individual service plan, Xanadu aimed to "assist clients to meet and develop their needs and interests by providing creative and diverse opportunities and experiences".

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<sup>20</sup> See chapter one, footnote 7 for details of the Commonwealth State Disability Agreement.

<sup>21</sup> In order to protect the privacy of the community of people with whom I did my fieldwork all names of people and places are pseudonyms.

<sup>22</sup> Individual Service Plans (ISPs) are written documents that detail the goals, needs, interests and supposed aspirations of each individual consumer. They also identify the person's achievements to date, various ways of attaining these goals, and efforts to enhance their skills, life experiences and social opportunities. According to contemporary disability rhetoric "consumers" (rather than clients or patients) is the term that is used to refer to intellectually disabled people. In this new era of consumer oriented welfare, intellectually disabled people are considered to be the consumers of the service for disabilities, and the staff are the ones who provide them with this service. This change in terminology, mirroring as it does other changes in practice and terminology in the field of intellectual disability, supposedly represents a shift in attitude, treatment and power.

This information on Xanadu appeared in the centre's transition plan. This plan outlined the services that Xanadu must provide to the consumers. It also stipulated the changes that were necessary in order for Xanadu to be fully compliant with the NSW Disability Services Act (1993). The Act also has a supporting set of Service Standards which reflect the principles and application of principles of the Act. These outline the responsibilities of staff to consumers and provide an account of consumers rights and the form of relatedness that staff must adhere to when dealing with consumers. The Standards focus on issues such as service access, individual needs, decision making and choice, privacy, dignity and confidentiality, participation and integration, developing a valued status, complaints and disputes, service management, employment conditions, support and skills development. Xanadu's daily activities reflected these requirements and standards of practice.

Implicit within the guidelines for the running of Xanadu was an ethos of training and management. The "needs and interests" of consumers are interpreted as specific and necessary social skills rather than as intimate relatedness. The aim is to develop a form of sociality in terms of skills and tasks that are socially acceptable and utilitarian. The mutuality that exists is based on attempts to equip people with these skills. Interaction, and the form of relatedness that exists within these institutional environments, is therefore primarily based upon regulation and training. As such, an institution is rarely able to acknowledge and sustain the capacity, or indeed legitimacy, of intellectually disabled people to produce and participate in mutual socialities through the production and mediation of meaningful symbolic systems. Combined with this is a degree of "ventriloquism", of well-intentioned but misdirected policy dictates that do not acknowledge or represent the inherent differences and aspirations of the people in question (Cowlshaw 1999: 222-

236).<sup>23</sup> Accordingly, staff adhere to procedural requirements even though these practices do not actually produce the desired outcomes. This was particularly evident in the meetings that were held each week whereby the consumers were required to speak without their participation and mutual sociality ever being genuinely achieved.

There are very real and practical limitations, restrictions and difficulties that contribute to this situation. The staff are restrained by legal obligations that do not adequately address the complexity of relating to intellectually disabled people. Not only do these determine the ways in which they have to engage with consumers, but the fact that they are almost always responsible for at least four consumers at any one time makes the intensity of developing and sustaining necessary levels of intimacy and mutuality very difficult. Staff are also moved around between different work environments and have spent varying amounts of time in the service. This makes it difficult to maintain an ongoing commitment to specific individuals. To add to these problems, paid employment does not generally involve a requirement to generate intense levels of human engagement and intimacy. Yet this is what is necessary in order to uphold and develop intellectually disabled people's sociality. All these issues, combined with the already considerable difficulties of sustaining mutuality with people who have very limited and specific modes of symbolic

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<sup>23</sup> Gillian Cowlshaw uses the term "ventriloquism" in her study of the relationship between racial power and intimacy in Australia. It describes the process whereby "certain imagined virtues and desires were attributed to Aboriginal people" (Cowlshaw 1999: 222), such that "community members were participating in alien forms of interaction and discourse, and were assenting to an agenda formed elsewhere" (Cowlshaw 1999: 233). Interestingly, these practices evolved during the 1970s when equality, freedom and self-determination became the official social policy towards Aboriginal Australians. The very real and systematic differences between Aboriginal and white people and their social practices were not able to be seriously incorporated within this new policy (Cowlshaw 1999: 223). This is one of the many parallels that exist in the history of practices and attitudes towards indigenous and intellectually disabled people.

expression, contribute to the problems involved in institutional encounters with intellectually disabled people.

### **In Xanadu**

Xanadu was set up in 1984 on the basis of a rent free agreement with the local hospital. It was located in a small cluster of rooms attached to the hospital and palliative care unit by a series of covered and ramped passageways. The hospital was a separate organisation, however, and any specialists who visited the centre came from DOCS rather than the hospital unit. In fact there was no contact whatsoever with the hospital staff, other than the occasional wave from some of them having their lunch at the canteen when the bus went past. This separation was also evident at the centre, for although it was busy with its own daily comings and goings, there was a sense of being cut off, both from the local environment and from the wider community. The hospital, a disorderly collection of buildings set amongst tall gum trees and paddocks, was situated on the outskirts of a small country town that relied on weekend tourism for its economic viability. This town was twenty kilometres from the main rural centre, the location of the DOCS office, other government services, the group homes, sheltered employment facilities and the main commercial businesses of the region.

Every weekday morning the consumers who attended Xanadu were picked up at their homes by one of two buses and driven to the centre to begin the day's activities. This included those people in the area who were considered the most dependent and intellectually disabled, and who were incapable of working at the local sheltered workshops.<sup>24</sup> Over the twelve months that I did

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<sup>24</sup> Sheltered workshops are now known as "business enterprises" in order to emphasise their incorporation in the general market place as profit making rather than charity organisations.

my fieldwork I came to know many of the intellectually disabled people in the area, not just those at the activities centre. This included people who worked in open employment (in supported positions at businesses such as Macdonalds or other takeaway food places), at the local sheltered workshops, or who were moving around between these and other services such as the post-school options programme.<sup>25</sup> However, it was the people at the centre and those who lived in two of the group homes in the area with whom I spent the majority of my time.<sup>26</sup> I engaged with them not through their records, believing as I do that these are private documents, but by interacting with them at the centre and at their respective homes. Rather than doing in-depth interviews, and asking my informants how they perceived and interpreted their lives, I spent my time just being with them and observing what was going on, what it was they were saying and doing, and how they related to one another, to the staff, and to myself. I also observed how the staff perceived, treated and related to the intellectually disabled consumers.

Of the twelve people who regularly attended the centre, nine were women and three were men. For the purposes of this study, I have given them the pseudonyms Kate, Cressida, Sarah, Mary, Rachel, Daniel, Joanne, Martin, Polly, Tony, Patricia and Jacky. Their ages ranged from Kate who was in her early twenties to Mary who was in her mid fifties, although the average age in 1996

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<sup>25</sup> The "post-school options programme" is a recent initiative that aims to provide pre-vocational training and recreational services for intellectually disabled people making the transition from school to a work-related activity.

<sup>26</sup> The majority of those living in the largest group home also came to Xanadu. Apart from one woman, those living in the second home included people who worked at various sheltered workshops in the region. There were other intellectually disabled people in the area who lived "independently" in the community. This meant that they lived in supported accommodation and were visited by employees of the Department of Community Services and other welfare services to assist with any issues or difficulties that might arise from living independently. I met a couple of these people but have not based this ethnographic study on their circumstances as my focus has been on the social experiences of those people who are more dependent and severely intellectually disabled.

was about 35. Three of the consumers were permanently confined to wheelchairs, while one of the men occasionally used his when experiencing the after-effects of epileptic seizures. The majority were on some form of medication, at least four were epileptic and two were incontinent. A number of the consumers had serious medical conditions that affected their health and lifestyle. Quite a few also had serious behavioural and/or psychological problems that periodically resulted in physical acts of violence, psychotic episodes, and extreme emotional outbursts. Some of these people had spent many years in large government institutions (Mary, Cressida, Joanne, Polly and Patricia). Two had lived with their families in the area and had moved into the group homes when they opened (Sarah and Jacky), while Rachel, Martin and David have always lived at home. Most people had at least one family member living in the region, and those who didn't had an advocate appointed to represent them at official meetings.

When I rang Xanadu to enquire about doing fieldwork I spoke to the coordinator who asked me to come and explain my research to him. He was supportive of my plans and, after checking with the Disability Services Area Manager at the local Department of Community Services, agreed to me coming to the centre on a daily basis as a "volunteer". When I was assigned the role of volunteer I assumed that it would make no difference to the way in which I proposed to relate to people. I soon realised, however, that it did, and that I too had to have a place within the division that separated the staff from the intellectually disabled consumers with whom they worked. As a volunteer I was in essence an unpaid staff member, and it was my "duty" to uphold the same regulations and standards that the staff had to observe.<sup>27</sup> In fact, I was

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<sup>27</sup> In her recent ethnographic study of the deinstitutionalisation process experienced by a group of intellectually disabled women, Kelley Johnson also comments on this phenomenon. She too found that she was under pressure to act as though she were a staff member, and that there was little space for her to operate outside these confined parameters (Johnson 1998: 4; cf. Goode 1980b; Gleason 1994; S. Taylor 1998b).

introduced to this whole new world of conditions, standards and practices on my very first day. I had some freedom to move around within the activities centre, choosing who I wanted to spend my time with and what activities I wanted to participate in for the day. But Xanadu regulations profoundly affected the way in which I was able to relate to the people whom I had come to the centre to get to know.

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When I first walked into the activities centre I was overcome by a feeling of familiarity. The smell, sounds and feel of the place were very similar to Stockton in its more recent manifestation. The fact that the centre was attached to a hospital only added to this familiarity.<sup>28</sup> The rooms were clinical and bare, with linoleum floors, plastic chairs and tables, and fake leather lounges. A large television dominated the corner of one room, and a pervasive smell of cleaning chemicals filled the air. There were few items in view in the main room, other than an urn, a radio, a paper shredding machine and a trunk overflowing with newspaper. A noticeboard with photographs from previous outings was on the wall of the second room. Any craft tools, games or puzzles were safely stored away in cupboards.

Every morning when I arrived at the activities centre I took my place amongst the group of consumers, making myself a cup of tea and settling into a chair at one of the tables in the front room to wait until the mornings' activities began. These were generally quiet moments of the day, and my

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<sup>28</sup> Xanadu's transition plan actually required that it move out of this location. Although this issue was consistently brought up at meetings the problem of financing such a move prevented it from happening in the near future. Three years later when I visited the centre it was still located at the hospital. Likewise, it has also been stipulated that Stockton must close because it contravenes the NSW Disability Services Act. Over the past decade the majority of Stockton's residents have been moved into community group homes. Those who still live at Stockton, including my sister, are supposed to move into alternative accommodation sometime in the next five years (although this time frame keeps changing).

entrance would be acknowledged by those gathered in the room in their own particular ways. Kate would give a wave of her hand and a nod of her head from her usual seat under the high window, her feet tucked up beneath her body as she rocked her chair backwards and forwards and sang to herself. Cressida, an older Aboriginal woman, would be in her usual spot as well, over by the urn and sink, sipping on her third cup of coffee for the morning. She would look up with a hint of a smile and point out her new clothes or the latest pain she was feeling. She would urge me to come and sit beside her and attend to these ongoing issues. Joanne would be seated over in the corner with her back to the room, continuing with the unfinished and unfinishable task of tearing up discarded newspaper into squares and filling up the garbage bin. She would hunch up her shoulders when I entered the room and never say hello, nor would she look at me. In contrast, a young man called Martin who was always bright and cheerful would lurch over to where I was standing and tell me about his weekend and how busy he had been, reaching into his pocket as he spoke for a handkerchief to wipe the dribble from his chin. Mary would look up from under her yellow baseball cap and mumble "hello" before falling back into a semi-slumber, or wandering outside to have a cigarette. Sarah would shout at me from the other end of the room to get her beads for her. I would use these initial moments to reorientate myself to the rhythms and moods of the room, ready to begin another day of observing and interacting with this group of people in order to understand and make sense of their world.

At first sight it appeared that these were the only people at the centre, but through a hallway and off to the right was another room where the staff were having their morning 'cuppa'. It was here that the coordinator had his desk, where all the records and relevant documents were filed, where the staff did their paper work, and where they ate their lunch and drank cups of tea and

coffee. There was a serving window through which they could see into the hallway and through to the second room where the television and craft equipment were kept. Only staff were allowed officially inside the staffroom. This included me as a volunteer, although at times the staff would accommodate for temporary transgressions by having consumers stay for a while if they did happen to venture in. This was so particularly in the case of one woman. After a few minutes, however, Patricia would be asked to leave the room and told to replace the rope on her way out.

Across the door that led into the staff room hung a rope and this simple device marked a threshold that could never be fully traversed. During the time I spent at the activities centre there was much discussion about replacing the rope with a door with double handles and locks. The staff, and especially the co-ordinator, were frustrated by consumers coming into the staff room and disrupting their work. No locks were fitted while I was there, but the rope and this discussion symbolised the demarcation between staff and consumers. It highlighted the role that the staff were employed to perform. The rope signified the fact that the staff had a duty to train the consumers, to provide them with opportunities to develop social skills rather than engaging with them through shared and negotiated symbol systems. It highlighted the fact that the consumers were there to be properly managed. The rope represented and reproduced the boundary between those who were categorised as intellectually disabled and those who were "normal". It reinforced the separation between consumers and staff, and signified the spatial and ideological institutionalisation of training and management practices. It reflected the form of relatedness that existed at the centre and perpetuated the notion that intellectually disabled people are supposedly lacking innate capacities for sociality and mutuality.

There were various daily activities that were part of this training regime, and each of them aimed to develop the vocational and social skills of the consumers. These ranged from delivering meals to the local elderly community (a community integration and access activity that formed part of a wider voluntary service called "meals on wheels"), visiting the library or shopping centre, and doing craft work at a local cafe with some community volunteers (a program that ended a few months after I started fieldwork due to lack of interest). Activities also included going ten pin bowling and doing some gardening at a small plot attached to a large wholesale nursery 30 kilometres away. In between these main activities people spent time just 'hanging around' the centre having cups of tea and coffee, wandering around between the rooms, or sitting outside in the garden. Occasionally they would also do some painting, drawing, cooking, or puzzles, look at magazines, have make-up put on, watch television, perform karaoke numbers, or, as one woman did, smoke with the staff. Every few months we would also go on an outing, to the nearby boat harbour for the afternoon, to a park, or, as on one occasion, to a special disabilities day at a local showground to watch a demonstration of police, fire and rescue service operations.

The activities centre also provided pre-vocational training in the form of a paper shredding machine. A number of consumers were encouraged to operate the machine as part of their skills enhancement programmes. Others spent time tearing up pieces of paper for shredding. While I was at Xanadu a group of women also spent a few weeks doing a paid contracted job that involved tying lengths of string to cardboard tags for use on industrial equipment. Through encouraging and developing these skills it was hoped that some consumers might eventually "move up" to one of the sheltered workshop environments and take their place in the wider community.

Every Monday afternoon a meeting was held during which consumers were encouraged to tell one another what they had done over the weekend. Once a month these meetings were more formal and dealt with procedural matters relating to the running of Xanadu. As there was often very little to discuss, these monthly sessions were used as an opportunity to go over the rights of the consumers enshrined in the NSW Disability Services Act and the accompanying Standards of Practice. Generally, however, a weekly routine was followed, and each person was allocated a morning and afternoon activity to assist them in the development of their social and vocational skills. These activities were also seen to provide forms of community access and integration.

The staff at the centre—of which there were three full-time, one part-time and three casual employees<sup>29</sup>—were employed to facilitate the training of these skills by making sure that the expected activities took place. This involved driving the consumers to and from various locations, as well as setting up the necessary equipment for different activities. These were part of their "hands-on" responsibilities, which also involved helping with mealtimes, toileting, medication, and any physiotherapy exercises that people needed to do. I too was expected to participate in these and other procedures, so that I also ended up helping with the orchestration of lunch, toileting, getting people on and off the buses and setting up activities, as well as chairing the weekly meetings.

The permanent staff members were also responsible for individual consumers as their case managers. In this role they participated in the formulation of individual service plans, kept daily records of each person's behaviour and activities, and noted any deviations from expected and acceptable behavioural standards. The staff attended meetings concerning

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<sup>29</sup> At any one time there were never more than five staff people rostered on at the centre. This included the coordinator who rarely took "hands-on" responsibility for the consumers. With twelve regular consumers this gave the ratio of staff to consumers at anywhere between 1:3 and 1:6.

those whom they were managing and communicated any information concerning that person to their guardian and DOCS personnel. These were the practices through which staff managed the consumers. They were based on a combination of behavioural management and bureaucratic order, and included record keeping, report writing, representation at meetings and making decisions about courses of action concerning behavioural "problems". In this role staff had the power to intervene in the consumer's lives based on their assessment of how consumers were behaving. This could range from recommending that a person be sent to an institution for a short and intensive period of drug enhanced therapy, to giving them an injection of Valium as a way of controlling their behaviour. These responsibilities and expectations were extended to other staff and could result in locking someone in solitary confinement for short periods of time, ignoring repetitive questioning or permanently maintaining a specified physical distance from certain persons who were considered dangerous. Such recommendations were included in consumer's personal records and individual service plans and served to inform the actions of staff towards consumers.

Staff were also expected to participate in the development of policies and procedures so that Xanadu would eventually become fully compliant with the Department of Community Services policies, the NSW Disability Services Act and the NSW Disability Service Standards.<sup>30</sup> These obligations were the cause of considerable frustration and stress for the staff, who complained that more of their time was taken up doing paper work than the hands-on activities that they were employed to perform. Most of the staff believed the expectations of the Act were unrealistic and contradictory, and were disillusioned by the low

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<sup>30</sup> While I was at Xanadu I was asked if I would work with the second most senior staff person to draw up a draft plan of Xanadu's policies and procedures. This meant going through the report on Xanadu done by a government appointed consultant and list all the areas that had been noted as contravening the NSW Disability Services Act. It also required making recommendations as to how these areas of Xanadu's operations could be changed.

morale, bureaucratic red tape and lack of support that plagues the NSW Department of Community Services. One of the issues that most frustrated them was the requirement that consumers participate in all decision-making procedures at the centre. The monthly meetings were a way of addressing this recommendation although, as I describe in a later chapter, these occasions often deteriorated into farce as the majority of the consumers lacked the capabilities to engage with the world in this way. The meetings became a formality, and a simulacrum of formality in the process, having all the external features of an official meeting but none of the actual substance.<sup>31</sup>

The staff were all NSW government employees and as such they had to comply with the conditions and standards outlined in the legislation and within numerous DOCS policies. They were actively discouraged from developing personal relationships with the consumers and were expected to maintain strict professional standards and practices in accordance with these policies. They were also required to relate to consumers according to the recommendations of each consumer's individual service plans. There were occasional breaches of these regulations. However, there was no systematic, structural or accepted way within these institutional environments to build upon the potential for mutual sociality. Training programmes for staff, while irregular, were aimed at teaching staff how to equip consumers for life in the community. They focused on issues such as behavioural management and sex education and reinforced

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<sup>31</sup> In using the term "simulacrum" I draw upon Baudrillard's notion of it as a "displacement of the real by empty signs" (Herzfeld 1997: 6). However, Herzfeld's (1997: 7) interpretation of simulacra as "an attempt to project familiar social experience onto unknown and often potentially threatening contexts" is also relevant here. The meetings disguise a true lack of substance and are also an attempt by staff and policy makers to make the unknown conform to "familiar social experience". In this sense, following Herzfeld (1997: 6), the "less literally face-to-face the society we inhabit, the more obviously cultural idioms become a simulacra of social relations". Although ostensibly engaged in "face-to-face" relations, the staff are obliged to engage with the consumers according to an ethos of training and management whereby the consumers are encouraged to develop socially acceptable dispositional behaviours.

the obligation to provide consumers with community integration and help them develop social skills. These skills were both vocationally and domestically oriented. They focussed on developing the ability to operate a paper shredding machine or place a certain number of objects into containers; two skills that were required for working in the local sheltered workshops. They also emphasised living skills such as independence, hygiene, cooking, cleaning, and acceptable interaction with the public. As discussed in chapters six and seven, none of the training programmes focused on how to foster communication, understanding and empathy between the staff and the people they worked with. Any tendency or desire to acknowledge intimacy and develop forms of mutuality had no support or encouragement.

Training consumers to acquire these social skills, and discouraging them from unacceptable behaviour, were the primary means through which staff related to the consumers. This was the form of relatedness that dominated life at Xanadu. It was based on an implicit and taken for granted interpretation of the consumers as deficient and abnormal beings who, because they lack certain capacities for reasoning and intelligence, are considered incapable of expressing and sustaining forms of symbolic activity through which mutuality and sociality can be developed. It was therefore assumed that the acquisition of particular social skills and a conformity to normative social behaviours were the necessary prerequisites for intellectually disabled people becoming socially integrated beings.

Forms of interaction and relatedness based on training appeal to an "elaborated code" that lies essentially beyond the grasp of intellectually disabled people (Bernstein 1971: 143-148). This does not mean that intellectually disabled people have no capacity for sociality and mutuality. On the contrary, their capacity for communicating through restricted and specific codes, although limited in their range of applicability, mode of articulation and contextual

specificity, does allow for the potential to develop negotiated systems of meaning through which mutuality and sociality are built. The symbolic violence that is done to intellectually disabled people in institutional environments occurs precisely because the forms of relatedness that exist do not build upon these already established codes. They do not allow for negotiation and mediation through the interpenetration of symbolic systems at their point of articulation. Institutional environments and relationships therefore undermine the capacity for intimacy. They also actively frustrate attempts by intellectually disabled people to explore mutuality in social life. Considering that social integration is an official government policy, it was disturbing to see that at its most salient point, the point of articulation between staff and consumers, the staff were actively discouraged from exploring mutual sociality.

### **The Intimate as Institutional**

Five months after starting at Xanadu I began doing fieldwork in one of the Department of Community Services group homes. I was interested to find out what home life was like for the majority of the people with whom I spent my days. I also wondered whether or not there was any continuity between the practices and relationships I observed at the activities centre and those taking place at home. Whereas a work environment, which Xanadu was supposed to emulate to a certain degree, usually has a number of legal, bureaucratic and administrative processes in place as part of its organisational structure, home life is generally considered to be a more intimate and personal environment. It is a site of the familial. As such, it is usually free of the institutionalised relationships, expectations, structures and protocols that characterise a work environment.

The first group home that I worked in was known as "Jeffrey Street".<sup>32</sup> The house was a beautiful, late nineteenth century building with north and west facing verandahs. It had large bay windows, high ceilings, thick stone walls, ornate railings and generous sized rooms. Situated on a large corner block about two kilometres from the centre of the main town, the home looked just like any other house along the street with a few extra cars parked outside. On making my way through the permanently closed gate and suburban leafy garden, however, it quickly became apparent that this was quite a different environment to any ordinary home.

When I first visited the house a white mini bus was parked in the driveway and two people, who turned out to be staff members, were sitting smoking at a plastic outdoor table in the concrete courtyard. Beside them a ramp led up to the back door that opened onto a wide dark hallway from which the four bedrooms, kitchen, dining room, television room and toilet block were all accessed. The front door was permanently locked and the verandahs inaccessible. The house was completely turned in upon itself. Most of the windows looked out onto brick walls or the enclosed yard so that the place had no relationship with the surrounding neighbourhood or environment. There was nothing remotely personal, intimate or familial about Jeffrey Street. Nor was there anything approaching the supposed requirements of community integration other than that the house was situated in a suburban street.

Jeffrey Street was the largest of the five government group homes in the area. It could accommodate anything up to eleven residents. Seven people, one man and six women, were permanent residents. Six of these people—Cressida, Sarah, Joanne, Polly, Tony and Patricia—came to the

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<sup>32</sup> Again, the names and locations of these group homes and the people living in them are pseudonyms. There were four DOCS group homes located in the main town. They were known as "Jeffrey Street", "Hervey Street", "Corrie Street" and "Brown Street". In addition to these, there was also a children's group home.

activities centre every weekday. They shared the group home with three other women: Jane, who stopped coming to the centre because of her age and frailty and spent each day at home with a staff member; and Jill and Kerry who were living at Jeffrey Street on semi-permanent respite.<sup>33</sup> Jill worked in open employment at a take-away pizza bar while Kerry floated around between various day programmes delivering pamphlets to letter boxes or washing cars. Most of the residents required medication, three were incontinent, and two were in wheelchairs. The permanent residents were generally considered by staff to be the least functional and most "hands-on" (or difficult) of all the consumers living in the region. Kerry could also be very difficult and aggressive and on a number of occasions her disturbing behaviour was dealt with using physical restraint and medication. Consequently, there were usually at least three staff persons rostered on duty at Jeffrey Street during the morning and evening shifts, and someone was always on night duty.

Owing to the requirements of the NSW Disability Services Act, Jeffrey Street would eventually have to be disbanded. The proposal was that the group be split between three smaller houses, two that would operate as permanent households, the third functioning as a respite centre. At the time, however, all but two of the residents, Joanne and Tony, shared a room with someone else, and both of them had spare beds in their rooms for casual respite residents. Kerry lived alone in a semi-independent flat attached to the house and was only occasionally allowed to come and have dinner with the other residents.

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<sup>33</sup> Respite care is temporary accommodation for intellectually disabled people who are living at home with their families. A few of the group homes had a spare bed that was allocated for this purpose, and families in the region had to put their names down on a roster in order to have access to this service. Kerry and Jill's situations were somewhat different in that they had been in respite for many months because their respective family's refused to take them back home. This is a course of action that a number of parents have taken with their intellectually disabled children as a way of protesting the lack of available respite facilities and government placements. It is also a way of getting their child some form of (albeit insecure) placement in a group home (Horin 1996a: 1; Horin 1996b: 9).

There were no personal or homely possessions in the main rooms. The laundry had shelves installed with each person's name marked on them for sorting clothes; the dining and television rooms were bare and cheaply furnished; the kitchen had lists of what people ate on the cupboard doors and there was no food in sight. The only indication in the main rooms that people lived here permanently was a portrait photograph of each consumer hanging in the hallway. The bedrooms were more homely as each consumer had a chest of drawers and bedside table upon which were arranged their few belongings, such as photographs of family, some jewellery, books, a tape recorder and music, or a favourite doll.

When I first began at Jeffrey Street I was asked to chair the weekly resident meetings that they, like Xanadu, had to have. As an unpaid volunteer I was seen to be independent and therefore the obvious choice for this new requirement whereby the consumers have their say in the running of the home. Once a week I would make my way to Jeffrey Street and meet up with everyone after their day's activities. We would hold the meeting and afterwards I would hang around for a few hours until bedtime, joining in with whatever was going on; watching television, bringing in the laundry, making lunches for the following day, having dinner, or sitting around having cups of tea. The meetings only lasted a few weeks before falling into the basket of the all too often discarded attempts at introducing the well-meaning but entirely inappropriate expectations of the Disability Services Standards and Act. Even though the meetings no longer occurred I was still able to go to the house each week for the afternoon and evening and while there was able to participate in and observe the home lives of those whom I spent my days with. Although the staff knew I was at the house to do fieldwork they expected that I act as any other volunteer and assist them with their duties, especially bathing, toileting, cleaning and feeding. The staff were suspicious of my presence at the house

and, unlike those whom I came to know quite well at Xanadu, left me well alone to do what was expected of me.

Like those at the activities centre, the staff at Jeffrey Street had a separate work space where all official information, medication and personal records were stored. They also used a separate bathroom. The permanent staff employed in the group homes were different to those who worked at the activities centre (although the casual workers tended to move between both places), but they were all still employees of DOCS. As such they were both bound by the same conditions, standards and practices, and displayed the same frustration and angry sentiments as the staff at Xanadu. Despite the pervasive institutionalised appearance of the place, it was more the routines and regulations, the policies and practices, that gave to Jeffrey Street a dominant ethos of training and management. It was the form of relatedness that existed between staff and residents that made the intimate environment of this home truly institutional. It quickly became clear that home life for those living in government funded accommodation differed very little from daily life at the centre. As I wrote in my notes after that first visit:

The kitchen is large and organised, with notices up for where food should be placed in the pantry and who has their tea and coffee in what way (although only the staff were included on this list). . . I was taken through to the office, a small room crowded with ledger and record books, individual books and daily programmes. I imagine the medication is kept in here as well. The house manager gave me the "morning shift folder" to have a look through, which gave details of who does what during the day and what is expected of the staff. It also gave information about keeping accurate records, recording "incidents" as they occur [which includes any aberrant behaviour by a resident or an altercation between them

and staff or other residents], checking medication twice, signing any written notes, and various other bureaucratic procedures and obligations.

It was assumed by the house manager that this was the information I needed in order to fulfil my role as a volunteer/fieldworker in the group home. The individual record books contained personal information, including medical histories, family contacts, and behavioural management details. They outlined the way that staff were to interact with and treat each of the consumers and, while I never read these files, I was regularly informed by the staff as to how I was supposed to deal with each person's idiosyncratic behaviour. The emphasis was on domestic skills training and changing undesirable behaviour rather than on an ethic of relating *per se*. There was little emphasis on intimacy, affection or the development of mutuality based on the shared and mediated production of sociality.

The Standards of Practice stipulated the legal procedures to which staff now had to adhere regarding consumer's rights. These guidelines, and other individual management plans, outlined the required modes of relating. However, staff were given no advice, support or direction as to ways of relating to these intellectually disabled people as fellow human beings. Despite the rhetoric of integration and rights contained in the NSW Disability Services Act, none of the requirements of the job incorporated the principle or policy of truly relating to the consumers as social beings. They did not acknowledge that for the majority of the residents, their contact with staff was the only social contact they had with non-intellectually disabled people. The outcome for intellectually disabled people could only be a very confined mutuality relatively lacking in intimacy. Even within a 'home', the training and management regime therefore could only produce a simulacrum of the socially normal.

A few weeks after starting fieldwork at Jeffrey Street, the house manager of the group home around the corner asked if I would also chair the weekly meetings that they had to have. "Hervey Street", as the home was called, was a smaller house and much less institutional in its feeling and set up. A short path, bordered with Daphne and Kangaroo Paw beneath overhanging Banksia and Jacaranda trees, hid the front door from view. Like all the other houses along this tree-lined street, the group home was a red brick bungalow. The only distinguishing feature was the extra car or two parked on the street outside. Only five consumers lived at Hervey Street and all were permanent residents. Sally and Jim worked together at the local sheltered workshop on the outskirts of town doing unskilled manual labour such as packing and sorting out nuts and bolts. Colin mowed lawns for a grounds maintenance operation that employed intellectually disabled men. Shauna worked at "Keynton", a paper shredding unit that recycled paper for packaging. Keynton operated out of a corrugated iron shed situated in an industrial complex on the edge of the main town.<sup>34</sup> Mary went each day to Xanadu. Each resident had their own bedroom which was filled with their personal belongings, and the main living areas of the house were also more crowded with the paraphernalia of domestic life. There was no separate office that could be locked up and kept off bounds such as the one at Jeffrey Street. Instead, the single staff member on duty did any paper work sitting at a table in the living room. Staff shared a bathroom with the residents and generally seemed to be more relaxed and engaged in the daily flow of the lives of these people.

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<sup>34</sup> The paper shredding unit operated under the control of Xanadu as a mini-sheltered workshop. Four people worked here on a daily basis (including Shauna), although they and the numbers changed from month to month as people moved from one location to another. While I was at the centre the responsibility for the paper shredding unit was transferred to one of the sheltered workshops. This was a requirement of the Commonwealth State Disability Agreement (1991) which stipulated that employment and activities centre responsibilities be separately managed by the relevant Commonwealth and State government bodies respectively.

While I was at Hervey Street I was privy to many discussions involving the daily domestic lives of the residents. These ranged from decisions over acquiring new furniture, disputes over domestic duties, discussions concerning some of the difficult personal relationships between residents, where to go for dinner on Friday evenings, as well as requests to move out of the house altogether. These discussions often took place during the meetings that I chaired, although they were also the subject of conversations that I had with both residents and staff over the six months that I visited the house. I began to notice, however, that beneath the apparent ease and familiarity of Hervey Street there existed a structure that was not easily negotiated or changed. As I wrote after having dinner at the house one night, "the routine marches on forever, without the flux of daily life intruding". I had stood up after dinner to help Shauna clear the table and wash the dishes but was harshly reprimanded by the staff member for intruding on Shauna's duties. Similarly, at one meeting, the issue of the weekly roster was raised by one of the residents (or rather as a request to the house manager from a resident's sister). The suggestion was that the roster be changed regularly for cooking and cleaning duties so that residents did not have to cook the same meal and clean the same room every week. The staff were reluctant to do this as to them it represented an organisational nightmare. Every aspect of the resident's lives had to be brought up at the weekly meeting, whether it was deciding how to spend their money or checking if they could have a friend over for dinner. Despite the fact that this was home, and that they were supposed to be in charge of their own lives, the residents were ruled by an order and structure that was not of their making and to which they constantly had to conform.

Despite differences in intensity, the same practices of management, separation and training that dominated the form of relatedness at Jeffrey Street and Xanadu also informed the relationships that existed between the staff and

residents at Hervey Street. Each resident at Hervey Street had an individual service plan that gave specific instructions as to how certain behaviour should be dealt with, what skills needed to be developed, and how far the consumer had come in their training. Staff often ignored the residents when they attempted to join in a conversation. Even though they shared a bathroom and did their work in the living area, the staff tended to have their 'smoko' or cup of tea by themselves. They often reprimanded the residents for their behaviour, such as when they violated this "relationship of separation" by asking the staff personal questions, sought affection from them, or talked to the staff rather than the other residents. Such behaviour was acceptable if directed to other residents, and indeed was regularly encouraged, but not if it was sought with the staff members.

One of the practices at Hervey Street that signified the continuation of this institutional ethos of training and management was hidden in the very centre of the house, in the filing cabinet that was discretely located in the main room behind a cupboard. It was here that all the personal records of the residents were stored, including family contacts, individual service plans, medication records and other private information. The cabinet was locked in order to protect the privacy of consumers, although the staff had access to this information. Privacy was maintained between consumers, but not between staff and consumer. Having the cabinet hidden behind the cupboard was an attempt at privacy. It was also a way of giving the domestic environment the appearance of normality. But it was not normal. It just concealed a managerial and institutional intrusion into the domestic and intimate space of these people's lives behind a veneer of normality. Consequently, the intimacy of daily domestic life became a site of separation and estrangement, a site for instituting practices of normality. It became yet another arena for implementing training and management practices.

And yet not everyone succumbed to this form of relating, nor did all of my fieldwork sites exhibit it equally. Certainly, Hervey Street was generally a pleasant environment to spend time in. Initially I supposed that this was due to the relative independence of the residents living there. However, when I visited the local sheltered workshops and post-school options service—places that only took the more independent and capable consumers in the area—I found an even more pervasive regime of training and management. The experience of Hervey Street staff, and their familiar round of 'home' engagements, did at least count for something.

Although rules and regulations were a dominant feature of all my fieldwork sites there were also a number of occasions when I witnessed them being broken. Such breaches took place in moments of physical affection and through expressions of genuine compassion. They included those occasions when Patricia came into the staff room at Xanadu, when staff teased and joked around with the consumers, when they gave Mary a cigarette and lit it for her, and when a few of them participated in the karaoke sessions. However, there was no systematic way of building upon these momentary connections. They were transgressions, and staff who did not conform to general practices and attitudes were ostracised. Such was the experience of one staff woman who had a very maverick and passionate approach to her work and engaged with the consumers as a friend, with empathy, compassion and affection. She had a difficult and mutually contemptuous relationship with the coordinator at Xanadu, and with various managerial personnel at the DOCS office, and eventually ended up being forced out of the centre. She later obtained casual work at one of the group homes but continued to find the atmosphere and regulatory practices that exist in disability services very frustrating and disturbing. Other staff members often told her that she was "too soft" on the consumers, and that her friendly manner disturbed their behavioural

management programmes. Those consumers who also failed to observe the rules of disengagement that underpinned these institutional environments were regularly put in their place.

What follows in the thesis is an examination and analysis of what I observed at these different fieldwork sites and a reflection on how the relationships, attitudes and practices that shape the institutional world of intellectual disability compare to the intimate mutuality that constituted my family life. My fieldwork experience exposed me to the various ways in which the perceptions and interpretations of intellectual disability that have informed the medical, psychological and behavioural records of intellectually disabled people were being instituted and acted upon. These perceptions and interpretations, while diverse, build upon and reinforce one another, giving form to the practices of training and management that shape the contemporary world of disability services and consequently, and more importantly, intellectually disabled people's lives. They reinforce an implicit assumption that deficits in levels of intelligence and reasoning ability automatically imply an incapacity for sociality. The fact that my siblings, and the people with whom I did my fieldwork, were capable of generating and sustaining their own patterns of symbolic behaviour upon which mutual sociality could be built contradicts this view.

While there have been some significant changes in the field of intellectual disability, both institutionally and ideologically, my fieldwork experience has led me to conclude that practices and attitudes are still moulded and informed by an interpretation of intellectually disabled people as deficient and abnormal. This abnormality is assumed to include an inherent incapacity for mutuality and sociality. The aim, therefore, is to provide the intellectually disabled with social skills and to train and manage their behaviour, as though this conformity and skill acquisition will allow them to become socially integrated beings. In the

following chapters I explore the historical roots of these interpretations and attitudes and show how they have become socially instituted. I analyse how they affect the lives of intellectually disabled people and how intellectually disabled people negotiate their way around these practices and attitudes. By comparing my relationship with my siblings to these institutional practices and interpretations, I highlight the necessity of mutuality and intimacy for perceiving and engaging with intellectually disabled people's sociality. I explore the fundamental differences between a mutually constituted and shared social world that is born of interdependent relationships and an institutionalised world where the relationship is one of authority, power, conformity and distance. In this latter milieu, rather than being a shared entity that all contribute to and shape in their way, the social world becomes a normative environment that values very circumscribed forms of sociality.

## Chapter Three

### A Pathological Embodiment

*This equivocal being, who seems to have been placed by nature  
on the very confines of humanity . . .*

*Philippe Pinel*

The denial of intellectually disabled people's capacity for mutuality and sociality, for meaningful and intentional interaction, was underlined in my siblings' records. These records included a combination of medical, psychiatric, psychological, educational and behavioural reports. They also included the daily observations made by staff at the institution where two of my siblings went to live. My family has had to negotiate these professional interpretations and practices; interpretations and practices that have the power to shape the social world within which intellectually disabled people reside. This is not to suggest, however, that there is unity and uniformity amongst these professional reports. They are diverse but are also linked together by an implicit "symbolic scheme" (Sahlins 1976).

In *Culture and Practical Reason*, Marshall Sahlins (1976) argues against materialist and utilitarian interpretations of culture, claiming instead that culture operates according to a "symbolic scheme". As Sahlins explains, his argument:

. . . takes as the distinctive quality of man not that he must live in a material world . . . but that he does so according to a meaningful scheme of his own devising . . . It therefore takes as the decisive

quality of culture—as giving each mode of life the properties that characterize it—not that this culture must conform to material constraints but that it does so according to a definite symbolic scheme which is not the only one possible (Sahlins 1976: viii).

While Sahlins (1976: 213) argued that Western bourgeoisie society operates according to a symbolic scheme of material rationality, I wish to argue that the institutional and clinical interpretation of intellectual disability operates according to a symbolic scheme of reason and normality.<sup>1</sup> It is the pathologising of intellectual disability as an abnormality according to the logic and significance of reason as the primary defining attribute of humanity that constitutes these interpretations. This scheme involves a notion of normality and reason where "reason" is understood as particular and normal human competencies. These competencies are recognised systems of meaning and forms of dispositional behaviour that reflect specific and conventional notions of mutuality. In addition, they identify these modes not only with normality, but ultimately with humanity itself.

As Jenkins has argued: "The concept of normality does two things simultaneously: it *describes* as normal that which is most *typical* or the usual state of affairs; it then *asserts* that this is also the way things *ought* to be" (Jenkins 1998b: 17; author's emphasis). The symbolic scheme of reason and normality denies and denigrates the modes of mutuality and sociality that intellectually disabled people engage in. It ignores their capacity for shared and negotiated systems of symbolic communication. The implication of this denial is that in order to become social beings intellectually disabled people must

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<sup>1</sup> The central place that reason plays in traditional theoretical interpretations of culture, including structuralism, functionalism and historical materialism, is one that Sahlins elaborates on in his discussion of the mind as more than just a rational tool but also a symbolic and constitutive entity (Sahlins 1976: 58-67). I explore this more fully in chapter four when I analyse the central place of reason, rationality and intelligence in Western conceptions of normality and humanness.

conform to normative social practices, dispositions and modes of articulation and relatedness. These attitudes and interpretations give form to the institutional practices of training and management. The symbolic scheme of reason and normality thus informs and orders institutional practices. It also informs clinical interpretations and perceptions of intellectual disability. I include here both medicine and psychology, as well as the practices enshrined in special education, behavioural management and normalisation policies. The symbolic scheme of reason and normality therefore exists as the implicit ideology or cultural assumption upon which these practices and interpretations are based.

Jenkins has argued that medical science uses its status as a rational, measurable, and objective interpretation of nature, the body and illness to claim a hegemonic role in the interpretation of intellectual disability (Jenkins 1998b: 17-18; cf. Conrad & Schneider 1985: 17-29; Gleason 1989: 7, 54-57; Illich 1990 [1976]; Mehan 1988: 80; Ryan & Thomas 1987; Taussig 1992: 108; B. Turner 1992: 9-15; Zola 1972). It is powerful, however, not only because it defines and categorises intellectual disability, but because, like material rationality, it combines the practical and utilitarian with that which is meaningful (Sahlins 1976: viii). In this sense the symbolic scheme of reason and normality exists within the material utility of medical science such that our "social world is presented as an enormous object [and hence natural] world" (Sahlins 1976: 195). Consequently, a particular notion of what constitutes humanness becomes associated with that which is normal and natural, and those who deviate from this norm are labelled abnormal and unnatural. It is not medicine *per se* that dominates the clinical interpretation of intellectual disability, therefore, but the symbolic scheme upon which medical interpretations depend.

My aim in this and the following chapter is to elucidate the formation of these implicit ideologies with regards to the clinical perception of intellectually

disabled people. In this chapter I focus specifically on scientifically informed medical perceptions and interpretations of intellectual disability. I outline the history of these medical interpretations and use my siblings' records to illustrate the methods by which intellectually disabled people become pathologised by reference to normality and reason. (In chapter four I specifically analyse the pathologisation of intellectual disability in terms of reason.) The way in which a diagnosis takes place, the judgements and accounts of physical and dispositional differences, and the practice of changing or treating these conditions as abnormal, are all manifestations of this symbolic scheme. I explore how this perception of abnormality has become grounded in the physical to produce an image of intellectually disabled people as isolated, bounded, and decontextualised from their social environment. As a consequence, the medical gaze has rested solely on the physical as pathological and has not recognised already existing systems of communication that allow for the articulation of relatedness. Neither has it attempted to engage with these.

Despite the fact that medical intrusions into the daily lives of intellectually disabled people have decreased in recent decades—some of their responsibilities having been taken over by psychologists, educationalists, therapists, social workers, policy makers and residential care workers (Foreman 1997: 225)—the symbolic scheme of reason and normality that underpins the medical model remains constitutive of the way in which these other disciplines conceptualise and treat intellectual disability. The institutional engagement with intellectually disabled people is therefore based on control, management, training and conformity. Its aim is to normalise that which has been constituted as abnormal. The form of relatedness that exists in institutional environments is therefore based on disengagement rather than the negotiation of difference through the shared use of objects and the mediation

of symbolic meaning. This symbolic scheme of reason and normality informs the principles and practices of organisations like Xanadu and the group homes. Institutional procedures are difficult to change because they embody an implicit symbolic scheme which is integral to a scientific culture.

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*In June 1996, I began my search for the medical records pertaining to my older brother and two sisters who had all been officially classified as mentally retarded. This journey took me from the Alder Hay Children's Hospital in Liverpool, England, to the Stockton Centre for Developmentally Disabled People on the New South Wales Central Coast, and, finally, to the Department of Community Services Disability Specialist Unit (the old Grosvenor Mental Deficiency Diagnostic Centre) in Summer Hill, Sydney. The potential nightmare of contacting all the people and places that my siblings had been taken to since 1962—from Newcastle Upon Tyne, Birmingham, and Liverpool in England, to numerous specialists in Perth between 1966 and 1967, and eventually to Sydney and Newcastle—was obviated when at Stockton I discovered that most of the family records dating back to 1965 had been collected, duplicated and collated in the files of Maryla and Stephen. Not only did these records display an account of the numerous tests that my siblings had undergone, but they also included within them more recent matters relating to the other children in my family; such as the borderline Fragile-X gene observed in my pregnant sister, and the death of my youngest brother in 1994.*

*My parents had taken all of my older siblings at different times to different people in search of an explanation for their epilepsy and developmental and behavioural differences.<sup>2</sup> Although the doctors in England had diagnosed one brother and sister as*

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<sup>2</sup> Of course, medical practitioners are not always the initial source of this judgment. It is often the observation of a child's different, unexpected, and asocial behaviour by parents, friends and teachers that leads people to seek medical or other professional advice as a way of interpreting and dealing with this behaviour. However, medical discourses (and their associated practices) have become the most powerful and determining interpretation of intellectually disability. Despite ongoing criticisms of the power of the medical interpretation (Ryan & Thomas 1987: 15-26), as well as debates between

*mentally retarded they offered no explanation for this. They connected the seizures with febrile activity and noted that they occurred in conjunction with ear, nose and throat infections, but made no inferences from this.<sup>3</sup>It was not until we came to Australia that the medical profession started offering more specific diagnoses, such as that of autism for my brother Stephen (although this was discounted by the professionals at Grosvenor despite my brother going to an Autistic school for two years in Sydney). With regards to the cause, the “problem” was definitely considered to be congenital and/or hereditary. As quoted from the medical reports, it was thought to be an “inherited disorder . . . the true identity [of which] will be disclosed with the natural course of the disease” (25/5/67). Later it became a “metabolic disorder” (12/12/69), then “an unknown metabolic disorder of recessive inheritance” (24/2/75), and, “although no definite diagnosis of the family disease was made in spite of many investigations, [i]t is [now] believed to be possibly a congenital metabolic disorder, manifesting [as] developmental delay, epilepsy, depigmentation and unusual behaviour patterns” (10/7/97).*

*On reading through the medical records I gained a haphazard and at times contradictory history of the family, the occasional incorrect piece of information being incorporated within this general perception of a familial abnormality. Much more apparent than any inconsistency in these details, however, is the constant reinforcing of assessments and diagnoses. Various medical authorities from 1962 to the present*

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medicine and psychology as to which discipline is best equipped to diagnose intellectual disability (Rose 1985: 131-8), the recent development of prenatal testing has reinforced the role of medicine as the primary source of the diagnosis of a foetus' potential intellectual or physical disability. Consequently, a judgement of abnormality is now being made prior to any possible observation of behaviour.

<sup>3</sup> It surprises me that nobody has investigated this connection. My family lived in northern England, in Newcastle Upon Tyne and Liverpool, between 1959 and 1965. Both cities were large, industrial, polluted environments and although there are suggestions that a number of intellectual disabilities are the consequence of environmental causes, such as lead poisoning or exposure to infectious diseases (Heaton-Ward 1978: 23-28), this has never been considered a possible cause of my siblings' intellectual disabilities. Instead, researchers are convinced that a genetic, biochemical cause will eventually be discovered. This is the only avenue of research that they have pursued.

*have drawn on this same historical material, just as they have utilised the same diagnostic tools to classify my siblings as retarded. All the details of the family, however, whether correct or incorrect, are dutifully added to the files in the hope that one day some biomedical specialist might finally crack the code to the "diagnostic puzzle" that my family represents. My own visit to the Disability Specialist Unit at Summer Hill in July 1997 was noted in their files, as was the information I gave them regarding the present situation of the family. When I spoke to the medical officer at the Unit about my family and the research I was doing she told me that an "Adelaide enzyme" might yield the final answer to my family history of intellectual disability. Pathologists in Adelaide are researching the effect of missing enzymes on congenital metabolic disorders and she believed that this fitted the particular peculiarities of my family's medical history.<sup>4</sup> In fact, this was where the most recent research on my family was being done.*

What follows is a brief outline of the history of the medical interpretation of intellectual disability interspersed with extracts from the medical reports of my siblings. I use these to show how methods which were long ago discredited are still being used in the diagnostic evaluations of intellectually disabled people. I then show how these evaluations are based on fundamental notions of what is considered to be un/natural, ab/normal, and less than/human, evaluations that are themselves based upon the symbolic scheme of reason and normality.

### **From Theology to Scientific Medicine**

Insanity or madness, and idiocy or imbecility, as mental illness and intellectual disability were respectively called until the early twentieth century, were recognised as mental disorders by physicians such as Hippocrates as early as

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<sup>4</sup> Developments in biochemistry and genetics have ascertained that amino acids are the building blocks of life, being as they are the main constituent of proteins and enzymes. Enzymes are a group of complex proteins (themselves made up of chains of amino acids) which act as catalysts in biochemical reactions (Collins English Dictionary).

the 4th century B.C.<sup>5</sup> Hippocrates, however, did not distinguish between insanity and idiocy, and neither did Galen, whose writings on mania and melancholy influenced medical thought throughout the Roman world for over 1500 years (Judge 1987: 7; cf. Porter 1997).

