Chapter One

Ethnographic Encounters I:
Growing up in a world of intellectual disability

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

This is one of my earliest memories, and like nearly all the memories I have up until the age of three and a half, it involves me playing with my sister Ursula. She was a beautiful, gentle child, with soft brown curly hair, olive skin and brown eyes. We were close in age; two years separated us, with three older siblings making five children in all at the time. Consequently, Ursula and I
spent a lot of time together, climbing fences on country picnics, playing on the
swings in the back garden, drawing pictures, looking at books, playing with
toys and having morning tea together as we watched Playschool\(^1\). Being older,
she was the leader and I dutifully followed her quiet but definite lead as we
moved through the daily activities and games of childhood. I do not remember
us ever talking with one another, or playing anything highly organised, but we
understood and communicated in the way that siblings close in age often do.
We existed in each other’s world, and within the wider world of our family.
When Ursula went to preschool I was devastated to be left alone at home,
packing my school bag each morning in the hope that one day I too would
follow her and my other older siblings into a larger world. The only difference
was that the world I would one day enter was profoundly different to the one
that three of my siblings experienced.

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

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\(^1\) Playschool is a popular children’s television programme that has been
running in Australia since the 1960s.

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

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

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

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

4 Like many terms that try to characterise and define a category of persons, autism is a controversial and contradictory concept. First coined by Leo Kanner in 1943 to describe what he called "early infantile autism", the term was used to define a particular group of children who from birth (or up to 30 months of age) did not fit the contemporary category of feeble-mindedness due to their cognitive potential (Kanner 1944). Kanner argued that autistic children exhibited similar patterns of unusual behaviour, including extreme aloyness or social aloofness, delayed echolalia, and the need for obsessive repetitive routines (Kanner 1944; L. Wing 1996). More recently it has been argued that autism presents as a spectrum of disorders with similar clinical symptoms rather than being a singular isolated disorder (Gray 1995; L. Wing 1996). According to Lorna Wing, these include "Asperger’s syndrome, a condition characterised by borderline or normal IQ; social isolation or naive, inappropriate social interaction; intensive interest in only one or two subjects; a narrow, repetitive life style; limited or inappropriate intonation and body language; and poor motor coordination" (L. Wing 1996: 327). David Gray argues, however, that despite occasional media assertions that autistic people are savants, displaying extraordinary powers of mathematical calculation or musical memory, up to four-fifths of all autistic people are profoundly mentally handicapped (Gray 1995: 102). Autism was originally thought to be a social condition caused by what was termed Refrigerator Mother Syndrome. More recent arguments claim that it is a neurological condition due to
child born into our family. She is very Polish in appearance, taking after my father, with olive skin, blue eyes, wide cheekbones and straight dark hair. Like Stephen and Ursula, she hasn’t any particular physical features that mark her as disabled and yet her physical presence is strikingly different. It is the way she holds herself, the way she walks, how she uses her hands; it is the way she is in the world. She lacks any of the self-consciousness, and indeed capabilities, that compel most people to act in accordance with accepted social norms.

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

**Meaning, Mutuality and Sociality**

metabolic or genetic disorders, pre or post natal brain injury or viral infections (Leser 1996: 45). However, as Gray points out, there is still no agreement as to what causes autism (Gray 1995: 99).
Far from being isolated, meaningless, non-symbolic, abnormal, or asocial, as the behaviour of intellectually disabled people is so often described (Connors & Donnellan 1993: 269; Goode 1990: 30; Kanner 1944: 211-4; Lea 1988; Leser 1996: 45; MacAndrew & Edgerton 1970: 28; Rose 1985: 37; Ryan & Thomas 1987: 47-8; L. Wing 1996: 327; cf. Taylor & Bogdan 1998: 198-199; Gleason 1989: 62; for similar criticisms of such interpretations), my siblings were continuously creating meaningful lives for themselves. They were also intricately engaged in the complex patterns of sociality and mutuality that constituted our family life. The issue of meaning and its relation to sociality is a central dimension of this thesis. Although I expand more fully on this in my final chapter, it is important to introduce what I mean by "meaningless" and "meaningful" behaviour when it comes to social perceptions of intellectually disabled people. In anthropological terms I take the expression of meaningful behaviour and interaction with others as forms of sociality, as that which is symbolic, structured and purposeful, which exists within an interpretable and predictable social context, and is open to change and transformation (Austin-Broos 1987: 142-5; Carrithers 1992; Geertz 1993a [1973]: 99; Kuper 1999; Parsons 1970 [1951]: 3-11; Sahlins 1976: 58-67). Sociality does not just mean becoming recognisably encultured, nor is it merely related to social structures and institutions (Carrithers 1999: 1033). It refers instead to the "intensity of social life", with the recognition that human existence and experience is fundamentally shared and social (Carrithers 1999: 1033; 1992: 1).

