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\(^1\) 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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\(^1\) 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' 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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2 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\(^3\) 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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\(^3\) 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\textsuperscript{4} 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.\textsuperscript{5} 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

\textsuperscript{4} Technical and Further Education, a form of tertiary trade training college in Australia.

\textsuperscript{5} Maryla and Stephen spent the 14 months that we were overseas living at Ryde Psychiatric Hospital in Sydney.

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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 children’s 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" 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. This led to investigations about what was causing the

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6 Fragile-X syndrome is considered to be the most common form of a genetically based intellectual disability (Dyken 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. Dyken 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 (Dyken 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).

7 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. 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. 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 Tegretol, 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).

8 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.

9 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.

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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). 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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10 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).  

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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11 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.12

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

12 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.\textsuperscript{13} 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

\textsuperscript{13} 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 \textit{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.

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appeared to be entirely unfamiliar with the ways in which mutuality might be built.\textsuperscript{14}

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:

\begin{quote}
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.
\end{quote}

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

\textsuperscript{14} 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?¹⁵

**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,

¹⁵ 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).16

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.

16 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.\(^{17}\)

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.

\(^{17}\) 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.\textsuperscript{18}

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.\textsuperscript{19} 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.

\textsuperscript{18} I explore these issues in more detail in chapter five.

\textsuperscript{19} 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.\textsuperscript{20} The activities centre was officially called the "Xanadu"\textsuperscript{21} 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.\textsuperscript{22} 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".

\textsuperscript{20} See chapter one, footnote 7 for details of the Commonwealth State Disability Agreement.
\textsuperscript{21} 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.
\textsuperscript{22} 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 (Cowlishaw 1999: 222-
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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23 Gillian Cowlishaw 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" (Cowlishaw 1999: 222), such that "community members were participating in alien forms of interaction and discourse, and were assenting to an agenda formed elsewhere" (Cowlishaw 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 (Cowlishaw 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. Over the twelve months that I did

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24 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.\textsuperscript{25} 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.\textsuperscript{26} 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

\textsuperscript{25} 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.

\textsuperscript{26} 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.27 In fact, I was

27 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. 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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28 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—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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29 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.30 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

30 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.  

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

31 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". 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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32 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.

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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. 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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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 behaviour 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.34 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.

34 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.