While no specific diagnostic distinction was made between these different mental disorders, there were various treatments that sought to either cure or ease the problem. Remedies such as blood-letting, the taking of bitters, immersion in water, rapid movement therapy, and even exorcisms were periodically performed from the ancient Greek era until the early 1800s to rid people of these afflictions (Judge 1987: 10-11). In fact, in 1744 in England, it became a legal requirement under the Vagrancy Act that all those suffering from mental disorders had to undertake such treatment (B. Turner 1987: 64-71). Yet despite these early medical treatments, it was generally thought that such disorders were manifestations of evil, or the result of divine retribution for some sin or moral transgression (Bijou 1992: 306; Haffter 1968: 55; Howe 1976 [1848]; Judge 1987: 38; Kanner 1967: 165; cf. Eberly 1991; Potter *et al.* 1976 [1853]: 64). Alternatively, the people so afflicted were sometimes thought of as Holy Innocents, their souls more amenable to God and their minds and bodies less corruptible by sin (Ryan & Thomas 1987: 86; Scheerenberger 1986: 51-55). This second view was less widespread, however, and medical treatments often

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<sup>5</sup>When discussing historical interpretations of intellectual disability I use the terminology in use during that particular era so that my portrayal maintains the original flavour of the period. When writing from my own perspective I use the term "intellectually disabled" rather than the broader and more politically correct term "developmentally disabled" (which includes people with a "severe, chronic disability . . . attributable to a mental or physical impairment or a combination of mental and physical impairments" [Pelka 1997: 96]). I do this partly because I am specifically focusing on people who have mental rather than physical impairments, and also because I wish to stress the role that intelligence and reason play in the perception of people who are intellectually disabled. The question of labelling and "correct" terminology has been a much debated topic of recent years in the disability field (Zola 1993). This debate, however, and the accompanying changes in terminology, often masks and detracts from the more important issue of the relatively unchanged perception and treatment of the people so labelled.

incorporated the former theological rendering, or were directly engaged with ridding the person of their spiritual malady.<sup>6</sup>

These methods, which dominated the treatment of mental disorders in the Western world for almost 2000 years, were ultimately challenged and influenced by the radical transformations in the observation, interpretation and understanding of nature that occurred during the Age of Reason in the sixteenth and seventeenth centuries. The emphasis on experimentation and precision, the use of new scientific technologies to observe the order and patterns of nature, and the reliance on mathematics, logic, deductive reasoning, and laws to elucidate the meaning of the universe, also profoundly affected the way in which the body and illness came to be perceived. Rather than adhering to former theological and pseudo-medical interpretations, physicians began searching for the cause of illness and disease within a person's bodily fluids, nervous system, and organs, including the brain.<sup>7</sup> They began examining and dissecting corpses in order to observe the relationship between disease, illness

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<sup>6</sup> According to Valerie Sinason, Protestants and Catholics in the seventeenth century believed that a mentally handicapped child was the creation of the devil and should therefore be put to death (Sinason 1992: 56; cf. Rosen *et al.* 1976: xiii; Kurtz 1981). Sinason argues that this perception of the handicapped person as a "flawed creation" continues to exist in psychoanalytic interpretations of intellectual disability just as it did in religious theories of the genesis of mental handicap (Sinason 1992: 60). As I go on to argue, this notion of a flawed creation, or what I call abnormality, also lives on in medical interpretations of intellectual disability.

<sup>7</sup> The methods of treatment and interpretation based on the notion that disease is part of the body has a history that of course dates back to early Greek and Roman theories of bile, blood, humours and the passions, as well as to their practices of immersion, surgery, purification, exorcism, and medication (Judge 1987: 9-10). However, as Roy Porter has pointed out, the Aristotelian-Galenic concept of disease was related to the notion of essences or substances which were themselves based on alchemical principles rather than on the laws and principles of matter. In the former rendering the body was believed to be affected by vital forces whereas in the latter it is assumed to function as a machine (Porter 1997: 203-215). Michel Foucault has argued that the shift that occurred in seventeenth century medicine was significant and radical because it resulted in the internalising of illness. Consequently, madness, as a specific type of illness, was no longer thought to be due to an external cause, or a social malady, but was believed to be caused by, and became an intrinsic part of, one's own body (Foucault 1995 [1961]; cf. Porter 1997: 242).

and the body, and, as Drew Leder argues in his essay on Descartes' concept of the body, this focus reduced the experience and interpretation of illness to a functional and mechanical problem (Leder 1992: 3).<sup>8</sup> It became fashionable to break down the body into its constituent parts in order to better understand the processes by which it operates and hopefully elucidate the laws of nature that govern these processes. It was believed that this would make it possible to treat disease through the manipulation, alteration, and later even the reproduction, of these specific components (Leder 1992: 20-1).

The transformation in the scientific, philosophical and medical interpretations of the universe not only altered the perception of the body and illness; it also profoundly affected the way in which human beings were conceptualised. F. Allan Hanson (1993) highlights the outcomes of this change in his book *Testing Testing: Social consequences of the examined life*. In it he argues that:

The positivist program embraced a new, scientific view of the human being. Previously, the knowledge that had been accumulated about the natural world was thought to bear little relevance to questions about the human condition, because human beings were not considered to be natural objects. Created in the image of God, and little lower than angels in the order of things, humans were thought to exist on a more elevated plane of being than the plants, animals, and inanimate objects that made up

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<sup>8</sup> The essays in *The Body in Medical Thought and Practice*, edited by Drew Leder, critique this Cartesian medical paradigm from both phenomenological and sociopolitical perspectives, arguing that it does not take into consideration the lived experience of illness, nor the political and social aspects of the power of medicine to define and discipline the body (Leder 1992: 1-6). Leder, however, does not ultimately challenge the "metaphysical paradigm" that informs Cartesian medical perceptions of the body. Instead, Leder proposes the relativisation of differing perspectives so that the framework is widened to include phenomenological understandings of illness alongside the knowledge of Cartesian medicine.

nature. All this began to change in the sixteenth and seventeenth centuries when, with the growth of a scientific world view, human beings lost their patina of divinity and were placed squarely within the realm of nature (Hanson 1993: 14-15).

Becoming part of nature, however, did not mean that all humans were perceived as equal and naturally normal. The laws that were seen to govern the functioning of the body/mind/self were only deemed to be natural if they conformed to preordained concepts of what was taken to be normal.

This concept of normality, of the norm or normalcy, is, as Lennard Davis (1995: 24) and Richard Jenkins (1998a: 150-53) both argue, relatively new. It emerged during the period from 1840 to 1860 and was associated with the development of nation states, nationalism, and industrialism, as well as with concepts of race, gender, criminality, and sexual orientation (Davis 1995: 26; Jenkins 1998a: 150). As Davis argues, it utilised, and was indeed based upon, statistical methods; methods that were originally used in the mid-1700s to inform state policy but which, by the late 1820s, increasingly came to be associated with the body (Davis 1995: 26). This concept of normalcy, however, related to far more than just physical attributes such as weight and height. It also came to be identified with an abstract notion of the average or normal man (Hacking 1990: 1). As Ian Hacking comments, this "enumeration of people and their habits" (Hacking 1990: 1) drew upon a combination of physical, social and moral attributes. As such it was fundamentally based upon the values, standards and aspirations of middle class Europeans, as well as on particular cultural competencies such as language, literacy and numeracy (cf. Davis 1995: 26; Jenkins 1998a: 151; Jenkins 1998b: 17).

This powerful combination of discourses of identity, morality and normality has had a profound effect on those who deviated from the norm, as Jenkins

(1998a: 150-3) points out. It created an abnormal, incompetent identity; an identity which was indelibly imprinted on the body. As Davis elaborates:

Thus the body has an identity that coincides with its essence and cannot be altered by moral, artistic, or human will. This indelibility of corporeal identity only furthers the mark placed on the body by other physical qualities—intelligence, height, reaction time. By this logic, the person enters into a relationship with the body, the body forms the identity, and the identity is unchangeable and indelible as one's place on the normal [bell or distribution] curve (Davis 1995: 31).

Combined with this creation of an abnormal identity and body was the evolutionary eugenicist notion that the human species could and should be improved.<sup>9</sup> The consequence of this was that certain characteristics, certain deviations from the norm, including such things as deafness, blindness, and intellectual and/or physical disabilities, were, in the national interest, to be eradicated. Controls on reproduction, and specifically the sterilisation of female idiots, were instigated in order to diminish deviations from the norm and improve the quality of the human race (Ashton 1995: 144-149; Davis 1995: 30-1; Jenkins 1998a: 152; Jenkins 1998b: 17-18). Therefore, not only did this "hegemony of normalcy" (Davis 1995: 48) breed an identity which was considered fundamentally abnormal, it also stipulated that this abnormality must be bred out of existence.

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<sup>9</sup> Although usually associated with the practices of Nazi Germany, eugenics was a highly respected and seemingly progressive scientific and social theory in the mid to late nineteenth century throughout much of the Western world, including Australia (Ashton 1995: 144-149; Davis 1995: 30-1). The movement is most readily associated with Francis Galton, who built upon Charles Darwin's theory of the evolutionary advantage of the fittest to argue that society, and indeed the human race, was ultimately perfectible and, with assistance, could undergo a process of progressive improvement.

Not only were humans incorporated into a materialist paradigm that therefore rendered their bodies as part of the laws and processes of nature, but some of the differences that distinguished people from one another, such as differences in intellectual capability, came to be considered as expressions of an inherently abnormal and unnatural body/mind/self.<sup>10</sup> The result of such theorising is that people with an intellectual disability have come to be perceived as somehow less than fully human (Jenkins 1998b: 19; cf. Bogdan & Taylor 1998: 246; Branson & Miller 1989: 159; S. Taylor 1998b: 195-196). Their identity has been discredited (Goffman 1974 [1963]: 5). As Jenkins puts it:

Here, by the classificatory logic of statistical frequency—and, indeed, by the classificatory logics of transformation and inversion which are so familiar from structuralism—*culture*, being typical for humans, becomes part of human *nature*. Thus incompetence in things cultural—the inability to learn language, etc.—may be interpreted as an indication of an unnatural and inferior humanity. Although not an animal, the person with intellectual disabilities may be classified as sub-human, an unnatural monstrosity (Jenkins 1998b: 19; author's emphasis).

In the nineteenth century, this scientific association of normality with human nature gained enormous legitimacy, supported as it was by the perception that science was "objective" and "beyond doubt or reproach" (Jenkins 1998b: 17-19; cf. Gleason 1989: 7, 54-57). Not only did medical science pathologise those who were intellectually disabled, it also positioned them as outside the range of normal humanness. Combined with the much older practice of associating humanness with the capacity for reason, it also denied to such people the

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<sup>10</sup> In the following chapters I explore in more detail the consequences of this theory of an abnormal mind/self on the institutional and clinical perception and treatment of intellectually disabled people. For the purposes of this chapter I focus more exclusively on the pathologisation of the body as abnormal.

capacity for human sociality. Competencies such as language are believed to represent this capacity, and are used to reinforce the symbolic scheme of reason and normality that has ordered and defined the institutional world of intellectual disability.

This perception of the body and human nature as either naturally normal or unnaturally abnormal has had a profound affect on the treatment of idiots and the insane. As L. P. Brockett noted in 1856, quoting a visitor to the New York Asylum for Idiots:

. . . the frightful number of these unfortunates, whose ranks encumber the march of humanity,—the insane, the idiots, the blind, the deaf, the drunkards, the criminals, the paupers—will dwindle away, as the light of knowledge makes clear the laws which govern our existence (cited in Brockett 1976 [1856]: 86).

Idiots were not only institutionalised or secluded from the wider community as part of "the great confinement"—along with all those others who did not conform to the norm and who no longer had a place in this newly industrialising society (Foucault 1995 [1961]: 38-54)—but science, as the tool which elucidates the truth and "light of knowledge", would ultimately alleviate humanity of this "encumbrance". All that was needed was to discover the "laws which govern our existence", including what it was that distinguished idiocy as an unnatural and abnormal disorder. The contemporary field of medical research has continued with this pursuit, and institutional practices still embody the assumption that intellectually disabled people are biologically based abnormal social beings who lack the capacity for meaningful and mutual sociality.

### **Defining Idiocy**

This new approach to human nature and the body was accompanied by dramatic increases in the specialisation and classification of illness, disease and disorder. Idiocy and insanity were subject to this new medical gaze, and to the associated nosological distinctions that characterised this scientific ordering of the world. What determined these classifications were fundamental distinctions between what was deemed to be naturally normal and unnaturally abnormal or deviant. The "normal" processes and functions that order human bodies were believed to have gone askew in those who deviated in any way from the norm. Until the early nineteenth century, however, there had been little development in the medical distinction between idiocy and insanity, despite John Locke's differentiation over one hundred years earlier.

Locke's 1684 definition of idiocy as distinct from insanity was based on the principle that "Idiots make very few or no propositions at all, and reason scarce at all" (cited in Digby 1996: 3; cf. Judge 1987: 30; J. Wing 1978: 245). Despite this distinction, however, idiots and the insane were still locked up in the same cells of the mental asylums until the early 1800s, and were not treated in specifically different ways until the 1830s. And it was not until 1866 in the United States and 1913 in England that a legal distinction between mental illness and mental deficiency was made (Manion & Bersani 1987: 233; Woods 1983: 1).<sup>11</sup> The distinction between idiocy and insanity that Locke had made in the late seventeenth century, however, was eventually elaborated upon by Philippe

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<sup>11</sup> Anne Digby (1996: 2) and Nikolas Rose (1985: 93) have both pointed out that a legal distinction between idiocy and lunacy based upon ownership and rights to property has precedents in England dating as far back as the 13th Century. However, as Digby points out, idiocy was still considered one of the forms of lunacy until the medico-legal distinction of 1913 (Digby 1996: 2). Coincidentally, the 1913 Act, which was passed in order to legally segregate those with an intellectual disability from society (Chappell 1998: 215), occurred at the same time that Freud's psychoanalytic method was gaining recognition as a legitimate treatment for various forms of neurosis and psychosis in Europe.

Pinel, Jean-Etienne Dominique Esquirol, Jean Itard and Edouard Séguin in the early decades of the nineteenth century.

Pinel, Esquirol, Itard, and Séguin were all trained physicians who had been influenced by the changes in medical and scientific practice that had taken place over the previous two centuries. These physicians were also the founding fathers of psychology, special education, and psychiatry. Through their work idiocy became, for the first time, a specific illness requiring medical treatment and diagnosis. It began to exist socially as a predominantly scientific rather than theological problem (Bijou 1992: 306). The medico-psychological theories of Locke, Esquirol, Pinel, Itard and Séguin also incorporated Enlightenment questions concerning the nature of man in a state of nature, the distinction between humans and animals, and whether innate ideas were possible—concerns which were profoundly based upon an interpretation of humans as rational beings (Rose 1985: 29-30).<sup>12</sup> As Goodey (1994) points out in relation to Locke's philosophical speculations, such questions drew upon observations of idiots and utilised the condition as a comparison from which to articulate what makes humans specifically human. However, this concept of humans as rational also had implications for the body, for it was through the senses, and sensory experience, that knowledge, ideas and abstract thought were believed to develop. And it was within the body, and particularly the brain, that the abnormal processes which marked the state of idiocy were deemed to reside.

In their essay "Upon the Necessity of Establishing a Scientific Diagnosis of Inferior States of Intelligence" Alfred Binet and Theodore Simon traced the historical classification of idiocy, albeit decrying its lack of precision and

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<sup>12</sup> In their discussion of the everyday lives of institutionalised profoundly mentally retarded people, Craig MacAndrew and Robert Edgerton also argue that such people provide interesting material for the study of "both the nature of man and the nature of culture-bearing animals" due to their being "on the threshold between man and not-man" (MacAndrew & Edgerton 1970: 28).

scientific empiricism (Binet & Simon 1976 [1905]: 335). They claimed that the French physician Jean-Etienne Dominique Esquirol (who was a student of Philippe Pinel's) first clearly distinguished idiocy as a specific medical condition, and that he based his classification on the centrality and power of speech which is often lacking in such people (Binet & Simon 1976 [1905]: 336). On noting the difference between idiocy and insanity, Esquirol wrote in 1832 that:

Idiocy is not a malady, it is a state in which the faculties are never manifested, or have never developed sufficiently for the idiot to acquire the knowledge which other individuals of his age receive when placed in the same environment. Idiocy begins either with life, or during the period which precedes the complete development of the affective and intellectual faculties; idiots are what they must remain during the entire course of their lives. Everything in the idiot reveals an organism either arrested or of imperfect development . . . Insanity and idiocy differ essentially, or else the principles of all classification are illusions. Insanity, like mania or mono-mania does not commence before puberty . . . Insanity may be cured; one can conceive the possibility of suspending the symptoms; there is a diminution, or privation of the forces necessary to exercise the faculties, but the faculties still exist . . . The insane man is deprived of possessions which he formerly enjoyed; he is a rich man become poor; the idiot has always been in misery and want. The state of the insane may vary, that of the idiot remains always the same. The one conserves much of the appearance of the complete man, the other retains many traits of infancy. In one case as in the other, there are no sensations or practically none; but the insane man shows in his organisation and also in his intelligence something of his past perfection; the

idiot is such as he has always been, he is all that he can ever be relative to his primitive organisation (Esquirol; cited in Binet and Simon 1976 [1905]: 336-7).

The overwhelming impression that Esquirol gives of idiocy is a condition thoroughly and incurably steeped in deficiency. This deficit is related to imperfection, to a lack of development, and results in a miserable existence. It resides in the faculties of communication, and affects one's affective, sensory and intellectual capacities. A person so afflicted is deemed to be beyond redemption. They are placed outside culture and sociality, and in the process are linked with that which is primitive, infantile and unformed.

Although Esquirol was adamant that idiocy was not a disease or illness, he did seek to understand its roots in some form of organic, physical defect, such as a lesion of the brain. Esquirol claimed, however, that similar lesions which might be discovered in the brains of the insane should not be considered the cause of their insanity (Binet & Simon 1976 [1905]: 337; cf. Barr 1904: 20). For Esquirol, idiocy was a functional problem with organic causes which began in the developmental period, and, as such, his view helped to establish a link between behavioural interpretations and biological causes, a perception that is sustained in contemporary definitions of developmental disability (see Accardo & Whitman 1996: 87; Pelka 1997: 96; Scheerenberger 1987: 13 for American and Australian definitions of developmental disability).

Philippe Pinel, the founder of modern psychiatry, is often hailed as the humanist who released the chains from the idiots and insane.<sup>13</sup> As head of the

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<sup>13</sup> Foucault (1995 [1961]: 264-265) critiques historical interpretations of the perception and treatment of madness as a teleological progression towards greater humanitarian practices. Rather than liberating the mad, Foucault argues that the interpretation and treatment of madness since the seventeenth century has actually led to greater constraint and surveillance (Foucault 1995 [1961]: 241-278). The cause and treatment of madness ultimately came to reside within the self, such that treatment required greater self-surveillance, moral control, and an acceptance of self-responsibility.

mental asylums at Bicêtre and Salpêtrière in Paris, Pinel was in a position to apply his practical methods of treatment and, through detailed observations and records of the inmates, set about the task of creating a nosology of insanity and idiocy. He was also aghast at the chaotic intermingling of idiots and the insane, and went about separating them physically as well as categorically.<sup>14</sup>

Writing thirty years earlier than Esquirol, Pinel had also found no empirical evidence that insanity was caused by an organic disease of the brain, claiming instead that it was a functional disorder due to disassociation of ideas, and that it could indeed be cured. Unlike Esquirol, however, Pinel was cautious about declaring an absolute relationship between defects in the cranium of idiots and their intellectual capabilities (Pinel 1962 [1801]: 4-5, 131; cf. Porter 1997: 495-497). The "Specific Character of Idiotism" was described by Pinel as a product of the "stupefied senses", of the "total or partial obliteration of the intellectual powers and affections; universal torpor; detached, half-articulated sounds; [and] in some cases, transient and unmeaning gusts of passion" (Pinel 1962 [1801]: 172). Like Esquirol, Pinel saw idiocy as a totally deficient state, and one which isolated those so affected in an asocial, meaningless world.

Some of their "natural indolence and stupidity" might be relieved through manual labour, Pinel claimed—a practice that is most readily associated with Samuel Tuke's moral treatment at his York Retreat (Foucault 1995 [1961]: 241-255)—but he still considered idiocy an essentially incurable malady (Pinel 1962 [1801]: 203). Consequently, Pinel devoted the majority of his life to the treatment of insanity. After all, what satisfaction could there be in focusing too much attention on an inherently incurable defect when the aim of the physician is to heal? Therefore, while both Pinel and Esquirol made a distinction between

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<sup>14</sup> In her "Memorial to the Legislature of Massachusetts, 1843", Dorothea Dix summed up the conditions of asylums, prisons, and almshouses in the north eastern States of America and was equally aghast at the "legalized barbarity" of these places that, among other things, did not distinguish between idiots and the insane (Dix 1976 [1843]).

idiocy and insanity, they also concluded that, unlike the insane, idiots were no more than human brutes—ineducable, incurable and subhuman—and were therefore best left to their own devices in the separate cells that now constrained them (Barr 1904: 33-4).

It was not until Edouard Séguin attempted to treat and train idiots in the 1830s that a serious effort was made to deal with people who were afflicted with this condition (Rosen *et al.* 1976: ix-xvii). Séguin's name is often associated with that of his teacher, Jean Itard, who had worked on a famous case concerning Victor, the wild boy from Aveyron. Victor had been captured near the woods of Aveyron in 1801 and taken to Philippe Pinel, who diagnosed him an idiot, and then to Jean Itard, who applied his theory of sense stimulation in the hope of civilising and educating this "wild but natural" child. Itard was unsuccessful, however, and claimed that Victor must indeed be an idiot since his mind could not be penetrated by the tactile, visual and sensory stimulation that was relentlessly applied to him (Rosen *et al.* 1976: xiv; Séguin 1976a [1864]: 154; cf. Rose 1985; Luckey 1967). Itard's experiments could only proceed on the basis that Victor was not an idiot. His failure to treat Victor, therefore, meant that the child's "natural" state was idiotic (Rose 1985: 37).

Séguin maintained Itard's "sensationalist" methodology but further elaborated and refined his methods and applied them to the training of idiots. Séguin believed that it was the method that was at fault, not the person. While accepting Pinel and Itard's prognosis that idiocy was an essentially incurable malady, Séguin challenged their assessment that such people were also inherently untrainable (Rose 1985: 37). He accepted the condition as an abnormality, but not as fixed. Consequently, Séguin became the first to acknowledge that idiots could learn and develop, as long as they had the correct and appropriate training.

Drawing on Locke's theory of a connecting or intermediary link between the senses and ideas, Séguin believed that there existed within all people "an intelligent reflecting power that, seizing the notions of external objects as furnished by the senses, reasons upon them and produces ideas" (Barr 1904: 34). Séguin believed that the senses were the doorway to the mind. Therefore the anomaly which creates the condition known as idiocy had to occur in the functioning of the senses. Rather than relentlessly repeating sensory stimulation, as Itard had done, Séguin deduced that the permanent impression of these stimuli required the comparison, selection and increasing complexity of tasks (Talbot 1967: 186). The senses must be stimulated one by one, and in conjunction with the other senses and parts of the body, so that "correct objective impressions" might eventually reach the mind (Séguin 1976b [1879]: 163-6). And, as with other philosophical and medical interpretations of the Enlightenment, this process was deemed to be a natural extension of the laws of Nature (Séguin 1976c [1880]: 174; Rose 1985: 29-30). Therefore, not only were idiots unnatural and abnormal, but the laws of nature provided the guide that would help transform this abnormality into something more normal.

Séguin termed his attempts to alter the mind of the idiot through sensory stimulation the "psycho-physiological method" (Séguin 1976b [1879]; Séguin 1976c [1880]). This method marked the first medical/psychological/ educational intervention into the lives of idiots; the overriding aim being to socialise and civilise them, to make them "normal". Séguin's methodology was inherently based on treatment and training, and relied upon assimilation and conformity to a norm. As such, it was founded on the principle of producing sets of dispositional behaviour which would correlate with socially recognisable and acceptable systems of communication and meaning. Even at its original moment, therefore, the treatment of idiocy was based on the transformation of "incorrect" and "abnormal" sensory impressions and behaviours into "correct"

and "normal" ones. It took as already problematic and dubious the nature of an intellectually disabled person's humanity, and sought to transform this abnormal nature by making it conform to pre-established notions of what normal human nature should be. It assumed that human nature is a precultural fact, and not the product of the symbolic scheme of reason and normality that identifies a particular range of meaning systems with "being human". This is not to deny that there are very real and tangible "material constraints" that make intellectually disabled people different, but that, as Sahlins has put it, as a culture we have conformed to these constraints "according to a definite symbolic scheme which is not the only one possible" (Sahlins 1976: viii). Competencies which are perceived as cultural deficits are used as proof of a deficient human nature (Jenkins 1998b: 19).

In the process, however, an intellectually disabled person's total capacity for sociality is also rendered deficient. Such people are then constituted as abnormal, unnatural and inferior; as less than human. Because of this there is no recognition that intellectually disabled people's particular sets of dispositions or language games are meaningful and symbolic. Nor is there any acknowledgment that these symbolic systems are able to be mediated and engaged with. There is no "rendering of difference as compatibility" as Diane Austin-Broos has put it, only the enforcing of a conformity built on a presumed incompatibility.<sup>15</sup> There is only the desire to instil in those who are different

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<sup>15</sup> The interpretation, perception and treatment of intellectually disabled people has many parallels with the history of racism, especially in relation to the experience of indigenous peoples. Indigenous people were originally thought to be the evolutionary remnants of our early human ancestors and as such on the inevitable path to extinction. When they defied this prognosis indigenous people were then encouraged, often forcibly, to assimilate to the dominant culture. Nowadays, despite the rhetoric of indigenous rights and self-determination, the onus for mediation, negotiation and change is always on indigenous people. Aside from issues of domination and power, the problems encountered in post/colonial encounters with indigenous cultures have been exacerbated by the enforced interaction of cultures that are based on entirely different symbolic schemes. In the case of the engagement of indigenous cultures with post/industrialised societies, this difference is embedded in both

dispositions that conform to recognisable and normative values. As a mode of engagement such practices and attitudes have nothing to do with mediating differences. They lack the mutuality and necessity for negotiation that underpins sociality and intimate relations, and ignore the fact that intellectually disabled people can engage in relations of interdependence; that they can engage with others as they are as part of a joint commitment (Carrithers 1992: 11).

### **The Causes of Idiocy**

By the mid 1800s idiocy had come to stand alone in the classification of mental disorders as a specific and identifiable condition. However, there was already dispute as to what idiocy was, what caused it, how to diagnose it, and how, or indeed whether or not, to treat it. In a scathing attack in 1864 on both the phrenological and anti-phrenological interpretations of idiocy, and the increasing emphasis on aetiology and classification, Séguin argued that focusing on theories of causation detrimentally undermined the more valid concerns for the education and treatment of those afflicted by the condition (Séguin 1976a [1864]: 155; cf. Wilbur 1976 [1880]; Barr 1904: 86; Bijou 1992: 306).<sup>16</sup> Despite

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the market place and in concepts of personhood (among other things); it is a factor of local kin-based relationships versus the impersonalised individualism of a consumer and labour based society (Austin-Broos; pers. comm.; cf. Cowlshaw 1999).

<sup>16</sup> Through his emphasis on training and treatment Séguin became one of the founders of special education (Gleason 1989). Samuel Gridley Howe was instrumental in setting up the first residential and educational facility in the United States solely for idiot children. He did so on the basis of Guggenbühl's Abendberg institution which had been set up in Switzerland in 1842. Johann Jakob Guggenbühl was a Swiss physician who had taken a keen interest in children who were classed as Cretins and believed that with a combination of brisk, fresh mountain air, a good diet, regular baths and physical exercise, various medications, and sensory training, these children could be cured. He set up the Abendberg in 1842 and, as Edgar Miller has pointed out (1996: 369), the institution rapidly gained an international reputation, with visitors from all over the world coming to view the methods and techniques in use. Howe was one of those visitors, as was Charles Dickens, and the institutions that sprang

Séguin's criticisms, and despite the fact that social and moral aspects were (and still are) considered potential causes of intellectual disability, the focus on aetiology, on the organic, pathological causes of idiocy, was established as a legitimate scientific concern by the late 1860s. Through such investigations it was hoped that a cure for idiocy might be found, that more specific treatments might be adopted, and that measures might be taken to prevent the existence of idiocy (Rosen *et al.* 1976: 205).<sup>17</sup>

Those who adhered to phrenological interpretations of idiocy, such as Franz Joseph Gall and George Shuttleworth, sought to discover a clear functional relationship between the shape, size and form of the cranium, the facial bone structure, and the person's identity and behaviour as an idiot (Judge 1987: 8; Séguin 1976a [1864]: 155; Shuttleworth 1976 [1881]; cf. Damasio 1994; Foucault 1984 [1976]: 31; Gould 1996: 22-3; Hanson 1993).<sup>18</sup> These interpretations were based on the principle that there is a norm, an average or standard, to which all human physical attributes could be compared, measured and evaluated (Davis 1995: 26; Hacking 1990: 1). And, just as Pinel had done, it was the Greek god Apollo who was used as the ultimate standard of human proportions, and indeed perfection (Pinel 1962 [1801]: 128).

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up throughout Germany, Britain, the USA, and indeed Australia, in the latter half of the nineteenth century were based on or influenced by Guggenbühl's Abendberg (Judge 1987: 27-8; Miller 1996: 369).

<sup>17</sup> This debate over treatment and cause marked a serious division between different methods for dealing with idiocy. It also instigated a split that led to the separation of medicine, psychology and special education as specific disciplines concerned with different aspects of the condition (Gleason 1989). However, those other disciplines that broke away from medicine, such as psychology, psychiatry and special education, continued to be informed by the symbolic scheme that pathologised the intellectually disabled as abnormal and asocial beings.

<sup>18</sup> In fact, the first anthropological excursions into the world of intellectual disability supported and provided evidence for these phrenological interpretations. Physical anthropologists with an interest in the evolution and variability of the human species initially sought to measure the anthropomorphic range of human variability. This eventually led to a concern with what is "normal" in human nature rather than with variations, and this "norm" was then used as the marker from which differences were measured and interpreted (Gleason 1989: 89-90; Hanson 1993).

While phrenological practices played a prominent role in early scientific interpretations of mental disorders, and stimulated further research into the anatomy and function of the brain and nervous system, they are now considered rather clumsy proto-scientific attempts at describing these conditions (Judge 1987: 8). Yet the present inclination to account for these disorders in genetic, organic or biochemical terms can just as readily be interpreted as a more refined method of correlating physical attributes with a comparably deficient social being. Whereas the methodology has changed, the theoretical assumptions have not. There is still a pathologising of intellectual disability that renders people as fundamentally abnormal in both the body and in the gamut of social dispositions. Despite changes in the methods used to assess and diagnose intellectual disability, the practice of noting physical characteristics, including measurements and descriptions of the cranium, remained common practice throughout the 1960s and 1970s. This is evidenced in the reports on my siblings.

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*Medical assessments of Maryla, Stephen and Ursula always began with an appraisal of their physical appearance, mobility and behaviour. On the whole they were considered to be attractive looking children, although their “unusual gait” was constantly referred to as an indication of their retardation. More specifically, however, physicians in England and Australia used phrenological evidence as part of their assessments, one of them commenting that my sister’s “head circumference was 19.5” [inches] and . . . that she had a rather odd shaped head, having a broad forehead, widely set eyes and a flat occiput” (10/2/65). Maryla is in fact very Polish looking, inheriting this appearance from my father’s side of the family. My other sister, Ursula, was thought “not to resemble either parent” and it was noted that she had a “prominent forehead, nose and right eyebrow” (25/5/67). An examination of Stephen at the same time noted that he “had a normal shaped head—51 cm. [in] diameter. His palate was*

*high arched and his ears, nose and eyes were normal. Dermatoglyphic pattern was normal on the hands. He had 4 areas of depigmentation over the posterior aspect of his torso—just above the sacro-iliac crest. There was syndactyly of [the] 2nd and 3rd toes of both feet and he walked with an unsteady gait stooped forward. Tendon reflexes were grossly exaggerated” (25/5/67).*

*As well as these physical descriptions of my siblings, post-mortem examinations were also performed on Stephen and Ursula when they died.<sup>19</sup> These were done in the hope of discovering a physical correlation between my siblings’ retardation and their brain structures. My brother’s autopsy reported a “widespread demyelinating condition of the brain” suggestive of some “unknown metabolic aetiology”. This diagnosis is still referred to in the current medical information on the family. When one of the psychiatrists in Perth discovered that my mother was pregnant for the sixth time, she commented in a letter to a fellow child psychiatrist in Sydney that she “needn’t say how important it will be to get hold of the brain of this sixth child just supposing anything went wrong with the birth” (30/10/67). Luckily my younger sister was spared this fate.*

*While I find it disturbing to read these assessments of my siblings it is not because their descriptions are inherently wrong. My siblings did walk in unusual ways, and did behave differently, and perhaps there are metabolic indicators that prove that their differences do have a physiological basis. However, in focusing purely on an embodied pathology and stressing that it is abnormal, such descriptions and assessments have denied to my siblings the capacity for a cultural identity and social competencies. The result is that their differences are perceived and interpreted as deficiencies; as core human deficiencies which rendered them acultural and outside the realm of sociality. To embody these differences in the physical nature of the person adds another layer of complexity by making this difference insurmountable. Rather than acknowledging that*

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<sup>19</sup> The use of post-mortem examinations to determine a connection between the body’s organs and the person’s disability is common practice, as Grace Woods has pointed out (Woods 1983: 48).

*they have limited but specific social competencies, the focus is on a deficient being who not only becomes pathologically embodied as abnormal, but must be trained and normalised in order to become part of social life.*

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John Langdon Down's 1866 classification of idiocy into six different types, each with its own aetiology, symptoms and possible cures, was a serious challenge to Séguin's anti-aetiological stance.<sup>20</sup> It also challenged the previous homogeneity of idiocy as a single category (Kanner 1967: 167; Rosen *et al.* 1976: xix).<sup>21</sup> Prior to Down, any differences that were acknowledged were believed to represent a vague and imprecise continuum from the lowest level of idiocy, through the intermediate state of the imbecile, and onto the most competent type of idiot, the moron or feeble-minded.<sup>22</sup> Rather than interpreting idiocy as

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<sup>20</sup> Other aetiological theories of the late nineteenth century were developed by William Wentworth Ireland and George Shuttleworth. Ireland believed that it was important to distinguish the causes of various forms of idiocy so that appropriate treatments and prognoses could be established (Ireland 1976 [1882]; cf. Binet & Simon 1976 [1905]). He outlined twelve classes of idiocy, stressing the difference between congenital and acquired causation based on what Kanner has called a "variety of specific structural anomalies in the central nervous system" (Kanner 1967: 168). Shuttleworth (1976 [1881]: 239) also distinguished between developmental, congenital and non-congenital causes of idiocy, claiming that the biggest difference existed between those where the idiocy was congenital.

<sup>21</sup> Interestingly, as Leo Kanner points out, the challenge to the homogeneity of both idiocy and insanity occurred at the same time, between 1866 and 1875 (Kanner 1967: 167).

<sup>22</sup> The terms used to describe these differences of degree in idiocy vary between different people. Jules Voison's symptomatic description of idiocy was divided into complete idiocy, incomplete idiocy, imbecility and mental debility, whilst Bourneville classified the state of idiocy into complete idiocy, profound idiocy, imbecility proper, slight imbecility or intellectual retardation, mental instability, and moral imbecility (Binet & Simon 1976 [1905]: 338-341). The term feeble-minded was in fact an American term that was adopted by the English in the 1860s to designate those who were the least mentally afflicted and the most capable of reasoning (Digby 1996: 2). There were, and still are, ongoing debates over whether there is a difference of degree between these gradations, or whether they are indicative of absolute differences in type, especially when it comes to those "borderline" cases of mild mental retardation or feeble-mindedness (Simonoff *et al.* 1996: 260). A whole class of people were also labelled "moral imbeciles", and the usual debates over whether this was a congenital, hereditary, or environmental condition prevailed. Alcoholics,

a sensory disorder, "disturbances of brain power . . . [or] simply nerve lesions in the narrowed sense of the term", as Pinel, Esquirol and Séguin had argued, Down claimed that idiocy and imbecility "were profound diseases involving almost every organ and system of organs in the body" (Down, cited in Miller 1996: 363). Down's contribution to the medical research on idiocy was a scientific and clinical distinction thoroughly embedded in the organic matter of the person. Research into Down's syndrome in the 1950s only served to strengthen this original interpretation of a specificity in typology by exposing an extra chromosome as the common feature of all people with Down's syndrome (Porter 1997: 587-8).<sup>23</sup>

Down has been immortalised in medical nomenclature, identified as he is with the "discovery" of what is known as Down's syndrome. As with places, diseases or syndromes often take the name of a person, albeit the name of the discoverer rather than the discoverer's hero or patron. Down initially termed this specific form of idiocy "the Mongolian type of idiocy" (Kanner 1967: 167).<sup>24</sup> Basing his classification on physiognomic features, such as the folded eyelid,

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tramps, prostitutes and criminals constituted this category and, according to Kerlin, they were thought to have a "mental disorder in which there is a loss or absence of control over the lower propensities, or in which the moral sentiments rather than the intellectual powers are confused, weakened or perverted" (Kerlin 1976 [1889]: 306).

<sup>23</sup> However, as Emily Simonoff *et al.* point out, the relationship between this "genetic anomaly" and either behaviour or IQ is questionable, and thus raises doubts as to any absolute relationship between the genetic cause of intellectual disability and the consequent behaviour of the person (Simonoff *et al.* 1996). I pick up on this issue later in the chapter.

<sup>24</sup> In 1846 Edouard Séguin described a condition which he termed "furfuraceous idiocy" and it was this condition that Down later termed "Mongoloid" (Porter 1997: 587). Cretinism was another common term for describing intellectually disabled people (Judge 1987: 39). It had been used by Felix Platter in the late sixteenth century to describe a specific condition identified by a short stature and protruding tongue, features which made it easy to confuse it with what was later called Down's syndrome (Judge 1987: 39; Porter 1997: 196-7). Cretinism is actually a specific type of intellectual disability now known as hyperthyroidism and was common in Switzerland in the nineteenth century due to low levels of iodine in the water supply (Judge 1987: 39; Porter 1997: 196-7). Along with Down's syndrome it was one of the first types of intellectual disability to be extensively researched as a disease (Judge 1987: 39).

broad nose, protruding tongue and round face that were common to these people, Down identified them as belonging to a particular class of idiots. However, more than just being a descriptive term, it also incorporated Down's initial theoretical conviction that such people represented an atavistic regression to a "lower race". Through a similarity in facial features, and particularly the epicanthic fold, Down associated these "Mongoloids" with people from Mongolia. There were also other forms of idiocy that represented throwbacks to other "races", including Ethiopian or Negroid, and Malay or American Indian (Borthwick 1996: 404-406; Judge 1987: 42-43; Kanner 1967: 167; Miller 1996: 367). Down later rejected these racial associations, arguing instead that aetiology was the most suitable means for classifying, treating and diagnosing types of idiocy. He based this classification on organic and pathological distinctions between congenital, developmental and accidental causes of idiocy, associating these with epilepsy or microcephaly, onset in puberty, and injury or illness respectively (Kanner 1967: 167-8). Down classified "Mongolian idiocy" as a congenital disorder and associated it with tuberculosis in the parents (Miller 1996: 368).

However, despite Down's rejection, the connection between idiocy, race and degeneracy had been made. As Anne Digby points out, the "diagnostic significance of physical aspects of mental defect [were] revealingly termed the 'stigmata of degeneration'" (Digby 1996: 8). Degenerationist arguments were based on both moral and evolutionary principles, incorporating references to lifestyle and behaviour as much as to the supposed potential of the human race to regress to an earlier human type. The atavistic argument was based on the "theory of recapitulation", a theory which postulated that the "higher human races had passed through and developed beyond the stages now represented by the existing civilisations of the lower races" (Borthwick 1996: 405). In such a theory, idiots were perceived as a throwback or reversion to our human

ancestors; ancestors who were contemporaneously represented by other "races" such as Mongolian, Malay and Ethiopian. These "racial" groups were inherently assumed to be at an earlier evolutionary developmental stage to Caucasians; socially, morally, intellectually and physically (Borthwick 1996; Miller 1996: 368).

Down was not alone in conflating race and idiocy within a singular classificatory logic. In a survey of the public exhibition of mentally retarded people between 1850 and 1940, Robert Bogdan (1986) describes how "freaks" were commonly used to justify and typify contemporary scientific and medical theories (cf. Mannix 1990: 91; Ryan & Thomas 1987: 105). Bogdan presents a number of examples—such as the "Aztec" children from St. Salvador who were exhibited in the 1850s as the missing link between apes and man, and the brother and sister from Ohio who were said to be members of an extinct tribe from the interior of Australia (Bogdan 1986: 121-4). Not only were these individuals supposed to represent the evolutionary link between animals and humans, but they were also idiots. As a consequence, indigenous people and the intellectually disabled were collapsed into a singular intermediary category as strange and subhuman examples of man's evolution from savagery to civilisation.

These consciously manufactured tales of lost beginnings and tragic ends are doubly fascinating in that scientists came from around the world to observe these "ethnological curiosities". They then used spurious information generated by the freak shows to classify people within the greater scheme of human variation and evolution. Bogdan notes that John Langdon Down had as one of his categories of idiocy the "Aztec type", and that both Shuttleworth and Ireland referred to these "Aztecs" in their own diagnoses and classifications (Bogdan 1986: 125). What is most interesting with regards to the increasing medicalisation of intellectual disability, however, is the fact that after the turn of

the twentieth century these "freaks" were often accompanied by a nurse rather than an attendant when performing in the shows (Bogdan 1986: 124). They were now not only ethnological curiosities, and representative of the missing link between humans and animals, they were also medical abnormalities.<sup>25</sup>

In the introduction to her forthcoming book on the history of the natural sciences, Jane Goodall compares the scientific approach to natural history with that of the numerous circus and freak shows of the nineteenth century. Goodall argues that both dealt with the systematic ordering of nature but in quite different ways. Whereas natural scientists reified nature through the display of comprehensive collections of fossilised specimens representing the normative stages and categories of the natural world, the circuses portrayed aberrations of this "natural order" as exotic, bizarre, sensational, and abnormal living specimens of transgression (Goodall; forthcoming). The ambiguous status of these aberrations was resolved by labelling them according to Linnean and Darwinian categories, as the missing link, the *homo troglodyte* or *homo nocturnus*. Therefore, rather than being a "caprice" or "freak" of nature, these aberrations became part of the very order of nature, but only in so far as they represented something absolutely other to those at the more "evolved" or "normal" end of the spectrum (Goodall; forthcoming). This is the ordering process that the intellectually disabled have been subjected to as scientists of all persuasions seek to fit them into their various models. It is the process that has pathologically embodied them as abnormal and unnatural beings.

By the late nineteenth century medical professionals had constituted themselves as the sole diagnostic and prognostic experts in the field of

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<sup>25</sup> In his book *Freaks: We who are not as others*, Daniel Mannix argues that circuses and freak shows actually provided the people who performed in them with an independent source of income. Due to growing moral outrage over the exploitative nature of the shows, however, they disappeared, and as a consequence the former performers were institutionalised and/or became entirely dependent on public welfare (Mannix 1990).

intellectual disability, interpreting it as an entirely organic disease (Digby 1996: 8). The medical interpretation constituted intellectually disabled people's differences as abnormal and pathological and grounded these within the physical. Medical science did more than just operate as a tool for categorising and classifying aberrations from the norm, it also had a significant and influential effect on those who were subject to its practices (cf. Conrad & Schneider 1985: 17; Zola 1972). As Foucault put it, a person who was "simple minded" came to be "a pure object of medicine and knowledge—an object to be shut away till the end of his life . . . but also one to be made known to the world of learning through a detailed analysis" (Foucault 1984: 31-2). Such people became objects of knowledge rather than subjects in their own right.<sup>26</sup> Their differences were constituted as absolutely different. They were different "not because they were like us, only damaged, but because they were intact and complete specimens of a lesser order of being" (Borthwick 1996: 406). And, as

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<sup>26</sup> This fate is poignantly portrayed in Werner Herzog's (1974) film "The Enigma of Kaspar Hauser". Based on a true story, the film tells the story of a young man—rumoured to be of noble origins—who was found standing in the town square of Nuremberg in 1828 in a seemingly catatonic state holding only a bible and a letter. Kaspar had supposedly spent his entire life in isolation, treated as an animal and chained to the wall of a cell. The film traces the various ways in which Kaspar is treated and used by his fellow countrymen; the local villagers, a family, the police, army, law, medical practitioners, philosophers and churchmen. He is an object of disgust, fear and fun for the villagers; treated as a vagabond criminal by the police; taught social manners by a kindly family; is masqueraded throughout the countryside as part of a freak show; becomes an object of fascination and potential knowledge for the doctors; a subject to be taught and trained by a "philosopher-psychologist"; and a source of theological speculation for the churchmen. Yet Kaspar does not conform to any of these attempts to manage, train or assess him. He has his own form of logic and understanding of the universe but it does not conform to the deductive reasoning Kaspar's teacher is trying to teach him. Kaspar is told he must learn to read and write in order that he come to know and understand God. Kaspar tires of all the attention focused on him and, like the noble savage he is at times portrayed as being, wants to return to his simple life in the cell. Those who wish him to assimilate to society are dismayed and decide that he must be an idiot after all. When Kaspar is murdered the doctors dissect his body and discover that he has an enlarged liver and abnormal cerebellum. The film ends with the head doctor skipping down the cobblestone lane with the medical report in his hand, having finally discovered the answer to the enigma of Kaspar Hauser.

beings who have been constituted as socially deficient, these differences precipitated the institutionalisation of training and management practices in order to transform such people into social beings.

### **Heredity, Degeneracy and Morality**

A whole range of theories existed in the nineteenth century claiming variously that idiocy was the consequence of sinful living or the intemperance of parents (but especially the mother), a result of syphilis, masturbation, indigence, or vice, or the product of the violation of natural laws (Barr 1904: 95; Brockett 1976 [1856]: 78; Howe 1976 [1848]; Ireland 1976 [1882]; cf. Gelb 1995: 2; Judge 1987: 38; Miller 1996: 368; Potter *et al.* 1976 [1853]; Rose 1985: 98; Rosen *et al.* 1976: xv-xx). Often, theological, moral and scientific modes of conceptualising idiocy existed side by side such that the laws of nature came to be proof of God's laws, and both served to justify social and moral norms. The supposed moral degeneracy of idiots was expressed in, and became a part of, their human abnormal biology. The ultimate conclusion to such opinions was that those who were affected by idiocy, as well as their progenitors, should not be allowed to reproduce (Ashton 1995: 145-147). Idiots, the feeble-minded and mental defectives were believed to be a "social menace" (Ashton 1995: 147), and were considered "unfit to continue the species" (Howe 1976 [1848]: 51).<sup>27</sup>

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<sup>27</sup> The combination of heredity and immorality as one of the primary causes of idiocy continued to be accepted as fact well into the late nineteenth and early twentieth centuries, as shown by Richard Dugdale's 1877 study of the "Juke" family, and Henry Goddard's 1912 study of the "Kallikaks" (Dugdale 1976 [1877]; Judge 1987: 49; Miller 1996: 366). Such accounts of the inherited degeneracy of idiocy and feeble-mindedness across a number of generations, and the association of these conditions with asocial, immoral and criminal behaviour, only added fuel to the eugenics scare that swept across North America and Europe in the 1920s (Judge 1987: 49; Wolfensberger 1977: 123). The prevention of this cycle of degeneration was thought to require the most stringent measures, including sterilisation, institutionalisation and the prevention of marriage or sexual relations between intellectually disabled people (Scheerenberger 1986: 61-2; cf. Charlesworth 1989: 82-3; Dugdale 1976

Despite the controversy and uncertainty surrounding the process of heredity in the nineteenth century, physicians continued accumulating data that suggested hereditary illnesses or diseases were the cause of certain conditions such as idiocy (Porter 1997: 587). William Wentworth Ireland, an American physician with an interest in the diagnosis and classification of idiocy, had strongly encouraged physicians as early as 1882 to note familial traits of epilepsy, idiocy and neurosis, and suggested that idiocy was the defect most likely to be inherited and was not just the result of sinful living (Ireland 1976 [1882]: 250). In 1904, Martin Barr, Chief Physician at the Pennsylvania Training School for Feeble-Minded Children, felt confident proclaiming that heredity was a proven law, and believed that it was one's social duty to preserve the integrity of society through understanding and thus preventing the continued "pernicious" inheritance of idiocy (Barr 1904: 123). There still remains a moral obligation on the part of parents to reduce the number of children who are born with intellectual or other disabilities.

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*The psychiatrist and paediatrician at the Grosvenor Diagnostic Centre informed my parents in 1967 that, while there was not "enough incontrovertible evidence at this time to give it a name", three of their children were mentally retarded and epileptic as a result of "a familial disorder as yet undisclosed". They also "touched upon the genetic*

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[1877]; Radford 1991; Rhodes 1993; Smith & Polloway 1993). These practices were legalised in many states of the United States of America in the 1930s (Judge 1987: 48-9). And, as Sabagh and Edgerton (1962) have documented, in North America in the 1950s it was a requirement that intellectually disabled people be sterilised before being released from mental institutions and returning to the community. While such practices are no longer accepted as legitimate ways of dealing with intellectually disabled people, and despite recent discussions over their rights to a sexual life (Held 1992; Rhodes 1993), intellectually disabled women are still being forcibly sterilised and/or prevented from having a menstrual cycle (Smith 1996, 1997a; Sweet 1997; Trumble 1997). One of the people I worked with, a woman in her late twenties, had a hysterectomy when she was fourteen and was going through early menopause at the time of my fieldwork.