Sociality refers to shared existence within a meaningful world and as such is based on mutuality and interrelations between people. In this sense mutuality is, as Michael Carrithers (1992: 11) has put it, a view "which stresses that people are so deeply engaged with each other that we can only properly understand them if we understand even their apparently private notions and attitudes as interpersonal ones". The contextual environment, and ultimately the form of
relatedness across the difference of intellectual disability, influences the way intellectually disabled people’s expressions, behaviour and experiences are perceived and interpreted. Different persons are constituted differently in different environments (Carrithers et al. 1985). The joint constitution of social life as a product of relations and degrees of mutuality across this difference only occurs if intellectually disabled people’s contributions to the social world are accepted on their own terms. However, without many of the predictable dispositions that act as the usual markers of sociality, intellectually disabled people are often presumed to lack any form of meaningful social existence at all. The idea that their sociality can constitute a mutuality with the intellectually able is largely dismissed.

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

5 While I use Wittgenstein’s "language games" in conjunction with Radcliffe-Brown’s "form of life" I do so by incorporating an enriched analytical content derived from symbolic anthropology and Carrithers' concept of mutuality. This combination allows me to analyse the forms of engagement and symbolic
forms of interaction is deliberately paradoxical. Rather than referring simply to Language writ large, I use the term in the broadest sense as a system of communication that mediates and interprets the intentions and experiences of those involved. The term is also useful because it connotes a domain of sociality and symbolic exchange that, although confined and limited in its nature, is also open to possibilities.\(^6\)

This interpretation raises serious questions about the ways in which intellectually disabled people traditionally have been treated and perceived; a perception that is embodied in Tredgold’s 1956 statement that "they have eyes but they see not; ears but they hear not; they have no consciousness of pleasure or pain; in fact, their mental state is one of entire negation" (cited in Bogdan & Taylor 1982: 15). It also raises problems for some contemporary policies within the field of intellectual disability, including the practices of normalisation, deinstitutionalisation, and community integration, and the push for equal rights and a quality of life. While these have been introduced as positive alternatives to the older practices of segregation and isolation, and are an attempt to protect intellectually disabled people from real and potential abuse, I argue later in the thesis that the forms of relatedness that exist in group homes and activities centres often preclude the possibility and the legitimacy of developing long-term relations of mutual engagement. The mode of sociality that constitutes such institutional environments (for, despite no longer being an institution, they are still institutional) is not conducive to producing a genuinely shared social milieu. Instead, these places are founded on the principles and mediation that exist in encounters with intellectually disabled people without entering into phenomenological interpretations of their lived experiences. I do this because I am not fully able to apprehend the experiences of my siblings from their perspectives.

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

Chapter One: Ethnographic Encounters I
page 16
practices of management, control, training and assimilation. These practices are themselves built upon the interpretation that intellectually disabled people are inherently abnormal and asocial, and that they are in need of being normalised and socialised in order to be meaningfully engaged with.