*implications for future children”, noting that my mother was a Roman Catholic and therefore probably did not use contraception (12/7/67). Dr R—the female doctor in Perth who became the ‘case manager’ for my family during the time that we lived there—responded to this comment on contraception by the doctors at Grosvenor saying that she had spoken to my mother and stressed the “imperative” need for contraception due to the family circumstances. Dr R was greatly relieved that my mother had already “sought the advice of a broad minded priest” and was taking the “pill”. “Thank goodness” she writes (24/7/67). One of the psychiatrists in Perth also wrote to her colleague prior to our forthcoming move to Sydney in the hope that “people will be able to accept them as they are and not feel too outraged at these good Catholics who have filled the world with such oddities” (30/10/67).*

*The potential problems associated with further reproduction was one of the specialists’ primary concerns. However, they were also concerned with the social, economic and intellectual climate of my familial home. In the medical records in England it was remarked upon that my father was of Polish origin, that he still spoke with a strong accent, was educated in the UK and had a PhD in mathematics. It was noted that my mother was of Irish descent, that she came from a medical family, and that, although she herself had a degree in law, she did not practice. It was also noted that the “social history” of the family was “good” because we had a five bedroom house, that the children were “well nourished”, and the “family co-operative”. Having made this assessment, social factors were subsequently discarded as a potential cause of my siblings’ retardation, although along with this were most other alternative causes, including environmental factors. The only factor that remains a potential cause is the biological.*

*In the hope of discerning this biological cause the medical professionals sought to discover whether there were any traces of a “familial disease” in earlier generations of my family. A “family and contact” history had been taken at the Alder Hay Children’s Hospital in Liverpool and this was added to by those at Grosvenor. It was noted that,*

*apart from the problems affecting the immediate family, a maternal great uncle had suffered from convulsions until the age of five, and that one of his daughters was epileptic; that a paternal uncle was mentally ill; that my mother's cousin had TB and that her paternal grandmother had also had TB.<sup>28</sup> It was also remarked upon that my own father may have had convulsions in childhood, and was slow to begin speaking—although this was considered unreliable evidence—and that my paternal great uncle was epileptic and possibly schizophrenic. My parents, however, were considered to be “healthy” (9/5/66). A slightly later family medical history suggests that there may have been “a background of epilepsy or degenerative brain disease, or even schizophrenia” on my father's side of the family and that my mother has “two cousins who had epilepsy” (19/5/67).<sup>29</sup>*

*A fabulous kinship chart was drawn up by the specialists at Grosvenor on which were marked the incidences of schizophrenia, tuberculosis and epilepsy that have occurred in my family over the past three generations. The chart also included the medical results of various biochemical, bacteriological, neurological and physical tests for each of the first five children in my family. It was hoped that this chart might indicate some pattern of the “very complicated picture of what appears to be a familial disease” (19/5/67). And, as already mentioned, this medical history is still being updated with recent information about the family. In 1988, a Paediatric Neurologist who saw Maryla at Stockton Hospital mistakenly wrote that “She is one, of apparently about eight children, of whom five have had neurological problems”. Interestingly, he was just as concerned about the possible effects of blood marriages on retardation as were those in the 19th century. In relation to the family's “hereditary neurological problems”, the neurologist wrote that, “apart from severe retardation, and death,*

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<sup>28</sup> It is interesting to note that tuberculosis was one of the diseases that John Langdon Down singled out as a particular cause of idiocy.

<sup>29</sup> On discussing these matters with my mother I discovered that some of the details of this information were incorrect, although there were incidences of epilepsy, retardation, mental illness and tuberculosis in the family.

*epilepsy seems to be a constant thread in the family history. There is no consanguinity” (17/6/88).*

What unites this history of medical and degenerationist hereditary theories is the underlying message that the people so affected, and their parents, are not fit candidates for reproduction. The segregation, sterilisation and study of intellectual disability was entirely directed towards ridding society of "this equivocal being, who seems to have been placed by nature on the very confines of humanity" (Pinel 1962 [1801]: 127). Even Séguin, who continued to pursue his educational treatment and training, supported this general assessment. Having pathologically embodied those who are intellectually disabled—and placed them in a category as sub-human, abnormal, unnatural, deficient, and asocial by virtue of their differences and limitations—the only "cure" was to train or ameliorate them; to make them conform to social norms or incarcerate them. The concern of the medical profession was amelioration, and it was the parents who were lectured to in order to prevent the supposedly "pernicious" inheritance of idiocy from continuing (Barr 1904: 123). The concern of the institution was management and training, and it too sought to eradicate intellectual disability by transforming such people into socially acceptable beings. Neither is able to accept and relate to intellectually disabled people as they are. There is a profound refusal within both medical science and the institution to negotiate and look for the possibilities of shared vehicles of meaning and sociality.

### **The Road to Genetics**

*The earliest mention of genetics as the possible source of my family’s particular circumstances was in 1966, when the senior physician at Walkersgate Hospital in Newcastle Upon Tyne wrote to Dr R in Perth saying that “It certainly sounds a very*

*queer family history and perhaps this is of genetic background" (16/5/66). Urine tests had been performed to determine the "normality" of amino acids ever since we lived in Liverpool but at that time genetic testing was still in its infancy. Although much was made of the inherited nature of the "disease" it was not until the mid 1970s that the first specific genetic tests were done on all of us children. I could find no records of these tests, however, and only have vague memories of the strange and clinical nature of the examination. I remember that it was inexplicably disconcerting to be having my genes tested for some familial disorder, and that my parents were equally anxious and distressed at the possible implications of these tests. The progress report from Grosvenor in 1975 did, however, comment on the "recessive inheritance" of this "unknown metabolic disorder". This diagnosis was repeated verbatim in 1986 for Maryla in a psychological report at Stockton, and the most recent tests that she has had are all genetically related enzyme tests.*

While there may well turn out to be a genetic basis to my siblings' intellectual disabilities, it is the uses to which genetic knowledge is put that raises serious issues for those with any form of genetic "defect", or even a predisposition to illness, disease or disability. Parents are often discouraged from reproducing in such circumstances. It is the implicit value, or lack of value, placed on intellectually disabled people's human and social status that perpetuates the notion that such people are pathologically and inherently abnormal, and that, as such, they lack the capacity for sociality. The development of genetics in the latter part of the twentieth century has only served to strengthen and reinforce this assessment.

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The metamorphosis from sin to genetics as a primary cause of intellectual disability places the breach of morality and normality both beyond and within the self. The soul, no longer a consideration of medical science, has now

become the genetic code of the person, and it is this that is blamed when a person transgresses the boundaries of "normality". Despite the conviction for over a century that inherited causes could and would be discovered for specific diseases and disabilities, no studies had been able to prove that this was actually the case. Interestingly, the final proof for the hereditary nature of certain diseases and disorders came through genetic research into Down's syndrome (Porter 1997: 587).

The publication of Charles Darwin's *The Origin of Species* in 1859, and the popularisation of this theory by his cousin Francis Galton, gave to notions of heredity an evolutionary and scientific perspective that, combined with Gregor Mendel's observations of how characteristics are passed on from one generation to the next, eventually led to the biomedical field now known as genetics (Judge 1987: 40-8).<sup>30</sup> Contemporary medical theories of intellectual disability have been greatly influenced by research in the field of genetics. They have built upon similar advances in biology and biochemistry, and have utilised new medical technologies that allow greater visual access to the body and its functioning. The observation of an extra chromosome in all Down's syndrome people in 1959 was part of this technological and scientific development, as was the understanding of the structure and hereditary capacity of DNA (Porter 1997: 588). These developments have encouraged faith in the use of medical scientific processes to understand and hopefully prevent "abnormal" conditions such as intellectual disability. For, as Peter Conrad and Joseph Schneider remark: "It is assumed generally that if one could only know the cause and thus

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<sup>30</sup> E. J. Yoxen has pointed out that the early "Mendelian geneticists" faced considerable criticism from their professional peers in the early twentieth century because their theories were not acceptable to contemporary notions of evolution and variation. Because of this, the field of genetics developed mostly within disciplines focusing on plant and animal breeding, disciplines devoted to the study of the general principles of heredity rather than with problems of variation. It was not until the 1930s that the relevance of earlier studies of potentially inherited abnormalities began to influence the biomedical fields in terms of aetiological reasoning (Yoxen 1982: 146-7).

the 'true' nature of the deviant behaviour, one could prevent or, more likely, control it closer to its source" (Conrad & Schneider 1985: 25).<sup>31</sup>

While many suggestions have been made as to the possible causes of intellectual disabilities—some of them genetic, metabolic and pathological, others environmental, nutritional and infectious, and still others, cultural or familial (Scheerenberger 1987: 40-61; Heaton-Ward 1978: 7-31; Whittemore *et al.* 1986: 8)—there always remains a residual group that resists classification and categorisation (Dykens 1995: 529; Scheerenberger 1987: 37-40). Despite the fact that only 25% of people with an intellectual disability are known to have a genetic basis to their disability (Bregman & Hodapp 1991: 708; Zigler & Hodapp 1986: 86-7), the medical model (and its associated practices) is still the dominant mode through which such people are treated and perceived (Mehan 1988: 80; Ryan & Thomas 1987: 15-26). The other 75% get drawn into the general paradigm of abnormality that the medical model espouses. In addition, medical researchers believe that a genetic or biomedical cause for all forms of disability will eventually be discovered. As Bregman and Hodapp comment in their review article, "Current Developments in the Understanding of Mental Retardation":

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<sup>31</sup> For Conrad and Schneider, deviance is a socially meaningful construct representing "human judgements of conditions that exist in the natural world" (Conrad & Schneider 1985: 31). Through their social constructionist and symbolic interactionist approach, Conrad and Schneider sought to understand the "meanings we attribute to different behaviour" (Conrad & Schneider 1985: 20). Following Howard Becker's 1960s theory of labelling, Conrad and Schneider considered the stigma attached to such designations as deviant, especially the effect it can have on a person's behaviour and identity, and how others perceive and treat such a person (Conrad & Schneider 1985: 20). However, due to their commitment to sociological interpretations of the nature of labelling, the authors never considered the actual lived realities of the people in question—the alcoholics, the mad, or the pro-abortionists. Just as clinical specialists remain beyond the boundary of abnormality that they themselves perpetuate and reinforce, Conrad and Schneider also do not enter the lives of the people they write about as subjects engaged in a continual process of interaction with these medically ascribed labels, identities and attributes. They criticise the designations that medicine creates, but remain just as much outsiders when it comes to really engaging with difference.

. . . developments in medical technology will reveal that those whose condition is presently due to unknown causes, especially those with mild intellectual impairments, will eventually be found to have biomedical causes for their cognitive and adaptive impairments (Bregman & Hodapp 1991: 707).

There are now thought to be over one thousand genetic "abnormalities" that are the cause of various types of intellectual disabilities, each having their own behavioural and physical manifestations (H. W. Moser, cited in Dykens 1995: 522). These include Down's syndrome, Fragile-X syndrome, Angelman's syndrome, Rett syndrome and Turner's syndrome, amongst others. Studies in the field of genetics have grown increasingly complex as researchers acknowledge the dynamic interplay of genetic and environmental factors, as well as the multiple interactions of individual genes in the production of a genetic "defect" (V. Anderson 1974; Bregman & Hodapp 1991: 715; Charlesworth 1989: 88; Simonoff *et al.* 1996). It is therefore no longer as simple as suggesting that a single gene is the sole determinant of a specific disorder. And, as Simonoff *et al.* stress, it is difficult to establish a direct causal relationship between genetic abnormalities and a persons' intelligence or behaviour because of the diverse manifestations of syndromes (Simonoff *et al.* 1996). However, despite such criticisms, the quest to discover "behavioural phenotypes" remains a legitimate scientific pursuit in the study of mental retardation (Anderson 1974; Bregman & Hodapp 1991: 709; Dykens 1995).

It is not so much that genetic interpretations of intellectual disability are a false assessment. It is rather the implication that as an abnormality it must be erased. The Human Genome Project is the latest development in this field. As Tom Wilkie comments, its primary aim after mapping and analysing each of the 3 billion "letters" within the DNA sequence will be to treat the "mistakes", "disorders" or "errors" of nature that produce diseases, defects and disabilities

(Wilkie 1993: 1-15; cf. Porter 1997: 588). It appears that Descartes' machine-body is being manipulated and "corrected" at ever more particular levels. The interpretations might have narrowed to specific diseases, germs, genes and enzymes, as Luchins remarks (1989: 593), but the perception of abnormality as an integral part of an intellectually disabled person's identity has been sustained, and the stress on prevention is still integral to this judgement.

In 1992, W. French Anderson stated that "[t]he goal of biomedical research is, and has always been, to alleviate human suffering" (W. Anderson 1992: 150). He went on to argue that "Gene therapy is a proper and logical part of that effort" (W. Anderson 1992: 150; cf. Charlesworth 1989). Such "therapy" is the controversial technique of altering a person's genetic make-up as treatment for their disorder. The emphasis on correcting or treating any genetic, biochemical or neurological defects as the cause of someone's "suffering" includes within it those people who are intellectually disabled. Individuals, and society as a whole, must work towards relieving the human gene pool of these disabling conditions, thereby preventing and minimising the effects and continued existence of these defects (W. Anderson 1992; Berg 1976; Chadwick 1992; Charlesworth 1989: 80-95; Marteau & Drake 1995). In fact, as Professor Lord Robert Winston, a leading geneticist and "reproductive engineer", recently commented, the "devastating effects" and "suffering" associated with genetic defects means "the choice of what to do once a defect is identified is relatively easy" (cited in Whelan 2000: 7).

Nowadays, with advances in prenatal genetic testing, parents who are potential carriers of any "disorder", or women who are at "risk" of having a disabled child, are encouraged to seek genetic counselling. Amniocenteses, ultrasounds, urine tests and even the traditional family tree are used to predict the genetic traits that might be passed on to one's child, and specially trained genetic counsellors interpret these tests and inform clients of any such potential

(Berg 1976; 44-45; Scheerenberger 1987: 61-6). In relation to reproduction, parents are encouraged not to continue with a pregnancy if there is evidence that the foetus is in any "serious" way abnormal. This includes such conditions as Fragile-X and Down's syndrome. Despite not knowing what the cause was, my parents were also strongly encouraged not to continue having children. Consequently, the moral weight of guilt, shame and blame still resides with the parents, who are made to take responsibility for the "choice" of reproducing an intellectually disabled child. As E. J. Yoxen comments:

Genetic disease strikes at some of the deepest and most intimate feelings about ourselves—as potential parents, as responsible people, as marital or sexual partners and so on. The appearance of hereditary disease in anyone's life, as a risk or a fact, is traumatic. It jeopardises some of the most fundamental beliefs that socialisation in contemporary society encourages us to hold (Yoxen 1982: 154).<sup>32</sup>

Those who advocate prenatal testing, genetic counselling and gene therapy, however, rarely do so without taking into consideration many of the ethical dilemmas that genetic research has produced (W. Anderson 1992; Charlesworth 1989; Cotton & Wansbrough 1996; Smith 1997b). They are aware of the controversial nature of gene therapy and the moral questions that this

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<sup>32</sup> Yoxen has also argued that genetics as a discipline developed within the restraining power of other biomedical interpretations of disease and abnormality such that "the phenomena with which genetics works are intellectual constructs" (Yoxen 1982: 145; cf. Charlesworth 1989: 90; Rapp 1988). This interpretation, while acknowledging that "many of the phenomena of genetic disease are grounded in material reality" (Yoxen 1982: 144), propounds the theoretical position that all phenomena are cultural or social constructions. As such, any perception of disability involves the projection of cultural and social meanings onto the material or person under observation. While Yoxen challenges the overtly deterministic interpretations of a biomedical approach, his idealist approach does not take into consideration the way in which such observations and perceptions become part of a person's lived reality. For him the process remains one way, whereas in fact it is the interrelationship of an individual's biomedical make-up with their being and experience in the world that creates a person's lived reality.

raises concerning human life.<sup>33</sup> But as Ruth Chadwick (1992: 119) points out, despite the problematic use of such terms as defect or handicap in the field of genetics, the moral role of geneticists is still fundamentally to replace "faulty parts" and repair any genetic defect.<sup>34</sup>

Treating intellectual disability as a medical defect or disorder marks out the condition as something that is not normal and natural. It consequently renders people so affected as abnormal, unnatural and less than human, as nature gone wrong. Their very being, their genetic makeup and biochemical balance, is perceived as fundamentally askew. Despite their particular differences, all the medical literature on intellectual disability unquestionably assumes a link between a person's abnormal genetic, metabolic or physiological make-up, and their behaviour, their being in the world, as intellectually disabled (Bregman and Hodapp 1991: 707). The social response to this perception, both clinically and institutionally, has been to treat such people as though they exist outside the realm of sociality. In doing so intellectually disabled people then become a deviation that must be eliminated, managed or trained. They must either be removed from the social altogether or else trained to acquire social skills that will enable them to participate in the social world. Yet intellectually disabled people already have the capacity for sociality and mutuality, albeit in

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<sup>33</sup> In his criticism of the implications of prenatal genetic testing Christopher Newell points out that such practices make society less tolerant of difference and disability. Newell argues that by accepting these tests and advocating their use "we are closing off various forms of humanness, and saying everyone has to be 'normal'" (cited in Smith 1997b: 11).

<sup>34</sup> The ethical dilemma implicated in the potential erasure of human diversity and difference also carries with it the problematic assumption that behaviour can be linked with specific genetic causes (Diprose 1991: 70; cf. Simonoff *et al.* 1996). In her analysis of the theory of genetics, Rosalyn Diprose claims that geneticists portray the laws of nature as though they are bounded and closed. Diprose argues, however, that genetics actually operates according to a process of adaptation and aberration that results in the continual production of diversity. In this sense, nature produces differences as manifestations of itself (Diprose 1991: 73). Therefore the idea that some differences are acceptable while others are not becomes a social and moral issue as much as an objective and scientific one.

unconventional and limited forms. It is often highly contextual and embodied, and requires participation in the negotiation and mediation of particular language games and symbolic systems. It is through such articulations of relatedness that the joint constitution of a shared social environment such as the one I have had with my siblings develops.

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*Even though my parents initiated contact with the medical profession and consistently sought from them a diagnosis of my siblings' conditions, there are indications throughout the records that my parents were unwilling or unable to accept the diagnoses of retardation they were given. In 1966, one of the doctors at Grosvenor wrote that "it is probably rather good that they have such strong defences against admitting [their problems]—they'd go under if they did" (7/4/66). Others were not quite so sympathetic. In May 1966 one of the doctors in Perth wrote that he had "told Dr. Klotz that [he] thought that Stephen was moderately retarded and that he would not reach normal intelligence. Dr. Klotz was obviously very disturbed with the present assessment of his condition but I felt that the time was ripe for him to be made aware of the situation fully" (9/5/66).*

*My parents were considered "difficult" because they challenged the interpretations of the medical profession and would read up on the medical literature when given any possible diagnosis. The doctors at Grosvenor "gained the impression that though a definite label would be a help to them in some ways (and was what they tried very hard to provoke us into giving) it would also add fuel to their well-established mechanisms of denial of their children's condition . . . Our impression was that part of the reason for their 'shopping around' . . . for opinions and advice (which seems to have been very ably given in the past) springs from their understandable difficulties in facing the tragic facts of their children's handicaps, apart from the realities of lack of appropriate educational facilities" (12/7/67).*

*The stigma attached to such a diagnosis was barely considered. The implicit blame attributed to my parents for having more children despite their family histories—with incidences of intellectual disability and epilepsy on my mother's side and mental illness on my father's—the possible congenital recessive disorder that they had supposedly passed onto their children, and the status of retardation as an abnormality that must be eliminated, managed, treated and institutionalised, all contributed to their anxiety and unwillingness to accept this definitive diagnosis. What did such a diagnosis say about who they were, let alone what their children were? The diagnosis was a final cut, a separation that put their children on one side of a divide, with themselves somehow straddling the gulf that separated their children as intellectually disabled from others in the community. It categorised their children as unfit for human social life, and assumed that they had no capacity for culture and sociality. My parents had given birth to a difference that was considered an aberration of normality, manifesting as a deficiency in social and intellectual capabilities, and the doctors wondered why my parents were so "difficult"! Such attributes are considered the most advanced and definitive human capabilities in our society and their children had been given close to zero on their score cards.*

*My own distress at reading the medical records resonated with my parents' responses. It is not so much that I too am implicated in this possible familial disorder, but that I, like all of my family, knew Maryla, Stephen and Ursula as human beings; as cultural beings; as integral and participating members within the sociality and mutuality that constituted our family life. Like the rest of us, my intellectually disabled siblings, albeit within their own limitations, existed within and helped to create the symbolic systems that operated as the medium through which we not only made sense of our shared environment but through which we communicated and related to one another. Despite limitations to this mutual engagement, and their tendency to revolve around very particular social idioms, symbolic practices and dispositions such as the jigsaw pieces and bits and pieces, our interactions with one another through such*

*objects were a way of meaningfully and purposefully engaging within our shared social world. We did not separate, isolate or strip my siblings bare of vestiges of human sociality. We did not perceive them as the medical anomalies they were constituted as being. And yet, the medical interpretation has had a profound effect on my siblings' experiences, increasing in intensity the more they moved outside the intimate and essentially closed world of the family and into the public social world of medicine, education, and, ultimately, the institution where two of them went to live. The practices and attitudes that my siblings have been subject to are similar to the treatment given to residents of Xanadu and the group homes. Their everyday regime embodied forms of institutional practice shaped by the legacy of medical science. This legacy includes the symbolic scheme of reason and normality that still informs the field of intellectual disability.*

## Chapter Four

### The Voice of Reason

*All our dignity, then, consists in thought.*

*It is upon this that we must depend, not on space and time,  
which we would not in any case be able to fill.*

*Let us labour, then, to think well: this is the foundation of morality.*

*Blaise Pascal*

Medical interpretations of intellectual disability have never existed in isolation. Even when first formulated they had to contend with religious interpretations founded upon moral notions of sin and guilt. Those that did emerge as scientifically informed medical understandings of the cause and manifestation of intellectual disability, however, still carried with them moral markers that made of this difference an immorality (or amorality) now rendered as an abnormality. Although medical interpretations dominated the assessment and treatment of idiocy throughout the nineteenth century—and while medicine has never lost its role in the overall diagnosis and interpretation of intellectual disability—there was considerable debate by the end of the century as to who was actually best qualified to make a diagnosis (Rose 1985: 101-102).

The power struggle between medical practitioners and psychologists to diagnose and categorise intellectual disability was ultimately influenced by the development of the intelligence test. Intelligence testing also marked the emergence of psychology as a rigorous scientific discipline in its own right, a discipline in search of hard factual evidence based on precision, testing, accuracy and statistical data (Rose 1985: 117; cf. Hanson 1993). The intelligence

tests' seemingly accurate and numerical assessment of cognitive capability gave to the interpretation of intellectual disability an absolute and quantifiable specification that had previously been lacking in medical interpretations. When intelligence tests were first introduced they became a powerful tool for clarifying the concept of mental retardation, and by 1914 had become the accepted method for "discovering the mentally slow" (Luckey 1967: 170-172). They were designed specifically for this purpose and, to this day, one of the most common uses of intelligence tests is for the diagnosis of mental retardation (Aiken 1996: 276).

Those with a measured intelligence quotient (IQ) of less than 70 on an intelligence test were—and still are, according to the World Health Organisation's classification—deemed to be intellectually disabled (Bijou 1992: 309; Bullock & Trombley 1999: 519-520; Schalock *et al.* 1994: 183). More specifically, the test was used to categorise levels of intellectual disability such as profound, severe, moderate and mild retardation, each of which was associated with particular IQ ranges (Accardo & Whitman 1996: 194; Woods 1983: 3-15).<sup>1</sup> Levels of intelligence were also ultimately used to determine the

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<sup>1</sup> Those with an IQ below 25 were considered to be profoundly mentally retarded, those with an IQ between 25 and 35 severely mentally retarded, those with an IQ between 35 and 50 moderately retarded, and those with an IQ between 50 and 70 mildly retarded (Accardo & Whitman 1996: 194; Woods 1983: 15-17; cf. Aiken 1996: 277-279; Judge 1987: 34; Bijou 1992: 310; Scheerenberger 1987: 12 for slightly different correlations of IQ scores with levels of retardation). These categories broadly relate to the earlier terms of idiot, imbecile, moron, and feeble-minded respectively. The change in terminology in the field of intellectual disability is sometimes hard to keep up with, especially as there is a tendency to use different terms in the United Kingdom, the United States and Australia at the same time. In the United Kingdom, the use of the generic terms "mental deficiency" and "mental subnormality" in the early twentieth century were subsequently changed to "mental handicap" and then "mental retardation" (Jenkins 1988b: 8; Woods 1983). The term now officially used to describe intellectual disability in the United Kingdom is "people with learning difficulties" (Jenkins 1988b: 8). In the United States mental retardation was originally called feeble-mindedness but officially became developmental disability through legislation enacted in 1970 (Kearney 1996: 22). In Australia, people with mental retardation and an intellectual disability have historically been termed "idiots" or "mental defectives" (Ashton 1995: 152), and are now also officially known as people with a developmental disability.

educability of children, with those having an IQ below 50 considered ineducable, and those with an IQ between 50 and 70 educationally subnormal (Rose 1985: 141; Ryan & Thomas 1987: 111; Woods 1983: 115).<sup>2</sup>

As an indicator of how influential intelligence testing has become, the condition of intellectual disability is now defined explicitly by reference to IQ and behaviour. The American Association on Mental Retardation defined intellectual disability in 1992 as "significantly subaverage intellectual functioning" occurring in the developmental period and associated with limitations in at least two of the following adaptive skills: "communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work" (cited in Schalock *et al.* 1994: 182). This recent definition of intellectual disability signified the transition from solely emphasising individual cognitive abilities to a growing concern with an individual's interaction with his or her environment. It accommodated for changes that were occurring in the areas of service provision and special education, as well as acknowledging that intellectually disabled people have the capacity to learn and develop. However, as Coles *et al.* point out, despite the recent stress on social skills and adaptation, the "individual's cognitive abilities nevertheless remain a central construct" in definitions and interpretations of intellectual disability (Coles *et al.* 1996: 187; cf. Accardo & Whitman 1996: 194). And, as Joanna Ryan has also argued:

... whilst there is considerable argument about the precise criteria for defining mental deficiency, and especially about where to draw

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<sup>2</sup> Such terminology emphasises adaptive behaviour rather than mental deficiency, as Lewis Aiken (1996: 278) points out. The National Association for Retarded Children (USA) have utilised a different classificatory system, only one that stresses relative functional independence rather than potential educability. The terms they proposed were "marginally independent" (IQ = 50 to 75), "semi-independent" (IQ = 25 to 50) and "dependent" (IQ = 0 to 25) (Aiken 1996: 278).

the line between 'defective' and 'normal', we do still have a reliable idea of how people who are clearly *mentally* deficient differ from those who are said to be of normal deficiency (Ryan 1973: 37-38; my emphasis).

While medical researchers often take for granted these deficiencies, instead focusing on determining the underlying biological causes of intellectual disability, psychologists have tended to focus specifically on the functioning of the mind and on assessing levels of intellectual impairment (Hodapp & Dykens 1994: 675). Despite their differences, however, the development of psychological assessments of intellectual disability has reinforced and perpetuated the symbolic scheme of reason and normality that the medical model adheres to. Both medical and psychological interpretations of intellectual disability have perpetuated the notion that reason, which is identified with levels of intelligence, is a necessary criteria of normal humanness and sociality. Consequently, intellectually disabled people are often denied an existence as social beings who are able to utilise symbolic systems. Their limited abilities to classify and figure the world beyond a confined environment are taken as a lack of reason. Such clinical interpretations have thereby overlooked the fact that mutuality and sociality make us human as much as extendable knowledge. Human personhood is shaped as much through the symbolic mediation of social relations as it is through the mediation of human, knowing relations with the non-sentient world. In short, sociality can be built through restricted codes even though these codes remain restricted.

As with medical diagnoses of intellectual disability, psychological interpretations are based on an empirical combination of observation and testing. Focusing specifically on the functioning of the mind and behaviour, psychological assessments also label intellectually disabled people as deficient and abnormal beings (Sacks 1986: 163-172; Shaddock *et al.* 1993: 52). In fact, as

Nikolas Rose points out, the entire development of psychology as a discipline has been profoundly based on studies of the "abnormal" (Rose 1985: 22-3). Like medicine, psychology pathologises the intellectually disabled, searching for deficits and aberrations from taken for granted norms, only this time in terms of a capacity for abstract reasoning measured as specific mental skills and communicative ability. These skills are decontextualised, isolated, abstract skills which depend upon a capacity for language; although it is language in its limited linguistic, verbal and literate sense rather than as the capacity for symbolic representation and mediation. Despite the recent interest in social skills and adaptation, psychological assessments and interpretations still tend to separate intellectually disabled people from their contextual environment. They still tend to test such social skills as acquired rather than applied skills. By not recognising or acknowledging intellectually disabled people's preexisting capacity for symbolic representation, mutual interdependence and sociality, psychology, like medicine, has made the social aspect of intellectually disabled people's lives secondary and obscure.

In this chapter I outline the history of psychological theories of intellectual disability, focusing in particular on the practice of psychometric testing as a significant factor in the diagnosis and classification of intellectual disability. I also explore some criticisms of intelligence testing and look at the latest developments in psychological interpretations of intellectual disability. I focus particularly on individual development, learning and social skills acquisition, and explore the influence of these more recent interpretations of intellectual disability on contemporary institutional practices. I draw again on my family's medical and psychological records to elucidate the role that these clinical assessments have played in the perception, interpretation and treatment of intellectually disabled people.

I also analyse the central place that reason has played in interpretations of normal humanness and meaningful sociality. I explore the association of reason with intelligence, in particular its identification with specific skills such as abstract reasoning, numeracy, and language. By isolating certain mental operations as the definitive mark of intelligence, and of reason and normal humanness, psychological assessments have radically decontextualised our sense of what constitutes humans as persons. It is these characteristics that perpetuate the underlying perception of intellectually disabled people as abnormal and outside the realm of mutual sociality. The practices of management and training that exist in institutional environments, as well as the forms of relatedness between staff and consumers, have reinforced these perceptions and interpretations. These practices are informed by clinical assessments, perceptions and interpretations, which are themselves shaped by the symbolic scheme of reason and normality.

### **Reason, Intelligence and the Development of Psychology**

One of the most enduring and central themes in the history of philosophy is the idea and ideal of reason and rationality as the defining attribute of humanity (Damasio 1994: 52; Lloyd 1993). According to Genevieve Lloyd, reason is thought "to express the real nature of the mind"; and it is through reason and the cultivation of rational thought that the unwieldy passions associated with the body are supposedly transcended (Lloyd 1993: 6).<sup>3</sup> In such

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<sup>3</sup> Rousseau argued that while the truth unfolds, it must also be cultivated through Reason perceiving the truth and purity of Nature (Lloyd 1993: 58). Similarly, though in a different way, Hegel claimed that "Reason . . . is the conscious certainty of being all reality". It is "the sovereign of the world", "the substance of the universe", which unfolds in History through the dialectic process of Becoming (Hegel, cited in Russell 1989 [1946]: 704-706). For Hegel, the mind, Reason, and human History are "all part of a grand unfolding of Nature into its self-conscious realisation as the Absolute" (Lloyd 1993: 70).

rationalist philosophies—which date back to Pythagoras but are most readily associated with Descartes—the intellect, rather than sensory experience or revelation, has been regarded as the source of knowledge and the necessary grounds for belief (Russell 1989 [1946]: 55-56).<sup>4</sup>

This celebration of reason as the necessary attribute of humanity and the source of true knowledge has also influenced, and been influenced by, Christian theology. In pictorial representations of the cosmos, such as those done by Robert Fludd in the early sixteenth century, the truth of God was portrayed as entering the soul through the three higher faculties of Reason, Intellect and Mind (Godwin 1979: 48, 70; cf. Dante 1985 [1314]). The body, in contrast, was reviled as "vile" and "corruptible" matter (Fludd, cited in Godwin 1979: 71). Idiots were variously thought not to have a rational soul or the capacity for divine illumination, although some, like the Platonists, did acknowledge that they had a corporeal soul (Goodey 1994: 216). Whereas for Fludd the soul, as distinct from reason, the intellect and mind, was also essential for the realisation of the truth of God (and nature), Enlightenment philosophers relegated this capacity to the mind, and particularly to rational, abstract reasoning.<sup>5</sup> Reason, however, has not only operated as a philosophical

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<sup>4</sup> The celebration of reason and rational thought as the sole source of truth, although a debatable philosophical assertion since its inception, has come under increasing fire over the past century from a number of perspectives. Not only has there been a reassertion of the belief that knowledge can only be attained through the senses (Merquior 1985: 17), but contemporary science and philosophy has been pervaded by a critique of the concept of a universal truth as either existent or knowable. Nietzsche, among others such as Artaud and Dostoyevsky, has been used as a source of inspiration for critiquing the celebrated place of reason (Felman 1989; Nye 1988). His own struggle with madness has gained revelational status as Western writers, philosophers and artists grapple with the consequences of the over-determinism of reason and rationality in Western notions of what constitutes humanness. While some, such as Deleuze and Guattari (1984), theorise madness as a more essential state of being, as potentially liberating and capable of rupturing the capitalist structure, there are others such as Foucault (1995 [1961]) who have sought to trace the consequences of our emphasis on reason and rationality for those who do not conform to its demands.

<sup>5</sup> The incorporation of the soul as an essential attribute of humanity did of course exist in the sixteenth century philosophies of those such as Descartes and Spinoza. However, the emphasis began to shift to deductive abstract reasoning rather than spiritual revelation as

and theological concept; it has also affected the way in which we interpret human nature. As Lloyd puts it:

Reason has figured in Western culture not only in the assessment of beliefs, but also in the assessment of character. It is incorporated not just into our criteria of truth, but also into our understanding of what it is to be a person at all, of the requirements that must be met to be a good person, and of the proper relationship between our status as knowers and the rest of our lives. Past philosophical reflection on what is distinctive about human life, and on what should be the priorities of a well-lived life, has issued in character ideals centred on the idea of Reason; and the supposed universality and neutrality of these ideals can be seriously questioned (Lloyd 1993: xviii).

The association of reason with that which is taken to be true, good, and natural has therefore influenced interpretations of what it means to be a person, of what constitutes the nature of human nature, and what is required to fulfil the criteria of normal humanness. While of course there are other ideals that inform a sense of personhood in Western culture, such as beauty, physical prowess, wealth and power—and while of course the interpretation of intellectual disability has no "consistency, coherence, or consensus *within* cultures" (Jenkins 1998b: 222; author's emphasis)—I argue that rational thought is the attribute most central to our perception of what constitutes a "real" and "normal" person. Whereas those who are lacking in beauty, strength, wealth and power still have to deal with the consequences of their situation, they are rarely thought to exist outside, or on the margins of, humanity, sociality and

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the means through which the truth of God's universal laws of nature could be perceived and proven (Hampshire 1956: 59-66, 105-141).

culture in the way that intellectually disabled people so often are. This is because reason is considered to be the normal and necessary attribute that makes human social life possible and, indeed, meaningful.

The association of reason with normality, and the connection of these to clinical interpretations of intellectual disability, has a history that dates back to the first medical definitions of idiocy. John Locke, who is considered the founder of modern psychology, was the first to argue that idiocy was first and foremost a problem that resides in the faculties of the mind (Goodey 1994: 217). Rather than upholding the Galenic propensity to search for physiological causes, Locke claimed that what characterised idiocy was an inability for abstract reasoning. For Locke, abstract reasoning was the mental faculty necessary for the association of ideas, understanding, and knowledge (Goodey 1994: 216-222). As Locke comments in Book II (chapter 11, paragraph 11-12) of the *Essay Concerning Human Understanding*:

How far idiots are concerned in the want or weakness of any, or all of the foregoing Faculties, an exact observation of their several ways of faltering, would no doubt discover. For those who either perceive but dully, or retain the Ideas that come into their Minds but ill, who cannot readily excite or compound them, will have little matter to think on. Those who cannot distinguish, compare, and abstract, would hardly be able to understand, and make use of Language, or judge, or reason to any tolerable degree but only a little, and imperfectly, about things present, and very familiar to their Senses. And, indeed, and of the forementioned Faculties, if wanting, or out of order, produce suitable defects in Mens' Understanding and Knowledge (cited in Goodey 1994: 219).

For Locke, "all knowledge, and hence mind itself, comes about by mental associations among sensory impressions" (Aiken 1996: 9), and the faculty of abstract rational thought was what made sense of these sensory impressions. This capacity to reason through the faculty of abstraction and discrimination was considered the essential and defining property of humans, and that which distinguishes us from animals (Goodey 1994: 240). By linking the capacity for reason and abstraction with knowledge, understanding, truth, and communication, Locke inadvertently condemned idiots to a state of imperfection, deficiency and abnormality. They were also considered to have little or no capacity for meaningful social action or interaction.

Locke's general interpretation of idiocy as an incapacity for abstract reasoning has been incorporated into contemporary psychological definitions and perceptions of intellectual disability (Goodey 1994: 250). His notion of abstract reasoning has also become one of the most central and defining features of the concept of "intelligence" (Aiken 1996: 19-20). Although intelligence has also been associated with mechanical and social skills, it is the understanding and managing of abstract ideas and symbols that are thought to constitute the higher, linguistically oriented aspects of reason and intelligence (Drever & Collins 1928: 9; Sacks 1986: 164). It is these skills that supposedly allow for understanding, knowledge, communication and meaning. Such interpretations of reason and intelligence have seriously undermined the intelligent and meaningful component of other, more concrete, modes of expression (Sacks 1986: 164). As Edgar Miller points out, "a strong theme in modern psychological conceptualizations of idiocy is that . . . afflicted individuals are unable adequately to process and derive proper meaning from the incoming information that is provided by the senses" (Miller 1996: 362).

Although idiocy has continued to be defined as a condition associated with dysfunctions in the faculties or processes of the mind, there have also been

slight divergences since Locke's definition as to what these specific mental problems actually constitute. In 1801 Pinel argued that idiots were marked by a "total or partial obliteration of the intellectual powers and affection" (Pinel 1962 [1801]: 172). Writing thirty years later, Esquirol claimed that idiocy was a condition most readily associated with a lack in language and speech (Binet & Simon 1976 [1905]: 336). For Séguin idiocy was a consequence of abnormal connections between sensory perception and the functioning of the mind, whereas for Howe "The poor idiot could not understand much of the spoken words by which *reason* manifests itself" (Howe 1976 [1848]: 45; author's emphasis).

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Scientific studies that sought to prove direct correlations between the brain, intelligence and cognitive functioning have a history in medico-psychological research dating back to the late eighteenth century (Judge 1987: 35-37; Gould 1996: 176). In breaking with dualist philosophies that radically separated the mind from the body/brain, phrenologists such as Franz Joseph Gall and Paul Broca studied possible connections between the shape of the cranium, cranial capacity, and the various functions of the brain (Damasio 1994: 14-16; Gould 1996: 22-23; Hanson 1993: 200-204).<sup>6</sup> By the 1890s, intelligence was generally considered to be a collection of mental faculties (Aiken 1996: 19), and Alfred Binet, who is heralded as the founder of intelligence testing, actually began his psychology career in the footsteps of Broca and Gall by seeking to equate

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<sup>6</sup> In *Descartes Error: Emotion, reason and the human brain*, Antonio Damasio (1994) eloquently describes the importance of phrenological endeavours of the eighteenth and nineteenth centuries. He argues that, long before their time, phrenologists perceived that the brain was not an amorphous, singularly functioning organ but rather a composite of many sites, each with its own specialised functions. Damasio acknowledges that phrenologists also posited many erroneous theories that left their indelible mark on later neurological and physiological research but maintains that their interpretation of brain specialisation has subsequently been proven to be correct (Damasio 1994: 14-16).

levels of intelligence with the cranial capacity of children's skulls. By the end of the 1890s, however, Binet was beginning to doubt the veracity of any such correlations and began questioning the unscientific and hidden biases that affect such measurements (Gould 1996: 176-8).<sup>7</sup>

There was also widespread concern towards the end of the nineteenth century over how to diagnose and recognise those whose disabilities were less obvious, those who were classified as feeble-minded and whose mark of disability was hidden from view (Rose 1985: 97-102). As well as this, there were growing concerns about the inordinate emphasis given to medical diagnoses of idiocy and feeble-mindedness, especially when it came to issues of educational placement (Rose 1985: 101-2). The eventual solution to these problems was resolved through the widespread development and application of intelligence testing. Rather than measuring the size and shape of skulls as the means for understanding the functioning of the brain, intelligence tests drew on the performative abilities of individuals recognised as particular abstract mental processes. Rather than measuring the external characteristics of a person's

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<sup>7</sup> F. Allan Hanson (1993: 204) has argued that the advent of modern testing procedures that "measure the differing capacities of individuals" had their roots in Darwinian theory. In opposition to Hobbes, Rousseau, Locke, Hegel and Marx, who all essentially believed in the fundamental equality of humankind, Darwin's theory of evolution was based on the necessary differences between humans out of which natural selection occurs. However, and this is an important point that Hanson does not pick up on, this process of evolution required that some species would disappear as the more successful ones adapted more fully to the environment. Francis Galton applied Darwin's notion of variation to the human and social realm and developed a systematic process of measuring and identifying these differences (Aiken 1996: 7-8; Hanson 1993: 205). Through his Anthropomorphic Laboratory that was set up in London in the 1880s, Galton measured and collated numerous human abilities, including variations in visual, auditory and weight discrimination, strength, memory, speed of perception, sensitivity to pain and head size (Aiken 1996: 8). These measures of sensorimotor skills upheld Locke's empirical philosophy that the senses were the doorway to intelligence, the measurement and hereditary nature of which Galton was particularly interested in (Aiken 1996: 9). In order to successfully deal with his mass of material Galton devised "the notion of the standard deviation and the statistical concept of correlation" (Hanson 1993: 205). This process set up the concept of the norm, of a basic and central standard of measurement and assessment of human differences. What began as a measure of difference and variation therefore became an evaluation of that difference in relation to a norm (cf. Gleason 1989).

body, intelligence tests examined the internal workings of the mind (Gould 1996: 23; Hanson 1993: 271).

### **Measuring Intelligence**

The development of testing and measuring intelligence as a wide-scale and state-sanctioned endeavour had its origins in late nineteenth century France with the work of Alfred Binet and his student, Theodore Simon. Binet and Simon bemoaned the lack of scientific precision in psychology and believed that a specific diagnosis of idiocy had to be based on objective, quantifiable facts rather than vague subjective interpretations. Rather than rely on the imprecise categories of idiot, imbecile, feeble-minded and moron, as was the trend of medical practitioners in late nineteenth century France, Binet and Simon sought a measurement that would objectively categorise a person both in relation to their innate intellectual abilities and in relation to all other people. They believed that a universal measure of intelligence would transcend the boundaries and idiosyncrasies of cultural nomenclature by providing statistical data untainted by caprice, subjectivity or indifference. It would allow for comparison, both across cultures and within an individual, especially with regards to assessing whether there have been (or indeed can be) changes in a person's intellectual capability. It would also allow for the assessment of treatment and training procedures, and for an investigation of whether idiocy can, in the end, ever be cured (Binet & Simon 1976 [1905]: 333).

Binet and Simon took as their primary assumption Esquirol's definition of idiocy as "a weakness of the intelligence" (Binet & Simon 1976 [1905]: 342) and Pinel's interpretation of it as a deficiency of intellectual faculties (Rose 1985: 33). Esquirol had also associated idiocy with a deficiency in language and speech (Binet & Simon 1976 [1905]: 336), and the tests that Binet and Simon devised

emphasised linguistic capabilities as central features of intelligence. Reminiscent of Locke, Binet and Simon's definition of intelligence was also based on the "ability to judge well, to comprehend well, [and] to reason well" (Aiken 1996: 19). Binet and Simon argued that an accurate classification of idiocy, although often combined with other observable physical symptoms, must take as its first principle the fundamental and determining cause of the problem as inferior states of intelligence. As they put it:

If the physician gives a child a diagnosis of profound idiocy or of imbecility, it is not because the child does not walk, nor talk, has no control over secretions, is microcephalic, has the ears badly formed, or the palate keeled. The child is judged to be an idiot because he is affected in his intellectual development (Binet & Simon 1976 [1905]: 342).

Binet and Simon believed that developing a test to measure intelligence would create a "precise basis for differential diagnosis" (Binet & Simon 1976 [1905]: 335). They argued that within the category "idiot" there existed a wide variety of states and types of intelligence in need of scientific differentiation. These differences, they believed, were not so much of type as of degree. As Binet and Simon put it: "These inferior states are indefinite in number, being composed of a series of degrees which mount from the lowest depths of idiocy, to a condition easily confounded with normal intelligence" (Binet & Simon 1976 [1905]: 331).<sup>8</sup> Therefore, it was the scientific ordering of differences between idiots that was necessary. The consequences of this, as Rose argues (1985: 141), had an overwhelmingly administrative and pedagogic aspect.

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<sup>8</sup> Working in the United States of America at the same time as Binet and Simon in France, Naomi Norsworthy also concluded that the difference between "ordinary children and defectives" was one of degree rather than of kind (cited in Luckey 1967: 172).

In their 1905 article, "Upon the Necessity of Establishing a Scientific Diagnosis of Inferior States of Intelligence", Binet and Simon outlined their reasons for establishing a measure of intelligence, stating that it was in response to a French Government directive to provide clear and precise criteria by which to distinguish "defective" from "normal" children. The purpose of this was ostensibly to weed defective children out of ordinary schools and provide them with special education (Binet & Simon 1976 [1905]: 331; cf. Digby 1996: 12-3; Gould 1996: 178-183; Hanson 1993: 208-212; Luckey 1967: 171; Rose 1985; Ryan 1973: 38-39). With the introduction of compulsory education throughout much of Europe, North America and the Western world in the late nineteenth century, the problem of children who were seemingly ineducable, or less easily educated, caused considerable problems for teachers. These difficulties were exacerbated by the problems associated with diagnosing idiocy and assessing the potential educability of such people (Aiken 1996: 5; Digby 1996: 12; Rose 1985: 101-2). The development of the intelligence test was seen as a remedy to this problem, and was devised specifically to assess mental deficiency.<sup>9</sup>

This assessment of intelligence and potential for educability had an altruistic basis, and drew on Séguin's belief that "defective" children could and would benefit from special training. However, despite Gould's (1996: 182-183) defence of Binet, it is clear that this altruism was marred by the perception of idiocy as a state that one did not wish upon others without absolutely irrefutable evidence. As Binet and Simon wrote: "To be a member of a special

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<sup>9</sup> Similarly, the first use of the intelligence test in North America was for the sole purpose of measuring and assessing mental deficiencies (Hanson 1993: 209). Henry Goddard, director of the Vineland Training School for Feeble-Minded Boys and Girls in New Jersey, initially wanted to test the accuracy of Binet's tests, and concluded that "Binet had certainly evolved a very remarkable set of questions . . . that . . . did work with amazing accuracy . . . [and that] whatever defects or faults they do have . . . the tests do come amazingly near what we feel to be the truth in regard to the mental status of any child tested" (Goddard 1976 [1910]: 358). Goddard translated the 1905 Binet-Simon Intelligence Scale in 1908 and then went on to revise and standardise this scale in 1910 (Aiken 1996: 16; Goddard 1976 [1910]).

class can never be a mark of distinction, and such as do not merit it, must be spared the record" (Binet & Simon 1976 [1905]: 331). To be classified as subnormal was the worst punishment a child could endure, and one that would effect his or her entire life. Consequently, Binet and Simon believed it was imperative that procedures based on "the precision and exactness of science should be introduced into [their] practice wherever possible" (Binet & Simon 1976 [1905]: 331).

Binet and Simon argued that the definitions of idiocy by Locke, Itard and Séguin, upon which some of the earliest tests of "intelligence" were based including Galton and Cattell's sensorimotor tests, were too simple and sensory in nature to adequately measure the complexity of intelligence (Aiken 1996: 10).<sup>10</sup> The assumed correlation between intelligence and sensorimotor skills upon which such tests were based was eventually disproved in the early years of the twentieth century (Aiken 1996: 9-10).<sup>11</sup> In comparison to intelligence tests, studies of motor and sensory perception were also considered to be "tests of the less complex mental processes" (Luckey 1967: 171-172). Instead of focusing solely on sensorimotor and perceptual skills, Binet and Simon developed a test that assessed a child's capacity to solve problems. Consequently, their 1905 intelligence test diagnosed and assessed idiocy in terms of specific and diverse mental abilities. These included abilities for abstract reasoning, memory, numeracy, comprehension, time orientation, object comparison, knowledge, and the combination of ideas into wholes (Aiken 1996: 13). In order to measure such skills Binet and Simon included in

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<sup>10</sup> James McKeen Cattell visited Galton's Anthropomorphic Laboratory in London and was familiar with Galton's particular form of "mental tests". Cattell then went on to develop these tests back in the USA (Aiken 1996: 7).

<sup>11</sup> Binet actually included sensorimotor skills in the earlier tests that he devised with Victor Henri, along with a complex mix of other tasks, abilities and observations, including moral judgement, mental addition, the recall of a series of digits and even cranial capacity (Aiken 1996: 11).

their test "tasks such as the naming of designated objects, comparisons of lengths of lines, repetition of digits, completion of sentences, and comprehension of questions" (Rosen *et al.* 1976: 327), as well as visual coordination, cognisance of food and objects, suggestibility, drawing from memory, and distinctions between abstract terms (Aiken 1996: 12). Their test ultimately assessed a child's capacity for judgement, comprehension and reasoning through verbal and perceptual materials, although the emphasis was always on the higher and more complex verbal abilities which came at the end of the test (Aiken 1996: 13).

Binet and Simon revised their initial test in 1908 in order to group the questions in terms of their difficulty for different ages rather than on the basis of their difficulty *per se* (Aiken 1996: 13; Rosen *et al.* 1976: 328). The "mental age" (MA) of the child was thus devised, and this represented the "age" at which the child had last been able to answer the questions. This revised test sought a comparison between different levels of mental ability and as such was based on the *a priori* assumption that a standard or normal level of intelligence could be correlated with age. Intelligence in Binet and Simon's model was therefore intrinsically bound up with theories of development. Binet and Simon sought to clarify the standard abilities of children at different ages and at different points in their intellectual development. As Henry Goddard—who translated and standardised the Binet-Simon Intelligence Scale in 1908 and 1910—acknowledged, by interpreting these normative abilities as "so fundamental and human that they do not depend upon training, [Binet] is able to say that to us, any normal child who has lived in the world three years is able to do such and such things" (Goddard 1976 [1910]: 357).

In 1916 Lewis M. Terman also revised and standardised the original Binet-Simon intelligence test and scale (Hanson 1993: 209). This new test, which Terman called the Stanford-Binet Intelligence Scale, is still in use today,

although since 1916 it has been revised three times, in 1937, 1960, and 1986 (Aiken 1996: 84-89). These tests include the measurement of perceptuo-motor skills and verbal tasks, as well as memory, judgement, interpretation, and abstract reasoning (Aiken 1996: 87-88). As well as popularising the use of intelligence testing in North America, Terman was also the first to incorporate the intelligence quotient (IQ) in his tests as a singular mark of intelligence. Devised by William Stern, a German psychologist who also developed Binet and Simon's intelligence tests, the IQ is a relative rather than absolute measure of intelligence. As the ratio of mental age to chronological age, the IQ produces a score that oscillates around the standard norm of 1 (or 100 when converted to a percentage) as indicative of average intelligence (Hanson 1993: 210-212; Luckey 1967: 172).<sup>12</sup>

Through the development, standardisation and application of intelligence tests by Binet, Simon, Terman, Goddard and others during the first decades of the twentieth century a new way of defining, assessing, and diagnosing idiocy was devised. Idiocy was a dysfunction of intelligence; the consequence of an inferior or abnormal cognitive ability. It was based on the association of reason with intelligence as an observable, testable and measurable phenomena. Such quantifications ultimately allowed for distinctions to be made between normal and abnormal levels of intelligence, the latter which then came to be associated with gradations of intellectual disability. Intellectually disabled people's

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<sup>12</sup> Terman's test, which was further revised by Robert Yerkes to allow for mass testing through the use of multiple choice questions, also represents the first mass application of the intelligence test, given with disastrous results, to army recruits in the USA preparing for World War One (Hanson 1993: 210-212). Goddard and Terman were both involved in this testing, the results of which were to be used to classify the sort of work each recruit should do. The average mental age of white American males, as Hanson points out, turned out to be 13, with those from other ethnic backgrounds recording even lower age levels. This difference in ethnic scores has been a crucial factor in criticisms levelled at intelligence testing, not withstanding the fact that the tests were used to weed out potentially intellectually undesirable immigrants to the United States.

deficiencies, abnormalities and incapacities have subsequently been quantified, measured and assessed by reference to such tests.

F. Allan Hanson (1993) has outlined the increasing dependence on testing in Western societies, in particular in North America, and argues that "our addiction to testing influences both society and ourselves as socially defined persons" (Hanson 1993: 1). Hanson's analysis encompasses both the way in which tests define and produce certain kinds of persons, as well as the means used to sustain a level of surveillance and domination over them (Hanson 1993: 3-4). While such an analysis tends towards totalising the cultural construction of identity with problematic consequences for issues of agency, it does highlight the role played by these constructions in shaping the way we think about and perceive others. Intellectually disabled people have been constructed as lacking in intelligence for their failure to adequately pass the tests that are supposed to measure intelligence.

The definition of intelligence and reason that is both assessed and reinforced through these tests has been implicitly interpreted within the parameters of decontextualised, isolated and abstract mental operations. Intelligence testing ultimately relied on the capacity for, and development of, abstract mental and linguistic abilities. The reliance on language in intelligence tests was recognised as a problem when it came to assessing those who lacked the required verbal and written communication skills (Luckey 1967: 172). Consequently, other tests were developed, such as the formboards of Healy and Witmer, and the Merrill-Palmer Test which relied on gestures rather than spoken communication (Aiken 1976: 205; Luckey 1967: 173). However, these tests were fundamentally assessments of abstract mental processes, and this became the hidden marker of normality, sociality and reason, a marker that is still dominant in contemporary definitions of intellectual disability. Rather than grounding abnormality in the physical as medicine has done, psychological interpretations

of intellectual disability have grounded reason and intelligence in certain abstract mental procedures, measurements and tests. As the most dominant and influential form of this, intelligence testing has embodied certain concepts of reason that have never been rendered in physical terms in the medical model. This clinical interpretation has fundamentally affected the institutional perception, management and treatment of intellectually disabled people. The psychological and medical records of my siblings attest to the ongoing reliance on intelligence tests and IQ scores as a means for diagnosing and assessing intellectual disability.

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*In November 1962, when specialists at the Alder Hay Children's Hospital in Liverpool were trying to determine the cause of Stephen's epileptic seizures, they noted that there was "no evidence of intra cranial calcification" (26/11/62). Apart from prescribing drugs for the epilepsy and performing numerous medical tests over the following three years, both on him and my three other older siblings, it was not until August 1965 that the first of many intelligence quotient (IQ) tests was performed. In keeping with the original purpose of Binet's IQ tests, Stephen was tested by the local school and child health doctors from the Public Health Office in Wallasey to determine whether or not he was fit to attend a 'normal' school. At the age of five and a half, he was made to perform the Revised Stanford-Binet Form L-M and was given an IQ of 38 and a mental age (MA) of one year and eleven months. Stephen was considered mentally deficient and it was suggested to my parents that he attend the special education school close by, which had been set up to provide for children who, on the basis of their intellectual capabilities, did not fit into mainstream education.*

*The principal paediatrician at the Alder Hay Children's Hospital wrote to Dr R in Perth that "This boy [Stephen] is definitely retarded, both from the physical and the mental points of view" (21/12/65). He based this assessment on the Stanford-Binet test*

*done in 1965 and a number of EEG and urine chromatography tests performed over the previous three years. That single test was the only mention of IQ and mental age for any of my siblings during the time that we lived in England. Within six weeks of arriving in Australia, however, and over the intervening 35 years, there have been numerous examinations of my siblings' psychological and intellectual capabilities. These, combined with medical examinations and social adaptability tests, have consistently diagnosed my brother and two sisters as mentally retarded, though the degree to which they were considered to be retarded has varied over time. The original IQ result was regularly referred back to as the hallmark, the yardstick, against which all subsequent tests were compared. It became indicative of whether there had been any improvement or deterioration in my siblings' retardation, or whether they were to remain forever fixed at a particular level of intellectual impairment.*

*Miss L—the psychologist from the University of Western Australia's Department of Psychology who tested and observed Maryla and Stephen on our arrival in Fremantle—focused particularly on their language (in)ability and performance on formboard tests.<sup>13</sup> She also described my siblings' behaviour during testing and how they related to my parents. Because Stephen had no speech he was tested on the 'performative' items of the Binet and Randell's I's test. It was noted that he passed "the straightforward formboards and other tasks where the requirements were more or less self evident, at a good 4 year level". However, as Miss L comments, "he did not comprehend identification and matching tests above the 3 year level". She deduced from these tests that Stephen's "manual dexterity and space-form perception" was at three-quarters the normal age, "but consider[ed] his language, conceptual and*

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<sup>13</sup> The use of formboards, or cut-out shapes that fit onto indents in a board, was first adopted by Itard and Séguin in their training of idiot children (Drever & Collins 1928: 12-13). The formboards were incorporated into the Stanford-Binet Intelligence Scale by Terman as performance tests to assess the capacity for concrete problem solving in children without relying on linguistic ability (Aiken 1996: 6; Drever & Collins 1928: 12-13).

*comprehension level [to be] considerably lower". She says this despite acknowledging that Stephen "appeared to understand everything his mother said to him" (15/2/66).*

*Maryla was also tested in 1966 at an age of 4 years and 4 months. Miss L wrote of Maryla that she was "hyperactive and distractible but not excessively so. The most obvious abnormality [being] a speech disturbance" (21/3/66). After testing Maryla on Randell's I's Performance test Miss L deduced that Maryla's median age was 3 years 6 months, and her IQ was 80±5. The Peabody Picture Vocabulary Test (PPVT)<sup>14</sup> assessed Maryla's verbal skills at 3 years and 4 months but Miss L concluded that her "comprehension and use of language [was] below this level and not within 'normal' range either in quality or content". She commented that Maryla "has a history of delayed development in motor skills as well as speech and [that] it is possible that the 'turns' are secondary to the abnormal development". However, Miss L also wrote that Maryla "was surprisingly good on manipulative tasks —passed two items at age level (formboards)". She notes that this "is similar to the performance of her brother Stephen . . . [and] the picture seems to be one of inconsistent development and selective disturbance of function" (21/3/66).*

*Through tests administered at the Grosvenor Diagnostic Centre the same 'discrepancy' was observed between verbal and formboard tests, the latter "which [Stephen] performed with insight and foreplanning". Yet the concluding impression was that "Stephen's overall level of social and intellectual development appears to fall within the upper half of the moderately retarded range" where "verbal skills fall well below the moderately retarded range but some performance abilities extend to a good mildly retarded level". The mean result between these disparate results produced a diagnosis in the "upper half of the moderately retarded range" (25/5/67). As someone who did not rely on spoken language to communicate, it is not surprising that my*

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<sup>14</sup> The Peabody Picture Vocabulary Test (PPVT) measures receptive vocabulary and intellectual functioning through the use of images rather than spoken words (Aiken 1996: 205).

brother “could succeed at none of the verbal items of this [Merrill-Palmer<sup>15</sup>] scale at its lowest limits—18 months to 2 years” (25/5/67).

By 1967 the results of the Merrill-Palmer test for intelligence had given Stephen an IQ of 45 and a mental age of 3 years and 1 month. He was 6 years and 10 months old. In 1969 the same tests produced a slight improvement in verbal skills, but not above the 2 year level, while on the performance tests he recorded a result of 5 and a half to 6 years of age (12/5/69). Stephen was still considered to be below the mildly retarded level, even on the performance tasks. In February 1975, during his final assessment at Grosvenor by a third psychologist using the same Binet L-M test, Stephen was given an IQ “below 30” and a mental age of 3-0 years indicating a “severe degree of intellectual handicap” (24/2/75). He was 14 years and 7 months of age. This result was referred to in all subsequent correspondence as the final assessment of Stephen’s intellectual disability.

Ursula was also tested at Grosvenor on our first visit in May 1967 and was given an IQ of 54 and a MA (mental age) of 2-0 years. She was 3 years and 7 months old. In 1969, just five days before she died, Ursula was again tested using the Merrill-Palmer Scale of Mental Tests. She was very upset, anxious and easily distressed, as the report indicates, and whether or not her performance was due to this, the psychologist noted that “Ursula refused many items, and consequently began failing at the 18 month level, though she did achieve some successes in the 3-1/2 to 4 year range i.e. in form-board type items”. Consequently “no real estimate can be made of her intellectual level except to say that the I.Q. obtained from testing, which would place her at the upper end of the moderately retarded range, seems to be lower than her hypothesised potential which would appear to be at least within the mildly retarded range” (12/5/69).

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<sup>15</sup> The Merrill-Palmer Scale is a performance test of a number of skills including "forms or other objects to be manipulated, as well as copying, remembering words and sentences, and matching or discriminating between forms" (Aiken 1996: 176). It is used as a popular non-verbal substitute for the Stanford-Binet Intelligence Scale (Aiken 1996: 176).

*As with Stephen and Ursula, Maryla was also tested during these visits to Grosvenor, although for her I have reports up to the present day. These reports continue to use the IQ and MA as indicative of intelligence, comprehension and social abilities. In 1967 it was noted that Maryla “was not sufficiently co-operative for her intellectual abilities to be assessed adequately”. This was partly owing to her “bizarre behaviour” during testing (12/5/67). Her MA was given at somewhere between 48 and 65 months using a combination of the Merrill-Palmer and the Peabody Picture Vocabulary Test. In 1969 a more precise assessment was recorded. On this occasion the Stanford-Binet test gave Maryla an IQ of 37 and a MA of 3 years and 1 month, while on the Merrill-Palmer she recorded an IQ of 54 and a MA of 4 years and 1 month. In March 1974, specialists from the NSW Education Department used the Binet Scale L-M to test Maryla once again, this time giving her an IQ of 35 and a MA of 3 years and 5 months. She was 12 years and 4 months old at the time.*

*In 1977, having already moved to Stockton Hospital, Maryla was once again intellectually assessed using the PPVT and the Stanford-Binet Form L-M. At 15 years and 8 months of age she was given a MA of 1 year 9 months and an IQ of less than 30 on the PPVT, and a MA of 3 years 10 months and an IQ of less than 30 on the Stanford-Binet test. The Clinical Psychologist who did the testing deduced that on “the basis of this assessment, Maryla would appear to be functioning within the severe range of mental retardation”, the results indicating that she has “deteriorated” since the tests done in 1974 (5/7/77). He suggests that this might be due to a recent ward change as it parallels a recent “regression in behaviour generally” and possible “adjustment problems”. In 1986, after an assessment using the same tests gave consistent results that “are comparable with those of previous testing” (ie. a MA of 2 years 7 months and an IQ of less than 40 on the PPVT, and a MA of 3 years 7 months and an IQ of less than 30 on the Stanford-Binet), Maryla was once again placed “in the severe range of mental retardation” (28/7/86). While recent correspondence from Stockton has generally been more concerned with behaviour modification and*

*individual service plans than intelligence testing and assessment, the classification of severe mental retardation drawn from these earlier tests remains consistent. These are referred to in any correspondence regarding possible community placement and other management and training plans for Maryla.*

### **The Loss of Meaning**

The interpretation of the mind primarily as a tool for reasoning has tended to overshadow many of the other complex and inter-related functions and attributes of the mind, including its relationship with the body and emotions (Damasio 1994: 197-199). It has also tended to prioritise only certain types of mental abilities as rational and capable of producing meaning. The focus on intelligence, and on the performance of tests to measure relative intelligence and mental age, indicates that at the heart of such practices is the very issue of reason itself. The mind has been prioritised as a tool for reasoning rather than as an entity through which symbolic meaning is created and communicated. Humanness has been defined according to reason, which has itself been associated with specific mental processes rather than with the capacity for sociality and engagement in social relations.

The positivist interpretations upon which anthropology's "practical reason" have been based are not dissimilar to such accounts of intelligence and reason. Writing about the development of anthropology, Sahlins explains that:

Mind appears in Morgan's theory as the instrument of cultural development rather than its author . . . Passive rather than active, simply rational rather than symbolic, the intelligence responds reflexively to situations it does not itself produce and organise, so that in the end a practical logic—biologic in the earlier stages,

technologic in the later—is what is realized in cultural forms  
(Sahlins 1976: 58).

In such accounts, the propensity to create culture and engage in sociality is only recognised as a product of a certain kind of mind. This mind is one that has responsive and rational capacities rather than creative and symbolic capabilities. The minds of those who are different, along with their actions and interactions, are perceived as abnormal aberrations rather than potentially productive of meaning and culture. This is the crux of the matter, the ultimate source to which I trace this distinction between some actions as meaningful and others as abnormal. The mind is perceived as the source of culture and sociality. Yet this mind depends on an association of reason with intelligence that excludes the different capabilities and products of some minds, and hence the people associated with them. Some people are normal, others abnormal. Some create and reproduce meaning, others never can. Some are considered encultured and social beings, others unencultured and asocial. Intellectually disabled people are considered incapable of creating meaning. They may use language, but not to convey meaning to others (Kanner 1944: 214).<sup>16</sup> While this is often the accepted *clinical* view, it also extends to anthropological accounts of intellectually disabled people. Craig MacAndrew and Robert Edgerton (1970: 28) argued that profoundly retarded people have a "dramatically impaired"

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<sup>16</sup> Kanner's early descriptions of infantile autism included a comment about meaning. He claimed that although some of the children he studied developed the ability to speak, they did not use language "to convey meaning to others" (Kanner 1944: 214). This, combined with the notion that autistic people cannot relate to others, serves to isolate them in a world of abnormality and asociality. Consequently, as David Leser (1996: 45) writes, it is assumed that "Autism sets up barriers that somehow engulf a child, making their world unfathomable to us and, indeed, our world unfathomable to them". This attitude towards autism was echoed in a recent television report (ABCTV 11/2/2000). In this programme the commentator stated that autistic children live in a "frightening world" with "no speech, no imagination, no social skills". Rather than leaving them in this isolated world, however, the report described a new therapy based on mimicking the actions and gestures of these children in attempts to draw them into the socially meaningful world represented by the therapists (cf. Gleason 1989; Goode 1980b).

capacity for culture and that this is related to their "lack of language skills". As they put it, while such people "respond to some symbols, they create symbols only rarely if at all" (MacAndrew & Edgerton 1970: 28).

Due to this assessment, and following Edgerton's lead, the sociocultural study of intellectual disability has tended to focus on social issues such as deinstitutionalisation, adaptation to the community, and the stigma associated with being labelled "mentally retarded" rather than on the possibility of meaningful interactions with severely mentally disabled people.<sup>17</sup> Yet my research has shown that severely intellectually disabled people do have the capacity to create and engage in symbolic, patterned behaviour, albeit in a limited and restricted form. The jigsaw puzzles and bits and pieces that my siblings used represent the purposeful production of a symbolic life. It has been through engaging with such symbolic activities that a mutual sociality has been mediated and my siblings' social identity supported. My intellectually disabled siblings may not have used language in conventional ways, nor expressed normative dispositional behaviours, but their capacity to create recognisable, repetitive and patterned modes of symbolic systems through their particular uses of objects provided the grounds for social engagement. In this sense, the jigsaws and bits and pieces became symbols of sociality. While my siblings' very real deficits in intellectual ability affected their range of symbolic expression, they did not entail an incapacity for sociality.

The identification of humanness, intelligence and reason with particular linguistic skills, symbolic expressions and mental operations has profoundly influenced the perception and interpretation of intellectual disability. This association has undermined and denied the creativity, humanness and sociality of intellectually disabled people, whose means of interacting with others,

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<sup>17</sup> These sociocultural studies are the focus of chapter five.

expressing themselves and making meaningful the world are generally embodied in very specific practices rather than the abstract and isolated skills measured in intelligence tests. As John Gleason emphasises in his observation of the meaning in profoundly intellectually disabled people's actions and interactions:

To see relationships among human systems and people is not the same as isolating variables and seeking correlations; rather, it is to explore the meaning in an event in a spatial and temporal context that respects the persons' patterns of interaction, communication and participation (Gleason 1994: 248).

As far as my siblings were concerned, there was no acknowledgment that an inability to conform to the testing procedures, that a failure to achieve a "normal" level of intelligence, could be indicative of a difference that cannot solely be interpreted in these terms. While there appears to be some consistency in the results of the intelligence and performance tests that my siblings have undergone since 1965, there is also a constant and underlying theme that suggests that my brother and two sisters all scored well on formboard and spatial tests. Interestingly, these abilities were responded to with surprise by those administering the tests.

The skills that my siblings did have, skills that I observed and admired as a child—such as their method of doing jigsaw puzzles, Maryla's collecting and patterning of bits and pieces, and Stephen's skill at balancing both himself and objects in a precarious manner—were given no serious credibility. They were not considered as evidence of an intelligence, of a different ability, adaptability and way of being in the world. Neither were they acknowledged as creative expressions, as the symbolic means through which my siblings expressed their particular forms of sociality and communicated with others. Instead, these skills

became indicative of an inconsistency in development. They suggested an aberration in the expected pattern of overall intellectual ability. As Gleason (1989: 7-8) and Johnson (1998: 71) have pointed out, intelligence and adaptability tests always stress intellectually disabled people's inabilities rather than what they can do.<sup>18</sup> "The focus becomes the handicap and the remediation of deficit areas rather than what the individual is doing", comments Gleason (1994: 256) and, as such, intellectually disabled people are rarely perceived as doing anything meaningful unless it correlates with socially prescribed behaviours and interactions. Notes from the medical and psychological records of my siblings are evidence of the way in which intelligence and reason has been associated with the capacity for meaningful human interaction. The presumption of asociality where particular forms of reasoning ability are lacking is evident.

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<sup>18</sup> Those people who exhibited particularly "unusual" skills were commonly known as "idiot savants", a term coined by John Langdon Down in 1887 (Treffert 1989: xxvii). In his study of this phenomenon and its history, Donald Treffert concluded that such people lack abstract reasoning and cognition, emotional expression and communication, and are aloof, hyperactive, impulsively driven and self-absorbed (Treffert 1989: 9-26). Treffert argues that idiot savants' special abilities do not rely on general intelligence, and are mimetic rather than creative, suggesting a different brain circuitry that bypasses the ones used in daily reckonings (Treffert 1989: 54). Treffert believes that these people exist in a world that lacks comprehension, relevance and meaning. The skills that they obviously have, be they mathematical, musical or artistic, are performed without understanding and represent a combination of functional and structural brain disorders—though Treffert stresses the need to emphasise the functional aspect of the disorder rather than its structural component (Treffert 1989: 230). What is most disturbing about Treffert's *Extraordinary People: An exploration of the Savant Syndrome*, is his desire to discover what it is that allows for such extraordinary skills so that the rest of the population can harness them (Treffert 1989: xiii). Treffert also perpetuates negative interpretations of intellectually disabled people, stressing their supposed lack of originality, creativity, communication, comprehension and meaning. Tragically, some of the people Treffert profiled lost their unique abilities once they were socialised into 'normal' behaviour patterns. In the case of one set of twins who communicated with one another through numbers, when they were separated they no longer had their mathematical mode of communication and became locked in an isolated world where no-one understood their means of communicating (Treffert 1989: 36-42, 80-1; cf. Sacks 1986: 199). Alternatively, Oliver Sacks argues that such people "may be truly and creatively intelligent, and not just have a mechanical 'knack', in the specific realms—musical, numerical, visual, whatever—in which they excel . . . and it is this *intelligence* which must be recognized and nurtured" (Sacks 1986: 184; author's emphasis).

*There are numerous examples in the medical notes of my sibling's seemingly strange behaviour or appearance: "The younger sister . . . is undoubtedly slow and has a funny gait" (7/4/66); "she was quite friendly with me—almost too friendly showing no shyness or anxiety to me as a person but is reported to be very anxious when out of doors" (7/4/66); "I thought [Stephen's] behaviour was decidedly hyperkinetic. He would concentrate for a few minutes at a time with certain toys but generally he wandered about the room opening and closing doors etc." (9/5/66); "she [Maryla] . . . demonstrates unusual behaviour" (19/5/67); "formal testing proved impossible, owing to Marylla's [sic] bizarre behaviour and inability to co-operate" (25/5/67); "all 3 children were hyperkinetic, impulsive and distractible. They rushed excitably about the room playing with toys only for short periods in a disorganised fashion, showing that quality of 'driven' over-activity characteristic of organic brain disease. All 3 appeared retarded clinically, especially Maryla. She also impressed as out of touch and somewhat bizarre in behaviour—she mouthed objects, ground her teeth constantly or emitted shrill shrieks. She is the most difficult to control, seems to have little sense of danger and has rushed out on the road in the path of oncoming traffic. She did some odd drawings and was left handed" (12/7/67). Commenting on Maryla's attendance at the University kindergarten, Dr R wrote that "On the days that Maryla was there is [sic] was necessary to bring in an extra mother solely to look after her, as she could not conform in class at all. On the other hand she would suddenly turn round read the lettering on the waste paper bin, or give one such other surprises" (19/5/67).*

*At Stockton, the progress notes observe that Maryla "often pretends to talk to herself and plays with imaginary objects" (1976), is continually "obsessed with her bits and pieces" and exhibits "very bizarre and inappropriate behaviour" (1978; 1983). In 1994 it was noted that her "obsessive behaviour" was still "difficult to manage". It was also noted in 1978 that Stephen had made "no progress in any areas of training. [His] obsessive behaviour, [and] main occupation [was] jumping over cracks in vinyl sheeting on the verandah, and doing jigsaw puzzles".*

What is most distinctive about these and other observations of my siblings' behaviour and capabilities is their "objective" nature. Not objective in the sense of being untainted by subjective impressions and biases, but objective in the sense that they are devoid of any interaction or attempt at communication. In all the reports that I read there is never any indication that my siblings were played or engaged with. Never did the examiner seek to enter their world, play their games, or interpret their drawings and behaviour as something other than abnormal. Their actions in the world were considered strange, bizarre, and beyond the reach of meaningful interaction. My siblings were perceived to be lacking in intelligence, and unable to reason, communicate and relate to the world as anything other than abnormal, isolated and dysfunctional persons. The only course these professionals took with my siblings was to classify and categorise their observations within the known parameters of pathology and normality. Any anomalies, any obvious skills that did not fit with this general impression, were responded to with surprise, but were also drawn back into a general diagnosis of intellectual disability through the overall perception of them as inherently abnormal and dysfunctional beings. Forms of reasoning deficit promoted the presumption of asociality even when evidence to the contrary was there.

### **Problems with Intelligence Testing**

Alfred F. Tredgold—a psychologist who specialised in mental deficiency and whose 1914 *Textbook on Mental Deficiency (Subnormality)* has been republished at least twelve times—criticised the practice of relying on intelligence tests as the sole diagnostic criteria of the deficiency. Tredgold's main criticism was that "the intelligence quotient and social behaviour are not perfectly related" (Tredgold & Soddy 1963: 3), a criticism that is still recognised in contemporary research

into the relationship between IQ and social adaptation (Hodapp & Dykens 1994: 680). Although criticising the unreliability of the IQ, its non-transference across different tests and its inconsistency, Tredgold argued that a diagnosis of mental deficiency must be based on the joint criteria of educability, social competence *and* intelligence (Tredgold & Soddy 1963: 3-7).

Edgar A. Doll's assessment of social competence and adjustment was a response to just such criticisms. The Vineland Social Maturity Scale was developed by Doll in the 1940s as an additional and holistic method for diagnosing mental retardation. Drawing on developmental models of learning and maturation, Doll developed the Vineland Scale in order to "quantify the evaluation of social competence as a global aspect of individual maturation at successive age levels" (Doll 1976 [1948]: 272). For Doll, social maladjustment was inadequate, irrational, unrealistic, undesirable, unconventional and socially objectionable (Doll 1976 [1948]: 270). Through the observation and assessment of behaviour and social skills such as communication, daily living, independence, socialisation and locomotion the social adequacy or inadequacy of a person would be determined (Aiken 1996: 213-215; Doll 1976 [1948]).

Therefore, it is not that intelligence tests were considered wholly invalid, but that they were not singularly appropriate tools for diagnosis. Mental deficiency was not just a deficiency in intelligence; it was combined with a deficiency in social skills, independent functioning, and personal and social responsibility (Aiken 1996: 213; Hodapp & Dykens 1994: 678; Luckey 1967: 172-173). The contemporary definition of intellectual disability is based on a combination of intelligence and adaptive behaviour and both are used in assessments of an individual's level of disability (Jenkinson 1996: 97). The psychological tests that my sister performed in 1986 as part of her assessment for potential community residential placement included the Vineland Adaptive Behaviour Scale (1984) to measure her social competency, as well as the Stanford-Binet Form L-M in

combination with the Peabody Picture Vocabulary Test to assess her intellectual capacity. An overall picture of Maryla's suitability for community placement was drawn from the results of these tests, and included an earlier and much cited medical diagnosis of "Recessive Metabolic Disorder of unknown aetiology" (28/7/86). In combination with medical assessments, such tests have been regularly used since 1965 to determine the social and cognitive capabilities of all of my intellectually disabled siblings.

During the 1970s, the practice of psychometrics, of intelligence testing, came under increasing attack from many quarters, especially with regards to potential discrimination on the basis of race, class and gender (Bijou 1992: 311-312; Hanson 1993: 259-268; Judge 1987: 35-37; Persell 1981; Ryan 1973; Wortis 1978). In his book, *The Mismeasure of Man*, Stephen Jay Gould argues against biologically determined theories that use a single quantifiable measure of intelligence and then reify and rank these results on a linear scale (Gould 1996: 20-56). Such data, Gould asserts, are subject to cultural constraints and tend to yield unintentionally biased results (Gould 1996: 59). As he writes of his book:

*The Mismeasure of Man* is not fundamentally about the general moral turpitude of fallacious biological arguments in social settings . . . It is not even about the full range of phoney arguments for the genetic basis of human inequalities. *The Mismeasure of Man* treats *one particular form* of *quantified* claim about the ranking of human groups: the argument that intelligence can be meaningfully abstracted as a single number capable of ranking all people on a linear scale of intrinsic and unalterable mental worth. Unfortunately . . . this limited subject embodies the deepest (and most common) philosophical error, with the most fundamental and far-ranging social impact, for the entire troubling subject of nature and nurture,

or the genetic contribution to human social organisation (Gould 1996: 20; author's emphasis).

Gould's account of the problematic and politically dangerous nature of intelligence testing is, as always, vivid and lucid. However, it is not just race, class and gender that is being categorised. Intellectually disabled people are undoubtedly the most affected of all people by these tests, and it is important to remember that the tests were specifically designed to separate them from the "normal" school population.

To define mental retardation according to cut off levels in IQ and mental age has always been a controversial practice despite its widespread use. These controversies have extended into debates over the definition of intellectual disability, of the relative worth of basing assessments and definitions of intellectual disability on IQ scores, whether assessments and definitions of intellectual disability should refer to intelligence at all, and, if not, what the criteria for defining mental retardation should rely upon. Sidney Bijou has criticised purely cognitive and intellectual functioning theories of mental retardation for their reliance on intelligence tests (Bijou 1992: 310-315). His main objection is that the test "attributes the immediate cause of retardation to a non observable, hypothetical variable which is called 'inefficient cognitive functioning', a variable derived by giving an individual's level of performance on an intelligence test a second name, that is, inefficient cognitive functioning" (Bijou 1992: 314). F. Allan Hanson (1993: 249) is even more explicit in his criticisms, arguing that the concept of intelligence is itself entirely a product of intelligence tests.

Jane Mercer (1975) has been more specific in her critique of the use of IQ scores and intelligence tests within the educational system. Mercer argued that such tests discriminate against the lower classes and non-Anglo ethnic groups,

and mark some children from these backgrounds as mentally retarded for the purposes of educational practices (Mercer 1975: 141). She claims that such assessments violate the rights of children, especially "their right to be evaluated within a culturally appropriate normative framework, their right to be assessed as a multi-dimensional human being, their right to be fully educated, their right to be free of stigmatizing labels, and their right to ethnic identity and respect" (Mercer 1975: 141). Chris Borthwick (1996) has taken this criticism even further, by arguing that the environmental biases that affect IQ scores for people from different cultural backgrounds also need to be considered with respect to people with Down's syndrome. Borthwick claims that:

If one asks why the relationship between IQ testing and people with Down's syndrome have [sic] not been analysed in the same terms as the relationship between IQ testing and blacks, the basic answer is that people with Down's syndrome are universally regarded as being essentially, rather than accidentally, different from the ruling culture. Liberals, conservatives, socialists and racists alike 'know' that people with Down's syndrome are intrinsically deficient (Borthwick 1996: 404).

While not wishing to enter the nature-nurture debate around which Borthwick's argument revolves—nor pursuing the claim that, aside from the normal prejudices, physical and perceptual impairments have also operated as the source of unhidden and unacknowledged biases in IQ assessments of Down's syndrome people (Borthwick 1996: 407-408)—I do wish to take up Borthwick's observation concerning the assumption of an absolute difference between the minds of intellectually disabled people and others.

Borthwick claims that the assumption of low intelligence as a "global characterisation" of mentally retarded people builds upon the racial analogy

instigated by John Langdon Down whereby "evolution, civilisation and intelligence were all equivalent to adulthood" (Borthwick 1996: 406). Despite the fallaciousness of such an equation, Borthwick argues, it underlies contemporary perceptions and interpretations of intellectual disability and such people's capacity for learning and language (Borthwick 1996: 408-409). However, the association of language and intelligence with adulthood, civilisation and evolution has far wider ramifications for intellectually disabled people than Borthwick attests. Because of the implicit association between the rational and abstract cognitive abilities that IQ scores are seen to represent and a capacity for communication and meaningful social interaction, intellectually disabled people have been positioned as being outside the social domain. Yet a capacity for mutual sociality relies on far more than just these limited mental operations. It relies on the capacity to create, engage in, and negotiate symbolic practices. If our sociality is fundamentally embedded in mutuality, then our capacity to interact is necessarily bound up in our ability to produce, mediate, negotiate, utilise and share symbolic systems of meaning. Strangely, this is not an issue that anthropologists have taken up with regards to criticisms of intelligence testing.

Focusing their discussions on child development, anthropological psychologists such as Sara Harkness and Charles Super have argued that interpretations of intelligence must be contextualised. They claim that "psychologists have sought to uncover the underlying rules of behaviour by experimentally detaching it from its usual context [while] anthropologists have sought explanations for human behaviour in its varying contexts" (Harkness & Super 1980: 2-3). Decontextualisation, they argue, ultimately affects the interpretation of behaviour and intelligence as behaviour is removed from its socially meaningful and structural site (Harkness & Super 1980: 5-8). While Harkness and Super interpret child behaviour as a cultural and social

phenomenon, they also tend towards interpreting those "other cultures" as somehow internally uniform and relative to one another.

Robert LeVine takes up the issue of intelligence in his essay on "Child Development and Anthropology", arguing that there is a continuity between cultural values, ideologies and beliefs, and the research paradigms that encompass studies of child development. LeVine claims that:

The psychological preoccupation with intellectual development and the relative neglect of social and affective development reflect the values Westerners place on the higher cognitive functions and on competitive achievement in that area, as well as the connections our institutions make between IQ tests, educational selection, and economic distribution . . . In other cultures, different individual characteristics will be seen as variable, problematic, and worthy of study. Thus the concern of psychologists with child behaviour variables most frequently reflects the concern of the culture in which their social perceptions are embedded (LeVine 1980: 77).

The tests of intelligence that are used to measure internal cultural variation do so on the basis of norms and standards that incorporate predetermined interpretations of what intelligence is in the first place. In this way, argues Robert LeVine (1980: 79), "folk beliefs acquired from one's culture incline one to identify the known range of variation at home with the limits of the normal and the natural for the human species". LeVine quotes studies that have specifically focused on cultural aspects of cognition. These suggest that cognition is directed towards different goals and uses different strategies within different social and cultural settings (LeVine 1980: 82). In this way, intelligence as an absolute and definable category and entity becomes highly problematic. It must therefore be seen as a social and cultural entity that has specific

meaning within the historical, economic and ideological constraints of particular cultures. By inference, intellectual disability must also be interpreted in this light. Within Western cultures intellectual disability has been interpreted according to the symbolic scheme of reason and normality. Consequently, intellectually disabled people have been perceived and treated as abnormal beings who are lacking in reason and intelligence and who therefore exist outside the parameters of meaningful sociality. In order to move beyond such assessments, the intelligence and meaning of intellectually disabled people's actions and interactions must be interpreted within their own socially meaningful contexts.

Intelligence is now acknowledged as an amorphous, complex and multifaceted concept, something that is difficult to define let alone measure and test (Hanson 1993: 249-283; cf. Humphrey 1992; Damasio 1994; Gould 1996; Wortis 1978). Within psychology itself there has been serious criticism and debate over the concept and definition of intelligence, especially with regards to whether it is innate and unchanging, and whether the IQ score is an adequate measure of intelligence (Bijou 1992: 310-313; Barnett 1986; Benson *et al.* 1993; Detterman 1987; Hanson 1993; Hodapp & Dykens 1994; Hodapp & Zigler 1986; Ryan 1973; Wortis 1978; Yirmiya *et al.* 1996). There has also been increasing doubt cast on the hereditary nature of intelligence, as Cliff Judge (1987: 36) outlined in his account of the controversy surrounding Cyril Burt's research into intelligence.<sup>19</sup> Despite these criticisms, research on the genetic nature of intelligence still continues (V. Anderson 1974; Dykens 1995; Heaton-Ward 1978; Judge 1987; Kaplan 1972; Zigler, Balla & Hodapp 1984). The

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<sup>19</sup> Burt's seemingly incontrovertible evidence supporting the hereditary nature of intelligence was based on experiments that he had done with identical twins. Burt was later accused of tampering with the data to prove his hypothesis. Judge argues that this had consequences for the whole nature-nurture debate on intelligence, and on the politics of access to education (Judge 1987: 36).

publication of Herrnstein and Murray's *The Bell Curve: Intelligence and class structure in American life* in 1994 brought the supposed relationship between race, intelligence testing and IQ to the forefront of heated debates once again. Despite these ongoing controversies there has been a return to utilising methods such as the intelligence test and IQ scores for grading and the placement of children in both "normal" and special schools since the mid-1990s (Carman-Brown & Fox 1996: 233).<sup>20</sup>

By 1986, the official term used to refer to intellectual disability in Australia had changed to developmental disability (Judge 1987: 34; Kearney 1996: 19-27)—or "DDs" as the staff at the group homes where I worked called the consumers. Developmental disability does not equate as closely with intellectual disability as mental retardation, mental deficiency and idiocy have done. It is a broad generic term that is based on common needs for service provision rather than a specific diagnosis. Developmental disability is defined as a severe or chronic disability associated with intellectual and/or physical impairment that is manifest in the developmental stage (ie. before 18 years of age). This impairment results in functional limitations in three or more areas of adaptive behaviour, including self care, learning, language, mobility, self-direction, independent living, and economic self-sufficiency (Accardo & Whitman 1996: 87; Kearney 1996: 19-21).

This recent change in terminology was a response to some of the criticisms levelled at the concept of innate intelligence embedded within intelligence testing and IQ scores, a concept which condemned children and adults diagnosed with low intelligence to a passive acceptance of their condition.

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<sup>20</sup> The NSW Department of Education stipulates that students requiring special education services "must have a full-scale IQ score of approximately two standard deviations or more below the mean on an approved individual test of intelligence". This IQ score is used in conjunction with an assessment of adaptive skills and school performance (NSW Department of Education 2000: 2).

Developmental models of intellectual disability, on the other hand, arose out of "a cataloguing of capabilities of retarded people" between the turn of the century and the late 1940s (Detterman 1987: 2). In North America, a focus on child development, and in particular the acquisition of language, was also being experimentally and quantitatively assessed from the early twentieth century (Luckey 1967: 171). And, in the 1950s, specific research by A. D. B. Clarke into the capacity for learning and development of intellectually disabled children ultimately influenced the psychological assessment and interpretation of intellectual disability (Bullock & Trombley 1999: 520). Reminiscent of Séguin's assertion over 100 years earlier, Clarke claimed that intellectually disabled people could learn complex skills and task analysis, but that their capacity to do so was subject to the effectiveness of training schedules (Bullock & Trombley 1999: 520).

The developmental model of intellectual disability—which was adopted by the highly influential International League of Societies for the Mentally Handicapped in 1971 and used for the purposes of appropriate programming—stated that "retarded children and adults are . . . capable of growth, learning, and development" (cited in Scheerenberger 1986: 65). It continues: "Each individual has potential for some progress, no matter how severely impaired he might be. The basic goal of programming for retarded individuals consists of maximizing their human qualities" (cited in Scheerenberger 1986: 65). The studies by Clarke and others had concluded that retarded people can change and learn, and that their retardation is in fact exactly what the term refers to, a retarded development; one that exists along a singular continuum with all other people but at a lower level. Having accepted this interpretation, the emphasis turned to the provision of appropriate services and methods to assist intellectually people to learn and develop. This is the principle that informs contemporary institutional practices and which I

observed at Xanadu and the group homes. It is the basic component of individual service plans and, in fact, is stipulated as a requirement of all services for intellectually disabled people.

Despite this shift in emphasis to learning and development, intelligence and reason are still crucial and central issues in the research on, and perception of, intellectual disability. Intellectual disability is still an *intellectual* disability. It is still a problem of the brain. Despite his support for the developmental model of intelligence, Douglas Detterman argues that "any theory of mental retardation must also be a general theory of intellectual functioning" (Detterman 1987: 11). As he argues: "Standardized measures of human intelligence as they currently exist in the form of intelligence tests are really global measures of system functioning; they were designed to be that" (Detterman 1987: 5). However, and this is the important point, intellectually disabled people's development is always one of innate "inefficient cognitive functioning" (Hodapp & Zigler 1986: 117; cf. Barnett 1986; Detterman 1987: 4).

Such clinical interpretations of intellectual disability are firmly embedded within the symbolic scheme of reason and normality that has shaped Western culture and consciousness. As a consequence of associating normal humanness with a particular interpretation of reason as intelligence, the practical, utilitarian, abstract, linguistic, logical and cognitive functions of the mind have been privileged as the necessary criteria for human sociality. Psychological assessments perpetuate this association by prioritising such intellectual capabilities. Medical interpretations perpetuate it through diagnoses that are mainly a search for genetic variation understood as an explanation for intellectual deficit and abnormality. The recommendation for dealing with such deficits and abnormalities has ultimately depended upon some form of institutionalisation. Historically, this included incarceration in mental asylums as much as it now embodies contemporary institutional practices of treatment

and training. At no time did medical or psychological clinicians propose that observations of my siblings' sociality was necessary, or that there was anything problematic in reading presumed social capacity from intellectual testing. Instead, my siblings were considered incapable of creating and engaging in socially meaningful actions and interactions. It was assumed that training, treatment and management were the only possible steps towards alleviating their presumed asociality. Such institutionalised practices were the general response to a diagnosis dominated by an unexamined association of reason, itself equated with levels of intelligence, with the capacity for human social being.

## Chapter Five

### A Sociocultural Phenomenon

*Since in Man the predominant feature is Mind,  
and since it is by its development and evolution  
that human progress has taken, and must take, place,  
it is clear that the question of its disease, and particularly of its defect,  
is one of supreme importance to the statesman,  
the sociologist, the philosopher, and the whole community.*

*Tredgold & Soddy*

As a consequence of these clinical assumptions, psychological and medical interpretations of intellectually disabled people have placed such people beyond normal or autonomous sociality. In sum, this situation has meant that intellectually disabled people are only ever professionally "known" in terms of their abnormalities or problems, be they physical, intellectual and/or behavioural. Such a "case history" approach not only informs the way that intellectually disabled people are perceived and treated but it also limits responses to them (Gillman *et al.* 1997). Despite more recent concerns with assessing intellectually disabled people's potential for social adjustment and competence, and acknowledgments that they can learn and develop social skills, such practices are still limited by institutionalised environments.

The overwhelming dominance of this clinical and institutional approach to intellectual disability has meant that such people's pre-existing capacity for sociality has rarely been acknowledged. Nor have their lives been readily examined from a sociocultural aspect. Intellectually disabled people may have

constituted a social concern or problem but they were not considered social beings worthy of social analysis. This neglect was influenced by the assumption that reason and intelligence were the necessary attributes for meaningful sociality. Without them, it was impossible to be a normal human, let alone a social person. However, just as concern for the proper diagnosis of borderline retardation or feeble-mindedness precipitated the development of intelligence testing, it was an interest in the life circumstances of mildly retarded individuals in the community that precipitated one of the first sociocultural studies of intellectual disability. Robert B. Edgerton (1967) is the person associated with the first ethnographic study of mentally retarded people, and while he inspired a number of analyses of intellectual disability from a cultural and cross-cultural perspective, to this day the study of intellectual disability still remains a relatively minor field within the social sciences. Following Edgerton's example, many sociocultural researchers in the field of intellectual disability have analysed the stigma and social consequences of being labelled mentally retarded. They have also focused on social welfare issues such as deinstitutionalisation, socialisation and community adaptation. In the first section of this chapter I outline the contribution of Robert Edgerton's research to the sociocultural field of intellectual disability, both through his own research and through those who were inspired by his approach. I then explore the uneasy alliance between these sociocultural studies of intellectual disability and disability studies—a multidisciplinary field of research which emerged at around the same time—especially with regards to critiques of the medical model of disability.

While the sociological and social welfare issues that Edgerton researched are important, central as they so often are to the life experiences of intellectually disabled people, there is often a tendency to focus on these at the expense of analysing other ways in which intellectually disabled people experience and

make meaningful their lives. The work of Robert Bogdan and Steven Taylor (1982) represented an important and significant shift in the sociocultural analysis of intellectual disability. Through the words of two mildly retarded informants Bogdan and Taylor provided the sociocultural field of intellectual disability with an "insiders view" of the lived experience of mental retardation. Bogdan and Taylor were also critical of Edgerton's uncritical acceptance of the clinical interpretation of mental retardation, arguing instead that such clinical interpretations must be analysed as a social construction; an approach which aligns their work more closely with disability studies. However, while the clinical model inadvertently denies intellectually disabled people's capacity for human sociality, the social constructionist model ignores the fact that intellectually disabled people are more than just the products of social constructions, projections and meanings. In the second section of this chapter I outline the contribution of Bogdan and Taylor, and show how their work has influenced contemporary social analyses of intellectual disability as a social construction.

As a consequence of Bogdan and Taylor's phenomenological method, a third "school" of thought has emerged in the sociocultural field of intellectual disability. In the final section of this chapter I explore in detail the work of David Goode (1980a, 1980b, 1984, 1990) and John Gleason (1989, 1994), who both emphasise issues of intimacy, relatedness, communication and meaning in their research with intellectually disabled people. Unlike Edgerton and Bogdan and Taylor's accounts, which predominantly focus on the experiences of mildly intellectually disabled people, both Goode and Gleason have focused their research on relationships with and between severely intellectually disabled people. While their concern with intimacy and relatedness has resonances with my own analysis, there are also significant differences, both between them, and between their work and my own. By comparing the difference between clinical

and intimate relationships with severely retarded persons, and their connection to differences in perceptions of such people's attributes and capabilities, Goode has argued that identities are socially generated. His work consequently remains partially within a social constructionist paradigm. Gleason, on the other hand, has focused his attention on the possibility of meaningful interactions between severely intellectually disabled people and uses these observations to critique some practices in special education. He argues that the pathologisation of intellectually disabled people as socially abnormal prevents educators from recognising the intent and meaning in such people's actions.

My own analysis of the clinical interpretation of intellectual disability as a product of the symbolic scheme of reason and normality seeks to understand why such people are perceived as socially abnormal and what the institutional consequences of this perception are. I also emphasise the fundamental sociality of severely intellectually disabled people and seek to interpret intimate and meaningful relationships with them by acknowledging that mutuality, interdependence and interrelatedness can constitute their social life. I argue that it is through the negotiation and mediation of symbolic systems that the mutuality and sociality of intellectually disabled people is manifest and recognised.

## Labelling and Stigma: The work of R. B. Edgerton

In 1963 Robert B. Edgerton criticised the fact that, despite the enormous amount of literature in the field of intellectual disability, nearly all of it was from the perspective of "social workers, psychiatrists, psychologists and other medical specialists" (Edgerton 1963: 372).<sup>1</sup> As such, he went on to argue, it only ever "consists of psychometric reports, demographic analyses, observations from the school, medical office or clinic, and short interviews with the retarded person or his family" (Edgerton 1963: 372; cf. Gillman *et al.* 1997).<sup>2</sup> Edgerton

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<sup>1</sup> Robert Edgerton trained as a graduate student in anthropology at the University of California at Los Angeles (UCLA) during the 1950s. He did his doctorate there under the tutelage of Walter Goldschmidt and then taught in the Department of Psychiatry and Anthropology at UCLA from 1962. Edgerton was also instrumental in the development of the Socio-Behavioural Research Group which was part of the Mental Retardation Research Centre at UCLA—one of the 12 university based research centres to exist in the United States in 1984 (Edgerton 1984a). Edgerton's main area of interest was psychological anthropology, which at that time was influenced by neo-positivist studies of the relationship between personality development, society and culture. His doctoral research was a projective study of the Menomini Indians of Wisconsin; a study that sought to elucidate whether or not "Menomini values, like their patterns of personality, were equally predictable in terms of an acculturative process" (Edgerton 1978: 449-450). After completing doctoral research Edgerton joined Goldschmidt's research team which was attempting to determine the effects of ecological and economic changes on cultural adaptation in East Africa. However, Edgerton had already begun doing research with mentally retarded people by this time, studying the effects of institutionalisation, and the institutional process, on personality and behaviour. It is this area of research for which he has become best known.

<sup>2</sup> It is arguable that there has been little change in the intervening period since Edgerton made this statement. Hugh Mehan points out in his study of educational handicaps that the medical model is still pervasive and dominant. As he puts it: "When mental states are equated with physical states, educational handicaps become equated with diseases" (Mehan 1988: 80; cf. Ryan & Thomas 1987). Despite the growth of literature exploring intellectual disability from a qualitative and sociocultural perspective, the majority of research is still biomedically and quantitatively inclined. The *Australian Journal of Intellectual and Behavioural Disability* only ever has such quantitative analyses, and while the social study of disabilities is starting to make a mark on the academic scene in Australia, it is still only through informal gatherings of like-minded researchers (such as the Social Relations of Disability Research Network which has monthly seminars at the University of New South Wales) rather than through any formal journal or school. Although disability studies has become more established in the academic scene in the United Kingdom and the United States

sought to change this through his many sociocultural studies of the lives of mentally retarded adults, although he is best known for his ethnographic account of deinstitutionalised people entitled *The Cloak of Competence: Stigma in the lives of the mentally retarded* (1967).