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

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7 The NSW (New South Wales) Disability Service Standards and the NSW Disability Services Act (1993) were passed by the NSW Legislative Assembly in accordance with the Commonwealth State Disability Agreement of 1991. Throughout the 1980s there had been agitation for changes to the treatment of intellectually disabled people in Australia. This resulted in the Richmond Report (1983) which examined conditions in NSW institutions and emphasised the ideologies of deinstitutionalisation and normalisation as an alternative social policy. The Commonwealth Disability Services Act was established in 1986 due to the recommendations of the Richmond Report and other similar reports and submissions. Each of the States agreed to pass a complementary Act to the Commonwealth Disability Services Act so as to uphold the Principles, Standards and Objectives of the 1986 Act. Under the present arrangements, the Commonwealth Government takes responsibility for employment services for all people with disabilities, while each of the States are responsible for all other services, including accommodation, activities centres and community programmes (NSW Department of Community Services 1996).
these differences, means that the institutional response to intellectual disability perpetrates a violence against the disabled. Being trained to conform to normative social practices and skills does not produce a social and cultural person. It is a procedure that attempts to transform someone who has already been constituted as "radically other" into a simulacrum of normality. Much of this thesis is concerned with analysing just what this process involves, and how it has come about.

The Intimacy of Living with Disabled Kin

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

8 Throughout the thesis I draw on the medical records for my family dating back to 1962. The dates refer to these notes, reports and letters.
mystery. Instead, it was the viewing of a film on autism brought to Australia by the English child psychiatrist and specialist on autism, Doctor Mildred Creak, that gave my parents their first inkling that Stephen might be autistic. For the first time they recognised his behaviour in another, and saw that he could be understood in terms of this recently defined "syndrome". They realised that they were not alone, and that there were special schools being set up that could provide for at least one of their children.

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

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

10 The majority of the literature that examines familial attitudes to intellectually disabled people tends to focus on the experiences and perceptions of parents, or else utilises the parent-child relationship as a source for interpreting an intellectually disabled person's actions and intentions (Booth 1978; Goode 1980a, 1980b; Gray 1995; Jacobs 1980; Kearney 1993a, 1993b, 1996). Much of the autobiographical and biographical literature on intellectual disability has also focused on the relationship of parents with their intellectually disabled child (O'Halloran 1993; Vohs 1993). While there are an increasing number of studies focusing on sibling attitudes to intellectual disability, these often tend to emphasise the difficulties or consequences of such a situation for the non-disabled sibling (Cleveland & Miller 1977). There is also a tendency to focus on the issue of service provision, and the role that the family should have in negotiations on their kin's behalf with such services (Bigby & Johnson 1995; Krupinski et al. 1983).
expectations, hopes, or disappointments. This was the world as I knew it, and these were my brothers and sisters, the people with whom I most closely associated. Although I became aware as I grew older that my siblings were different, it was quite some time before I was affected by the view that this difference was something of which to be ashamed.

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

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

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11 A Holden is an Australian car made by General Motors.
12 The word Esky is a trademark term that refers to a portable insulated icebox used for keeping food and drink cold.

Chapter One: Ethnographic Encounters I
page 20
the long paddock grass, or lay in the sun until it disappeared behind some trees. Finally we would pack up all our things and crowd back into the car.

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

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

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

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

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

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13 I use the word liminal in accordance with Victor Turner’s use of Arnold van Gennep’s concept of "the liminal phase" as a transitional and transformative phase that exists between two other social states (V. Turner 1967; 1969: 94). Robert Murphy has also used liminality as an explanatory concept to describe the social state that physically disabled people find themselves in (Murphy 1990: 131). Rather than being transformed into a new social role, as van Gennep’s liminal stage implies, Murphy argues that the disabled are unable to recompose themselves within the social world and therefore permanently exist at the threshold of, and oftentimes outside, the formal social system (Murphy 1990: 45, 131). Being neither sick nor well, disabled people remain ambiguous persons whose social and human status is in doubt. They are forever "betwixt and between" in the words of Victor Turner (V. Turner 1969: 95; Murphy 1990: 131). Interestingly, for Turner, there is a "certain homology" between people whose social status is inferior or marginal and liminality as a state of "weakness" and "passivity" (V. Turner 1969: 99). Turner also argues that many of the ritualised transitional qualities of liminality in tribal societies have become permanent institutionalised states in more complex societies (V. Turner 1969: 107). In my use of the term, liminality incorporates these dual aspects. It
people to just be in the present, to be themselves, their presence justified by the momentary movement that demanded nothing other than that they be in that bus.