The most significant feature about *The Cloak of Competence* was that for the first time the lives of mentally retarded people, as conceived and articulated by them, were deemed to be worthy of social analysis. There was, however, still an underlying social welfare concern in Edgerton's ethnography, especially with regards to the problems associated with deinstitutionalisation and social adaptation. Despite this, Edgerton gave to his subjects complex, multifaceted, and dynamic social and psychological experiences, transforming them from objects of study into subjects with their own, albeit problematic, points of view (Gerber 1990).<sup>3</sup> Where previous studies had focused primarily on external quantitative assessments of how mentally retarded people adjusted to the community, Edgerton filled a void by providing an ethnographic account of their everyday lives, thoughts and emotions, and how they felt about being retarded and living in the community (Edgerton 1967: 7-8; cf. Edgerton 1963; MacAndrew & Edgerton 1970 for an account of the everyday lives of institutionalised adults).

Although Edgerton was trained as an anthropologist, and used ethnographic techniques such as interviews and narrative description as his means for understanding the life experiences of his subjects, he did not draw upon contemporary anthropological theories of culture as his theoretical tool. Culture, at that time in American anthropology, was understood to be a collective, learnt and reproduced phenomenon, a "set of [symbolic]

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of America, the relationship of intellectual disability to disability studies still remains problematic, as I shall argue later in the chapter.

<sup>3</sup> I pick up on some of Gerber's criticisms of Edgerton's work later in the chapter.

representations that shaped action and informed events" (Kuper 1999: 165). Mentally retarded people, Edgerton argued, did not adequately learn or reproduce cultural patterns, nor could they be interpreted as a separate culture or subculture (MacAndrew & Edgerton 1970; cf. Gerber 1990: 10).<sup>4</sup> Consequently, despite Ruth Benedict's (1934) earlier anthropological analysis of epilepsy and abnormality as cultural concepts, and despite the fact that intellectually disabled people do utilise symbolic representations as their means for interacting with others, Edgerton turned to Erving Goffman's symbolic interactionism and his analyses of labelling, stigma and total institutions to interpret the life stories and experiences of the people he studied.<sup>5</sup>

In the early 1960s Goffman had applied the technique of participant-observation in his study of the stigmatising effects of total institutions on an individual's identity and self-esteem (Goffman 1990 [1961]; Goffman 1974 [1963]). While Goffman (1990 [1961]: 130) acknowledged that those on the "back wards" (ie. the mentally retarded) could have "a livable and continuously

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<sup>4</sup> In characteristic style, Edgerton changed this assessment and later argued that groups of mentally retarded people such as those working in a sheltered workshop could be studied as a distinct culture with their own beliefs, practices and meanings (Edgerton 1984d: 501).

<sup>5</sup> In 1934 Ruth Benedict published an essay entitled "Anthropology and the Abnormal". Rather than dealing with questions of why abnormalities occurred or how they could be treated, the whole notion of abnormality as a cultural phenomenon was instead put under scrutiny. Through an analysis of cultural attitudes towards abnormalities such as epilepsy, Benedict concluded that the perception of such conditions is culturally relative and based upon different values and interpretations of both human behaviour and social roles (Benedict 1934). Benedict argued that the American Indian cultures which she studied valued the trance states that occur with epileptic seizures and associated them with the authoritative and honoured role of spiritual mediums. In contrast, Western cultures perceive epilepsy as "blots upon family escutcheon and as evidences of dreaded disease" (Benedict 1934: 61-2). Where the latter are branded "abnormal and reprehensible", the former interpretation of epilepsy makes it "an essential attribute of ideal man" (Benedict 1934: 72). Consequently, Benedict argued, both normality and abnormality are culturally and morally defined, such that normality "is primarily a term for the socially elaborated segment of [the chosen range of] human behaviour in any culture [while] abnormality [is] a term for the segment that that particular civilisation does not use" (Benedict 1934: 73).

meaningful social world" once seen from the inside, he stopped short of analysing their experiences, or "moral careers", claiming that such people lacked the complexity and learning capacity essential for self preservation through role-playing, denying, and passing. In contrast, Edgerton argued that mildly mentally retarded people could and did have the capacity to develop ways of dealing with their stigmatised identity, and that they do attempt to pass as normal in efforts to conceal the stigma of their discredited identity (Edgerton & Sabagh 1962; Edgerton 1967; cf. Gerber 1990: 11-14).

Goffman had also been influenced by symbolic interactionism, a theory of social life most readily identified with the social psychology of George Herbert Mead. Mead (1934: 1-24) argued that humans are distinguished by their capacity for language, for symbolic representation, and that meaning, rather than being inherent in things or a consequence of abstract rationality, emerges through the interaction of the self with society. One sees oneself in relation to others, and how others perceive us, but also through the social roles that we enact. Therefore, it is the social meanings that people attach to the world and others that determines their actions (Taylor & Bogdan 1998: 11) As Kathryn Pyne Addelson puts it (in paraphrasing Herbert Blumer, a student of Mead's who gave to symbolic interactionism its specifically sociological dimension): "It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life" (Addelson 1991: 81).

In the 1960s Howard Becker (1963, 1964) and Edwin Lemert (1967) applied some of the insights of symbolic interactionism to their analyses of the social processes by which certain behaviours are labelled as deviant. They theorised that the problem of deviancy lay not in the act itself but within the institutionalised and professional definitions and interpretations of behaviour that labelled as deviant those behaviours which deviated from the norm. In this way the process of labelling both produced and reinforced deviant behaviours

in a self-perpetuating, circular relationship such that a person incorporated this definition into their self-image and played out the deviant role assigned to them (Whitehead 1993: 49-50; cf. Conrad & Schneider 1985; Ferns 1993: 135-6; Mehan 1988).

While Edgerton incorporated the theories of labelling and symbolic interactionism in his analyses of mental retardation, he was critical of the application of deviancy theory to the experiences of mentally retarded people. The dominant Parsonian/Durkheimian viewpoint was that deviance was a product of disturbances in the social equilibrium rather than a natural product of human nature. This "oversocialized view of man" (as Dennis Wrong put it; cited in Edgerton 1978: 445), claimed that humans internalise the rules, values and laws of society and culture and that they conform to these in order to sustain social harmony and self-esteem (Edgerton 1978: 445-449). Alternatively, as Becker and Lemert argued, deviancy is a social category that serves to support the status quo or to maintain group identity in contrast to dominant social expectations (Edgerton 1970: 538-539). Edgerton was frustrated with both these interpretations of deviance, arguing instead that it was a complex process which involved both deviant acts and deviant persons, and that the causes must be sought in the interaction of sociocultural environments with human nature (Edgerton 1978: 470). With regards to mentally retarded people, however, Edgerton stated that the metaphor of deviance was inappropriate because such people do not consciously or intentionally deviate from the status quo (Edgerton 1970: 539; 1967: 209). Consequently he preferred to use the term incompetence, and focus on issues of stigma and labelling, rather than adhering to the theoretical concept of deviance.

Despite this general interest in competence, stigma and labelling, Edgerton's early forays into the field of intellectual disability were somewhat different in their preoccupations. They focused instead on the social relations and

friendships of retarded individuals. One of these early studies was a profile of the "complex social relations" that "elite" patients in a mental hospital had with one another (Edgerton 1963). These "elite" patients were comprised of a subgroup of inmates of mainly Black and Mexican-American people from low socioeconomic backgrounds. They were not necessarily the "high grade" inmates (the 21% who were the highest functioning with an IQ above 50)<sup>6</sup> but were defined by their shared, often self-appointed, status as delinquents (Edgerton 1963: 374). The elite patients set themselves apart from the other inmates, claiming that they were not mentally retarded and therefore should be in a prison or home with other delinquents rather than a mental institution.<sup>7</sup>

In another early paper Edgerton and Craig MacAndrew argued that, despite the general perception of severely mentally retarded people as possessing "only the barest rudiments of those qualities which are taken to be peculiarly human", they do have the capacity for enduring and elaborate friendships with one another (MacAndrew & Edgerton 1966: 613). Through a description of a long term, emotional and "extraordinarily intense and pervasive friendship" between two institutionalized males, Edgerton and MacAndrew argued that severely retarded people do engage in complex relationships that "are testimony to the essentially human character of even the most retarded among us" (MacAndrew & Edgerton 1966: 620). However, unlike mildly retarded individuals who have the capacity to "invest their

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<sup>6</sup> The other groups within the institution, the "low grades" and "middle grades" are defined by having an IQ below 20 (30% of inmates) and an IQ between 20 and 49 (49% of inmates) respectively (Edgerton 1963: 373).

<sup>7</sup> Interestingly, especially with regard to Benedict's earlier analysis of abnormality, one of Edgerton's concerns in this essay was with the issue of "normality" in social relationships and behaviour. He posed a number of questions about the "intra- and inter-personal nature of 'normality'", emphasising the seemingly "normal" and complex nature of the behaviour and social relationships of this elite group, arguing that low IQ does not necessarily prohibit a person from engaging in appropriate and competent social behaviour (Edgerton 1963: 384). However, despite this initial interest in normality, Edgerton never went on to explicitly explore the concept of "normality" as a complex social and theoretical issue.

behaviour with meaning" (Edgerton 1984c: 503), Edgerton and MacAndrew argued that people with profound intellectual disabilities have very little or no ability to create or respond to symbols (MacAndrew & Edgerton 1970: 28). By associating a "lack of language skills" with "impoverished cultural and social behaviour", Edgerton and MacAndrew (1970: 28) consequently disregarded the social and symbolic nature of other forms of behavioural expression and action. They ignored the means through which such people do communicate and engage with others, such as repetitive dispositional behaviour or the conscious utilisation of objects. In accordance with a symbolic scheme that identifies human sociality with language, reason and intelligence, such an interpretation relegates profoundly mentally retarded people to a status as "*less* human than some infra-human species" (MacAndrew & Edgerton 1970: 28; authors' emphasis). Despite acknowledging a capacity for relationships, this interpretation denied profoundly mentally retarded people's capacity for a broader sociality.

Due to this interpretation, and because of his growing interest in the problems associated with deinstitutionalisation, Edgerton went on to exclude profoundly and severely retarded people from his anthropological analyses of the social and personal issues that deinstitutionalised mildly mentally retarded people have to contend with. He argued that severely retarded people cannot and do not exist in socially normal and acceptable circumstances and therefore were not suitable candidates for deinstitutionalisation. By extension, neither were they suitable for his study of the consequences of deinstitutionalisation. Those who were borderline retardates, and who had the capacity for "some intellectual tasks", were, Edgerton believed, capable of adhering to certain necessary social standards and conditions and were therefore worthy of social analysis (Edgerton 1967: 2-3).<sup>8</sup> This concern with the life experiences of mildly

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<sup>8</sup> Edgerton's distinction between mild, moderate and severe mental retardation is sometimes confusing and contradictory. At times he argued that mildly

retarded people set the parameters for the sociocultural study of intellectual disability for over a decade. Not until David Goode's (1980a; 1980b) analysis of relationships between severely retarded children and their parents did the focus shift to picking up on Edgerton's earlier analysis of the possibility of social relations between severely retarded people and others.

### **Edgerton's 'The Cloak of Competence'**

Edgerton's *The Cloak of Competence* was published in 1967 at a time when there was widespread criticism of the power of medicine, psychiatry, and the large mental institutions to interpret and control the lives of mentally ill and retarded individuals (for example see Goffman 1990 [1961], 1974 [1963]; Foucault 1995 [1961], 1986 [1963]; Laing 1960; Szasz 1977 [1961]). Due to this increasing social pressure, mildly retarded and mentally ill patients began to be released into the community, although there were concerns as to how they would fare and what factors should be taken into consideration when deciding who to deinstitutionalise. Edgerton spent the majority of 1960 and 1961 observing, interviewing, and analysing the lives of a group of mildly mentally retarded adults in order to gain some insight into these and other concerns. Most of his informants had been deinstitutionalised in 1954 from Pacific State Hospital—a large state hospital in California specifically for mental patients from which Edgerton drew the material for his earlier papers—and were now attempting to live as members of the general community. Through a series of formal but

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retarded people were the casualties of sociocultural factors, including poverty, malnutrition, parental neglect and racial discrimination (Edgerton 1978: 456; Edgerton 1984a: 26-27, 37-40). However, he also argued that their incompetence was innate, and a real disability that they must constantly deal with (Edgerton 1967). In contrast, and more consistently, Edgerton wrote that those who were severely mentally retarded were undoubtedly "organically" or "clinically" so, and that their inabilities were due to this rather than any sociocultural factors (Edgerton 1984a: 26). He also stated that up to 75% of those labelled retarded fell into the mild category (Edgerton 1984a: 26).

loosely structured interviews Edgerton sought to elicit from these people their experiences of being mildly mentally retarded. Using these interviews Edgerton built up life histories through which he formulated themes that were of concern for mildly retarded people living in the community. These included such issues as their relations with others, including sex, marriage and fertility; their neighbourhood, home and possessions; their self-perception, outlook on life, and employment, and what they did with their spare time (Edgerton 1967: 44).<sup>9</sup>

Theoretically, however, Edgerton was more concerned with how mildly retarded people coped with life on "the outs" (as life outside the institution was called), and how they adapted to living in the community. He sought to understand the consequences of processes of institutionalisation, incompetence and labelling, and argued that deinstitutionalised mildly retarded people relied heavily on the support of non-retarded "benefactors" in order to successfully cope with life outside the institution (Edgerton 1967: 193). They also accumulated personal belongings to give the appearance of normality, made up biographies that denied their hospitalisation, or stated that, unlike the severely mentally retarded, they had been wrongly institutionalised and labelled as retarded. Despite this common denial of their retardation and institutional past, Edgerton argued that deinstitutionalised mildly retarded people still had to deal with the reality of being incompetent, and that it was this which most affected their life circumstances (Edgerton 1967; Luckin 1986: 94).

As a consequence of this assessment, Edgerton aimed to assess "the critical problems that these retarded people face in the management of their

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<sup>9</sup> These issues, and the general theoretical concerns that Edgerton had with the consequences of labelling, stigma and dependency, were returned to by Edgerton in his follow-up studies of this same group of individuals (Edgerton & Bercovici 1976; Edgerton, Bollinger & Herr 1984).

incompetence" (Edgerton 1967: 142). Through analyses of their perceptions and experiences of life in the community, he argued that they utilised a "cloak of competence" to hide both the stigma of their discredited past as well as their inherent incompetencies (Edgerton 1967: 59-69, 143). Edgerton and Sabagh had earlier argued that attempts to pass as normal through "aggrandizement" were positive and necessary indicators of mentally retarded people's capacity to live outside the institution (Edgerton & Sabagh 1962). Edgerton changed his interpretation in *The Cloak of Competence* and claimed that such attempts at passing and denial were in fact negative and indeed rather sad attempts at hiding the true and devastating nature of their retardation (Edgerton 1967; cf. Gerber 1990).

Not only were many of the people Edgerton studied dealing with the daily incompetencies of being illiterate and innumerate. They also found that being labelled retarded, and being associated with others who were even less competent than themselves, was the worst possible stigma they had to endure (Edgerton 1967: 146-149). As Edgerton put it:

The label of mental retardation not only serves as a humiliating, frustrating and discrediting stigma on the conduct of one's life in the community, but it also serves to lower one's self-esteem to such a nadir of worthlessness that the life of a person so labelled is scarcely worth living (Edgerton 1967: 145).

They cannot accept themselves as mentally retarded and have self-esteem, Edgerton argued, because the stigma of retardation is total. Therefore to maintain self esteem mildly mentally retarded people must deny their retardation (Edgerton 1967: 207-212). Not only do they utilise a "cloak of competence" to pass as normal, but, as Goffman (1974 [1963]: 5) had also stated, they have to deal with the perception that as people with a demonstrable

stigma they were seen as "not quite human". This is a point that Jenkins (1998b: 19) has also made, although for him the focus is on competency rather than stigma and the association of cultural concepts of (in)competency with the constitution of the nature of normal humanness.

Edgerton argued that the stigma of mental retardation is expanded to subsume all possible competencies and that such people are "by definition, incompetent to manage any of [their] affairs [and are] forever doomed to [their] condition . . . There is no cure, no hope, no future. If you are once a retardate, you remain one always" (Edgerton 1967: 207). Mentally retarded people may seek ways to deal with this stigma, but they can never alleviate it entirely. Despite Edgerton's criticism of IQ scores (and other measurements of skills and competencies) as valid indicators of the potential success of social adjustment to the community—and his argument that age, personality, education, training, class and ethnicity are far better indicators of how an individual will fair after being deinstitutionalised (Edgerton 1967: 196-197)<sup>10</sup>—the subjects of Edgerton's study were all, according to him, burdened by the stigma and reality of their low intelligence. Aside from seeing this as a consequence of both the clinical reality of retardation and the stigma of being labelled as such, Edgerton does not analyse why competencies associated with cognition and intelligence (in the narrowest of senses) have remained so central

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<sup>10</sup> This concern with predicting the potential success of community adaptation is an issue that Edgerton takes up in his later studies. Edgerton and Bercovici (1976: 490) argued that the determining of what constitutes "successful community adaptation" is highly ambiguous and controversial, meaning as it does different things to different people, and especially to retarded people (a point that Edgerton takes up as one of the essential aims of research, ie. to discover what is meaningful for retarded people). The notion of successful community adaptation also has very complex, unspecifiable and multifaceted factors associated with it, and needs to be understood within a particular context and over long periods of time rather than being just a measure of skills, personality and competencies (Edgerton & Bercovici 1976: 489-495). Despite these concerns, however, quantitative assessments of social skills and competencies are still used in Australia as a means for determining the potential success of deinstitutionalising intellectually disabled people, as I discovered when I read my sister's case notes.

to our perceptions of "normal" humanity. Neither does he explore why the stigma of retardation should be so irredeemable in our culture; why such people are discredited in all aspects of their lives; and why we accept only certain forms of subjectivity, creativity and interaction as valid, meaningful and social.

Rather than analysing these issues, Edgerton argued that the solution to the problems associated with the stigmatised identity of mental retardation was to change the mental-medical-psychological aspects of the term into a behavioural one that does away with any reference to the stigma of low intelligence and incompetence (Edgerton 1967: 212). He suggests this for several reasons, all of them associated with improving the adaptation of mentally retarded people to life in the community. It is to encourage mentally retarded people to be "willing participants in their own improvement"; to make them more socially acceptable in their appearance and behaviour; more independent, productive, satisfied, and open to being educated (Edgerton 1967: 212-214; 1984c: 502). Ironically, despite Goffman's (1990 [1961]: 154-155) criticism of the pressure on mentally ill inmates to adopt the medical view of themselves as inherently ill, Edgerton is arguing that the acceptance of the "sick-role" is essential for successful community adaptation. As Séguin's treatments had done more than a century earlier, the process of community adaptation includes attempts to transform people who have been categorised as asocial and abnormal into normal and socially acceptable persons. The practice of training and management regimes in contemporary deinstitutionalised settings is an ongoing aspect of this.

### **Edgerton's Influence on the Study of Intellectual Disability**

Through his use of Goffman's concept of stigma, in combination with Becker and Lemert's notions of labelling, Edgerton set the parameters of the debate

for the early sociocultural study of mental retardation. This confined it for the next decade (and even beyond in some cases) to concentrating on the consequences of labelling and stigma on a retarded person's self-identity and experience (Angrosino 1998a; Bogdan & Taylor 1976; Christensen 1992; Davies & Jenkins 1997; Gordon 1975; Heshusius 1981; Jenkins 1998a; Koegel 1986; Kurtz 1981; Langness & Levine 1986; Lea 1988; Mardiros 1989; Mercer 1975; Mest 1988; Raybeck 1988; Rowitz 1988; Susman 1993; Zetlin & Turner 1984). Many supported Edgerton's 1967 conclusion of the dominant and negative stigmatising effects associated with the label of mental retardation (Bogdan & Taylor 1982; Langness & Levine 1986; Kurtz 1981; Mercer 1975; Raybeck 1988). Following Edgerton's later conclusions (Edgerton & Bercovici 1976; Edgerton 1984b, 1986), others have argued that the consequences of labelling are dynamic, complex, unpredictable, and not always negative (Angrosino 1998a; Davies & Jenkins 1997; Gordon 1975; Mardiros 1989; Mest 1988; Rowitz 1988; Susman 1993; Zetlin & Turner 1984).

Those such as Douglas Raybeck (1988) argue that labelling is a process that is dependent on social types. Consequently, "large scale social units" have negative labelling effects due to decreasing interdependence and interpersonal information and increasing inequalities and formal mechanisms for treatment. This is the sort of process that Louis Rowitz outlines, whereby the label of retardation "becomes intertwined with the entire diagnostic process and with the approved interventions associated with that diagnosis" (Rowitz 1988: 1). Rowitz argues that the inclusion of mental retardation within the generic label of developmental disabilities has led to increased confusion and homogenisation in the areas of service provision (Rowitz 1988: 2). There are others, such as Marilyn Mardiros (1989), who claim that Mexican-American parents utilise the medical label of mental retardation in positive ways to gain access to essential services such as special education (a point which Rowitz

[1988: 2] also acknowledges as one of the positive effects of labelling). Charlotte Aull Davies and Richard Jenkins (1997), on the other hand, argue that incorporating the label "learning difficulties" into one's self identity is a complex process. To be properly understood it needs to be separated into discourses about learning difficulties and experiences of being disabled in this way. Despite these differences in opinion the focus on the impact of labelling and stigma has had far reaching consequences in the area of policy development and implementation. Through the influential work of Wolf Wolfensberger (1977), the negative consequences of being labelled mentally retarded and deviant were criticised and an alternative, known as the principle of normalisation, was instigated throughout the social services for intellectually disabled people in the USA, Europe and Australia.<sup>11</sup>

Following in the footsteps of Edgerton, and associated with the Socio-Behavioural Research Group of the Mental Retardation Research Centre at UCLA, were those who advocated the life history approach to the study of mental retardation (Edgerton 1984b; Langness & Levine 1986). Rather than adhering to a "case history" approach that pathologises and objectifies those who are mentally retarded—and countering the overtly theoretical, quantitative, and technical accounts of mental retardation that exist in psychology and statistical sociology—researchers who adopt the life history approach use informal interviews to develop individual biographies that express the unique and diverse lived experience of being retarded (Gillman *et al.* 1997; Goodley 1996). Such accounts stress and acknowledge the subject's own interpretations and experiences of life (Easterday 1980: 221), and provide him or her with opportunities to articulate an authentic self-identity and voice (Atkinson & Walmsley 1999: 209; Booth & Booth 1996: 55).

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<sup>11</sup> Wolf Wolfensberger's theory of normalisation and the institutional practices associated with it is discussed in greater detail in chapter six.

In their different ways, researchers such as L. Langness, Robert Whitmore, Paul Koegel and Harold Levine have sought to portray what they termed an "emic" or "insider's version" of mental retardation.<sup>12</sup> Using life histories they focused particularly on issues of socialisation and incompetence and sought to portray the complex and dynamic interplay of these with environmental, social, familial, institutional and biological factors (Whittemore, Langness & Koegel 1986; Edgerton 1986). As Koegel, and Levine and Langness, point out, it is possible to be socialised into a state of incompetence through a labelling process that precipitates a loss of exposure to normal social experiences (Koegel 1986; Langness & Levine 1986; cf. Edgerton 1986). In this way, Langness and Levine argue, incompetence becomes a double bind. A person is not only perceived and labelled as inherently incompetent but becomes socially incompetent through their lack of social experiences (Langness & Levine 1986: 197).

This interest in the processes through which people are categorised as incompetent has continued to be a central feature of sociocultural studies of intellectual disability. Focusing on these processes through the lens of stigma and labelling theory, however, has often overshadowed an interest in the life experiences of intellectually disabled people from other perspectives. As well as this, incompetence has tended to be analysed as an individual experience rather than as a social phenomenon. In a recent collection of essays edited by Richard Jenkins (1998b) these theoretical concerns have been taken up and analysed from various perspectives. The notion of incompetence has been expanded to incorporate such issues as the effects of culture, economics and class on perceptions and constructions of competence and incompetence. The relationship of (in)competence to ideas of identity, personhood, sociality and normality has also been explored. And, as the form of the term

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<sup>12</sup> Bogdan and Taylor (1982) were in fact the first to study mental retardation in this way.

"(in)competence" indicates, each of these more recent analyses acknowledges that any study of "incompetence" must inherently include within it the social and cultural notions of "competence" upon which it is based (Jenkins 1998b: 223).

The utilisation of narratives, life histories and auto/biographical based research with intellectually disabled people has also continued and proliferated in contemporary sociocultural studies of intellectual disability. These methods of research are used as tools for making visible the experiences of intellectually disabled people; people who are generally denied this opportunity because it is often believed that they have "no capacity for understanding or conveying their own situation or experiences" (Atkinson & Walmsley 1999: 209; cf. Easterday 1980: 217). Some, such as Danny Goodley (1996), stress the need for a critical reappraisal of the potential downfalls of this approach, particularly the assumption that social theory can be readily linked with an individual's life history. Goodley (1996) is also critical of the potential to assimilate a person's life story to the researcher's own point of view (cf. Booth & Booth 1996: 63). However, the general assessment is that such research provides an important means for gaining access to the experiences of intellectually disabled people. As Tim and Wendy Booth argue, rather than interpreting the problems encountered with this style of research as a consequence of the person's disabilities, narrative research should be developed in such a way as to include the stories of all of those who have difficulty articulating themselves (Booth & Booth 1996: 67).

Some of these life history and auto/biographical accounts of intellectually disabled people have been analysed in terms of the metaphors that such people develop to account for their life circumstances and experiences. Lois Easterday (1980) recounts the story of a young man who used military terms and adopted a military autobiography to account for his time in an institution. Reminiscent

of Goffman, Easterday (1980: 220) argues that this man substituted one total institution for another as a way of managing his spoiled and stigmatised identity. Although also analysing mental retardation within the parameters of stigma, Michael Angrosino (1992: 171-172) has sought instead to understand the "interactive communicative contexts" through which mentally retarded persons "create culturally appropriate metaphors by which to convey their sense of identity to others". Rather than focusing on the content of their life histories, Angrosino emphasises the "formal, stylistic properties of the narrative as the main conveyors of meaning" (Angrosino 1992: 173). He argues that the "metaphors of stigma" that mentally retarded people utilise help to produce meaningful and "shareable" accounts of their identity and selfhood (Angrosino 1992: 175-176; cf. Angrosino 1994; Angrosino 1998b).

Most sociocultural researchers in the field of intellectual disability have generally been concerned with analysing the consequences of social, welfare and educational policies. Just as Edgerton had done, they tend to focus on issues such as deinstitutionalisation and community adaptation (Begab & Richardson 1975; Heshusius 1981; Howard 1990; Johnson 1998; Langness & Levine 1986). Others have analysed the consequences of quality of life programmes (Atkins 1998; cf. Edgerton 1975) or special education practices (Blatt 1981; Gleason 1989). The aim is to improve the lives of intellectually disabled people by changing the way that these and other services are provided (Atkins 1998; Begab & Richardson 1975; Blatt 1981; Edgerton 1986; Gleason 1989, 1994; Goode 1984, 1990; Henschel 1972; Taylor & Bogdan 1989). Edgerton too went on to write many articles about mentally retarded people, constantly expanding and reworking his analyses and even criticising his own negative projections of the stigma associated with being labelled mentally retarded in follow-up studies with the people who provided the material for *The Cloak of Competence* in the 1960s (Edgerton & Bercovici 1976; Edgerton

1984b; Edgerton, Bollinger & Herr 1984).<sup>13</sup> Edgerton continued exploring issues of community adaptation, as well as taking on new social welfare concerns such as the implementation of normalization policies (Edgerton & Bercovici 1976: 485-6) and the problems associated with aging and providing a quality of life for the mentally retarded (Edgerton, Bollinger & Herr 1984). He also inspired others to study mental retardation from a cultural and social perspective, emphasising both the value of quantitative analyses and participant-observation, and the necessity of studying the perception and treatment of mental retardation in non-Western settings (Edgerton 1970, 1984a; cf. Manion & Bersani 1987).<sup>14</sup>

Edgerton's call for cross-cultural studies of retardation has been taken up by those such as Anne-Marie Henschel (1972), Joseph Westermeyer (1979), Larry Peters (1980), Marilyn Mardiros (1989), M. Miles (1992), Jeanne Connors and

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<sup>13</sup> In these studies Edgerton discovered that the stigma of mental retardation had become less of an issue for these people, as had their reliance on benefactors (Edgerton & Bercovici 1976: 490-1; Edgerton, Bollinger & Herr 1984). Luckin comments that this decrease in stigmatisation was partly due to a shift in the social perception of those who were unemployed. He argues that this was a result of changing socioeconomic circumstances and increasing welfare dependency in the USA during the 1970s. As a consequence of this, ex-patients felt less "different" to many others in the community (Luckin 1986: 95).

<sup>14</sup> Edgerton has written extensively about the importance of long-term participant-observation as a useful methodology for unobtrusively entering the lives of mentally retarded people and understanding their experiences and points of view within a specific context (Edgerton & Langness 1978; Edgerton 1984a; Edgerton 1984c). However, rather than just describing their lives and presenting a picture of the world from their perspective, Edgerton stressed that participant-observation also requires an objective detachment so that the researcher can analyse what these lives and experiences have to offer to a broader study of labelling, stigma, socialisation, institutionalisation, and personality development (Edgerton 1984c: 498). Such an approach, Edgerton argues, allows the researcher to analyse the underlying meanings and contradictions inherent in people's expressions of self, exposing more fully who these people are rather than just what they think they are (Edgerton 1984c: 499). Although historically associated with anthropological studies of other cultures through the early fieldwork of Malinowski and Boas, participant-observation has more recently been taken up as a standard methodology in the other social and behavioural sciences. Many of the people whose work I discuss later in this chapter have utilised some form of participant-observation in their research.

Anne Donnellan (1993), Patrick Devlieger (1988), Mark Nuttall (1998), Susan Reynolds Whyte (1998), and Sylvia van Maastricht (1998). The general aim has been to understand the significance of intellectual disability within particular cultures (Mardiros 1989: 55), especially with regards to the "medical" issues of diagnosis, aetiology and treatment (Dentan 1967; Devlieger 1998; Miles 1992; Westermeyer 1979). Implicit within some of these studies is a critique of the dominance of the Western medical interpretation of intellectual disability, and the inappropriateness of Western models of treatment and policy development that are themselves based on cultural notions of independence and training (Maastricht 1998; Miles 1992: 249; Nuttall 1998; Whyte 1998). Others, such as Westermeyer (1979: 315), argue that similar interpretations of mental retardation over dispersed areas "suggests a common human experience with types of mental disorder, and a common need for understanding or explaining these disorders" (cf. Peters 1980). Despite the growing interest in intellectual disability from a cross-cultural perspective, it is still a relatively small field, as Connors and Donnellan (1993: 267) acknowledge; a reality that is perhaps indicative of some of the difficulties associated with studying people who do not readily play the role of informants.

### **An Uneasy Alliance: Intellectual disability and disability studies**

At the time of Edgerton's groundbreaking sociocultural analysis of mental retardation the disability movement was also gaining momentum. This movement was comprised of a politically and socially motivated group of physically disabled people calling for self advocacy, equal rights, and equal access to services such as education, housing and transport, as well as employment (Barnes 1998: 68; Barton 1998: 58). Grass roots groups such as the Independent Living Movement in the USA and the Disablement Income Group

in the UK were pushing for radical changes to the way that disabled people were treated—socially, economically and politically—and challenging the barriers that segregated, oppressed, and excluded them from full participation in society (Barnes 1998: 69-70; de Jong 1982; Finkelstein 1998: 35-36).

Social theorists also began to argue that the problems associated with disability were as much a result of the social construction and experience of disability as it was a consequence of a physical condition (Barnes 1998: 69). These initial criticisms, although still steeped in what Colin Barnes (1998: 69) has termed a "rehabilitation role", marked the emergence of the social model of disability. Influenced by functionalism, symbolic interactionism, social constructionism and labelling theory in the USA, and by historical materialism in the UK, the social model of disability not only challenged the dominance of the medical interpretation of disability, but it also ultimately criticised medically informed sociological interpretations founded upon Parson's concept of the "sick role" (Barnes 1998: 66).

The existence of health and illness in society raised fundamental issues for Parsons, especially in relation to "the functional prerequisites of the social system" (Parsons 1970 [1951]: 430). Parsons' functional interpretation of illness argued that sickness was a deviation from the functionally cohesive and socially prescribed norm of good health. The onset of illness potentially incapacitates people, preventing them from fulfilling their social obligations. The sick role provides a legitimate way of being in this temporary state. Illness thus becomes an alibi for incomplete sociality. However, this state is not without its own set of institutionalized obligatory practices. Those who experience illness must conform to the rules and demands of the sick role as a legitimate way of alleviating expectations to fulfil their normal social obligations (Parsons 1970 [1951]: 430-437). Parsons provides four obligations that must be adhered to by the patient if she or he is to be legitimately accredited the status of the sick role.

These include: "exemption from normal social role responsibilities"; accepting the passive role of being cared for by others; realising that this state is itself undesirable and that there is an obligation to "get well"; and seeking "technically competent help" in the form of a physician (Parsons 1970 [1951]: 436-7). Any threat to the cohesion of the social system is thereby alleviated through adherence to these socially and medically instituted practices, and a person can exist as a sick person so long as they accept these conditions (cf. Murphy 1990: 19; Conrad & Schneider 1985: 31).

Like the physically disabled that Robert Murphy (1990) wrote about, however, an intellectually disabled person may be categorised as medically unwell but they are not in a temporary state of sickness. Theirs is not a momentary deviation from normal obligations but a permanent state of being. Their status and social role as sick is therefore more complex than the illness that Parsons wrote of, although the same institutional relationships and obligations cross over into the clinical and institutional experiences of intellectually disabled people. Like the sick, they too become prisoners of the medical profession and must work towards their own rehabilitation in order to become accepted members of the community. They too are exempt from normal social responsibilities, must be cared for by others, are in an undesirable state that must be ameliorated or prevented, and are subject to the professional assistance of institutional and clinical staff. But as people who can never possibly transcend their difference, disabled people in general are forever trapped within the liminal and ambiguous state of being permanently damaged (Murphy 1990: 129-131). This is their abnormality.

The medical sciences, along with other medically informed sociological interpretations such as Parsons' sick role, argues Barnes (1998: 66-67), individualised disability. Medical science constituted the disabled person as the problem such that the individual experience of disablement was taken to be the

sole cause of any social or personal problems. By accepting this as natural fact, medical sociologists were seen to perpetuate this individually informed, pathologically based paradigm. Like disability theorists, Edgerton was also critical of the dominance of the medically informed literature within the field of mental retardation. However, his work—and the work of sociocultural theorists such as Langness, Levine, and Goode, who, along with Edgerton, were all associated with the Socio-Behavioural Research Group of the Mental Retardation Research Centre at the University of California, Los Angeles—cannot be readily incorporated within this social model of disability.<sup>15</sup> Unlike disability theorists, and more in keeping with medical sociologists, they accepted the reality of retardation as a physical phenomenon.<sup>16</sup> Rather than interpreting it as a social construction, Edgerton sought to determine the individual consequences of the stigma attached to being labelled retarded, and the difficulties that arose from living in the community with real incompetencies (Edgerton 1967).

In contrast, the social model of disability claims that disability is fundamentally a social rather than individual problem and it was in opposition to such medical interpretations that the social model evolved. Rather than analysing individual experiences, disability theorists sought to expose the social and systematic nature of disability (Abberley 1987; Oliver 1986, 1990). They consequently argue that the stigma, oppression, and deprivation associated with disability are a consequence of the social construction of disability as an abnormal deviance and/or the social relations and structures embedded in capitalist societies (Barnes 1998: 69; Barton 1998). As Anne Chappell puts it:

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<sup>15</sup> I use the term "sociocultural theorists" to refer to those who study intellectual disability from a sociocultural perspective but do not adopt the social constructionist position advocated by those whom I have termed "disability theorists".

<sup>16</sup> Included in this is the work of John Gleason (1989; 1994) which I discuss later in the chapter.

The analysis of disability presented by the social model is that disability is a social construct created by a range of historically and culturally specific factors. It is the social and economic structures of a particular society which create disability through processes of prejudice, exclusion and discrimination (Chappell 1998: 212).

The separation of the individual from the social, of the physical from the cultural, is signified in disability studies through the politically correct use of the terms "impairment" and "disability" respectively. While this allows for an analysis of the sociocultural, historical, political and economic aspects of disability, the sole focus on the social has meant that the personal experience and consequences of impairment have been seriously under-theorised. Only in the past few years have disability theorists begun to explore the meaning, embodied experience, and social consequences of impairment (Hughes & Paterson 1997; Meekosha 1998; G. Williams 1998). Rather than analysing it as a purely individual and personal phenomenon, however, those such as Gareth Williams have combined a materialist phenomenological approach with symbolic interactionism to explore the "interpretative process whereby individuals construct meaning from their experiences" (G. Williams 1998: 240; cf. Davis 1995; Hughes & Paterson 1997; Meekosha 1998). More recently there have been studies that have criticised this social/medical dichotomy, and argued that it is important to acknowledge that differences are both grounded in the body and subject to social interpretations (Atkins 1998: 7; Singer 1999).

The recent focus on the body, on the dis-abled body in opposition to "able-bodiedness", and on abnormality as a physical rather than intellectual construction, has problematic implications for those whose impairment is intellectual. As Anne Chappell (1998: 214-216) argues, intellectually disabled people have been marginalised within the discourse of disability studies due to this emphasis on the body, and on physical and sensory rather than intellectual

impairments. It is, she claims, one of the consequences of including all forms of impairment within a singular analytical category as "disabled". Rather than critiquing the social model in total, however, Chappell (1998: 212) suggests that the particular experiences of intellectually disabled people should be included within this model of disability—along with all those other variables such as age, gender, ethnicity, class and sexuality which make the experience of disability diverse and specific.

Although there are obviously many important insights that the social model of disability has brought to the study of those who are disabled—such as the shift to focusing on the social structures that exclude disabled people and the sociocultural constructions that inform professional and social perceptions and treatments of those who are disabled—there are also some serious limitations to the social model. Even the analysis of impairment, while offering personal insights into the lived experience of disablement, in many ways perpetuates some of these problems. By constituting the medical model of disability as the primary cause of the problems associated with being disabled, disability scholars have denied the objective reality of intellectual, physical or sensory impairments. Consequently, they have ignored the social implications of differences that are undeniably embedded in the biological, and which constitute part of the experiences and identity of those who are disabled. Like labelling theory, it analyses the sociocultural experience of being disabled as a projection of social meanings and constructions. By incorporating intellectually disabled people within social analyses as "just like you and me", disability and labelling theorists have unwittingly denied to these people their real and actual differences. In the words of Robert Gordon, such an approach has fostered a "fundamental lack of respect for the meaning of real human differences" (Gordon 1975: 138).

## **A Social Construction: The work of Bogdan and Taylor**

The work of Robert Bogdan and Steven Taylor marked a significant shift in the interpretation and analysis of intellectual disability. Like Edgerton, Bogdan and Taylor emphasised the usefulness of qualitative research methods with intellectually disabled people (Taylor & Bogdan 1998). However, unlike Edgerton, they stressed the importance of phenomenology as a methodological tool. Bogdan and Taylor argue that the primary concern of the social scientist should be to understand "the social actor's frame of reference", the meanings they attach to things in their lives, and how these meanings influence the way that people act in the world (Taylor & Bogdan 1998: 3-7). Drawing on a combination of Mead's symbolic interactionism and Berger and Luckman's social constructionism, Bogdan and Taylor also argue that human behaviour and action is a product of how people define and interpret the world, and that the aim of social research is to understand how people construct their realities (Taylor & Bogdan 1998: 10).

Edgerton's work was criticised by Bogdan and Taylor for adhering to a medical interpretation of mental retardation (Bogdan & Taylor 1982: 208-214). While acknowledging the devastating impact of the stigma associated with being labelled mentally retarded, Bogdan and Taylor do not accept the argument that a part of this stigma is a result of being incompetent and retarded. In their book, *Inside Out: The social experience of mental retardation*, Bogdan and Taylor (1982: 5) argued instead that, rather than being an "objective condition", the entire meaning of the label of "mental retardation" is dependent on social and cultural concepts "that exists in the minds of people who attach that label to others" (cf. Taylor & Bogdan 1989: 23; Bogdan & Taylor

1976: 47).<sup>17</sup> For them, mental retardation is fundamentally a social construction.

As Bogdan and Taylor put it:

. . . the crucial issue in regard to the concept of mental retardation is not that some people (the poor, minority group members) are falsely labeled, or that the 'mildly retarded' are unfairly grouped with the severely or profoundly retarded. Rather, we dispute the efficacy and validity of the concept 'retarded' for any person, including those with the most profound organic neurological impairments (Bogdan & Taylor 1982: 5).

Therefore, rather than telling us anything about the mentally retarded, the term "mental retardation" tells us about society and the methods by which people who do not fit the demands of industrialised society are perceived, categorised and administered (Bogdan & Taylor 1982: 9; Bogdan & Taylor 1976: 51). Through the application of treatments and services, and the experience of being institutionalised and stigmatised, Bogdan and Taylor argue that people labelled mentally retarded, rather than using a "cloak of competence" to hide the stigma of being retarded, have been covered with a "cloak of incompetence" that is impossible to discard (Bogdan & Taylor 1982: 222).

Through interviews with Ed and Pattie, two mildly retarded individuals who had experienced life in an institution but were now living in the community, Bogdan and Taylor (1982: 222) provide an account of the subjective, lived experience of mental retardation. Bogdan and Taylor acknowledged and empathised with Ed and Pattie as human beings with their own point of view. Their aim was to understand how Ed and Pattie constructed, thought and felt about the world and their place in it (Bogdan &

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<sup>17</sup> For Robert Murphy, disability is a "social malady" that is defined by society and given meaning through culture (Murphy 1990: 4). It is a sociocultural rather than a biomedical phenomenon; a "metaphor of the human condition" and an "allegory of all life in society" (Murphy 1990: xi).

Taylor 1982: 20). In contrast to Edgerton, Bogdan and Taylor therefore became the first to fully acknowledge the integrity and lived experiences of mentally retarded people from their own perspectives (Gerber 1990: 4; cf. Bogdan & Taylor 1982: 4-18; Bogdan & Taylor 1976; Taylor 1998a).

David Gerber (1990) has argued that, by interpreting mentally retarded people as naturally and clinically retarded, Edgerton was unable to fully appreciate and respect these people's own interpretations of their lives as anything other than attempts at dealing with the stigma of their retardation. Whenever they provided social reasons for their retardation it was interpreted as denial. Consequently, what they said about themselves was not taken at face-value. It was only ever a mask, and Edgerton, as the social analyst, was the one who could stand aside and interpret it as such. Therefore, argues Gerber, Edgerton failed in his attempt to understand the self-conceptions of mentally retarded people and subsequently denied them a valid voice (Gerber 1990: 5, 18). Rather than giving authoritative value to their experiences and interpretations, Edgerton reinterpreted, or rather subverted, mentally retarded people's experiences and explanations, seeing these as proof of their inability to accept the reality of their circumstances (Gerber 1990: 10-15).<sup>18</sup>

In contrast, Bogdan and Taylor acknowledge the importance of the social context within which human variation is thought to exist, and claim that it is the way these differences are "thought about that matters" (Bogdan 1992: 316). However, they do not acknowledge or interpret the relevance of assertions of difference made by their informants when comparing themselves to those who

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<sup>18</sup> Gerber recognises that it is unfair to retrospectively criticise Edgerton for not adhering to later interpretations of mental retardation as a social construction (Gerber 1990: 5-6), an interpretation which Gerber himself problematically accepts as true and unquestionable. Gerber acknowledges that Edgerton did, in some of his later articles, propose that cultural, social, economic and political systems could lead to different interpretations of retardation. However, Gerber also argues that Edgerton still fundamentally adhered to a clinical model, believing that a universal baseline level of competence could be discovered for all cultures (Gerber 1990: 6).

are severely mentally retarded. Although Bogdan and Taylor are keen to emphasise the similarities between mentally retarded and "normal" people, both Pattie and Ed—in much the same way as Edgerton's (1967: 146-149) informants—had a deep disgust and fear of those who were profoundly retarded, and were offended by any association with them, categorically and in daily institutional life (Bogdan & Taylor 1982: 55, 133).

As well as this, Bogdan and Taylor—like Edgerton and those social theorists who adopted a life history approach to the study of intellectual disability—have primarily focused on the life experiences of those who are mildly mentally retarded. Despite arguing that all who are labelled retarded are subject to the social construction of them as such, in most of Bogdan and Taylor's work the social experiences of severely retarded people have not been analysed. The reliance on interviews and the recording of life stories is often inappropriate for those who have more limited forms of communication. Also, while being labelled intellectually disabled has serious social consequences for all who are caught up in the clinical and institutionalised system of services, it is not always expressed as a personal concern for those who are more severely affected.

The tendency to focus on the social experiences of those who are categorised as mildly retarded circumvents the problems encountered when analysing the lives of those who are more severely and obviously affected by their disability. While social, cultural, historical and material factors have a profound affect on the lives of all those who are labelled intellectually disabled, they do not constitute the entirety of intellectually disabled people's lives. Interpretations that only take these aspects into account, and which perceive the experience of intellectual disability as a product of sociocultural constructions and structures, tend to deny that intellectual disability is an ontological reality that makes a real difference to the experience of being intellectually disabled. Consequently, Bogdan and Taylor are unable to deal

with the real implications of difference as productive of the sociocultural world rather than just the products of it.

Bogdan and Taylor have recently criticised their own earlier work for adhering to a "sociology of exclusion" by only emphasising the consequences of stigma, deviance, labelling and stereotyping (Bogdan & Taylor 1998: 242-243). They now acknowledge that there are a variety of ways in which mentally retarded people are perceived, and that a significant number of social relationships with such people emphasise acceptance rather than exclusion. Through familial relationships, religious convictions, humanitarian concerns and/or friendship, they argue, it is also possible for retarded persons to be positively perceived and treated. Consequently, in such circumstances, mentally retarded people's disabilities do not have a stigmatising or "morally discrediting" effect (Taylor & Bogdan 1989: 27). Bogdan and Taylor call for a "sociology of acceptance" as a way of understanding this phenomenon, arguing that such intimate and accepting relationships are important in mentally retarded people's lives (Taylor & Bogdan 1989: 22; cf. Bogdan 1992). As they put it:

. . . the definition of a person is not determined by either the characterisation of the person or the abstract social or cultural meanings attached to the group of which the person is a part, but rather by the nature of the relationship between the definer and the defined (Bogdan & Taylor 1998: 243).

Despite this emphasis on relationships, the constructionist approach that Bogdan and Taylor adopt still focuses on differences in the definition and social meaning of those who are retarded. It explores how these definitions determine the way that such people are subsequently treated and perceived. Difference for Bogdan and Taylor, although not denied, is primarily a

consequence of social definition and categorisation, and what is important is the meaning attributed to difference through the perspectives of those who are not disabled (Bogdan & Taylor 1998: 245). Consequently, Bogdan and Taylor's interpretation of mental retardation remains thoroughly within the rubric of symbolic interactionism and social constructionism. Their particular approach has also perpetuated and reinforced Edgerton's earlier dismissal of anthropological theories of culture and symbolic representation as relevant for interpreting the sociocultural experiences of intellectually disabled people. This has meant that intellectually disabled people have been interpreted as social beings only in so far as they are products of the labels attributed to them. While we gain a sense of severely intellectually disabled people as human beings whose humanness is a product of social relations with others, we do not gain a sense of the meanings that they themselves create, nor of them as the authors or independent sustainers of mutuality and sociality.

An emphasis on the social definition of, or meanings attributed to, intellectual disability became increasingly prominent in the work of those who took up Bogdan and Taylor's social constructionist paradigm. This includes cross-cultural studies of intellectual disability, analyses of representations of intellectual disability in the media, as well as post-structural and deconstructionist accounts of the concept of intellectual disability. Rather than interpreting intellectual disability as an ontological state of being, the tendency in these cases is to use the variability of cultural and historical concepts of "mental retardation" as proof of its inherent emptiness as a concept (Manion & Bersani 1987; cf. Connors & Donnellan 1993). In such analyses the focus tends to shift towards a concern with categories, constructs and labels, as well as to social institutions and structures, and how these impact upon the interpretation of intellectual disability. Rarely does it enter into intellectually disabled people's lives as ones which are more, or other, than just the consequences of these

supposedly overarching and deterministic constructs. In such accounts it is impossible to get a glimpse of who intellectually disabled people actually are, how they relate to and engage with others, and what sort of meaningful worlds they inhabit and produce.

Analyses of images and representations of intellectual (and other) disabilities in film, literature and the media by Paul Longmore (1985), Alan Gartner (1982) and Robert Bogden *et al.* (1982) ignore the inherent sociality of intellectually disabled people, implying that their experiences are entirely the product of such stereotyping. The same can be said for more contemporary analyses of intellectual disability that employ post-structural, postmodern and/or deconstructionist methodologies. Such approaches to the study of intellectual disability take these constructions as already given, as already determining the social experiences of intellectually disabled people. They seek to either explore more fully the social and individual consequences of discursive practices (Cocks & Allen 1996; Johnson 1998), or to release intellectually disabled people from the negative grip of these constructions by deconstructing those very constructions that supposedly constrain them (Branson & Miller 1989; Ellis 1998).

Many contemporary researchers who explore cross-cultural conceptions of intellectual disability also tend to focus solely on the social and cultural categories and meanings associated with intellectual disability. Describing their research with the Navajo, Connors and Donnellan stated that:

The diagnoses of the individuals in this study included severely multiply handicapped, severely mentally retarded, autistic, Down's Syndrome, and educationally mentally retarded. All were non-verbal and unable to express their own experiences; thus, data were gathered from families, neighbors, caretakers, and others

directly involved with these individuals as to how they were regarded in the Navajo world view, to what extent the individual was considered a competent member of the culture, how the behaviour associated with the disabilities as [sic] dealt with, and how problematic this might be (Connors & Donnellan 1993: 269).

Connors and Donnellan's study provides valuable information on some of the sociocultural and historical differences in the perception, treatment and interpretation of those who are regarded as intellectually disabled. It also acknowledges that institutional practices exist within a specific sociocultural context. However, Connors and Donnellan also deny or disregard three very important issues. One is that the researcher, and the culture in question, must recognise the differences they are observing as some form of intellectual disability in order to study them as such—an issue that, as Jenkins (1998b: 4) points out, raises epistemological problems concerning the use of "intellectual disability" as an analytical category at all. Secondly, it is assumed that being intellectually disabled, these people are therefore "unable to express their own experiences". And thirdly, that cultural constructions are the most significant and theoretically meaningful aspect of a social analysis of intellectual disability.

Unwittingly, such analyses perpetuate the clinical interpretation of intellectual disability by ignoring the fundamental sociality of intellectually disabled people. We tend to learn more about what they signify and represent as objects of sociocultural construction rather than who they are as subjects engaging in relationships with others. They may be products of cultural categories but are not analysed as active participants in social life. They may experience what it is to be labelled retarded but are not theorised as people interacting with others as part of the mutual sociality of everyday life. This denies to intellectually disabled people a status as encultured beings, who,

although limited in their ways of participating in the social world, do seek ways of meaningfully and socially engaging with others.

### **Intimacy and Relatedness: The work of Goode and Gleason**

While also drawing on the methodological principles of participant-observation and qualitative analysis, the work of David Goode and John Gleason has provided us with a different and, I would argue, potentially more significant insight into the lives of intellectually disabled people. Rather than focusing solely on the stigma of labelling or the social construction of retardation, both Goode's and Gleason's work therefore represents at least a partial break with the first two "schools" of sociocultural analysis. Instead, Goode emphasises the centrality of intimacy and familiarity in the construction of a positive identity for intellectually disabled people, while both he and Gleason have made the intentional and purposeful interactions of people with severe and profound multiple disabilities the subject of their, albeit slightly different, analyses. While intimacy and relatedness may have been implied as attributes of the social lives of those with mild intellectual disabilities, they had never been the focus of analysis. Nor had they been emphasised in relationships with, and between, those who are severely intellectually disabled.<sup>19</sup>

The first person to discuss intimacy and relatedness in relation to intellectually disabled people was David Goode.<sup>20</sup> Employing a combination of ethnomethodological and phenomenological techniques, Goode sought to enter the everyday world of multiply impaired children in an attempt to

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<sup>19</sup> An exception to this is Edgerton's early paper with MacAndrew on the possibility of friendship between two severely retarded individuals (MacAndrew & Edgerton 1966).

<sup>20</sup> Interestingly, David Goode was trained in ethnomethodology at UCLA by two of Edgerton's colleagues, Harold Garfinkel and Melvin Pollner. Goode was also led to his research subjects by Edgerton (Taylor & Bogdan 1998: 123).

discover the grounds for their intersubjectivity (Goode 1980a; 1980b; 1990). Rather than interpreting their behaviour and interactions according to the sorts of "'scientifically' produced standards of 'normality'" that clinicians utilise, Goode emphasised the importance of "naturalistic" contextual data gained through the observation of interactions in everyday life (Goode 1980a: 97). As Goode put it, such clinical interpretations are:

. . . 'specifically indifferent' to the familial context of action. They decompose meaningful familial interaction into clinically locatable problems with regard to—in fact sometimes in direct contradiction with—the lived realities of everyday family life (Goode 1980a: 97).

Goode's earliest work drew upon his interactions with a congenitally deaf-blind and retarded girl called Chris who lived in a state hospital ward. Rather than interpreting Chris' behaviour as meaningless, faulty, and in need of remedial training—as the staff did, and which he too initially attempted to do—Goode sought to understand it on its own terms (Goode 1980b: 193-198). Recognising that Chris lived in a significantly different perceptual/cognitive world to his own due to her disabilities, Goode decided that "only intimate and persistent interactional contact . . . would be likely to enable [him] to enter [her] world" (Goode 1980b: 187-188). Consequently, Goode developed "interactional strategies" which included mimicking Chris' repetitive behaviour and her perceptual, tactile engagement with the world in order to build up a basis for intersubjectivity on Chris' terms.

Goode discovered that Chris responded enthusiastically to sound stimulation, especially to the rhythm and frequency of music, as well as to touch. She used her tongue for sensory gratification and to gain information about objects in her world. As well as these, Chris exhibited "autostimulatory behaviours" such as finger flicking, rocking and head swinging in response to

light and sound, although as Goode points out, the use of her senses was also goal-oriented (Goode 1980b: 189-190). Chris also loved physical interaction, and although she did not recognise or utilise linguistic symbols, Goode argues that through her sensory interaction with the world and others, she did communicate (Goode 1980b: 191). Chris used gestures, gross physical movement and "background expectancies", such as sitting at a table in the dining room to express her hunger, to communicate her needs and desires to others (Goode 1980b: 191-192).

Chris' difficulties stemmed from her lack of audiovisual perceptual abilities, upon which, Goode argues, "we build our systems of symbolic communication and organize our practical interactional activities" (Goode 1980b: 192). However, through long term and intimate observations of her behaviour and interactions Goode was able to gain an appreciation of Chris' abilities, and perceive the rationale, intelligence, inventiveness and purpose in her actions (Goode 1980b: 197-201). Goode argues that we all live in an intersubjective and shared world. Drawing on Schutz's epistemological queries as to the possibilities and nature of this shared world, Goode states that "we progressively developed common schemes of communication, congruent practical relevancies, mutually defined things to do in the world, and so forth" (Goode 1980b: 204-205). Through entering Chris' world on her own terms, Goode sought to establish such "common schemes of communication".

Although at first Goode attempted to simulate Chris' deafness and blindness, he realised that he needed to let Chris direct their interactions in order to gain insight into what the world meant to her (Goode 1980b: 193-195). This involved allowing Chris to play with him in such a way that she gained sensory gratification from their interactions. It included such things as having Goode rhythmically tap her ears, play music, swing Chris on his knee and rock her. Through these interactions, and through mimicking Chris' actions, Goode

recognised that there was an inherent purpose and rationale to Chris' behaviour. There was a definite pattern to Chris' actions through which she sought rhythmic sensory stimulation and gratification (Goode 1980b: 197-199).

Goode's interactional encounters with Chris were ground-breaking for the sociocultural study of intellectual disability. They represented the first written sociocultural analysis of a severely intellectually and physically disabled person's world. In doing so, Goode recognised that it was possible to find intention and meaning in such a world. Rather than embodying culture in linguistic capabilities and recognisable cultural enterprises, Goode acknowledged that it was possible to develop a sense of a shared world through purposeful and intimate interactions (Goode 1980b: 203-205).

Goode's interest in the possibility of developing communication and a meaningfully shared and intimate world was elaborated upon in his analysis of the communication system that existed between an alingual deaf-blind and retarded child (Breta) and her family (Goode 1980a; 1990). His primary concern in this situation was with whether or not such a "communicational relationship" should be considered abnormal or extraordinary (Goode 1990: 29). Drawing again on Schutz, Goode argued that all communication is, to a degree, partial, incomplete and incoherent. While this may be intensified in relationships with severely intellectually disabled people, in essence it represents the same form of communication that we all utilise (Goode 1990: 29-30).

The ways in which behaviour and gestures are interpreted, such as inferring knowledge based on prior experience, supplying props and leading questions, and filling in the gaps which exist in relationships, has been interpreted by Goode as "behavioural sculpting" (Goode 1980a: 101). He argues that in the relationship between Breta and her mother the intention of this "sculpting" was not entirely for the benefit of outsiders, but that it existed in order to

"normalize' the look and feel of the family *for themselves*" (Goode 1980a: 101-102; author's emphasis). It was a way of including Breta in the ongoing dynamic interactions of the family, not in conformity to expected norms of behaviour, but in terms of how her behaviour was being interpreted by those in intimate daily contact with her.

Goode incorporated severely intellectually disabled people within his social analyses, and stressed such people's involvement in the wider social world through intersubjectivity, interaction and intimacy. In his work with Chris, Goode was the one to develop and engage in the necessary interactional strategies for intersubjectivity. He used observations of these intimate interactions as source material for his analysis (Goode 1980b). In his research with Breta, Goode utilised the perspectives and interactions of an (intimate) outsider (Goode 1980a; 1984). As Goode himself acknowledged, he gained access to Breta via her mother's "intimate glossed knowledge" and not through his own interactions (Goode 1980a: 111).

While Goode's primary interest has been to analyse the possibility of communication and intersubjectivity between severely physically and mentally retarded people and others, he has become best known for his contribution to social constructionism. In a similar vein to Taylor and Bogdan's (1989) more recent emphasis on a "sociology of acceptance", Goode (1984) developed the notion of "socially produced identities". For Goode, "radically different identities" are produced as a result of differences between intimate, accepting relationships with profoundly physically and mentally retarded persons and clinical, objective perceptions that interpret such people as negative and entirely deficient, subhuman beings (Goode 1984: 229). Drawing on a number of examples of different types of relationships, including his observations of Breta's relationship with her mother, Goode argued that familiarity and

intimacy are the necessary factors for perceiving recognisable human attributes and competencies in a severely retarded person (Goode 1984: 244-245).

Although intimacy may change the subsequent perception of, and form of engagement with, a severely intellectually disabled person, it is the social construction of intellectual disability and the symbolic interaction of meaning based upon these constructions that Goode emphasises. As Goode elaborates, the idea of a socially produced identity:

. . . refers to how a person's identity—who he or she is taken to be in terms of the significance or meaning attached to his or her body and behaviours—emerges out of a concrete and particular social situation and is the product of social interaction with that situation (Goode 1984: 231).

Despite his argument that communication implies far more than linguistic competency, Goode later stipulated that the persons he studied "do not use symbolic language" (Goode 1990: 30). Therefore, although he focused on the possibility of intersubjectivity and communication, Goode went on to emphasise differences in the social perception of intellectually disabled people rather than analysing the symbolic systems that are developed and mediated through the course of mutual interaction.<sup>21</sup>

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<sup>21</sup> Chris Atkins (1998) has taken up the issue of intimacy that arose out of the work of Goode and Bogdan and Taylor and applied it to an analysis of quality of life policies. Rather than emphasising access to services, lifestyle, integration and deinstitutionalisation as the necessary components for an improved quality of life for people with severe multiple impairments, Atkins argues that such people's quality of life, and indeed their very identity and "situated belonging", depends on the interactions that they have with significant others (Atkins 1998: 7-8, 241). The intimate support through "just little things" that carers provide for people with severe multiple impairments allows them to just be (human), and to be accepted (Atkins 1998: 263). Atkins claims that contemporary practices in the field of intellectual disabilities have the potentially devastating effect of isolating people in a world where they do not become known and where the meaningful things in their lives are never perceived (Atkins 1998: 238-9). As she comments: "Removal of nurses who have become intimate with people with severe multiple impairments means that their definition of quality of life

John Gleason (1989; 1994), on the other hand, has pursued a course of analysis that focuses on such issues through observing the meanings and intentions that exist in severely multiply disabled people's interactions with one another. Gleason argues that the way these people engage with one another, and indeed with others who are non-disabled, is generally perceived as aberrant, meaningless and in need of transformation (Gleason 1989: 62; cf. Gleason 1994; Goode 1980b: 192-193; Lea 1988; S. Taylor 1998b: 198-199). Gleason claims that this clinical interpretation of behaviour is the result of a profound disturbance in disabled people's physical form and function. This has meant that everything such people do, that all their actions and interactions, have been observed and interpreted in the light of their disabilities and deficits (Gleason 1994: 256-257). This subsequently denies to severely disabled people the possibility of having their own already unique modes of meaningful interaction within the specificities of their disabilities (Gleason 1994: 248).

With an interest in analysing the consequence of therapeutic and special education practices—which included changes brought about by deinstitutionalisation and normalisation policies—Gleason spent five years observing the interactions of a group of residents at a state school for physically and mentally retarded people. The emphasis in special education,

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collapses for, without intimate interaction, there cannot be individualised support for humans being" (Atkins 1998: 239; the term "humans being" is drawn from the work of Draper and acknowledges that we are all human social beings who engage with one another and the social world via our individual identities, our bodies and emotions). This same concern was raised in the work of Goode (1984: 246) and Taylor and Bogdan (1989: 33-34). It also resonates with some of Gleason's arguments concerning the problems inherent in contemporary special education practices, although his approach marks a significant departure from these other interpretations. In a very different way, and drawing her theoretical orientations from postmodernism and deconstruction rather than interactionism and phenomenology, Elisabeth Ellis (1998) has explored the "spatial politics of disablement" that separates non-disabled from disabled people. Rather than adhering to what she interprets as modernist and dichotomous modes of oppositional identity upon which this separation is based, Ellis calls for an inclusive ideology based on "webs of nurturance" which she identifies as familial proximity and connectedness (Ellis 1998).

from Séguin's early treatments right up to the present day, has been to instil in intellectually disabled people more conventional modes of communication and interaction. This has meant that staff tend to see and interpret the behaviour of residents in terms of the conventional and dominant clinical and pathological view of mental retardation. It has also meant that they only see as meaningful and cultural those actions that conform to normative behaviour. While severe and profound disabilities may set limits to the possibilities for communication and interaction, Gleason argued that it does not inherently define what such people do. Nor does it determine the quality of their actions and interactions (Gleason 1989: 10).

Gleason (1994: 260) argues that the implicit meaning and intention in severely multiply disabled people's interactions can be observed if it is acknowledged that what they are doing conforms to a recognisable pattern and has relevance and meaning for them. By maintaining a sense of the context within which these actions and interactions take place Gleason was able to observe the intentional patterns in these people's behaviours towards one another. By adopting a methodology that interpreted the relationship between form and function in the production of meaningful content—rather than focusing on the disturbances caused by a disruption to form and function—Gleason acknowledged that such actions and interactions are meaningful (Gleason 1994: 247-249; Gleason 1989: 79, 106, 152). He consequently sought to understand what the behaviour and interactions amongst the residents might mean to them (Gleason 1989: 2).

The contributions of Goode and Gleason to the sociocultural field of intellectual disability are highly significant and important. In their different ways both incorporated severely intellectually disabled people into the social world that was under analysis. Goode emphasised the importance of intimacy and relatedness, while both he and Gleason acknowledged the meaning and

intention in severely disabled people's actions and interactions with others. The analyses of Goode and Gleason have many resonances with my own research with intellectually disabled people. So does the discrepancy between their own and staff observations and interpretations, the latter of which were based on historically and clinically mediated perceptions. While I also emphasise these issues, I utilise different theoretical tools to interpret the fundamental sociality and symbolic intentionality of intellectually disabled people's actions and interactions. Like Goode, I emphasise the role that intimacy and relatedness play in the recognition of severely intellectually disabled people's sociality. In doing so, however, it is important to emphasise just what is meant by intimacy, and to distinguish my own use of the term from how it has been used by others.

Goode used the concept of intimacy to highlight the nature of long-term, empathetic relationships that people can have with those who are severely intellectually disabled (Goode 1984). Through intimacy, Goode argued, a positive social identity can be developed that emphasises the humanness and competencies of the disabled person. Intimacy in this sense allows for the production of a positive social identity. Intimacy also implies acceptance (Bogdan and Taylor 1989), or, as Atkins has put it, "assisted belonging" (Atkins 1998). The purpose of intimacy in these analyses is to highlight differences in the ways that severely intellectually disabled people are perceived and related to, especially in comparison to clinical interpretations. While I accept that these are aspects of intimacy, I argue that it is through what Schneider (1968: 52) has termed an "enduring, diffuse solidarity" that intimacy exists. Intimacy, therefore, is not just about acceptance of another, nor is it solely the necessary factor in the production of positive social identities. Intimacy emerges through mutuality, which itself exists as the fundamental ground of sociality.

Drawing on Wittgenstein's (1998 [1953]) notion of language games, and Geertz's (1993b [1973]) concept of culture, I argue that meaning is public and that it exists in the use to which words and objects are put. Behaviour in this sense becomes symbolic, interpretable and meaningful; patterned dispositions to act and interact in certain ways. Through intimacy, mutuality and relatedness these symbolic systems and dispositions are recognised and engaged with. Such symbolic practices contribute to the form of life or sociality that is consequently created through such engagements. Intimate encounters with intellectually disabled people allow for an awareness of their particular symbolic practices and dispositions. The tragedy is that few people in intellectually disabled people's lives have the aspiration to generate a sociality and mutuality based on intimacy. Clinical interpretations tend to deny or disregard that such forms of sociality and mutuality are even possible and relevant. The practices of training and management that have been instituted on the basis of these interpretations have subsequently had a profoundly dominant and disturbing effect on intellectually disabled people's life experiences.

## 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"<sup>1</sup>, 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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<sup>1</sup> 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).<sup>2</sup> 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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<sup>2</sup> 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). There 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

1980a: 14-15). 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)<sup>3</sup> 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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<sup>3</sup> Program Analysis of Service Systems Implementation of Normalizing Goals.

standing for a whole new ideology of human management" (Wolfensberger 1977 [1972]: 27).<sup>4</sup>

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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

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<sup>4</sup> 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.<sup>5</sup>

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.

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<sup>5</sup> 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).<sup>6</sup>

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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<sup>6</sup> 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.<sup>7</sup>

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

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<sup>7</sup> 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.<sup>8</sup> 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).<sup>9</sup> 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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<sup>8</sup> 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).

<sup>9</sup> 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 mattress 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).<sup>10</sup> 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).<sup>11</sup> 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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<sup>10</sup> 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 WWII emphasis on efficiency, progress and empirical science.

<sup>11</sup> 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.<sup>12</sup>

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

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<sup>12</sup> 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.<sup>13</sup>

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<sup>13</sup> 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.

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.<sup>14</sup> 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 work place. 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 work place or activity centre in an attempt to alter and ameliorate the problem.

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<sup>14</sup> 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).<sup>15</sup> 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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<sup>15</sup> 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.<sup>16</sup>*

*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 manag[ing] her*

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<sup>16</sup> 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.<sup>17</sup> 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

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<sup>17</sup> The continuation of institutionalised attitudes and practices within smaller residential services in the community has been well documented (Halpern *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.<sup>18</sup> 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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<sup>18</sup> 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.

## Chapter Seven

### Relating Across Difference

*. . . humans are delicately attuned to one another, and to themselves in relation to others, in a taut web of interaction.*

*The maintenance or destruction of that web are matters of absorbing interest and overriding importance.*

*Michael Carrithers*

To be human is to be embedded in social relations. Sociality is therefore fundamentally based on interactions between people. Since people with intellectual disabilities are caught up in relations with others—with kin, staff, professionals, and friends—it is on these relationships that an analysis of their identity as social beings must turn. The form that these relationships take, however, varies across different environments, and can be related to differences in the ways that intellectually disabled people are constituted. The different ways in which such people are perceived and constituted both produce and are a product of these relationships. Institutionalised forms of relatedness with intellectually disabled people are based upon and reinforce the symbolic scheme of reason and normality. In such circumstances, intellectually disabled people are perceived as though they are abnormal, deficient and asocial beings. Accordingly, their actions and interactions in the world are perceived as essentially opaque and meaningless. In keeping with the Greek and Latin etymology of the term "idiot", people with profound intellectual disabilities are perceived as ignorant and private persons. They are seen to lack the rational tools necessary for knowledge and social relatedness.

As a consequence of this perception and interpretation, intellectually disabled people are treated by those in clinical and institutional environments as though they have no capacity for sociality as they are. Through the principles of normalisation and integration, an ethos of management and training is therefore instituted as a means for drawing these people into the social world. The forms of relating that exist in institutional environments build upon these practices and interpretations. In such circumstances, staff are expected to maintain and reinforce a form of relating based on separation and disengagement rather than mutuality and interaction. This lack of mutuality, however, prevents staff from perceiving and engaging with the potential symbolic nature and meaning of intellectually disabled people's actions and interactions in the world. This subsequently limits intellectually disabled people's possibilities as social beings.

The consequence of instituting integrationist policies that are themselves based upon the symbolic scheme of reason and normality is that, paradoxically, intellectually disabled people are forced to conform to social norms that they are never expected to be able to uphold. In attempting to normalise that which has been constituted as abnormal, integrate that which has been constituted as radically other, and socialise that which has been constituted as asocial, staff seldom have the opportunity to engage with the intellectually disabled people they work with as anyone other than people to be trained, to be constantly worked on. Relationships that do exist are more akin to assimilationist policies than the true mediation and negotiation of difference that is necessary for the joint constitution of social life.

In this chapter I explore the role that relationships play in the lives of intellectually disabled people. In the first section of this chapter I analyse the weekly meetings that took place at Xanadu and Hervey Street in order to illustrate ways in which institutionalised forms of relatedness come to exist in

practice. These meetings, and the regime of training and management outlined in the previous chapter, serve to heighten, maintain and reproduce differences between the staff and consumers. Relationships between consumers themselves are also considered to be meaningless and socially inadequate. Because their capacity for symbolic representation and meaningful sociality is largely denied, what they do and say is also often ignored. However, my fieldwork experience and my relationships with my siblings have shown me that intellectually disabled people do utilise various symbolic means through which they engage with one another and with the wider world (cf. Gleason 1989). In the second and third sections of this chapter I explore these expressions and relationships and contrast them with the staff's interpretations and perceptions of consumer's purported asociality. The type of complex scenarios that sometimes ensue is illustrated by the narratives of illness and pain that were a regular component of my interactions with many of these intellectually disabled people.

In the concluding section I turn to focus explicitly on issues of sociality and mutuality. The capacity to create symbolic systems and patterns through which meaning is able to be shared, negotiated, mediated and/or recognised, is a fundamental component of humanness and a necessary feature of sociality. It provides the means through which we interact and engage with one another. Profoundly intellectually disabled people are limited in their capacity to create and use symbolic representations. Those that they do utilise tend to be more immediate, concrete, contextual, and embodied. Their capacity for sociality is therefore almost entirely based on the immediacy of engaging with, negotiating and mediating very particular dispositions and symbolic systems. Such negotiation is essential for sustaining and supporting intellectually disabled people's humanness. These ideas return to the starting point for this analysis and thereby act as a summation of the argument.

## Managing Meetings

Institutionalised forms of relatedness are generally based on maintaining and enforcing separation and disengagement. These are evident in the formal standards of practice to which staff are expected to adhere. They also exist in the modes of training and management that constitute the daily activities and practices within the activities centre and group homes. During my fieldwork I witnessed the instituting of this form of relating at the weekly meetings that took place at the activities centre and group homes. These meetings were a requirement of the NSW Disability Services Act (1993), according to which all consumers of a service provider are legally required to participate in the decision making and running of services. The staff at Xanadu were particularly frustrated by these requirements. They believed that such policies were impossible to implement, based as they are on an ideology of rights and equality that has little to do with the reality of severely intellectually disabled people's capabilities. It was not that the consumers were all right as they were. Their differences were still considered abnormal and asocial, and in need of training and management. It was just that including them in decision making processes was seen as a misguided ideal that was impossible to achieve. Yet the area manager who was responsible for disability services in the region had made it clear that these meetings had to take place, that she would be checking the minutes to make sure that they did, and would be using them to "keep in touch with what was going on".

The coordinator of Xanadu decided that the way to deal with this requirement was to separate the meetings into casual weekly gatherings, where people talked about what they had been doing over the weekend, and to hold the more formal meetings concerning management and decision

making at Xanadu once a month. When the first of these meetings had been held, during a consultancy period with Coopers & Lybrand in mid-1995, the procedure had been to get people to stand when they talked.<sup>1</sup> At the monthly meetings this formality was continued, although there was rarely anything of substance to be discussed, and the consumers rarely had anything significant to contribute, or so the staff believed. Consequently, these meetings usually took the form of a staff member reading through the Standards of Practice outlined in the Act, and asking the consumers questions about these standards.

Apart from recounting these Standards and letting the consumers know what was happening at Xanadu, one of the aims of the monthly meeting was to hear whether anyone had any problems that they wanted to discuss. Mary often spoke at this point and told everybody at the meeting that she was not happy at the centre, that she wanted to leave and spend her days at the group home where she lived instead. She said she was too old to be coming to Xanadu every day and that she did not like it there. Despite the fact that such problems were ostensibly matters to be dealt with, Mary was encouraged by the staff to talk about something positive instead, for example, the things she did like about the centre. This was in accordance with Mary's behavioural management guidelines. At this point, Mary would retreat into an angry silence, and refuse to participate in the meeting any more. Alternatively, Martin sometimes used these formal meetings to find out about future matters, such as when his parents were to meet with his case manager to discuss Martin's individual service plan. Martin was told that this was an inappropriate topic for discussion and that he should wait until he returned home to ask about it.

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<sup>1</sup> Coopers & Lybrand were employed by the NSW Government to oversee the period of transition after the Disability Services Act was passed. It was their job to ascertain whether or not the group homes and activities centres complied with the requirements of the Act, and to outline the necessary steps needed to be taken for them to become fully compliant. An employee of Coopers & Lybrand visited Xanadu over a six week period in 1995, and it was during this period that the first meetings were held that incorporated consumers in the decision making processes at Xanadu.

Having used all his effort to stand, Martin would sink back down into his chair and lapse into silence, along with all the other consumers.

The formalities and agenda of these monthly meetings were dispensed with at the more casual weekly meetings. All the consumers were expected to participate in these weekly meetings, and a regular time was set aside each week for them to occur. They existed as one of the activities that consumers engaged in. The coordinator felt that it was necessary to encourage "more normal interaction between people" and as such he decided that the consumers should sit rather than stand when speaking at the meetings, and discuss things in an informal and relatively casual manner. However, there were still a number of rules that governed the procedure: everyone was to sit in a rough circle waiting for a staff member to begin proceedings; minutes were to be kept as a record of what people had said; only one person was to speak at a time; and the discussion was to remain focused on the topic at hand. Only one or two staff people were usually present at these meetings, the others using this time to catch up on some paper work or sit outside and take a break. A staff member would chair the meeting while I usually took down the minutes. What follows is a description of one of the meetings that took place a few months after I started fieldwork.

It was Monday afternoon and everyone had returned from their morning's activities to have lunch at the centre. After lunch, once all the lunch boxes had been put away, the tables wiped down, aprons removed, and people toileted, the staff wheeled, encouraged, or guided all the consumers into the television room for the weekly meeting. The minute book was recovered from a filing cabinet in the staff room, and myself and Bill, the staff member who usually chaired the meetings, also took our places at one of the tables in the room. There was no agenda to be followed, so the meeting took the usual form of getting people to say what they had been doing over the weekend. Before Bill

had a chance to formally open the meeting Shauna spoke up. It was her birthday, and she was excited about the party she was having at home after work the next day. Shauna worked shredding paper at Keynton and lived at Hervey Street with four other people, including Mary. Although not a regular occurrence, she had come to Xanadu after work with her co-workers and consequently joined in with the afternoon meeting. Shauna was a bubbly, talkative person and on this particular occasion was addressing herself to Bill. He reminded her, however, that she was to talk to the others present at the meeting, not to him.

After Shauna had redirected her excited monologue to the group of consumers gathered at the meeting Bill asked her to ask somebody else if they would like to tell everyone what they had done over the weekend. Shauna said "Kate". She did not ask her anything, just said her name. Kate flapped her hands and rocked in her chair, so Bill then asked Kate to ask somebody else to talk and she pointed at me. I told everyone that I had been to Bondi Beach over the weekend and had eaten fish and chips. Martin asked if I had enjoyed myself at Bondi, and then he asked Rachel what she had done over the weekend, but Rachel asked Shauna again. Bill was trying to get Rachel to ask Mary what she had been doing, prompting her by saying, "what do you want to ask Mary?" It wasn't right to go back to someone who had already spoken. This was against the aim of the meeting where everybody was to have their turn at speaking, at least each of the consumers present.

Without being prompted Mary asked Rebecca to speak, but Rebecca was quite happy sitting back in the lounge cuddled up beside her. Mary then asked Kate, who was still rocking in her chair. At this point Patricia came in to the room and told us that her "friend"—as the person who was paid to take Patricia out shopping or to lunch on a regular basis was officially called—had been to visit over the weekend, and then she wandered back out again. Daniel would

not answer the question when Bill put it to him. He just kept saying "beddies" over and over and flapping his hands. Joanne refused to speak, and Cressida became annoyed about something and did not want to talk either. Nobody said anything much about what they had done over the weekend. Not that this information was unknown. The staff already knew what the consumers had done as it was a regular part of their Monday morning conversations with staff from the houses and the relatives of the consumers. In any case, most of the consumers lived in one or other of these homes and had spent time together over the weekend. However, this was the topic that was instigated by staff to encourage "more normal interaction" between the consumers.

While everyone was sitting around in silence Martin suddenly asked Mandy what she had done over the weekend. Mandy was one of the casual staff members who worked at Xanadu two to three days a week. She had come in from having a smoke outside and was sitting on the bench along the back wall observing the meeting. Mandy seemed embarrassed that she was being asked this question and quickly said that she had been to a friend's place for lunch before reminding Martin that this meeting was for them, the consumers, and not the staff, and that he should direct his question to one of the others present instead of to a staff member. I had started to write Mandy's comments in the minute book but she told me not to. She said that staff comments did not form a part of the meeting because the meetings were for the consumers. It was as though the staff were meant to be invisible; that their presence at these meetings were as facilitators, or observers, but not participants. They were there to train, manage and foster interactions between the consumers rather than being potential participants in these interactions.

We sat around for a while after the meeting had ended until one of the other staff members came in to tell us that it was "home time". Everyone was at once animated. Those that could grab their bags, headed out to the carpark

and climbed into their respective mini-buses to be driven home. Others were wheeled out. After everybody had gone from the room, Bill turned to me and said: "It's really hard having these meetings because you have to prompt them so much and put words in their mouths, but if you don't do that they'd say nothing. They've got very limited communication, but what else can you do?" Bill had been trying desperately to get the consumers to talk to each other, but conceded in the end that "it was almost impossible!" He thought that it happened occasionally but that it was never really successful.

What surprised me about Bill's comments—especially since he was different to most of the other staff members in that he spent a lot of time with the consumers and genuinely liked them and the work that he did—was that he too was convinced that these intellectually disabled people did not spontaneously talk or interact with one another. While it is true that their ways of engaging with one another were generally idiosyncratic, non-normative and highly particular, the consumers did, however, develop and engage in mutual relations with one another in ways that were meaningful and purposeful to them. Each person had their own specific modes of communication and expression and the consumers engaged with one another through these and through the objects that surrounded them. The shifting allegiances and animosities between the consumers made these relationships highly emotional, changeable, complex and immediate. While it was not always possible to interpret the motivating dynamics of these relationships, they definitely existed, and provided an underlying mood and temperament to every single day. Therefore, rather than attempting to transform the ways that the consumers engaged with others by teaching them socially normative skills and practices that they were not able to adequately sustain, these modes of expression and interaction could have become the grounds from which staff sought to incorporate the consumers into a broader sociality.

However, this was not the accepted or expected role of staff. They were under an obligation to provide the consumers with opportunities to develop their social skills, and learning how to communicate and interact with one another during the weekly meetings was one of these skills. In order to do so required that the consumers learn to absorb a different set of social practices and, just as Cowlshaw observed during her fieldwork with Aboriginal people, "Teaching the discipline and etiquette of meetings and consultation became an end in its own right" (Cowlshaw 1999: 232). This extended into "managing the voice of others", and resulted in a form of "ventriloquism", whereby the participants in the meeting were spoken for and where their own different modes of interacting and participating were rendered irrelevant (Cowlshaw 1999: 234). The weekly meetings at Xanadu had no other purpose than to instruct the consumers in socially normative skills and practices. In this, the meetings became an end in themselves. There was nothing to "meet" about other than to learn how to "meet".

These meetings did not just take place at the activities centre. They were expected to be a regular feature of life in the group homes as well. Although the meetings at Jeffrey Street only lasted a few weeks, those at Hervey Street continued every Tuesday evening for the duration of my fieldwork. During these meetings the house manager, or staff person on duty, would outline the agenda for discussion. This was usually taken from a list that staff had compiled of issues that had come up during the week, although the residents were also expected to contribute to the agenda at the beginning of the meeting. If they forgot to mention something it was left for the following week. The same format that was used at Xanadu was also followed at the house meetings. The meetings were chaired, minutes were taken, and the consumers sat around in a circle and were expected to speak in turn, speak out, and stick to the agenda.

Like the meetings at Xanadu, Mary used these house meetings to raise the problem of her continuing attendance at Xanadu. She also often said that she was unhappy in the house, and that she would prefer to go back to the institution where she once lived. Shauna, who usually had plenty to say, was unusually quiet whenever she was asked if she wanted to say anything at these meetings. Sally usually said "Elvis" or "Rock and Roll" when anything was said to her. Colin rarely said anything, although if a suggestion was made as to where they should go for dinner or what sort of furniture needed to be bought he generally agreed with it. Such household decisions were easily manipulated by the staff, or by the more capable consumers. They only had to ask leading questions or make a suggestion and the other residents would mostly agree. At least publicly. Sometimes the residents complained afterwards but were told that they had to speak up at the meeting if they were unhappy, and that the decision had already been made and agreed to. This happened on one occasion when Jim asked if he could have his girlfriend over for dinner. Colin and the girlfriend do not get on, but rather than opposing the suggestion, Colin agreed to it, only to complain later to the staff person that he did not want this woman coming to the house. She told him that he had to make his point during the meeting, and to the relevant person, rather than complaining to her in private. Despite being good friends, Colin was rather in awe of Jim, and would never have disagreed with him publicly.

There was a lot of discussion at these house meetings about "financial methodology", which was basically a proposal to drastically cut the amount of allocated funding from DOCS in an attempt to deal with a budget deficit. The staff were very distressed about this, especially as it meant that their numbers would be cut and pay conditions altered. The effect on the homes would be that staff would no longer be paid for their night-time shifts, even though they would still be required to stay overnight. The house manager told the residents

that this would mean that they would have to be in bed by 10.30pm. The residents were all rather concerned about this and agreed with the staff that the proposed changes were bad. The staff were quite open about their opposition to these proposals but their comments were "off the record", as were all of the comments they made, and were not included in any minutes. Like the meetings at Xanadu, whatever the staff said was irrelevant as far as these records went. The meetings were solely for the consumers.

While the staff were involved in these meetings as facilitators and minute takers, and even made suggestions at various stages during meetings concerning the running of the household, they were not participants. The residents were therefore regularly reminded that they were to direct their comments to one another rather than to staff. I was also expected to maintain this distance. When in the chair, I had to facilitate the meetings, and direct people to speak, but when Mary said "sorry" to me after a meeting for saying that I could not stay for dinner in response to my having to ask her to stop talking to Shauna, the staff person told her that she did not have to apologise to me but to her fellow residents. Mary then tried to apologise to the staff person but was once again redirected to apologise to the other consumers.

There are two inter-related issues here. One concerns the relationship between staff and consumers; the other is the perception that staff need to facilitate and train the consumers to relate to one another meaningfully. Before analysing the relationships between consumers, I wish to explore more fully the consequences of the institutional forms of relatedness that exist between staff and consumers.

### **Instituting Relationships based on Disengagement and Separation**

Following the weekly meetings at Hervey Street I usually stayed around until after dinner, watching television with the consumers, listening to music, or having cups of tea while sitting outside on the patio. Sometimes I would be shown the latest acquisition, a new table, some clothes or bedding, by one of the consumers. These were more casual moments of the day, and people moved around pursuing their own concerns. Yet there was still an ongoing and pervasive atmosphere of separation and disengagement. The staff did not engage with the consumers as fellow social beings. They were there to manage the house, and spent their time updating records or training consumers to learn domestic living skills. The staff rarely sat down with the consumers and passed the time just having cups of tea together, a smoke, or a casual chat. They rarely engaged with the residents through the residents' own interests. In fact, the consumers were forbidden to ask personal questions of the staff, and were discouraged from being affectionate and making personal contact. It was all right for the consumers to do this with one another, but not with the staff. Even within the relative intimacy of this home environment, the staff were on duty, and this involved maintaining the relevant and expected training and management procedures. It involved maintaining a form of relatedness based on separation and disengagement.

When I first visited "Keynton"—the paper shredding workshop that operated as part of Xanadu—I met a staff person called Julia who was very passionate about her work. She was disturbed by the departmental policies, the new legislation, and the attitudes of staff, and found herself alienated from her fellow workmates most of the time. Keynton operated out of a large corrugated iron shed situated in a concrete industrial landscape. Despite this, the atmosphere was very relaxed and friendly. The four consumers who worked at Keynton seemed to know the men who worked in the other buildings. They also appeared to enjoy their time with Julia, who sat and

chatted with them, or read and knitted, while they did their shredding. After work, Julia and the consumers would sometimes go for a drive to the local park for a walk, and on one occasion they all went up to the city to visit a woman who used to work with them. While I was sitting in the doorway with Julia, talking and soaking up the afternoon winter's sun, she explained to me that it was illegal for her to touch one of the women in the way that she had just done. Kathy had said that she needed the toilet, and Julia had put her arm around Kathy's shoulder to guide her to the bathroom. In an environment where touch is such an integral component of communication, this legislating against physical interaction only serves to further isolate and separate intellectually disabled people from others in the community. The rule that staff are to refrain from developing personal and emotional relationships with consumers contributes to this atmosphere of separation. Despite these requirements, a small number of staff did become emotionally attached to particular consumers, taking a special interest in their welfare. But the principle creates an environment where this now has to be done surreptitiously.

On one of my first days at Xanadu, while I was helping out at the nursery repotting plants and weeding the garden beds, I was told by two of the staff members not to become too familiar with any of the consumers in case they became attached to me. I was told that their behaviour changes if a staff person whom a consumer has become attached to leaves or is not on duty, and the aim is to maintain consistent behaviour. I was also told not to be affectionate, and that none of the staff were officially allowed to take consumers home with them. Whenever I arrived at the activities centre, group homes, or workshop I invariably felt a pressure to sit and talk with the staff as though I was one of them. While I was not officially a staff person, it was into this role that I was placed. At Xanadu the staff always had their morning tea and lunch in the staff room while the consumers sat in the front room around the tables. Staff would

make sure that those who needed it were medicated and that everyone had their lunches and a drink, but they rarely sat down and ate with the consumers. If ever I did they encouraged me to eat with them instead.

Unlike the majority of staff, I joined in with the activities as though I too were a participant, threading string onto cardboard, playing ten pin bowls, singing karaoke songs, delivering "meals on wheels", or just hanging around watching television, drawing, or having cups of tea. Although I could participate in these various activities I was also expected to lend a hand with their orchestration and assist with toileting and feeding. In this environment there were only two positions that could be occupied; that of staff or consumer. Even the consumers would turn to me at times as though I was one of the staff, asking me if this was "my day on", if they were allowed to have another cup of coffee, or to try and get me to do something for them. So although my status as a volunteer was essentially ambiguous I was constantly drawn into the world of the staff, by their own calling, by the expectations of the consumers, and by the legal requirements governing my actions as a volunteer. It was not possible for me to share the world of these intellectually disabled people, not because of any inherent difference between them and my siblings, but because the structure and expectations of the environment continued to reinforce a division that ultimately separated these people and myself as fundamentally different.

This atmosphere of separation was in accordance with the legal culture of rights and obligations that now exists in these environments (cf. Johnson 1998; McVilly 2000).<sup>2</sup> Guidelines for engaging with the consumers were provided by

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<sup>2</sup> Although this new ideology of rights fundamentally affects the way that staff relate to and treat intellectually disabled people, the problems encountered when relating in ways other than those which have been socially and institutionally sanctioned pre-exists this legislation. Aldo Gennaro—a theatre teacher and performer who was instrumental in the performance of "Madame Butterfly" at the Sydney Opera House in 1979 by a group of intellectually disabled adults from the Lorna Hodgkinson Sunshine Home —was sacked

a combination of the Disability Services Act and its accompanying Standards of Practice, Department of Community Services policies, and individual management plans. The structural and legal constraints of this institutionalised environment perpetuated the interpretation of the intellectually disabled consumers as abnormal and asocial beings in need of training and management. These produced an environment where the forms of relatedness were based on rules of disengagement rather than an ethic of relating *per se*. The meetings reflected this relationship of separation and disengagement. So too did the practices of training and management. It was also evident at every moment throughout the day; in the casual encounters between staff and consumers, and the actions and attitudes of staff generally. The wearing of latex gloves by staff whenever they toileted and bathed consumers was one such practice. Despite the rhetoric of hygiene that underlay this practice, there was a definite sense in which staff were keen to avoid all possible physical contact with consumers. They used separate crockery and cutlery, and had their own toilet which was kept locked. On one woman's birthday, the staff at Xanadu covered the chocolate cake with gladwrap so that she could not dribble when she blew out the candles on the cake that they too wanted to eat. Others were said to smell, and the staff argued over whose turn it was to bathe and toilet them. This separation and fear of contagion was deeply etched into staff attitudes and behaviour and reflects the perception that the intellectually

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from his position because his way of relating to these intellectually disabled people was deemed inappropriate and unacceptable (Rex Swinton; former Board Member of Sunshine; pers. comm.). The multi-award winning documentary, *Stepping Out* (dir. Chris Noonan 1980), that was made of this performance and the lead up to it shows Gennaro and the performers relating to one another primarily through touch and physical affection. When interviewed by Caroline Jones on her ABC Radio program "The Search for Meaning", Gennaro cited his own experience of muteness as a child, and his initial inability to communicate when he first went to the USA, as foundations for his particular form of drama teaching. As Gennaro commented, his style of teaching relied on those "little signals" as a type of energy, on creativity and communication through physical and emotional expression, as essential components of the theatrical process (Jones 1995: 113-122).

disabled are somehow inherently diseased, dirty, and potentially contagious. As Mandy said to me one day: "no wonder we get sick working here, getting spat on and pissed on".

This separation was generally combined with an attitude of authority and control, communication taking the form of sarcasm, patronising, hassling and teasing.<sup>3</sup> This was particularly evident at Xanadu, Jeffrey Street, the sheltered workshops and post-school options programme. There were times when I was also drawn into this mode of relating as well, so pervasive and dominating was it. If ever the consumers responded by speaking to the staff in the same way, as Martin had a tendency to do, they were immediately reprimanded. One day, not long after buying a new car, I was discussing with Martin where was the best place to buy a car stereo. I was in the staff room and he had wheeled himself over to the window to talk with me. Two of the other staff asked what we were talking about and when I told them they laughed and said that I could have just made it up as no-one else could understand what Martin was saying. Martin's face and ears were burning and he was visibly upset by their laughter. I felt stranded in the staff room with them, conscious that he was on the other side. One day when I went out with the post-school options group for a picnic I watched as one of the staff members joked around with the young intellectually disabled adults in a rough but friendly sort of way. Every now and then, however, she would look over to me and wink as though the joke was on them and that this was a secret that we shared.<sup>4</sup>

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<sup>3</sup> In her ethnographic account of life in a group home, Mary Howard (1990) also shows that staff interactions with residents were based on authority, control and separation. These were due to the "deficiency view of the resident", Howard argues, and this view was used to legitimise the role of the staff (Howard 1990: 167).

<sup>4</sup> Johnson (1998: 4) also talks about this pressure to conform to staff expectations and behaviour, finding that it was almost impossible not to get drawn into the activities of the unit where she did her fieldwork. On one occasion Johnson found herself helping a staff member "manhandle" a woman who was attacking another resident before realising what she was doing. At other times she noticed the amusement or bewilderment of staff at her

Communication amongst the staff was generally about the consumers, not with them, and whenever I came in and said "hello", or made some comment about the day, it was assumed by staff that it was to them that I was talking. When a young woman came to start work at the centre she was introduced to me as another volunteer, and although Mary was standing right beside us both and telling this woman her name, she was ignored. Nor was she introduced. When we went to do ten pin bowling it was only the consumers who took their turn at knocking over the pins. The staff sat back and made sure that everyone had their go, and kept a tally of the score—an aspect of the game that only interested a couple of people—but they did not join in. Delivering "meals on wheels" was a different matter because sometimes a staff person had to accompany the consumer to the door to make sure the duty was performed. Yet even in this activity the staff sustained their separation. They were there to train the consumers to perform this social activity, but were not actual participants in it. On one occasion Mandy complained that she was being "left alone" to do the "meals on wheels" when in fact she was accompanied by six consumers.

These forms of relatedness carried over into the group homes as well. They informed the general practices of staff and were the dominant mode of engagement between staff and consumers. One woman was employed by DOCS to work specifically as a "community integrator" for those living in the group homes. This involved initiating activities such as taking a few of the consumers to the local pub to play pool or the pokies. Sometimes it involved going to a film, out to dinner, or to a fun parlour. The community integrator

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attempts to engage with the women in ways that were different to the general practices of behaviour management or custodial duty (Johnson 1998: 44). One of the women whom I interviewed—who had worked at Xanadu as the coordinator a number of years prior to my doing fieldwork there—told me that after about four months she began to notice that her own behaviour and attitudes were shifting and becoming like that of other staff members, a process which she found deeply distressing but highly pervasive.

told me that she hated this job; that she found it tedious, embarrassing and frustrating. For her it was not about going out with the consumers but going out to do something for them. It was about providing an environment in which the consumers could be socially integrated with the community. It was about taking them to public places but not about actually fostering integration through staff/consumer relations. The staff saw themselves as the mediators or facilitators of community integration. Despite the obligation on behalf of staff to foster social integration, they did not see themselves as a part of the community to which the intellectually disabled people were supposed to be integrated. Yet true integration requires the fostering of mutual relatedness, and this also has to occur through staff relationships with the consumers.

The expectations and requirements of these institutionalised environments, however, precluded the possibility of developing long term relations of mutual engagement.<sup>5</sup> There was no sense in which true integration, which depends upon the creation of mutual spaces of engagement and joint contributions to the social world, could be produced. Because sociality had been defined in terms of particular and normative dispositional behaviours and competencies, a regime of training and management had been implemented in order to foster the development of this sociality. Yet sociality is fundamentally embedded in social relations. Without relationships born of intimacy, mutuality and solidarity, without the negotiation and mediation of different symbolic systems, it is impossible to produce and sustain a genuinely shared social milieu with intellectually disabled people.

The importance of relationships for social integration and an adequate quality of life has been well documented in some of the recent literature on

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<sup>5</sup> Oliver Sacks has stated that in order to perceive the inherently human, intelligent and creative aspect of intellectually disabled people he needed to drop his neurological gaze based on "defectology" and enter into genuine social relationships instead (Sacks 1986: 163-167; cf. Sacks 1995).

intellectual disability (Atkins 1998; Bigby 2000; Fullagar & Hardakar 1993; McVilly 2000; Ralph & Usher 1995; Rapley & Beyer 1996). Keith McVilly (2000: 7) has pointed out some of the "ethical dilemmas" that arise when the professional caring role that staff are employed to perform becomes blurred by a personal relationship. Some of these dilemmas include the potential incompatibility of different expectations associated with these roles, possible power imbalances, and potential conflicts of interest (McVilly 2000: 7).<sup>6</sup> These are very real problems that staff have to contend with, not least because of the overtly legal nature of their responsibilities. These requirements were introduced in part to protect both the consumers and the staff; the consumers from potential abuse by staff and the staff from potential threats of violence from consumers. They were also introduced to protect staff from accusations of abuse. Because of these possible dilemmas, there is a tendency in institutional environments to emphasize the development of social relations of intellectually disabled people with others who are not also staff members.

Both McVilly and Christine Bigby argue that the duty of staff towards people with intellectual disabilities is therefore to increase the number of people with whom consumers have social contact (Bigby 2000: 16-17; McVilly 2000: 17). Bigby specifically stresses the need to enhance "informal support networks" for people with intellectual disabilities arguing that the formal service system cannot "adequately fulfill tasks that require long term commitment, advocacy, or an affective relationship" (Bigby 2000: 17). While these are the sorts of intimate relationships that people usually have with family members and close friends, there is a tendency to criticise the dependency on family members as often the sole social relationship for people

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<sup>6</sup> Despite the emphasis on facilitating relationships and broadening the social contact of intellectually disabled clients with others, the Department of Health and Human Services in Tasmania has stipulated that staff working in disability services "should not encourage social contact between themselves and clients with whom they work, outside working situations" (cited in McVilly 2000: 7). However, this contact with staff *is* their social world.

with intellectual disabilities (McVilly 2000: 6). Rather than rely on family relationships, the aim is to broaden the social network and nurture informal social systems in order to foster friendships, such that the success of community integration is sometimes measured by the number of relationships that intellectually disabled people have with non-staff and non-family members (McVilly 2000: 6). While relationships with people outside the institutionalised environment of the group home or activities centre are important, they are encouraged without adequately addressing both the underlying requirements for mutual sociality and the potential role that staff can play in fostering this. Rather than training intellectually disabled people to conform to normative social standards staff have the capacity to create an environment within which intellectually disabled people are acknowledged as social beings. It is this that can then be extended into the wider community. In order to do this, however, it is necessary that intellectually disabled people be seen as the potential authors and sustainers of mutuality and sociality.