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

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

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

Chapter One: Ethnographic Encounters I
page 23
our sociality was built. As Schneider elaborates, family in the United States, as a cultural category, is based on the principle of solidarity:

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

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

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

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

We spent many long hours together as children with all the accoutrements of middle class life around us; books, toys, jigsaw puzzles, games, crayons, television, a swimming pool, swings, sandpit, a table tennis table, as well as a large garden with trees to climb and plenty of room to run around in. The difference was that my intellectually disabled siblings often played and used these objects in ways that were socially different and unexpected. These were ways that did not conform to normal and predictable dispositions that generally act as markers of sociality—although as a child I accepted their engagement with these things as ordinary and everyday. In fact, I was drawn into their world just as much as they were drawn into the wider world of the family. Their way of utilising objects and engaging with us gave shape to the world that we all lived in. Through such mutual encounters "we progressively developed common schemes of communication, congruent practical relevancies, mutually defined things to do in the world, and so forth" (Goode 1980b: 204-205)—as Goode has described it in reflecting on his own interactions with a severely intellectually disabled person. These engagements therefore and interpret an often ignored potentiality in social relations with profoundly intellectually disabled people.
produced a specific form of life, "a certain set of actions and interactions amidst persons which are... interconnected in such a way that we can give a general analytical description of them as constituting a system" (Radcliffe-Brown 1965 [1952]: 6).

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Maryla and Stephen both loved playing with jigsaw puzzles. In fact the whole family partook in this rainy day activity, enjoying the satisfaction of completing a picture by fitting the last piece of the puzzle into place. For Maryla and Stephen, however, the process was always somewhat different, and the interest went way beyond rainy days to become an almost permanent preoccupation. Stephen had a special knack for finding pieces by sight alone. He worked not with the picture, nor the emerging image, but with the shapes themselves. His task was to work from one end of the puzzle to the other, putting each piece into place one after the other in rows, rarely picking up the wrong piece that was next in line. He would sometimes do these puzzles picture side down as if to prove that it was the satisfaction and pleasure of recognising shapes that motivated him. Stephen's sounds of delight and satisfaction whenever he found a particularly difficult piece seemed proof of this. Often he would get up in the middle of the night to continue with his jigsaw puzzle and Joseph or I would try to get him back to bed before he was discovered by our father. At other times, if Stephen lost a piece down the back of the skirting-board as he sometimes did, he would come up to my mother with a large knife in his hand to let her know he needed help retrieving it. Doing jigsaws was one of Stephen's primary pleasures in life and I will forever have memories of him and Maryla half lying side by side on the rugs in the living room, the pieces spread out on the floor around them, as they did their respective puzzles.
Maryla is both more elaborate in her approach to the jigsaw puzzles but also less capable. She begins each new puzzle by spending hours laying out the pieces in a snake-like domino pattern across the floor, picture side down. When she has completed this she then turns each piece over and replaces it in another snake-like domino pattern picture side up. Having done this, and talking to herself at the completion of each stage in a sort of incantation that comments on what she has just done and is about to do, Maryla then begins the slow task of putting together the puzzle in the same way that Stephen did, beginning at one end and working her way across the board to the other side. Sometimes she would have to call on Stephen to help her with a piece, and he would respond with delight at being able to do it better than she could. Rarely would she let anyone else help her. If we ever came too close to where Maryla was sitting she would get distressed and want us to move away. It didn't help that we were mostly younger than her and as babies had a habit of wanting to eat the pieces. Her memory of this, and the potential threat to her ordered world that our intrusions represented, were reasons enough to keep us at bay no matter how much we wanted to participate. It was all right to be close by if we were involved in some other activity but not if it was clear we were trying to intrude on her enterprise.