The tragic irony in this situation is that while today the emphasis is on normalisation and integration, those who work most closely with the intellectually disabled are usually the least integrated with them. At the very point where contact takes place between staff and consumer, at this site of potential mutual sociality, the differences and distance between the two groups are highlighted, reinforced and perpetuated. The place where the dissolution of the boundary between intellectually disabled people and others could take place becomes instead the site of its most forceful institution. Bound up in their obligations of a duty of care, and their role in instituting training and management practices, the staff rarely have the opportunity to engage with the intellectually disabled consumers as participants within a shared social environment.

The need to change the dynamics and principles of staff relationships with intellectually disabled people has been addressed by a number of researchers. The emphasis has generally been the need to better encourage integration and normalisation (Brandon 1991: 42-50; Goode 1984: 246; Peters 1980; Ryan & Thomas 1987; Shaddock *et al.* 1993). As staff members at an organisation for intellectually disabled people, Simone Fullagar and Ken Hardaker argue that relationships need to be based on friendship and mutual respect rather than pedagogic principles. As they write: "We have no choice but to transform the relationship between ourselves as 'service workers' and the people with intellectual disability we support. If we cannot do this, we cannot expect the rest of society to change the way they relate to this group of people" (Fullagar & Hardaker 1993: 43). Despite such criticisms, there has been no attempt on behalf of the formal service system to address these issues. In fact, the implementation of recent policies and practices has made it even more difficult to attain.

About six months after I began my fieldwork I happened to meet Terry, one of the former coordinators of Xanadu. Terry told me that she had eventually left the activities centre because she could not condone the new system that had been implemented while she was away on maternity leave. This was the system of marking off activities and the behaviour of the consumers on a daily basis. As Terry commented, this gave the staff a sense of security at having performed their duties. Training programmes for staff were also introduced at this time, and dealt with behaviour modification techniques, first aid, and issues around sexuality. They were about intervention, training, management and control. Terry stated that never once did she come across material that dealt with issues of communication between staff and consumers. Any communication problems were seen to be between the consumers themselves, as though the relationships between consumers and staff were not

the ones that needed working on. When leaving Xanadu at the end of the year I invited everyone to my place for a BBQ. After endless telephone calls and miscommunication with the coordinator we ended up having to have a picnic in a local park because there were concerns that I would not be legally covered if an accident happened while the consumers were in my house. The consumers were disappointed, as were most of the staff, and it was a sorry end to my year with them as we sat in the patchy shade beneath some scraggy gum trees in a local park with our sandwiches and cordial.

## Managing Relations Between Consumers

At Xanadu the staff genuinely believed that the weekly meetings were an attempt to foster "real" and "normal" interactions between consumers. In order to foster such "normal" interactions the staff would try to encourage each person who spoke to ask another person what they had been doing over the weekend. They were encouraged to ask questions, tell narratives about their lives, and be curious about each other. In doing so, the consumers were being directed to express themselves through normative, though highly formalised, modes of communication. This practice of training and instituting normative dispositional communication and behaviour, combined with an interpretation of the consumers as incapable of inherently meaningful symbolic representation and sociality, resulted in the staff being oblivious to, or dismissive of, the often dynamic, complex and socially meaningful interactions of the consumers.

Patricia, more than most of the other consumers at the centre, constantly sought to engage with the staff, often coming into the staff room in order to be with them. She was a small woman, and very strong, and although Patricia did not speak much she was constantly engaging with people through physical contact. Sometimes she would place the top of her head against a staff person's arm, back or chest. She would stand like this for a while, waiting for some response, which usually involved the other person briefly putting their arm around her. At any moment however, Patricia might grab hold of their head and grip it in a neck vice, or hit out at their stomach or arm. Sometimes she would pat them on the head saying "there, there". Patricia would remain like this until asked to leave and replace the rope that was supposed to be kept across the doorway.

This type of interaction did not just take place with the staff. Patricia was a real "mother hen", and was always moving about the room comforting people or assaulting them, one action often following the other in rapid succession. She could give the softest of cuddles to someone who had been crying, or suddenly lash out in anger, swearing and cursing, hitting her head against the table or slamming the cupboard doors. Almost every day the same scenario took place. Polly would be walking around the room in circles, talking incessantly to herself in a high pitched voice. Patricia would get really annoyed with Polly and tell her to "shut up", and then start swearing to herself, hitting the table and her head with her fists, at which point everybody else in the room would get tense and upset. Cressida would visibly retreat into herself, folding her large frame further into the chair as if hoping to disappear from view. Joanne would walk out of the room and sit at the corner table in the television room in order to continue unimpeded in her task of tearing up newspaper. Kate would start rocking even more furiously than usual as though she could drown out the noise and disruption by immersing herself in this rhythmic movement. And Martin would hunch his shoulders up around his ears and tell Patricia to "shut up" and stop upsetting people. At this point Patricia would become even more annoyed and would hit out at people, either verbally or physically, telling them that they were "shits" or "fucks" or hitting them on the back.

It intrigued me when I was told by one of the staff members that Patricia only did this to get attention from the staff. It was hard to convince him that she did it even when they were not present—although, of course, there was always the possibility that she might have been doing it for my benefit. There were many times when the interactions were less violent and unpredictable. One morning when I walked into the local community centre where we had been meeting up once a week I was greeted with sighs of relief from the staff

as they were short staffed. The two staff members were sitting outside in the sun while most of the consumers were indoors, seated at various tables around the room. They were waiting for their morning's activities to begin, which would entail a visit to the library or the local shops. As I wrote that evening:

They had all had their morning 'cuppa' and were just waiting around. Then Bill came in and gave Martin some crayons to draw with, and it seemed that everyone was to do some craft work if they wanted to. They don't have to do it if they don't want to and most of them usually don't. I sat with Martin and started doing some drawing as well. He was using different colours and doing his usual line drawing. We chatted about my car, and as my partner hadn't fixed up a stereo in it, Martin said he was very lazy and that he'd throw a bucket of cold water over him! While we sat there, Cressida came up and sat behind me and she too started to do a bit of drawing on the edge of the paper. She talked about her new clothes, and her nail polish, and then Kate came and sat with us. Rachel wheeled herself in from outside and we had a full table. Rachel told me she had a new spiral book [for drawing in] and wanted to show it to me but realised she'd left it at home. It was a pleasant morning and I listened and watched as they all talked to one another, touched one another or generally responded to each other's presence. Kate and Cressida were talking quietly about something and seemed to understand each other, but then Cressida turned to me and said that Kate was kicking her. That didn't sound like the Kate that I knew, who was so loving and gentle, but later Rachel told Kate to stop laughing at her. I asked Rachel if she liked Kate and she said emphatically, "no!" I wonder what else goes on between Kate and the others.

This is just one example of the many scenes that I witnessed. There were often shifting allegiances, and strong expressions of friendship or animosity. This was evident in the repetition with which people sat with certain others. It was also evident in the bouts of physical and verbal abuse that a couple of the consumers were wont to display, especially Patricia. Sometimes there were demonstrative displays of affection and pleasure; a big hug, kisses, and holding of hands among friends. Sometimes it just extended to being aware if someone was unwell or in a bad mood. At other times there would be a quiet murmuring, a gentle buzz of acknowledgment and engagement between those present. But more often than not there was just a general sense of being together, of sharing space and time, with a familiarity that dispensed with the necessity of formal interaction. Like Bourdieu's (1999 [1972]: 78) notion of a "habitus", there were familiar patterns of dispositions that informed these interactions. This familiarity emerged from their shared environment and was generally based on relating to one another through their bodies, the objects that they shared, and the immediacy of each person's emotions and actions, rather than the more formal and socially elaborated forms of interaction and self expression encouraged during the meetings. Yet the staff constantly sought to train the consumers to conform to this other, normalised, mode of interaction and expression, and interpreted their actual ways of being and engaging with one another as asocial.

## Narratives of Pain and Illness

As I pointed out in chapter six, it was expected that the staff be doing things for the consumers, with the aim of providing a socially conforming and normative environment within which they, the consumers, could enter the social world and develop social skills. Accordingly, activities such as cooking, visiting the library, painting, delivering "meals on wheels", going ten pin bowling, shredding paper, tying bits of string to cardboard tags, tracing letters, and gardening were part of the weekly agenda. The meaning and purpose of these activities was assumed to be inherent in the activities themselves. In fact, their very meaning was assumed, and it was this meaning as a socially normative phenomena that was being made available to the consumers. Meaning was thought of as a preexisting social fact rather than a product of interaction and use. It was taken as normative, and these activities therefore conformed to socially accepted modes of engaging with the world. The staff were given the task of introducing these activities as part of an integrationist and normalisation-driven agenda. They set out to train the consumers to conform to these broader social activities. The fact that the consumers did not share these meanings, nor the purpose behind them, was taken as indicative of their asocial and abnormal existence. The accepted belief that they were incapable of creating and utilising potentially meaningful symbolic systems meant that staff did not engage with the consumers on terms set by the consumers themselves.

The consequences of this belief were sometimes complex and often disturbing. In attempts to institute socially normative activities and encourage the development of social skills, the staff often denied or ignored attempts by consumers to communicate to them a sense of self.<sup>7</sup> Even when utilising

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<sup>7</sup> This sense of intellectually disabled people as lacking a coherent and meaningful self is similar to the experiences of those who are physically disabled. Robert Murphy argues in his autobiographical ethnographic account

socially recognisable modes of interaction, such as narratives of self, the consumers were still redirected in their accounts, or else ignored altogether. They were still judged as abnormal and asocial. This was the case with Mary, whose stories about her former life in an institution, the death of her mother and sister when she was young, and her outspoken dislike of the centre and group home where she spent almost all of her time, were taken solely as manifestations of an unstable and psychotic state of mind. They were never encouraged, nor engaged with. It was also the case with Cressida, whose narratives of pain and illness constituted the major form of interaction she initiated with others.

Cressida was in her mid-40s, an Aboriginal woman who lived in Jeffrey Street, the largest of the government funded group homes in the area. Prior to moving into a group home almost ten years ago, Cressida had spent many years living in an institution. I came to know Cressida over the course of my fieldwork, both through the activities centre and from my weekly visits to Jeffrey Street. As we sat there day after day, working at tying pieces of string to bits of cardboard, having cups of tea while waiting for the day's activities to begin, travelling in the buses, or watching television at her home, I began to notice a pattern in the way she communicated with me. We would be sitting quietly, side by side, the buzz of the local radio station or television filling up the silences. Almost lost in our own reveries I would be drawn back by the plaintive voice of this softly spoken woman telling me that she was ill, that she had a sore, or that her stomach pained her. I noticed that as Cressida said this she would reach out her hand and touch her stomach, which was the part of her body that was generally the cause of this pain. In doing so she would gesture ever so slightly to me, an offering or invitation to touch her also in that place. I would do this, as one does to a person in pain, and Cressida would sit

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of physical disability, that the social experience of permanent disability is transformed into a state of being a damaged self (Murphy 1990: 85).

back as though enjoying a soothing massage on tired muscles; the relief in her body was palpable. I would ask her if that was better, or if that was the spot which was sore, and she would affirm that it was but would not want me to remove my hand.

This interaction went on for months, and I began to notice that it was not only Cressida who engaged me in conversations over her body, and its pain and illnesses. Others at the activities centre would also come up to me and tell me they were sore or sick. Sometimes, if I was to touch one of them accidentally while helping to take off a jumper or replace a shoe, or just in passing at some stage during the day, they would cry out at me in pain, telling me that it was sore where I had just touched them. Of the twelve who regularly came to the centre, five were frequently evoking pain or illness as part of our interactions. And of another seven people whom I came to know through the group houses, three were often telling me that they were sore, in pain, or unwell.

Very little attention was paid by the staff to any of this behaviour. Like most of the consumers comments and actions, they were seen to be meaningless, purposeless, and irrelevant. They were interpreted as just another manifestation of intellectually disabled people's abnormal selves. I was told by the staff that Cressida was a hypochondriac, and that the way to respond to her running commentaries on pain, illness and suffering, was to ignore it; to not respond in any way that allowed her to indulge in these "fantasy" illnesses. Cressida would be told to go to the toilet if she complained of having a pain in her gut. That was generally the extent of the staff reaction. There was to be no touching, no caressing, no soothing. There was to be no interaction. There was nothing really wrong with Cressida so there was no real need to respond to her. It was best ignored so as not to be encouraged and condoned. In fact, as a worker, one is seen to have achieved a certain level of professionalism and

control once such behaviour is interpreted as hypochondria. Yet it did not seem to matter how often the staff told people not to make such a fuss out of nothing, they continued to do it. It did not matter how often Cressida was ignored, or told to go to the toilet, she continued to tell me that she was in pain and reach out for me to touch her. One afternoon, when I arrived at the group home where Cressida lived, I discovered that she was in hospital; that she had become increasingly adamant about the pain in her stomach, finally prompting staff to take her to a doctor. It turned out that Cressida had a blocked bowel.

This sequence of events played on my mind for the varying ways in which Cressida and her narratives of pain were being treated. First it was denial; there was nothing really wrong and such behaviour was interpreted as hypochondria. Along with all of Cressida's behaviour, it was discounted and identified with other disability behaviour. Then came an acceptance that perhaps there actually was something wrong, medically speaking, and the response was to gain confirmation from a practitioner and have the problem dealt with professionally. When Cressida came home from hospital, distressed at having had needles in her buttock and a drip in her arm causing her yet more pain, there was no acknowledgment from staff that she was to be treated with special care or indulged in any way. She was not allowed to play out the role of patient once she had left the hospital. There was never any recognition that it had taken the staff a number of months to respond to Cressida's signs of distress. In fact it was all forgotten quite quickly. And Cressida's ongoing narratives of pain and illness continued to be ignored just as they always had been.

Intellectually disabled people often remain voiceless and powerless, without the ability to ascribe to themselves an identity that is not reflective of their social status as abnormal. It is assumed that such people have nothing to say, that they have "no capacity for understanding or conveying their own situation

and experiences" (Atkinson & Walmsley 1999: 209; cf. Bogdan & Taylor 1982; Booth & Booth 1996; Felske 1994). I would contend that the response of the staff to the narratives of pain I witnessed were in part a consequence of such interpretations. They also represent an internalisation of the sick role, as Susan Lea argues (Lea 1988: 66-67). There are so few ways in which intellectually disabled people come to be socially positioned and "known" that they themselves are forced to articulate their experiences and identities within this paradigm. However, rather than interpreting such narratives as negative consequences of labelling, as Lea (1988: 66-67) does, I would argue that intellectually disabled people use these narratives of pain and illness to try to insert themselves into the social milieu. They do so through attempting to create a "shared space of disclosure" (C. Taylor 1985).<sup>8</sup>

Charles Taylor uses this term to describe the space within which the self is constituted, arguing that a shared space of disclosure is based on the various communicational and symbolic means through which people come to be subjects both for themselves and for others (C. Taylor 1985: 271-273). As with most theories of culture and language, Taylor's operates at two, albeit inter-related, levels. There is the constitutive and productive nature of language and culture that can be said to operate at the meta level, at the institutional or pedagogic level, informing and forming persons as particular types of persons according to a normative notion of what constitutes personhood. There is also the "interactional" aspect of language and culture that operates to create shared spaces within which people engage with one another. The former is the level at which the symbolic scheme of reason and normality operates, and within which practices of training and management are instituted. It produces a formal, formalised, and public sense of personhood according to an inherited, institutionalised and socially prescribed interpretation of meaning and identity.

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<sup>8</sup> I am indebted to Diane Austin-Broos for drawing my attention to Taylor's work.

Taylor argues that within "modern society and culture" people are expected to project and express themselves in an abstract and self-reflective manner, using the rational tools of language to articulate their experiences in a readily acceptable and socially recognised form (C. Taylor 1985: 280). This contemporary form of a space of disclosure evolved out of a Western preoccupation with the role of reason and contemplation in the expression, and indeed experiences, of the self and personhood (C. Taylor 1985: 280). However, as Taylor argues, this preoccupation "utterly banishes earlier views of specialised spaces of disclosure, so that they even cease to be fully comprehensible" (C. Taylor 1985: 280). While true of other cultures and historical periods, this is also true of the contemporary institutional encounter with intellectually disabled people.

Not only are the ways that intellectually disabled people disclose a sense of themselves rendered incomprehensible, but staff are also expected to teach these people to learn how to conform to normative modes of self-representation and expression based on the central roles of reason, self-reflexivity, and language. Reason and intelligence have been associated with the capacity for sociality and, in order to become social beings, intellectually disabled people need to be trained to develop the necessary spaces of disclosure through which they can present themselves to others as social persons. The staff are under an obligation to encourage this as part of the expectations of community integration and normalisation. They have a sense of what such a space of disclosure entailed, based on historical and cultural perceptions of selfhood, and sought to train the development of these normative interactions and communications during the meetings. The intellectually disabled consumers were being asked to constitute themselves in terms of a particular space of disclosure, a narrativized space based upon

impersonal accounts of their lives rather than on an embodied and immediate response to others.

However, there is also another level at which language operates, and it is through the combination of both that the narratives of pain I was witnessing can be understood. Language, according to Taylor, is also used as the vehicle through which people are brought together. Language in this sense does not just apply to spoken narratives. It refers to all symbolic activity or "forms" (C. Taylor 1985: 272-272). It can therefore include the symbolic practices of intellectually disabled people, including gestures, bodily contact, the utilisation of objects, and behavioural dispositions. While restricted in their applicability and range of expression, such symbolic practices do have the capacity to generate forms of sociality. Through interacting with others on the basis of these symbolic practices and disclosures it is possible to create a "rapport between us . . . what one might call a public space, or a common vantage point from which to survey the world together" (C. Taylor 1985: 273). This then becomes a way of domesticating a space, of transforming it and making it livable. My sister's bits and pieces constitute such an activity, as did my brother's use of jigsaw puzzles. These actions were ways of making things happen in the world, of transforming the world. They became the vehicles through which meanings could be mediated and sociality shared. They created a "public space" through which we could interact with one another.

The narratives of pain I witnessed during my fieldwork were an attempt on behalf of intellectually disabled people to create a rapport, a common vantage point or "shared idiom" (Herzfeld 1997: 3), through which to view the world. Through Cressida's actions and narratives of pain I was drawn into a common space, a space of pain and illness that I was both familiar with and with which I could empathise. Her narratives became one of the means through which we related to one another, and in this sense created a level of intimacy and

understanding that made our shared world meaningful and social. Like Geertz's (1993a [1973]) notion of culture as a system of shared symbols, these narratives of pain were generated by a shared symbolic system. They also generated this symbolic system in the process of being articulated. It was, in Wittgensteinian terms, a language game that worked—or that should have worked—and the creation of this space of disclosure gave Cressida the possibility of presenting herself as a public self, a social being, a person who existed within a meaningful and socially shared world.

The added complexity to this situation, however, is that in attempting to constitute a shared space of disclosure through the sick role and narratives of pain and illness, intellectually disabled people like Cressida are not engaged with because what they do and say is not taken as potentially meaningful. Unlike the sick, who can get better, these people are perceived as permanently "unwell". Like the sick, they must work towards their own rehabilitation but can never actually attain it because they are always and already constituted as outside the social. In the process, their narratives and expressions of self are disregarded. They cannot have anything meaningful to say, therefore, the staff do not engage with them as such. Even when expressing herself according to the normative standards of pain and medical illness, and even when utilising recognisable narratives of self, Cressida's attempts at communication were put under suspicion. The act misfired because there was no faith in the possibility of mutuality. Cressida was denied the valid and authoritative status as a person capable of representing herself to others.<sup>9</sup> Her attempts to enter into the social milieu through her body and narratives of pain and illness were invalidated and her status as a person both participating in and creating a shared social

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<sup>9</sup> This issue of the lack of authenticity and a valid voice for intellectually disabled people has been explored by a number of people, including Angrosino (1992; 1994), Atkinson and Walmsley (1999: 209), Bogdan and Taylor (1976; 1982; 1989), Booth and Booth (1996: 67), Branson and Miller (1989; 1992), Brown and Smith (1989), Johnson (1998), and Ryan and Thomas (1987).

world were consequently denied. Interestingly, my siblings never used such narratives of pain and illness at home, perhaps because there were other means through which they and their actions were socially legitimised.

By denying and ignoring these narratives of pain, illness and selfhood, staff undermine one of the means for mutual interaction that intellectually disabled people's sociality and identity depend upon. While the intellectually disabled people at Xanadu and the group homes were continually engaging with one another, the lack of opportunity to develop shared spaces of disclosure with non intellectually disabled people limited the consumers' possibilities for exploring a broader, socially inclusive sociality and self-identity. When extended to all their forms of symbolic practice, this loss of interaction and mutual relatedness with non-intellectually disabled people prevents the development of shared or negotiated symbolic systems or language games based on who intellectually disabled people actually are. By denying intellectually disabled people valid and potentially shared spaces of disclosure within which they are able to express themselves as social beings, the constitution of sociality as a joint and mutual endeavour is consequently undermined. The opportunity to sustain a mutuality with non-intellectually disabled others contributes to intellectually disabled people's humanness, and their capacity to exist in the world as social beings. To prevent this is to lock intellectually disabled people into a world where their symbolic, communicative and social capacities are limited to interactions with their fellow intellectually disabled consumers. It also results in practices of training and management that are utilised as the means for drawing these people into the social milieu.

The people with whom I worked, and my brother and sister, all expressed themselves in an immediate, embodied, concrete and highly contextual manner. This was as much an attribute of the narratives of pain that Cressida

utilised, and the incantations and running commentaries that my sister engaged in, as it was an aspect of other ways of acting in the world. These expressions occurred through the objects that surrounded them, such as the jigsaw puzzles and books and bits and pieces of my siblings, or the beads, drawings and glass bulbs that people were using at the centre. Sometimes these expressions of self occurred through their bodies, their emotions and the gestures that they made towards one another. Robert Desjarlais comments that such forms of expression and engagement represent an "acutely tactile engagement with the world", arguing that they involve a "poetics of exchange, confrontation, finite acts, and momentary occupations" that are fundamentally different to socially conventional narrative forms of expression (Desjarlais 1996: 86-7).<sup>10</sup> Due to the loss of spatial, political and economic grounds upon which people are usually able to assert themselves, Desjarlais argues that mentally ill and homeless people are often forced to rely on their bodies as the primary means for expressing themselves and articulating their experiences. As Desjarlais puts it: "With the loss of many possessions, and the public slant to physical movements and functions, the body becomes, at times, the most prominent instrument of engagement, awareness and retrospection" (Desjarlais 1996: 78). The narratives of illness and pain I witnessed during my fieldwork represent such tactile modes of engagement, as did the acts of friendship, frustration or animosity that were expressed through physical encounters. These involved such things as holding hands, sitting side by side on the couch touching one another, or patting someone gently on the head, as much as it involved pinching, hitting and scratching another person. Such

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<sup>10</sup> The possibility that experience is an historically and culturally constituted phenomenon rather than an "existential given" is one that Desjarlais also examines in his ethnographic encounters with homeless and mentally ill people (Desjarlais 1996: 72). Desjarlais claims that Western notions of "experience" are predicated on notions and forms of reflexive interiority, a narrative flow, hermeneutic depth, individual agency and transcendence. All of these aspects and expressions are thought to reflect and inform the true self (Desjarlais 1996: 73). Desjarlais argues, however, that experience and selfhood are instead the products of social, political, cultural and environmental factors.

modes of engagement were constantly utilised by the consumers in their relations with one another, but they were also enacted by the consumers in their encounters with staff. Patricia did so when she came into the staff room and grabbed hold of a staff member. David did so when he came up to a staff person wanting them to scratch his head. Cressida did so when reaching out to staff to touch her in the place that was sore. For others with whom I worked these expressions of self involved patterns of dispositional behaviour, such as walking in circles, rearranging the furniture or rocking in a chair. These were the dispositions and patterns through which they expressed themselves, and through which meaning could potentially be negotiated and mediated. These were the actions through which mutuality and sociality could be developed and sustained.

Yet the potential for mutual sociality with intellectually disabled people based upon such symbolic practices is not recognised or aspired to in institutional environments. The ethos is entirely one of training and management; of conformity and assimilation to normative standards. In this situation, whatever intellectually disabled people do and say is interpreted as abnormal and meaningless. Maryla's collection of bits and pieces is labelled obsessive compulsive; Cressida's daily accounts of her bodily aches and pains are dismissed as hypochondria; Mary's stories about her mother and sister's deaths, and accounts of her experiences at various institutions, become indicative of an oncoming psychotic episode; Kate's rocking and singing are thought to be obsessive and disruptive; Joanne's silence and separation from others while tearing up newspaper an aspect of her autism; Patricia's alternating aggression and affection an expression of her intellectual disability combined with an abusive past. By interpreting these dispositional acts as solely pathological and abnormal, and ignoring attempts on behalf of the consumers to use these as the basis for their encounters with others, the

opportunity to produce a genuinely shared and interdependent mutual sociality with non-intellectually disabled people is lost.

Through instituting practices of reason and normality staff encourage the development of decontextualised skills and behaviours. These are based upon a particular concept of what it means to be human, of what it means to be a person. In our society, the attributes and practices that are most highly valued are those of rational, conceptual, abstract thought, and of productive and economically viable work. Intellectually disabled people do not fulfil these expectations, and their expressions of self and encounters with others often remain localised, contextual and immediate rather than abstract and decontextualised. Relationships are usually with those in one's immediate environment, with those with whom one comes into direct contact. These include other intellectually disabled people and staff, as well as family members and family friends. Intellectually disabled people's concerns are often immediate, emotional and bodily. While the possibilities for their sociality and mutuality are limited by these restrictions, it is possible to engage with intellectually disabled people and develop socially meaningful relationships through these actions in an inclusive rather than exclusive way. This requires accepting their ways of being as legitimate and their expressions of self as potentially meaningful. It requires engaging with them through intersubjective, mutually inclusive relationships.

## Conclusion

### A Place for the Intellectually Disabled

*. . . the innate capacities for sociality may be in individuals, but they are completed only between them.*

*Michael Carrithers*

While meaning and sociality is reproduced and recreated as an inherited interpretation of the world, it is also socially produced. It arises out of shared experiences and interactions such that people's actions and behaviours become meaningful and interpretable as an emergent aspect of their shared sociality. The meaning of intellectually disabled people's behaviour is open to negotiation and interpretation once it is accepted that they have such a capacity, and once they are engaged with in this way. When I first spent time with the people at Xanadu I had no understanding of what they were doing. Their behaviour, actions and emotional expressions seemed *ad hoc* and chaotic. I was an outsider, and while they lacked the tools to articulate and express themselves in ways that were socially familiar and acceptable, I lacked the relatedness with them that was necessary to understand who they were and what were their concerns. Over time, and through sharing their environment with them, as they wanted to be, I began to perceive a coherence to their identities and expressions that could operate as potential sources of mutual sociality. This occurred with Sarah and her beads (pp. 249-250), Cressida's narratives of pain (pp. 310-313), Tony and his glass bulbs (pp. 252-254), Joanne and her newspapers (pp. 248-249, Pearl's alternating acts of aggression and affection (pp. 260, 307-308), Jacky's reordering of furniture (p. 254), Polly's

circular walks (p. 309), Mary's stories (p. 263), Kate's rocking (pp. 250-251, 261), and Martin's drawings (p. 251-252).

These activities and dispositional behaviours reminded me of my siblings and their jigsaw puzzles, bits and pieces, and incantations. Within the domestic environment that we shared, these behaviours and enterprises became the source of our interactions with one another. They became the means through which our relationships were mediated and, although there were limits to the range of these relationships, there was an implicit understanding that these actions constituted fields of mutuality. They created spaces of disclosure through which mutuality could exist. By being perceived and accepted as symbolic practices, the ways or games through which my siblings sought to be and present themselves produced the specific sociality or form of life that I described in chapter one. It was only through our relations and interactions with one another that these were realised.

In order to perceive their actions and behaviours as socially meaningful I had to relate to my siblings, to be in relationship with them, to share a sociality. I had to perceive, interpret and mediate their ways of being in the world as ones which had their own dispositional patterns and integrity. These were specific, contextual and particular modes of expression, and their sociality remained meaningful, negotiable and communicable only through the intimacy of my actual engagements with each sibling. Because of their restricted and highly contextualised natures, the particular language games that became the vehicles for mutuality required a level of commitment and an intensity of engagement that usually only exists in relations of diffuse and enduring solidarity. The patience, empathy and acceptance that is necessary to engage with another who has very idiosyncratic and limited dispositions is one that is difficult to create, particularly in a work environment. Yet this is exactly what is necessary for intellectually disabled people to be recognised as, and to

become, social beings. The development of sustainable forms of sociality for intellectually disabled people therefore requires some very special circumstances, and ones that are not able to be created in the sorts of institutionalised environments that exist at present.

The forms of relatedness that exist in institutional environments preclude the capacity, or indeed necessity, of building relations of mutual sociality. Cultural, structural and legal obligations informed and reinforced these forms of relating. The limited social imagination of institutional environments has made a rational working being the only model of a social human being that it is possible to cultivate. Without mutual sociality, however, humans lose what it is that makes them encultured and social beings. Without this, behaviour also loses its socially meaningful aspect. As Carrithers observes:

The speech we learn only makes sense in respect of the others we learn it from and to whom we direct it. The values in behaviour we acquire are sensible only in the perspective of others, or in our own imagination of others' perspective. Indeed culture, here meaning just largely mental goods, forms of knowledge, and values to live by, which we have learned or created, is intelligible only in its use by people and in respect of other people. Cultures, in other words, presuppose relationships (Carrithers 1992: 30).

Once interdependent relationships with intellectually disabled people are denied, once the necessity of intimate interaction is abandoned, such people's behaviour is perceived as bizarre and abnormal.<sup>1</sup> This is all the more so

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<sup>1</sup> There are many ethnographic accounts that illustrate the tendency of social groups to perceive outsiders as strange, inhuman and abnormal (de Castro 1992; Hodgen 1964; Jackson 1998; T. Turner 1995). As Eduardo Viveiros de Castro points out in his study of an Amazonian society, those doing the defining only see themselves as the norm, as real and proper human beings and people (de Castro 1992: 38). The lack of, or distance in, relatedness that

because intellectually disabled people's actions and interactions do not generally conform to predetermined cultural patterns and expectations. It is increased in amplitude many times because intellectually disabled people tend to utilise contextualised, restricted, concrete and embodied modes of communication which demand intimate interaction. My experiences at the centre and group homes, introduced in chapter two, made this painfully clear. The consumers were at the activities centre and group homes because their behaviour was perceived and interpreted as asocial and abnormal. Consequently, everything they did and said was treated as such. Therefore there was no development of shared or negotiated vehicles of meaning based on the consumers own creative potential. There was no sense that this was even possible. The activities and practices that were instituted were attempts to inject something socially meaningful into their lives.

The assumption in such practices is that meaning only exists in that which is culturally recognised. As described in chapters three and four, the culturally recognised is defined in terms of a symbolic scheme of reason and normality. However, while humans do things with and to one another in accordance with accepted schemes, there is also an emergent aspect to meaning and sociality that allows for the creation of new patterns of interaction, new relationships, and new meanings. Our capacity to create symbolic systems through which meaning becomes shared, recognised, negotiated and/or mediated is a fundamental component of our humanness. This capacity, the infinite

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such encounters are based upon tends to preclude the possibility of perceiving these others as like oneself. It is only through contact that these perceptions are challenged, although of course, as postcolonial theorists point out, constructions of others do continue to be based upon initial projections of what is not the self onto the other (Said 1991 [1978]). I would argue however that such post-structural accounts of "self" and "other" simplifies the complexity of relatedness across difference. Like Johnson's (1998) account of intellectually disabled women, they tend to only emphasis the construction of identity of the "other" as a product of discourse, rather than analysing identity, subjectivity and meaning as an emergent aspect of social practice.

variability and creative potential of patterns that are created by humans, is not limited to "a foreordained dictionary of images to which the world conforms" (Carrithers 1992: 165). Rather, "humans' ability to recognize themes or patterns and variations is . . . infinitely extensible" (Carrithers 1992: 165).

Interpreting meaning as potentially infinite and extendible means that culture and sociality are continually unfolding through processes of interaction and transformation based on social practices and relations (Barth 1966; Carrithers 1992). Rather than meaning inhering in an object, or depending solely on rationality, mentalism, and culture as a static entity, meaning becomes a symbolic and emergent aspect of negotiation, use and practice (Bourdieu 1999 [1972]; Saleeby 1994). It arises from relations of power and knowledge as much as it evolves through the intimate interactions of daily life. The institutional and clinical world of intellectual disability is thoroughly entangled in relations of power and knowledge. This is what Johnson's "discourse of intellectual disability" refers to (Johnson 1998: 77; cf. Cocks & Allen 1996: 305-6; Ryan & Thomas 1987: 114). It is what the symbolic scheme of reason and normality produces. The sociocultural critiques discussed in chapter five are a response to the power embodied in such clinical and institutional accounts.

The fact that intellectually disabled people are perceived and treated by clinical professionals and institutional staff in such profoundly disabling ways is an aspect of this power relationship. This is in part a result of the break in relating that takes place when the point of interaction is no longer based on the desire to communicate with, and understand, intellectually disabled people as they are. Rather than seeking the potential and emergent meaning in what intellectually disabled people are doing, clinical specialists seek to understand why and how their actions do not adhere to socially normative behaviours. They apply a meaning to it based on the symbolic scheme of reason and

normality, assuming in the process that such people are inherently incapable of creating meaning, mutuality and sociality because they lack the supposedly necessary normative social and mental capabilities. Such interpretations rely on associating reason and intelligence with a capacity for sociality. Consequently, what intellectually disabled people do is categorised as abnormal and in need of normalisation. As described in chapter six, a whole apparatus of training and management is introduced in institutional environments in an attempt to foster socially normal expressions and behaviours. These include domestic and vocational skills training. Therefore, relating no longer operates as a bridge of emergent and productive meaning between different people but becomes a one-way process of indoctrination and assimilation.

As described in chapter five, social constructionist and discursive analyses such as those by Bogdan and Taylor (1982; 1989), Goode (1984), Branson and Miller (1989) and Johnson (1998) show how intellectually disabled people are socially perceived and positioned. They show how meaning becomes projected onto "the other" (Johnson 1998: 62-63), and how these ideologies and discourses get incorporated into daily practices by structuring the environments within which intellectually disabled people reside. As Johnson states:

My concern with the subjectivity of the women led inevitably to an exploration of the basis for its constitution by others. Increasingly I became aware that knowledge and the power involved in prescribed associated practices were crucial in determining how the women's subjectivity was 'captured' by others, so the ways in which knowledge, practices and power were exercised in relation to the women became a dominant theme in the study (Johnson 1998: 14).

While I agree with Johnson's arguments about the power of discursive practices to form and inform intellectually disabled people's lives, such post-structural interpretations do not consider the possibility of "knowing" intellectually disabled people outside these formal institutional paradigms. Neither do they interpret intellectually disabled people as more than just "others", the product of projected social meanings. For Johnson (1998: 62-63), even familial relationships are informed by these dominant discourses. Like the social constructionist interpretations of Bogdan and Taylor (1982; 1989), Goode (1984), and Connors and Donnellan (1993), such post-structural accounts do not see meaning and subjectivity as an emergent aspect of social practice and mutuality. Meaning is only socially prescribed meaning. It is how others constitute the intellectually disabled and, although open to diversity and difference due to differences in types of relationships (Goode 1984), meaning is not something which the intellectually disabled are seen to be capable of creating for themselves. It is not something that is seen to be integral to their expressions of self or their mutual encounters with others.

Without denying the importance of these social constructionist and discursive interpretations of intellectual disability I have attempted to move beyond these to show the necessary conditions for creating a meaningful mutual sociality with intellectually disabled people. I have done so by acknowledging that it is through social relations and practices, rather than solely social structures and discourses, that sociality, identity and meaning is produced (Bourdieu 1999 [1972]; 1994). While the symbolic scheme of reason and normality informs institutional and clinical practices, and denies to intellectually disabled people the necessary conditions for mutual sociality, it does not constitute the totality of their social experiences and possibilities.

The people I write about present a challenge to usual concepts of culture. They represent a break with any recognisable re/production of culture. They

do not generate acceptable patterns of behaviour nor do they learn the lessons of culture and reproduce its norms. The gestures of intellectually disabled people are the product of different dispositions, unexpected and unpredictable ones, although once they are engaged with these gestures become meaningful in relation to the person producing them and the context within which they occur. They may not have as their precursor the historical predispositions of a particular culture, but in being made, in being produced, they become a part of that culture. Such gestures do not remain the sole object of that person because in their production these actions and behaviours become part of the wider world, existing beyond the individual person. They are in the world, interacting with it and at the same time producing and shaping it. They exist in relation to others who share this world.

The reorganisation of found objects into the highly treasured and precious collection of bits and pieces that my sister engages in is precisely such an act. The purposeful and patterned encounters with jigsaw puzzles that both she and my brother engaged in also represented such an act. They have both significance for my siblings and reorder the world with which they are interacting. These actions are not performed in a vacuum; they are using the same objects that the rest of us interact with in new and creative ways. They also have an impact on the lives of those who are not intellectually disabled. As kin, we were all involved in their significance and played a role in relation to whatever it was that was signified. The immediacy and intimacy of our relationships with one another were necessary to support them as such. I did not come to perceive the meaning in what my sisters and brother did because of my construction of them as a sister, brother or human being. On the contrary, I came to relate to them as people, as social beings, because we existed within a mutually unfolding social world. I related to them and discovered meaning and purpose in who they were because of our mutual

sociality. This required an intimacy that was founded on our shared encounters with the world, but also on my awareness that what they were doing made sense and had meaning; it resonated with my own attempts to make meaning out of life.

The form of sociality that is therefore required to uphold and develop intellectually disabled people's sociality depends upon two interrelated factors. It depends upon the acceptance of intellectually disabled people's actions and expressions as forms of symbolic practice upon which mutuality and sociality can be built. It then depends upon engaging with such people through these very particular symbolic forms, thereby allowing these unconventional behaviours and activities to become the vehicles through which sociality is mediated. While this is more likely to be realised in a familial environment, it is not limited to familial relations. It is almost impossible to achieve in an institutional environment where the practices of training and management founded upon a symbolic scheme of reason and normality are what informs the dominant modes of relatedness. Even in a familial environment, however, it is difficult to sustain sociality over long periods of time. Yet there are aspects of the forms of mutual sociality that evolve out of familial relations which can be built upon in the creation of alternative social environments for intellectually disabled people. The issue becomes one of searching for the means through which a social milieu can be created that recognises, supports and sustains these very particular forms of sociality. The forms of relatedness that are necessary rely upon some sort of vocational aspiration, where the motivation and level of commitment goes beyond an institutionalised service industry founded solely on work as a commodity, and extends to relations built upon mutual and diffuse solidarity. Through such engagements, intellectually disabled people's specific and restricted symbolic practices and expressions are both recognised and able to be engaged with as such. By denying to intellectually disabled

people the opportunity and capacity to relate to others meaningfully as they are, they lose the very thing which is necessary for them to express themselves as social beings.

## References Cited

- Abberley, Paul. 1987. The Concept of Oppression and the Development of a Social Theory of Disability, *Disability, Handicap & Society* 2(1): 5-19.
- Accardo, Pasquale J. & Whitman, Barbara Y. 1996. *Dictionary of Developmental Disabilities Terminology*. MacLennan & Petty Pty Limited: Sydney.
- Addelson, Kathryn Pyne. 1991. *Impure Thoughts: Essays on philosophy, feminism & ethics*. Temple University Press: Philadelphia.
- Aiken, Lewis R. 1996. *Assessment of Intellectual Functioning*. Second Edition. Plenum Press: New York.
- Anderson, V. Elving. 1974. Genetics and Intelligence, *Mental Retardation and Developmental Disabilities* 6: 20-43.
- Anderson, W. French. 1992. Human Gene Therapy: Scientific and ethical considerations. In Ruth F. Chadwick (ed.), *Ethics, Reproduction and Genetic Control*, 147-163. Revised Edition. Routledge: London.
- Angrosino, Michael V. 1992. Metaphors of Stigma: How deinstitutionalized mentally retarded adults see themselves, *Journal of Contemporary Ethnography* 21(2): 171-199.
- Angrosino, Michael V. 1994. On the Bus with Vonnie Lee: Explorations in life history and metaphor, *Journal of Contemporary Ethnography* 23(1): 14-28.
- Angrosino, Michael V. 1998a. Mental Disability in the United States: An interactionist perspective. In Richard Jenkins (ed.), *Questions of Competence: Culture, Classification and Intellectual Disability*, 25-53. Cambridge University Press: Cambridge.
- Angrosino, Michael V. 1998b. *Opportunity House: Ethnographic stories of mental retardation*. Altamira Press: Walnut Creek.
- Arbus, Diane. 1972. *Diane Arbus: An aperture monograph*. Millerton: New York.
- Arbus, Diane. 1995. *Untitled*. Thames & Hudson: London.

- Ashton, Paul. 1995. Changing Approaches to the Developmentally Disabled. In Shirley Fitzgerald & Gary Wotherspoon (eds.), *Minorities: Cultural diversity in Sydney*, 140-156. State Library of NSW Press: Sydney.
- Atkins, Chris. 1998. 'Just Little Things': Nurses' perceptions of quality of life for people with severe multiple impairments. PhD Thesis, The University of Sydney, NSW.
- Atkinson, Dorothy & Walmsley, Jan. 1999. Using Autobiographical Approaches with People with Learning Difficulties, *Disability & Society* 14(2): 203-216.
- Austin, John L. 1975 [1962]. *How To Do Things With Words*. Clarendon Press: Oxford.
- Austin-Broos, Diane J. 1987. Clifford Geertz: Culture, sociology and historicism. In Diane J. Austin-Broos (ed.), *Creating Culture: Profiles in the study of culture*, 141-159. Allen & Unwin: Sydney.
- Austin-Broos, Diane J. 1997. *Jamaica Genesis: Religion and the politics of moral orders*. The University of Chicago Press: Chicago.
- Australian Broadcasting Commission TV. 2000. *The 7.30 Report*, 11/2/2000.
- Barnes, Colin. 1998. The Social Model of Disability: A sociological phenomenon ignored by sociologists? In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 65-78. Cassell: London.
- Barnett, W. Steven. 1986. Definition and Classification of Mental Retardation: A reply to Zigler, Balla, and Hodapp, *American Journal of Mental Deficiency* 91(2): 111-116.
- Baron, Stephen, Riddell, Sheila & Wilkinson, Heather. 1998. The Best Burgers? The person with learning difficulties as worker. In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 94-109. Cassell: London.
- Barr, Martin W. 1904. *Mental Defectives: Their history, treatment and training*. P. Blakiston's Son & Co: Philadelphia.

- Barth, Frederick. 1966. *Models of Social Organisation*. Royal Anthropological Institute Occasional Paper No. 23. Richard Madley Ltd.: London.
- Barton, Len. 1998. Sociology, Disability Studies and Education: Some observations. In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 53-64. Cassell: London.
- Becker, Howard S. 1963. *Outsiders: Studies in the sociology of deviance*. Free Press of Glencoe: New York.
- Becker, Howard S. (ed.). 1964. *The Other Side: Perspectives on deviance*. Free Press of Glencoe: New York.
- Begab, Michael J. & Richardson, Stephen A. 1975. *The Mentally Retarded and Society: A social science perspective*. University Park Press: Baltimore.
- Benedict, Ruth. 1934. Anthropology and the Abnormal, *The Journal of General Psychiatry* 10: 59-80.
- Benson, Glenis, Abbeduto, Leonard, Short, Katherine, Nuccio, Jill Bibler & Maas, Fay. 1993. Development of a Theory of Mind in Individuals with Mental Retardation, *American Journal of Mental Retardation* 98(3): 427-433.
- Berg, Joseph M. 1976. Genetics and Genetic Counseling. In Joseph Wortis (ed.), *Mental Retardation: An annual review, Vol. VIII*, 41-57. Bruner/Mazel Publishers: New York.
- Bernstein, Basil. 1971. *Class, Codes and Control: Volume 1, Theoretical studies towards a sociology of language*. Routledge & Kegan Paul: London.
- Bernstein, Basil. 1977. *Class, Codes and Control: Volume 3, Towards a theory of educational transmissions*. Revised Edition. Routledge & Kegan Paul: London.
- Berry, Richard J. A. & Gordon, R. G. 1931. *The Mental Defective: A problem in social inefficiency*. Kegan Paul, Trench, Trubner & Co: London.
- Bigby, Christine. 2000. What is Informal Support and Why is it so Important? *Intellectual Disability Australia* 21(4): 16-17.

- Bigby, Christine & Johnson, Kelley. 1995. Alone or Together: Family relationships of older adults with intellectual disability, *Australian Disability Review* 2: 66-76.
- Bijou, Sidney W. 1992. Concepts of Mental Retardation, *The Psychological Record* 42(3): 305-322.
- Binet, Alfred & Simon, Theodore. 1976 [1905]. Upon the Necessity of Establishing a Scientific Diagnosis of Inferior States of Intelligence. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 329-354. University Park Press: Baltimore.
- Blatt, Burton. 1981. *In and Out of Mental Retardation; Essays on educability, disability, and human policy*. University Park Press: Baltimore.
- Bleasdale, Michael. 1996. Evaluating 'Values': A critique of value theory in social role valorization, *Australian Disability Review* 1: 3-21.
- Bogdan, Robert. 1986. Exhibiting Mentally Retarded People for Amusement and Profit, 1850-1940, *American Journal of Mental Deficiency* 91(2): 120-126.
- Bogdan, Robert. 1992. A 'Simple' Farmer Accused of Murder: Community acceptance and the meaning of deviance, *Disability, Handicap & Society* 7(4): 303-320.
- Bogdan, Robert, Biklen, Douglas, Shapiro, Arthur & Spelkoman, David. 1982. The Disabled: Media's monster, *Social Policy* 13(2): 32-35.
- Bogdan, Robert & Taylor, Steven. 1976. The Judged, Not the Judges: An insider's view of mental retardation, *American Psychologist*, January: 47-52.
- Bogdan, Robert & Taylor, Steven. 1982. *Inside Out: The social meaning of mental retardation*. University of Toronto Press: Toronto.
- Bogdan, Robert & Taylor, Steven J. 1998. The Social Construction of Humanness: Relationships with people with severe retardation. In

- Steven J. Taylor & Robert Bogdan, *Introduction to Qualitative Research Methods: A guidebook and resource*, 242-258. John Wiley & Sons: New York.
- Bogdan, Robert & Taylor, Steven J. 1989. Relationships with Severely Disabled People: The social construction of humanness, *Social Problems* 36(2): 135-148.
- Booth, Timothy A. 1978. From Normal Baby to Handicapped Child: Unravelling the idea of subnormality in families of mentally handicapped children, *Sociology* 12(2): 203-221.
- Booth, Tim & Booth, Wendy. 1996. Sounds of Silence: Narrative research with inarticulate subjects, *Disability & Society* 11(1): 55-69.
- Borthwick, Chris. 1996. Racism, IQ and Down's Syndrome, *Disability & Society* 11(3): 403-410.
- Bourdieu, Pierre. 1994. *Language & Symbolic Power*. Polity Press: Cambridge.
- Bourdieu, Pierre. 1999 [1972]. *Outline of a Theory of Practice*. Cambridge University Press: Cambridge.
- Brandon, David. 1991. The Implications of Normalization Work for Professional Skills. In Shulamit Ramon (ed.), *Beyond Community Care: Normalisation and integration work*, 35-55. Macmillan Education Ltd: Hampshire.
- Branson, Jan & Miller, Don. 1989. Beyond Integration Policy: The deconstruction of disability. In Len Barton (ed.), *Integration: Myth or reality?* 144-167. The Falmer Press: London.
- Branson, Jan & Miller, Don. 1992. Normalisation, Community Care and the Politics of Difference, *Australian Disability Review* 4: 17-28.
- Bregman, Joel D. & Hodapp, Robert M. 1991. Current Developments in the Understanding of Mental Retardation: Biological and phenomenological perspectives, *Journal of the American Academy of Child Adolescent Psychiatry* 30(5): 707-719.
- Brockett, L. P. 1976 [1856]. Idiots and Efforts for Their Improvement. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental*

- Retardation: Collected papers, Vol. I*, 69-86. University Park Press: Baltimore.
- Brown, Hilary & Smith, Helen. 1989. Whose 'Ordinary Life' is it Anyway? *Disability, Handicap & Society* 4: 105-119.
- Brown, Hilary & Smith, Helen. 1993a. Assertion, Not Assimilation: A feminist perspective on the normalisation principle. In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 149-171. Routledge: London.
- Brown, Hilary & Smith, Helen (eds.). 1993b. *Normalisation: A reader for the nineties*. Routledge: London.
- Brown, Roy. 1982. The Structuring of Integrated Programs for Intellectually Handicapped People, *Australian Rehabilitation Review* 6(1): 28-36.
- Bullock, Alan & Trombley, Stephen (eds.). 1999. *The New Fontana Dictionary of Modern Thought*. HarperCollins Publishers: London.
- Burton, Mark. 1996. Introduction. In Errol Cocks, Charlie Fox, Mark Brogan & Michael Lee (eds.), *Under Blue Skies: The social construction of intellectual disability in Western Australia*, 1-12. Centre for Disability Research and Development, Edith Cowan University: Perth.
- Carman-Brown, Kylie & Fox, Charlie. 1996. Doctors, Psychologists and Educators: The professions and intellectual disability. In Errol Cocks, Charlie Fox, Mark Brogan & Michael Lee (eds.), *Under Blue Skies: The social construction of intellectual disability in Western Australia*, 205-247. Centre for Disability Research and Development, Edith Cowan University: Perth.
- Carrithers, Michael. 1992. *Why Humans Have Cultures: Explaining anthropology and social diversity*. Oxford University Press: Oxford.
- Carrithers, Michael. 1999. Review of Bruce Kapferer (1997) "The Feast of the Sorcerer: Practices of consciousness and power", *American Ethnologist* 26(4): 1032-1033.

- Carrithers, Michael, Collins, Steven & Lukes, Steven (eds.). 1985. *The Category of the Person: Anthropology, philosophy, history*. Cambridge University Press: Cambridge.
- Chadban, Shauna. 1991. Case Study: Reducing Compulsive Behaviour by Providing a Contextually Relevant Alternative. Unpublished paper.
- Chadwick, Ruth F. 1992. The Perfect Baby: Introduction. In Ruth Chadwick (ed.), *Ethics, Reproduction and Genetic Control*, 93-135. Revised Edition. Routledge: London.
- Charlesworth, Max. 1989. *Life, Death, Genes and Ethics: Biotechnology and bioethics*. Australian Broadcasting Commission: Sydney.
- Chappell, Anne Louise. 1992. Towards a Sociological Critique of the Normalisation Principle, *Disability, Handicap & Society* 7(1): 35-51.
- Chappell, Anne Louise. 1998. Still Out in the Cold: People with learning difficulties and the social model of disability. In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 211-220. Cassell: London.
- Christensen, Carol A. 1992. Deviant, Disabled or Different: The politics of labelling, *Australian Disability Review* 3: 5-12.
- Cleveland, Douglas W. & Miller, Nancy. 1977. Attitudes and Life Commitments of Older Siblings of Mentally Retarded Adults: An exploratory study, *Mental Retardation* 15(3): 38-41.
- Cocks, Errol. 1989. *An Introduction to Intellectual Disability in Australia*. Australian Institute on Intellectual Disability: Canberra.
- Cocks, Errol & Allen, Matthew. 1996. Discourses of Disability. In Errol Cocks, Charlie Fox, Mark Brogan & Michael Lee (eds.), *Under Blue Skies: The social construction of intellectual disability in Western Australia*, 282-318. Centre for Disability Research and Development, Edith Cowan University: Perth.

- Coles, E. M., Freitas, T. T. & Tweed, R. 1996. Assessment of Understanding by People Manifesting Mental Retardation: A preliminary report, *Perceptual and Motor Skills* 83(1): 187-192.
- Comaroff, Jean. 1985. *Body of Power Spirit of Resistance: The culture and history of a South African people*. The University of Chicago Press: Chicago.
- Connors, Jeanne L. & Donnellan, Anne M. 1993. Citizenship and Culture: The role of disabled people in Navajo society, *Disability, Handicap & Society* 8(3): 265-280.
- Conrad, Peter & Schneider, Joseph W. 1985. *Deviance and Medicalization: From badness to sickness*. Merrill Publishing Company: Columbus.
- Cotton, Richard & Wansbrough, Ann. 1996. Ethics and the Gene Machine, *The Sydney Morning Herald*, 1/7/1996, Opinion: 15.
- Cowlshaw, Gillian. 1999. *Rednecks, Eggheads and Blackfellas: A study of racial power and intimacy in Australia*. Allen & Unwin: Sydney.
- Crawshaw, Gill. 1994. Is There an Urgent Need for the Development of a Social Model of Impairment? *Australian Disability Review* 4: 27-35.
- Cuvo, Anthony J. 1976. Decreasing Repetitive Behaviour in an Institutionalized Mentally Retarded Resident, *Mental Retardation* Feb: 22-25.
- Dalley, Gillian. 1993. Social Welfare Ideologies and Normalisation: Links and conflicts. In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 100-111. Routledge: London.
- Damasio, Antonio R. 1994. *Descartes' Error: Emotion, reason, and the human brain*. G. P. Putnam's Sons: New York.
- Dante. 1985 [1314]. *The Divine Comedy*. New York: Penguin Books.
- Davies, Charlotte Aull. 1998. Constructing Other Selves: (In)competence and the category of learning difficulties. In Richard Jenkins (ed.), *Questions of Competence: Culture, classification and intellectual disability*, 102-124. Cambridge University Press: Cambridge.

- Davies, Charlotte Aull & Jenkins, Richard. 1997. 'She Has Different Fits to Me': How people with learning difficulties see themselves, *Disability & Society* 12(1): 95-109.
- Davis, Lennard J. 1995. *Enforcing Normalcy: Disability, deafness, and the body*. Verso: London & New York.
- de Castro, Eduardo Viveiros. 1992. *From the Enemies Point of View: Humanity and divinity in an Amazonian society*. The University of Chicago Press: Chicago.
- de Jong, Gerben. 1982. Independent Living: A social movement, *Australian Rehabilitation Review* 6(1): 46-56.
- Deleuze, Gilles & Guattari, Felix. 1984. *Anti-Oedipus: Capitalism and schizophrenia*. Transl. Robert Hurley. Athlone: London.
- Dentan, Robert K. 1967. The Response to Intellectual Impairment Among the Semai, *American Journal of Mental Deficiency* 71(4): 764-766.
- Detterman, Douglas K. 1987. Theoretical Notions of Intelligence and Mental Retardation, *American Journal of Mental Deficiency* 92(1): 2-11.
- Desjarlais, Robert. 1996. Struggling Along. In Michael Jackson (ed.), *Things as They Are: New directions in phenomenological anthropology*, 70-93. Indiana University Press: Bloomington.
- Devlieger, Patrick J. 1998. (In)competence in America in Comparative Perspective. In Richard Jenkins (ed.), *Questions of Competence: Culture, classification and intellectual disability*, 54-75. Cambridge University Press: Cambridge.
- Digby, Anne. 1996. Contexts and Perspectives. In David Wright & Anne Digby (eds.), *From Idiocy to Mental Deficiency: Historical perspectives on people with learning disabilities*, 1-21. Routledge: London.
- Diprose, Rosalyn. 1991. A 'Genethics' that Makes Sense. In Rosalyn Diprose & Robyn Ferrell (eds.), *Cartographies: Poststructuralism and the mapping of bodies and spaces*, 66-76. Allen & Unwin: Sydney.

- Dix, Dorothea L. 1976 [1843]. Memorial to the Legislature of Massachusetts, 1843. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 3-30. University Park Press: Baltimore.
- Doll, Edgar A. 1976 [1948]. The Relation of Social Competence to Social Adjustment. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. II*, 267-275. University Park Press: Baltimore.
- Drever, James & Collins, Mary. 1928. *Performance Tests of Intelligence: A series of non-linguistic tests for deaf and normal children*. Oliver & Boyd: Edinburgh.
- Dugdale, Richard L. 1976 [1877]. Hereditary Pauperism as Illustrated in the 'Juke' Family. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 269-282. University Park Press: Baltimore.
- Dybwad, Gunnar. 1976 [1969]. The Importance of Prevention in Mental Retardation. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. II*, 335-343. University Park Press: Baltimore.
- Dykens, Elisabeth M. 1995. Measuring Behavioural Phenotypes: Provocations from the 'new genetics', *American Journal on Mental Retardation* 99(5): 522-532.
- Easterday, Lois M. 1980. War is Hell and Hell is War: The autobiography of a retarded adult. In Jerry Jacobs (ed.), *Mental Retardation: A phenomenological approach*, 208-223. Charles C. Thomas: Springfield, Illinois.
- Eberly, Susan Schoon. 1991. Fairies and the Folklore of Disability: Changelings, hybrids, and the solitary fairy. In P Narváez (ed.), *The Good People: New fairylore essays*, 227-250. Garland Publishers: New York.

- Edgerton, Robert B. 1963. A Patient Elite: Ethnography in a hospital for the mentally retarded, *American Journal of Mental Deficiency* 68: 372-497.
- Edgerton, Robert B. 1967. *The Cloak of Competence: Stigma in the lives of the mentally retarded*. University of California Press: Berkeley.
- Edgerton, Robert B. 1970. Mental Retardation in Non-Western Societies: Toward a cross-cultural perspective on incompetence. In H. C. Haywood (ed.), *Social-Cultural Aspects of Mental Retardation*, 523-559. Meredith Corporation: New York.
- Edgerton, Robert B. 1975. Issues Relating to the Quality of Life Among Mentally Retarded Persons. In Michael J. Begab & Stephen A. Richardson (eds.), *The Mentally Retarded and Society: A social science perspective*, 127-140. University Park Press: Baltimore.
- Edgerton, Robert B. 1978. The Study of Deviance: Marginal man or everyman? In George D. Spindler (ed.), *The Making of Psychological Anthropology*, 444-476. University of California Press: Berkeley.
- Edgerton, Robert B. 1984a. Anthropology and Mental Retardation: Research approaches and opportunities, *Culture, Medicine & Psychiatry* 8: 25-48.
- Edgerton, Robert B. 1984b. *Lives in Process: Mildly retarded adults in a large city*. American Association on Mental Deficiency: Washington D.C.
- Edgerton, Robert B. 1984c. The Participant-Observer Approach to Research in Mental Retardation. *American Journal of Mental Deficiency* 88(5): 498-505.
- Edgerton, Robert B. 1986. A Case of Delabeling; Some practical and theoretical implications. In L. L. Langness & Harold G. Levine (eds.), *Culture and Retardation: Life histories of mildly mentally retarded persons in American society*, 101-126. D. Reidel Publishing Company: Dordrecht, Holland.
- Edgerton, Robert B. & Bercovici, Sylvia M. 1976. The Cloak of Competence: Years later, *American Journal of Mental Deficiency* 80(5): 485-497.

- Edgerton, Robert B., Bollinger, Marsha & Herr, Barbara. 1984. The Cloak of Competence: After two decades, *American Journal of Mental Deficiency* 88(4): 345-351.
- Edgerton, Robert B. & Langness, L. L. 1978. Observing Mentally Retarded Persons in Community Settings: An anthropological perspective. In Gene P. Sackett (ed.), *Observing Behaviour: Volume I, Theory and applications in mental retardation*, 335-348. University Park Press: Baltimore.
- Edgerton, Robert B. & Sabagh G. 1962. From Mortification to Aggrandizement: Changing self-concepts in the careers of the mentally retarded, *Psychiatry* 25: 263-272.
- Ellis, Elisabeth. 1998. Reaching Out/Reaching In/Reaching Across: Identity and the spatial politics of disablement and enablement. Honours Thesis, Macquarie University, Sydney.
- Emerson, Eric. 1993. What is Normalisation? In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 1-18. Routledge: London.
- Felman, Shoshana. 1989. *Writing and Madness: (Literature/Philosophy/Psychoanalysis)*. Cornell University Press: Ithaca, New York.
- Felske, Aileen Wight. 1994. Knowing about Knowing: Margin notes on disability research. In Marcia H. Rioux & Michael Bach (eds.), *Disability Is Not Measles: New research paradigms in disability*, 181-199. L'Institut Roehher Institute: Ontario.
- Ferguson, Philip M. 1987. The Social Construction of Mental Retardation, *Social Policy* 18(1): 51-56.
- Ferns, Peter. 1993. Promoting Race Equality through Normalisation. In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 134-148. Routledge: London.
- Finkelstein, Vic. 1998. Emancipating Disability Studies. In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 28-49. Cassell: London.

- Flynn, Robert J. & Nitsch, Kathleen E. (eds.). 1980. *Normalization, Social Integration, and Community Services*. Pro-Ed: Austin, Texas.
- Foreman, Phil. 1997. Medicine, Health and Intellectual Disability, *Journal of Intellectual & Developmental Disabilities* 22(4): 225-226.
- Foucault, Michel. 1984 [1976]. *The History of Sexuality: An introduction*. Transl. Robert Hurley. Penguin Books: London.
- Foucault, Michel. 1986 [1963]. *The Birth of the Clinic: An archaeology of medical perception*. Vintage Books: New York.
- Foucault, Michel. 1995 [1961]. *Madness and Civilization: A history of insanity in the age of reason*. Transl. Richard Howard. Routledge: London.
- Fullagar, Simone & Hardaker, Ken. 1993. Debating Disability: A critical review of current issues in service provision for people with intellectual disability, *Australian Disability Review* 4: 36-46.
- Gartner, Alan. 1982. Images of the Disabled/Disabling Images, *Social Policy* 13(2): 14-15.
- Geertz, Clifford. 1993a [1973]. Religion as a Cultural System. In Clifford Geertz, *The Interpretation of Cultures*, 87-125. Fontana Press: London.
- Geertz, Clifford. 1993b [1973]. Thick Description: Toward an interpretive theory of culture. In Clifford Geertz, *The Interpretation of Cultures*, 3-30. Fontana Press: London.
- Gelb, Steven A. 1995. The Beast in Man: Degenerationism and mental retardation, 1900-1920, *Mental Retardation* 33(1): 1-9.
- Gerber, David A. 1990. Listening to Disabled People: The problem of voice and authority in Robert B. Edgerton's 'The Cloak of Competence', *Disability, Handicap & Society* 5(1): 3-23.
- Giddens, Anthony. 1978. Introduction. In Max Weber, *The Protestant Ethic and the Spirit of Capitalism*, 1-12. George Allen & Unwin: London.

- Gillman, Maureen, Swain, John & Heyman, Bob. 1997. Life History or 'Case' History: The objectification of people with learning difficulties through the tyranny of professional discourses, *Disability & Society* 12(5): 675-693.
- Gleason, John Joseph. 1989. *Special Education in Context: An ethnographic study of persons with developmental disabilities*. Cambridge University Press: Cambridge.
- Gleason, John J. 1994. Theoretical Framework for What Persons with Severe and Profound Multiple Disabilities Do in Context. In Marcia H. Rioux & Michael Bach (eds.), *Disability Is Not Measles*, 245-263. L'Institut Roehher Institute: Ontario.
- Goddard, Henry H. 1976a [1910]. Four Hundred Feeble-Minded Children Classified by the Binet Method. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 355-366. University Park Press: Baltimore.
- Godwin, Joscelyn. 1979. *Robert Fludd: Hermetic philosopher and surveyor of two worlds*. Thames and Hudson: London.
- Goffman, Erving. 1974 [1963]. *Stigma: Notes on the management of spoiled identity*. Penguin: Harmondsworth.
- Goffman, Erving. 1990 [1961]. *Asylums: Essays on the social situation of mental patients and other inmates*. Anchor Books: New York.
- Goodall, Jane. [forthcoming] *Out of the Natural Order*. Routledge: London.
- Goode, David A. 1980a. Behavioural Sculpting: Parent-child interactions in families with retarded children. In Jerry Jacobs (ed.), *Mental Retardation: A phenomenological approach*, 95-118. Charles C. Thomas: Springfield, Illinois.
- Goode, David A. 1980b. The World of the Congenitally Deaf-Blind: Toward the grounds for achieving human understanding. In Jerry Jacobs (ed.), *Mental Retardation: A phenomenological approach*, 187-207. Charles C. Thomas: Springfield, Illinois.

- Goode, David A. 1984. Socially Produced Identities, Intimacy and the Problem of Competence Among the Retarded. In Len Barton & Sally Tomlinson (eds.), *Special Education and Social Interests*, 228-248. Croom Helm: London.
- Goode, David A. 1990. On Understanding Without Words: Communication between a deaf-blind child and her parents, *Human Studies* 13: 1-37.
- Goodey, C. F. 1994. John Locke's Idiots in the Natural History of Mind. *History of Psychiatry*, 5: 215-250.
- Goodley, Danny. 1996. Tales of Hidden Lives: A critical examination of life history research with people who have learning difficulties, *Disability & Society* 11(3): 333-348.
- Gordon, Robert A. 1975. Examining Labelling Theory: The case of mental retardation. In Walter R. Gove (ed.), *The Labelling of Deviance: Evaluating a perspective*, 83-146. John Wiley & Sons: New York.
- Gould, Stephen Jay. 1996. *The Mismeasure of Man*. Revised and Expanded. W. W. Norton & Co: New York.
- Gray, David E. 1995. Lay Conceptions of Autism: Parent's explanatory models, *Medical Anthropology* 16(2): 99-118.
- Hacking, Ian. 1990. *The Taming of Chance*. Cambridge University Press: Cambridge.
- Haffter, Carl. 1968. The Changeling: History and psychodynamics of attitudes to handicapped children in European folklore, *Journal of the History of Behavioural Sciences*, 4: 55-61.
- Halpern, Joseph, Sackett, Karen L., Binner, Paul R. & Mohr, Cynthia B. 1980. *The Myths of Deinstitutionalization: Policies for the mentally disabled*. Westview Press: Boulder, Colorado.
- Hampshire, Stuart. 1956. *The Age of Reason: The 17th century philosophers*. Mentor Book: New York.

- Handelman, Don. 1981. Introduction: The idea of bureaucratic organization, *Social Analysis, Special Issue: Administrative Frameworks and Clients* 9: 5-23.
- Hannan, Lynne. 1990. Stigma, Felt Identity and the Chronically Mentally Ill: An ethnographic study of the chronically mentally ill in an Australian community. PhD Thesis, The University of Sydney, NSW.
- Hanson, F. Allan. 1993. *Testing Testing: Social consequences of the examined life*. University of California Press: Berkeley.
- Harkness, Sara & Super, Charles M. 1980. Child Development Theory in Anthropological Perspective. In Charles M. Super & Sara Harkness (eds.), *New Directions in Child Development: Anthropological perspectives and child development, No. 8*, 1-5. Jossey-Bass Inc: San Francisco.
- Heaton-Ward, W. Alan. 1978. *Left Behind: A study of mental handicap*. The Woburn Press: London.
- Held, K. R. 1992. Ethical Aspects of Sexuality of Persons with Mental Retardation, *Sexuality and Disability* 10(4): 237-243.
- Henschel, Anne-Marie. 1972. *The Forgotten Ones: A sociological study of Anglo and Chicano retardates*. University of Texas Press: Austin.
- Herrnstein, Richard J. & Murray, Charles. 1994. *The Bell Curve: Intelligence and class structure in American life*. The Free Press: New York.
- Herzfeld, Michael. 1997. *Cultural Intimacy: Social poetics in the nation-state*. Routledge: New York.
- Heshusius, Lous. 1981. *Meaning in Life as Experienced by Persons Labeled Retarded in a Group Home: A participant observation study*. Charles C. Thomas: Springfield, Illinois.
- Hodapp, Robert M. & Dykens, Elisabeth M. 1994. Mental Retardation's Two Cultures of Behavioural Research, *American Journal of Mental Retardation* 98(6): 675-687.

- Hodapp, Robert M. & Zigler, Edward. 1986. Reply to Barnett's Comments on the Definition and Classification of Mental Retardation, *American Journal of Mental Deficiency* 91(2): 117-119.
- Hodgen, Margaret T. 1964. *Early Anthropology in the Sixteenth and Seventeenth Centuries*. University of Philadelphia Press: Philadelphia.
- Horin, Adele. 1996a. 'Can't Cope': Mentally-ill children dumped, *The Sydney Morning Herald*, 5/11/1996: 1.
- Horin, Adele. 1996b. Running on Empty, *The Sydney Morning Herald*, 5/11/1996, Agenda: 9.
- Howard, Mary. 1990. 'We Don't Have No Say in Our Lives Anymore': An anthropologist's study of group home life for adults with mental retardation, *Adult Residential Care Journal* 4(3): 163-182.
- Howe, Samuel G. 1976 [1848]. On the Causes of Idiocy. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 31-60. University Park Press: Baltimore.
- Hughes, Bill & Paterson, Kevin. 1997. The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment, *Disability & Society* 12(3): 325-340.
- Humphrey, Nicholas. 1992. *A History of the Mind: Evolution and the birth of consciousness*. Simon & Schuster: New York.
- Illich, Ivan. 1990 [1976]. *Limits to Medicine: Medical nemesis: The expropriation of health*. Penguin: New York.
- Ireland, William W. 1976 [1882]. On the Diagnosis and Prognosis of Idiocy and Imbecility. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 248-261. University Park Press: Baltimore.
- Jackson, Michael. 1998. *Minima Ethnographica: Intersubjectivity and the anthropological project*. The University of Chicago Press: Chicago.

- Jacobs, Jerry. 1980. The Retarded Child: Family modes of adaptation. In Jerry Jacobs (ed.), *Mental Retardation: A phenomenological approach*, 57-93. Charles C. Thomas: Springfield, Illinois.
- Jenkins, Richard. 1993. Incompetence and Learning Difficulties, *Anthropology Today* 9(3): 16-20.
- Jenkins, Richard. 1998a. From Criminology to Anthropology? Identity, morality, and normality in the social construction of deviance. In Simon Holdaway & Paul Rock (eds.), *Thinking About Criminology*, 133-160. University of Toronto Press: Toronto.
- Jenkins, Richard (ed.). 1998b. *Questions of Competence: Culture, classification and intellectual disability*. Cambridge University Press: Cambridge.
- Jenkinson, Josephine C. 1996. Identifying Intellectual Disability: Some problems in the measurement of intelligence and adaptive behaviour, *Australian Psychologist* 31(2): 97-102.
- Johnson, Kelley. 1995. Out of the Shadows: Deinstitutionalisation. In Phillip A. Swain (ed.), *In the Shadow of the Law: The legal context of social work practice*, 210-225. The Federation Press: Sydney.
- Johnson, Kelley. 1998. *Deinstitutionalising Women: An ethnographic study of institutional closure*. Cambridge University Press: Cambridge.
- Johnson, Kelley. 2000. Locked In . . . And Locked Out: Women with intellectual disabilities: Coming out of the institution, *Health Sharing Women* 11(1): 15-19.
- Jones, Caroline. 1995. *The Search for Meaning Collection*. ABC Books: Sydney.
- Judge, Cliff. 1987. *Civilization and Mental Retardation: A history of the care and treatment of mentally retarded people*. Magenta Press: Mulgrave.
- Kanner, Leo. 1944. Early Infantile Autism, *Journal of Paediatrics* 25: 211-217.
- Kanner, Leo. 1967. Medicine in the History of Mental Retardation: 1850-1965, *American Journal of Mental Deficiency* 72(1): 165-169.

- Kaplan, Arnold R. 1972. Genetics. In Joseph Wortis (ed.), *Mental Retardation: An annual review, Vol. IV*: 57-62. Grune & Stratton: New York.
- Kearney, Penelope. 1993a. Defiance, Not Denial. Adjusting to life with a child who has significant developmental disability. Paper presented to *Embracing the Future. AWCH National Conference, 7-8 October*. University of Western Sydney, Nepean.
- Kearney, Penelope. 1993b. Listening to the Parents of Children with Developmental Disabilities. Paper presented to *Quality and Equality in Intellectual Disability. 29th ASSID Conference, 30 November-5 December*. Newcastle, NSW.
- Kearney, Penelope M. 1996. Between Joy and Sorrow: Being the parent of a child with a developmental disability. Masters Thesis, University of Western Sydney, Nepean, NSW.
- Kerlin, Isaac N. 1976 [1889]. Moral Imbecility. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 303-310. University Park Press: Baltimore.
- Kiernan, C. C. 1978. Behaviour Modification. In Ann M. Clarke & A. D. B. Clarke (eds.), *Readings from Mental Deficiency: The changing outlook*, 382-456. Methuen & Co: London.
- Koegel, Paul. 1986. You Are What You Drink: Evidence of socialized incompetence in the life of a mildly retarded adult. In L. L. Langness & Harold G. Levine (eds.), *Culture and Retardation: Life histories of mildly mentally retarded persons in American society*, 47-63. D. Reidel Publishing Company: Dordrecht, Holland.
- Kraft, Ivor. 1961. Edouard Séguin and 19th Century Moral Treatment of Idiots, *Bulletin of the History of Medicine* 35(5): 393-418.
- Kuper, Adam. 1999. *Culture: The anthropologists' account*. Harvard University Press: Cambridge, Massachusetts.

- Kurtz, Richard A. 1981. The Sociological Approach to Mental Retardation. In Ann Brechin, Penny Liddiard & John Swain (eds.), *Handicap in a Social World*, 14-23. Hodder & Stoughton: Kent.
- Laing, Ronald D. 1960. *The Divided Self: An existential study in sanity and madness*. Tavistock: London.
- Langness, L. L. & Levine, Harold G. 1986. *Culture and Retardation: Life histories of mildly mentally retarded persons in American society*. D. Reidel Publishing Company: Dordrecht, Holland.
- Lea, Susan J. 1988. Mental Retardation: Social construction or clinical reality? *Disability, Handicap & Society* 3(1): 63-69.
- Leder, Drew (ed.). 1992. *The Body in Medical Thought and Practice*. Kluwer Academic Publishers: Dordrecht.
- Lemert, Edwin M. 1967. *Human Deviance, Social Problems and Social Control*. Prentice-Hall: Englewood Cliffs, New Jersey.
- Leser, David. 1996. Prisoners of Autism, *The Sydney Morning Herald*, 11/5/1996, Good Weekend: 42-53.
- LeVine, Robert A. 1980. Anthropology and Child Development. In Charles M. Super & Sara Harkness (eds.), *New Directions in Child Development: Anthropological perspectives and child development, No. 8*, 71-86. Jossey-Bass Inc: San Francisco.
- Lloyd, Genevieve. 1993. *The Man of Reason: 'Male' and 'female' in Western philosophy*. Second Edition. University of Minnesota Press: Minneapolis.
- Longmore, Paul K. 1985. Screening Stereotypes: Images of disabled people, *Social Policy* 1(16): 31-37.
- Luchins, Abraham S. 1989. Moral Treatment in Asylums and General Hospitals in 19th-Century America, *The Journal of Psychology* 123(6): 585-607.
- Luckey, Bertha M. 1967. The Contributions of Psychology to the Problems of Mental Retardation with some Implications for the Future, *American Journal of Mental Deficiency* 72(1): 170-175.

- Luckin, Bill. 1986. Time, Place and Competence: Society and history in the writings of Robert Edgerton, *Disability, Handicap & Society* 1(1): 89-102.
- Lundgren, Nancy. 1998. Learning to Become (In)competent: Children in Belize speak out. In Richard Jenkins (ed.), *Questions of Competence: Culture, classification and intellectual disability*, 194-221. Cambridge University Press: Cambridge.
- MacAndrew, Craig & Edgerton, Robert. 1966. On the Possibility of Friendship, *American Journal of Mental Deficiency* 70(4): 612-621.
- MacAndrew, Craig & Edgerton, Robert. 1970. Man Without Culture. In Philip K. Bock (ed.), *Culture Shock: A reader in modern cultural anthropology*, 18-28. Alfred A. Knopf: New York.
- Manion, Mary L. & Bersani, Hank A. 1987. Mental Retardation as a Western Sociological Construct: A cross-cultural analysis, *Disability, Handicap & Society* 2(3): 231-245.
- Mannix, Daniel P. 1990. *Freaks: We who are not as others*. Re/Search Publications: San Francisco.
- Mardiros, Marilyn. 1989. Conception of Childhood Disability Among Mexican-American Parents, *Medical Anthropology* 12: 55-68.
- Marteau, Theresa M. & Drake, Harriet. 1995. Attributions for Disability: The influence of genetic screening, *Social Science & Medicine* 40(8): 1127-1132.
- McCord, William T. 1982. From Theory to Reality: Obstacles to the implementation of the normalization principle in human services, *Mental Retardation* 20(6): 247-253.
- McGill, Peter & Emerson, Eric. 1993. Normalisation and Applied Behaviour Analysis: Values and technology in human services. In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 60-83. Routledge: London.

- McVilly, Keith R. 2000. Sorry, I'm a Support Worker not your Friend? The importance of relationships, *Intellectual Disability Australia* 21(4): 6-7, 17-18.
- Mead, George Herbert. 1934. *Mind, Self and Society: From the standpoint of a social behaviourist*. The University of Chicago Press: Chicago.
- Meekosha, Helen. 1998. Body Battles: Bodies, Gender and Disability. In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 163-180. Cassell: London.
- Megahey, Norman. 1996a. Living in Fremantle Asylum: The colonial experience of intellectual disability 1829-1900. In Errol Cocks, Charlie Fox, Mark Brogan & Michael Lee (eds.), *Under Blue Skies: The social construction of intellectual disability in Western Australia*, 13-52. Centre for Disability Research and Development, Edith Cowan University: Perth.
- Megahey, Norman. 1996b. Making a New Profession: Social trainers and intellectual disability. In Errol Cocks, Charlie Fox, Mark Brogan & Michael Lee (eds.), *Under Blue Skies: The social construction of intellectual disability in Western Australia*, 248-281. Centre for Disability Research and Development, Edith Cowan University: Perth.
- Mehan, Hugh. 1988. Educational Handicaps as a Cultural Meaning System, *Ethos* 16(1): 73-91.
- Mercer, Jane. 1975. Sociocultural Factors in Educational Labeling. In Michael J. Begab & Stephen A. Richardson (eds.), *The Mentally Retarded and Society: A social science perspective*, 141-157. University Park Press: Baltimore.
- Merleau-Ponty, Maurice. 1962. *Phenomenology of Perception*. Transl. C. Smith. Routledge and Kegan Paul: London.
- Merquior, José G. 1985. *Foucault*. Fontana Press: London.
- Mest, Grace M. 1988. With a Little Help from Their Friends: Use of social support systems by persons with retardation, *Journal of Social Issues* 44(1): 117-125.

- Miles, M. 1992. Concepts of Mental Retardation in Pakistan: Toward cross-cultural and historical perspectives, *Disability, Handicap & Society* 7(3): 235-255.
- Miller, Edgar. 1996. Idiocy in the Nineteenth Century, *History of Psychiatry* 7: 361-373.
- Murphy, Robert F. 1990. *The Body Silent*. W. W. Norton: New York.
- New South Wales Department of Community Services. 1996. *Orientation to 'Policies for Working with People with Disabilities'*.
- New South Wales Department of Education and Training. 2000. *Special Education Services: Disability criteria*.
- Nirje, Bengt. 1976. The Normalization Principle and its Human Management Implications. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. II*, 361-376. University Park Press: Baltimore.
- Nirje, Bengt. 1980. The Normalization Principle. In Robert J. Flynn & Kathleen E. Nitsch (eds.), *Normalization, Social Integration, and Community Services*, 31-50. Pro-Ed: Austin, Texas.
- Nirje, Bengt. 1985. The Basis and Logic of the Normalization Principle, *Australian and New Zealand Journal of Developmental Disabilities* 11(2): 65-68.
- Nuttall, Mark. 1998. States and Categories: Indigenous models of personhood in northwest Greenland. In Richard Jenkins (ed.), *Questions of Competence: Culture, classification and intellectual disability*, 176-193. Cambridge University Press: Cambridge.
- Nye, Andrea. 1988. *Feminist Theory and the Philosophies of Man*. Routledge: New York.
- O'Connor, Neil & Tizard, Jack. 1956. *The Social Problem of Mental Deficiency*. Pergamon Press: London.
- O'Halloran, Judy M. 1993. Welcome to Our Family, Casey Patrick. In Ann P. Turnbull, Joan M. Patterson, Shirley K. Behr, Douglas L. Murphy, Janet

- G. Marquis & Martha J. Blue-Banning (eds.), *Cognitive Coping, Families, and Disability*, 19-29. Paul H. Brookes: Baltimore.
- Oliver, Mike. 1986. Social Theory and Disability: Some theoretical issues, *Disability, Handicap & Society* 1(1): 5-17.
- Oliver, Mike. 1990. *The Politics of Disablement*. Macmillan: London.
- Olshanky, Simon. 1977. Changing Vocational Behaviour Through Normalization. In Wolf Wolfensberger, *The Principle of Normalization in Human Services*, 150-163. National Institute on Mental Retardation: Toronto.
- Parsons, Talcott. 1970 [1951]. *The Social System*. Routledge & Kegan Paul: London.
- Pelka, Fred. 1997. *The Disability Rights Movement*. ABC: Clio Inc.: California.
- Perrin, Burt & Nirje, Bengt. 1985. Setting the Record Straight: A critique of some frequent misconceptions of the normalization principle, *Australian and New Zealand Journal of Developmental Disabilities* 11(2): 69-74.
- Persell, Caroline Hodges. 1981. Genetic and Cultural Deficit Theories: Two sides of the same coin, *Journal of Black Studies* 12(1): 19-37.
- Peters, Larry G. 1980. Concepts of Mental Retardation among the Tamang of Nepal, *American Journal of Mental Deficiency* 84(4): 352-356.
- Pinel, Philippe. 1962 [1801]. *A Treatise on Insanity*. Hafner Publishing Company: New York.
- Porter, Roy. 1997. *The Greatest Benefit to Mankind: A medical history of humanity from antiquity to the present*. HarperCollins Publishers: London.
- Potter, Alonzo, Kane, John K., Martin, James, Wood, George B. & Cleaveland, Charles D. 1976 [1853]. Education of Idiots: An appeal to the citizens of Philadelphia. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 61-68. University Park Press: Baltimore.

- Radcliffe-Brown, A. R. 1965 [1952]. *Structure and Function in Primitive Society*. Cohen & West: London.
- Radford, John P. 1994. Intellectual Disability and the Heritage of Modernity. In Marcia H. Rioux & Michael Bach (eds.), *Disability Is Not Measles: New research paradigms in disability*, 9-27. L'Institut Roehrer Institute: Ontario.
- Radford, John P. 1991. Sterilization Versus Segregation: Control of the 'feebleminded', 1900-1938, *Social Science and Medicine* 33(4): 449-458.
- Ralph, Alan & Usher, Erica. 1995. Social Interactions of Persons With Developmental Disabilities Living Independently in the Community, *Research in Developmental Disabilities* 16(3): 149-163.
- Ramon, Shulamit (ed.). 1991. *Beyond Community Care: Normalisation and integration work*. Macmillan Education Ltd: Hampshire.
- Rapley, Mark & Beyer, Stephen. 1996. Daily Activity, Community Participation and Quality of Life in an Ordinary Housing Network, *Journal of Applied Research in Intellectual Disabilities* 9(1): 31-39.
- Rapley, Mark & Hopgood, Laura. 1997. Quality of Life in a Community-Based Service in Rural Australia, *Journal of Intellectual & Developmental Disability* 22(2): 125-142.
- Rapp, Rayna. 1988. Chromosomes and Communication: The discourse of genetic counseling, *Medical Anthropology Quarterly* 2(2): 144-157.
- Raybeck, Douglas. 1988. Anthropology and Labeling Theory: A constructive critique, *Ethos* 16(4): 371-397.
- Rhodes, Rita. 1993. Mental Retardation and Sexual Expression: An historical perspective, *Journal of Social Work and Human Sexuality* 8(2): 1-27.
- Richmond, D. 1983. *Inquiry Into Health Services for the Psychiatrically Ill and Developmentally Disabled*. State Health Publication: NSW.
- Riley, Mark. 2001. Kiddie Cocaine: It's the drug of the new generation. *The Sydney Morning Herald*, 21/2/2001, News: 1, 10.

- Roos, Philip. 1977. Reconciling Behaviour Modification with the Normalization Principle. In Wolf Wolfensberger, *The Principle of Normalization in Human Services*, 137-149. National Institute on Mental Retardation: Toronto.
- Rose, Nikolas. 1985. *The Psychological Complex: Psychology, politics and society in England, 1869-1939*. Routledge & Kegan Paul: London.
- Rose-Ackerman, Susan. 1982. Mental Retardation and Society: The ethics and politics of normalization, *Ethics* 93(1): 81-101.
- Rosen, Marvin, Clark, Gerald R. & Kivitz, Marvin S. 1976. *The History of Mental Retardation: Collected papers, Volumes I & II*. University Park Press: Baltimore.
- Rowitz, Louis. 1988. Homogenization of Deviance, *Mental Retardation* 26(1): 1-3.
- Russell, Bertrand. 1989 [1946]. *A History of Western Philosophy*. Unwin Paperbacks: London.
- Ryan, Joanna. 1973. IQ: The Illusion of objectivity. In Ken Richardson & David Spears (eds.), *Race, Culture and Intelligence*, 36-55. Penguin Books: Harmondsworth.
- Ryan, Joanna & Thomas, Frank. 1987. *The Politics of Mental Handicap*. Free Association Books: London.
- Sabagh, G. & Edgerton, Robert B. 1962. Sterilized Mental Defectives Look at Eugenic Sterilization, *Eugenics Quarterly* 9: 213-222.
- Sacks, Oliver. 1986. *The Man Who Mistook His Wife for a Hat*. Picador: London.
- Sacks, Oliver. 1995. *An Anthropologist on Mars*. Picador: Sydney.
- Sahlins, Marshall. 1976. *Culture and Practical Reason*. The University of Chicago Press: Chicago.
- Said, Edward W. 1991 [1978]. *Orientalism: Western conceptions of the orient*. Penguin Books: London.
- Saleeby, Dennis. 1994. Culture, Theory, and Narrative: The intersection of meanings in practice, *Social Work* 39(4): 351-359.

- Schalock, Robert L., Stark, Jack A., Snell, Martha E., Coulter, David, L., Polloway, Edward A., Luckasson, Ruth & Spitalnik, Deborah M. 1994. The Changing Conception of Mental Retardation: Implications for the field, *Mental Retardation* 32(3): 181-193.
- Scheerenberger, Richard C. 1986. A Brief History of Mental Retardation. In Joseph Wortis (ed.), *Mental Retardation and Developmental Disabilities Vol. XIV*, 50-68. Elsevier: New York.
- Scheerenberger, Richard C. 1987. *A History of Mental Retardation: A quarter century of promise*. Paul H. Brookes: Baltimore.
- Schneider, David M. 1968. *American Kinship: A cultural account*. Prentice-Hall: Englewood Cliffs, New Jersey.
- Schutz, Alfred. 1972 [1967]. *The Phenomenology of the Social World*. Transl. G. Walsh and F. Lehnert. Heinemann: London.
- Séguin, Edouard. 1976a [1864]. Origin of the Treatment and Training of Idiots. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 151-159. University Park Press: Baltimore.
- Séguin, Edouard. 1976b [1879]. Psycho-Physiological Training of an Idiotic Hand. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 161-167. University Park Press: Baltimore.
- Séguin, Edouard. 1976c [1880]. Psycho-Physiological Training of an Idiotic Eye. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 169-180. University Park Press: Baltimore.
- Shaddock, A. J., Guggenheimer, S., Rawlings, M. & Bugel, E. 1993. Having Your Say: Perceptions on the involvement of people with an intellectual disability in decisions about their lives, *Australian Disability Review* 2: 45-53.

- Shearer, Ann. 1982. Services to Australia: Some observations, *Australian Rehabilitation Review* 6(4): 36-46.
- Shuttleworth, George E. 1976 [1881]. Some of the Cranial Characteristics of Idiocy. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 237-245. University Park Press: Baltimore.
- Simonoff, Emily, Bolton, Patrick & Rutter, Michael. 1996. Mental Retardation: Genetic findings, clinical implications and research agenda, *Journal of Child Psychology and Psychiatry* 37(3): 259-280.
- Simpson, Murray K. 1996. Normalisation and the Psychology of 'Mental Retardation', *The Sociological Review* 44(1): 99-118.
- Sinason, Valerie. 1992. *Mental Handicap and the Human Condition: New approaches from the Tavistock*. Free Association Books: London.
- Singer, Judy. 1999. Odd People In: The birth of a community amongst people on the 'Autistic Spectrum'. Honours Thesis, University of Technology, Sydney.
- Sinson, Janice C. 1993. *Group Homes and Community Integration of Developmentally Disabled People: Micro-Institutionalisation?* Jessica Kingsley Publishers: London & Philadelphia.
- Smith, Deborah. 1996. What Price a Womb? *The Sydney Morning Herald*, 8/7/1996, Agenda: 11.
- Smith, Deborah. 1997a. Hundreds of Disabled Girls are Illegally Sterilised: Researcher, *The Sydney Morning Herald*, 8/7/1997, News: 1.
- Smith, Deborah. 1997b. Passed Imperfect, *The Sydney Morning Herald*, 7/4/1997, Features: 11.
- Smith, J. David & Polloway, Edward A. 1993. Institutionalization, Involuntary Sterilization, and Mental Retardation: Profiles from the history of practice, *Mental Retardation* 31(4): 208-214.

- Stella, Leonie. 1996. Normalisation and Beyond: Public sector residential care 1965-1990. In Errol Cocks, Charlie Fox, Mark Brogan & Michael Lee (eds.), *Under Blue Skies: The social construction of intellectual disability in Western Australia*, 92-136. Centre for Disability Research and Development, Edith Cowan University: Perth.
- Stone, Deborah A. 1984. *The Disabled State*. Temple University Press: Philadelphia.
- Susman, Joan. 1993. Disability, Stigma and Deviance, *Social Science & Medicine* 38(1): 15-22.
- Sweet, Melissa. 1997. 1,000 Disabled Girls 'Illegally Sterilised,' *The Sydney Morning Herald*, 15/12/1997, News: 7.
- Szasz, Thomas S. 1977 [1961]. *The Myth of Mental Illness: Foundations of a theory of personal conduct*. Paladin: Frogmore, Herts.
- Szivos, Sue. 1993. The Limits to Integration? In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 112-133. Routledge: London.
- Talbot, Mabel. 1967. Edouard Séguin, *American Journal of Mental Deficiency* 72(1): 184-189.
- Taussig, Michael. 1992. *The Nervous System*. Routledge: New York.
- Taylor, Charles. 1985. The Person. In Michael Carrithers, Steven Collins & Steven Lukes (eds.), *The Category of the Person: Anthropology, philosophy, history*, 257-281. Cambridge University Press: Cambridge.
- Taylor, Steven J. 1998a. 'Children's Division is Coming to Take Pictures': Life in a family with mental retardation and disabilities. In Steven J. Taylor & Robert Bogdan, *Introduction to Qualitative Research Methods: A guidebook and resource*, 221-241. John Wiley & Sons: New York.
- Taylor, Steven J. 1998b. 'They're Not Like You and Me': Institutional attendant's perspectives on residents. In Steven J. Taylor & Robert Bogdan, *Introduction to Qualitative Research Methods: A guidebook and resource*, 192-204. John Wiley & Sons: New York.

- Taylor, Steven J. & Bogdan, Robert. 1989. On Accepting Relationships Between People with Mental Retardation and Non-disabled People: Towards an understanding of acceptance, *Disability, Handicap & Society* 4(1): 21-36.
- Taylor, Steven J. & Bogdan, Robert. 1998. *Introduction to Qualitative Research Methods: A guidebook and resource*. Third Edition. John Wiley & Sons: New York.
- Tredgold, Roger F. & Soddy, Kenneth. 1963. *Tredgold's Textbook of Mental Deficiency (Subnormality)*. Tenth Edition. Baillière, Tindall & Cox: London.
- Treffert, David A. 1989. *Extraordinary People: An exploration of the Savant Syndrome*. Bantam Press: London.
- Trent, Jr., James W. 1995. *Inventing the Feeble Mind: A history of mental retardation in the United States*. University of California Press: Berkeley.
- Trumble, Stephen. 1997. Sterilisation of Minors: Urgent research needed! *Intellectual Disability Australia* 18(2): 7.
- Turner, Bryan S. 1987. *Medical Power and Social Knowledge*. Sage: London.
- Turner, Bryan S. 1992. *Regulating Bodies: Essays in medical sociology*. Routledge: London.
- Turner, Terence. 1995. Social Body and Embodied Subject: Bodiliness, subjectivity, and sociality among the Kayapo, *Cultural Anthropology* 10(2): 143-170.
- Turner, Victor W. 1967. *The Forest of Symbols: Aspects of Ndembu ritual*. Cornell University Press: Ithaca, New York.
- Turner, Victor W. 1969. *The Ritual Process: Structure and anti-structure*. Routledge & Kegan Paul: London.
- van Maastricht, Sylvia. 1998. Work, Opportunity and Culture: (In)competence in Greece and Wales. In Richard Jenkins (ed.), *Questions of Competence: Culture, classification and intellectual disability*, 125-152. Cambridge University Press: Cambridge.

- Vohs, Janet. 1993. On Belonging: A place to stand, a gift to give. In Ann P. Turnbull, Joan M. Patterson, Shirley K. Behr, Douglas L. Murphy, Janet G. Marquis & Martha J. Blue-Banning (eds.), *Cognitive Coping, Families, and Disability*, 51-66. Paul H. Brookes: Baltimore.
- Ward, Linda. 1993. Foreword. In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, x-xi. Routledge: London.
- Weber, Max. 1978 [1930]. *The Protestant Ethic and the Spirit of Capitalism*. George Allen & Unwin: London.
- Westermeyer, Joseph. 1979. Folk Concepts of Mental Disorder among the Lao: Continuities with similar concepts in other cultures and in psychiatry, *Culture, Medicine and Psychiatry* 3(3): 301-317.
- Whelan, Judith. 2000. Designer Babies Not the Way to Go, Says a Lord who Knows His Genes, *The Sydney Morning Herald*, 31/10/2000, News: 7.
- Whitehead, Simon. 1993. The Social Origin of Normalisation. In Hilary Brown & Helen Smith (eds.), *Normalisation: A reader for the nineties*, 47-59. Routledge: London.
- Whittemore, Robert D., Langness, L. L. & Koegel, Paul. 1986. The Life History Approach to Mental Retardation. In L. L. Langness & Harold G. Levine (eds.), *Culture and Retardation: Life histories of mildly mentally retarded persons in American society*, 1-17. D. Reidel Publishing Company: Dordrecht, Holland.
- Whyte, Susan Reynolds. 1998. Slow Cookers and Madmen: Competence of heart and head in rural Uganda. In Richard Jenkins (ed.), *Questions of Competence: Culture, classification and intellectual disability*, 153-175. Cambridge University Press: Cambridge.
- Wilbur, Hervey B. 1976 [1880]. Eulogy to Edouard Séguin, 'Remarks by Dr. H. B. Wilbur'. In Marvin Rosen, Gerald R. Clark & Marvin S. Kivitz (eds.), *The History of Mental Retardation: Collected papers, Vol. I*, 181-187. University Park Press: Baltimore.

- Wilkie, Tom. 1993. *Perilous Knowledge: The human genome project and its implications*. Faber & Faber: London
- Williams, Donna. 1996. *Like Color to the Blind: Soul searching and soul finding*. Bantam Books: Sydney.
- Williams, Gareth. 1998. The Sociology of Disability: Towards a materialist phenomenology. In Tom Shakespeare (ed.), *The Disability Reader: Social science perspectives*, 234-244. Cassell: London.
- Wing, J. K. 1978. *Reasoning About Madness*. Oxford University Press: Oxford.
- Wing, Lorna. 1996. Autistic Spectrum Disorders, *British Medical Journal* 312: 327-328.
- Wittgenstein, Ludwig. 1998 [1953]. *Philosophical Investigations*. Blackwell Publishers: Oxford.
- Wolfensberger, Wolf. 1977 [1972]. *The Principle of Normalization in Human Services*. National Institute on Mental Retardation: Toronto.
- Wolfensberger, Wolf. 1980a. A Brief Overview of the Principle of Normalization. In Robert J. Flynn & Kathleen E. Nitsch (eds.), *Normalization, Social Integration, and Community Services*, 7-30. Pro-Ed: Austin, Texas.
- Wolfensberger, Wolf. 1980b. The Definition of Normalization: Update, problems, disagreements, and misunderstandings. In Robert J. Flynn & Kathleen E. Nitsch (eds.), *Normalization, Social Integration, and Community Services*, 71-116. Pro-Ed: Austin, Texas.
- Wolfensberger, Wolf. 1983. Social Role Valorization: A proposed new term for the principle of normalization, *Mental Retardation* 21(6): 234-239.
- Wolfensberger, Wolf. 1995. Social Role Valorization Is Too Conservative. No, it is too radical. *Disability & Society* 10(3): 365-367.
- Wolfensberger, Wolf & Thomas, Susan. 1994. A Critique of a Critique of Normalisation, *Australian Disability Review* 1: 15-19.

- Woods, Grace E. 1983. *Care of the Mentally Handicapped Past and Present*. John Wright & Sons: Bristol.
- Wortis, Joseph. 1978. Introduction: The history of intelligence, *Mental Retardation and Developmental Disabilities: An annual review, Volume VIII*: xiii-xvi. Bruner/Mazel Publishers: New York.
- Yirmiya, Nurit, Solomonica-Levi, Daphna, Shulman, Cory & Pilowsky, Tammy. 1996. Theory of Mind Abilities in Individuals with Autism, Down Syndrome, and Mental Retardation of Unknown Etiology: The role of age and intelligence, *Journal of Child Psychology and Psychiatry* 37(8): 1003-1014.
- Yoxen, E. J. 1982. Constructing Genetic Diseases. In Peter Wright & Andrew Treacher (eds.), *The Problem of Medical Knowledge: Examining the social construction of medicine*, 144-161. Edinburgh University Press: Edinburgh.
- Zetlin, Andrea G. & Turner, Jim L. 1984. Self-Perspectives on Being Handicapped: Stigma and adjustment. In Robert B. Edgerton (ed.), *Lives in Process: Mildly retarded adults in a large city*, 93-120. American Association on Mental Deficiency: Washington D. C.
- Zigler, Edward, Balla, D. & Hodapp, Robert. 1984. On the Definition and Classification of Mental Retardation, *American Journal of Mental Deficiency* 89: 215-230.
- Zigler, Edward & Hodapp, Robert M. 1986. *Understanding Mental Retardation*. Cambridge University Press: New York.
- Zola, Irving Kenneth. 1993. Self, Identity, and the Naming Question: Reflections on the language of disability, *Social Science & Medicine* 36(2): 167-173.
- Zola, Irving Kenneth. 1972. Medicine as an Institution of Social Control, *The Sociological Review* 20(4): 487-504.