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

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

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

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

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

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

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

Chapter One: Ethnographic Encounters I
page 29
she pulled out each piece one by one, adding some to her collection while
discarding others over the side of the chair as rubbish. She even said that it was
rubbish. I was unable to see what the determining feature was that separated
these objects. Those that I would have considered rubbish, such as the broken
bits of plastic or metal, were quickly coveted and added to her collection, while
others such as the earing or rubber band were thrown away. While she
obviously appreciated the gift of bits and pieces, I hadn't quite understood their
meaning and value to her.

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

In the past Maryla always held these bits and pieces tightly in her fist for
most of the day, but there were times when she carefully and methodically laid
them out on the floor. This would generally be every meal or bath-time, or
when she went to bed, as this was when her hands had to be free. Like the
jigsaws and books, the laying out of these bits and pieces has always had a very
particular and repetitive aspect to it. It is done with complete dedication,
concentration and seriousness, and follows the same basic pattern each time.
Maryla repeats over and over to herself what she is about to do in a similar
incantation to the ones that she uses at traffic lights or when doing the books
and jigsaw puzzles. After going through this for up to five minutes, Maryla then proceeds to lay the pieces out on the floor in a spatial pattern so that each piece is equidistant from others. This is done in a precise order; usually the reverse order in which she collected them. After doing this she leaves them there on the ground but always has one eye out making sure that no-one goes near them. Of course, this is the only chance the rest of us have to reclaim some personal or necessary item, such as the screws and plastic pieces from the toilet that she snatched up while it was being fixed, some jewellery she might have found in a drawer, or a collection of paper clips from on top of a desk. These moments are usually laden with anxiety and tension as we dispute the nature, value, meaning and ownership of these objects. At times there is also humour involved, especially when family members tease Maryla about wanting something from her collection. Unless it is absolutely imperative that we reclaim an object, the tendency has been to allow Maryla to keep it, allowing her meaning, value and significance of the items to supersede our own.

At Stockton, Maryla has recently been trained to keep her bits and pieces in a purse so that her hands are not always clenched. She had been working in the craft room and was collecting bits of off-cut cotton and other pieces of fabric and the sweating that this caused in her palms was damaging her skin. Although this was given as the reason for initiating the change in habit it is clear from Maryla’s case notes that her collection also caused a fair amount of frustration for the staff. Too much time was involved in convincing Maryla to put the pieces down, and too much time was taken up in her actually doing so. This has now been altered due to the whole purse being picked up and put down in one go. Yet Maryla still spends much of her time searching for objects to add to this collection, and now that the items are hidden away it is much harder to see and reclaim a lost possession.
Every evening, the staff at Stockton lock Maryla’s purse in the locker that stands beside her bed. This is to prevent Maryla from spending much of the night arranging her bits and pieces. We are supposed to do this as well when she comes home for a weekend. The first time this happened, however, my mother and I decided to let Maryla have the purse as we both agreed that her bits and pieces are her primary love in life. Despite recommendations to the contrary, coming home should be a special time rather than merely a continuation of institutional practices.\textsuperscript{18} I shared the room with Maryla that evening and watched as she spent half the night laying out the pieces on top of the sheets before finally falling asleep with them beside her.

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

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

\textsuperscript{18} I discuss this issue further in chapter six.
person in line. We have all learnt how to play these conversation games, and can easily get Maryla upset if we do not respond to her appropriately.

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

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

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

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

As a girl, I adored Stephen, and was often in awe of him. He had a talent and humour that still brings a smile to my face when I think of him. One of his favourite occupations was building precariously balanced towers using such
objects as milk bottles, playing cards and children's blocks. My brother Joseph remembers playing with Stephen as a young child and commented that:

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

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

When I asked Joseph about his memories of those early years he recalled that he related to Maryla and Stephen through play rather than verbal communication. Joseph was aware of the difference that this made to their relationship, especially when he saw how other siblings related to one another, but he still remembers those times as fun and loving despite their difficulties. When I asked him whether his relationship with Stephen was affectionate, Joseph responded emphatically, saying: "Oh yes, yes, we certainly did [have affection]. We got on very well on the whole . . . It was fun. He certainly was fun and it was nice having him around and I believe I loved him".
Often Joseph was the only one who could influence Stephen. Consequently he was put in charge of Stephen whenever we went out on picnics or to the beach. Stephen had a habit of running away as soon as the car doors were opened and Joseph was invariably the one to chase after him and encourage him back. Mealtimes were another occasion that required careful intervention, either in terms of getting Stephen away from his puzzles and to the table, or enticing him to eat his meal long after the rest of us had finished. Joseph sat next to him at the table and it seemed that Stephen would respond to what Joseph said more than anyone else. My mother commented that even when Stephen was very young he "was absolutely devoted to Joe; followed him around with his eyes, if not with his body. [He] just adored Joe and would light up the minute he saw Joe . . ." When Joseph left to go to boarding school I took over his role in relation to Stephen. My memories of this time are very special because Stephen would often turn to me if he wanted something done, or for acknowledgment that he’d finished his meal or jigsaw puzzle, and that interaction made me feel very close to him. There were few words involved, if any, but the interaction was conscious, affectionate, and purposeful.

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

It is more an object relationship that my siblings have with the world, rather than a conceptual one, and yet on one occasion Maryla quietly removed the laundry clothes from the baby’s bassinet and replaced them with a photograph of my new nephew while no-one was around. In her world certain objects are for specific uses; sometimes this is in accordance with the rest of us, at other times it is use of her own determination. This relationship to the world, while also involving long and repetitive explanations and affirmations in Maryla’s case, partly replaces other forms of sociality that usually exist between people. Rather than engaging through complex verbal communication and normative social interactions, my intellectually disabled siblings often related to each other.
and the rest of the family through objects. All of us were drawn into this world due to our relationships with one another and our shared engagement with the objects that surrounded us. These objects symbolically mediated our worlds (see Comaroff 1985: 1-6). They accommodated our differences. Their ability to be vehicles for more than one system of meaning, and for systems of different orders, was crucial in the maintenance of our mutuality (cf. Geertz 1993a [1973]).

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

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19 By use I do not mean something that exists purely for utilitarian purposes (cf. Sahlins 1976), as if it were concerned only with some purposeful application towards a specific objective. Use here takes on a more ephemeral aspect, implying both the purposeful action and utilisation of objects as well as the outcome of a desire to relate to another person. For, if the meaning of things, and indeed the meaning of language, lies in its use, it must first operate as something which exists between people. It exists in the very act of communicating and engaging with others. It is the outcome of being in the world with others and making sense of this world as a negotiated and potentially shared phenomenon. It is meaningful action and practice that constitutes the social world. This communication, and the sharing of such language-games, constitutes a life form, existing as it does within the immediacy of a social context which is itself a product of the specificity of those who give life to its form.
meaning itself exists as the public expression and manifestation of use and practice (cf. Austin 1975 [1962]; Geertz 1993b [1973]). As such, meaning is shared, and generates shared experience, but is also constantly open to negotiation (Austin-Broos 1997: 8-11; Bourdieu 1999 [1972]).

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

Therefore, not only are intellectually disabled people such as my siblings fundamentally able to engender forms of sociality, mutuality and intimacy, but their ways of doing so involve an engagement with the world. By virtue of our coexistence, and the degrees of mutuality and intimacy that we shared, this world became significant for all of my family. While to some degree the rest of us were kept outside my siblings' specific modes of engagement with these
objects, we were also invariably drawn into and affected by their consequences. My family provided the space within which this articulation was acknowledged and engaged with. It came to be a cultural environment all of its own, and those of us within it developed ways of acting and interacting through the objects that surrounded us. These objects became sites for the mediation and negotiation of differently articulated but symbolically meaningful systems.

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

. . . they did want me to insist that he spoke, or tried to speak, before he got what he wanted, before he, for instance, got a glass of water. And I found this very time consuming and irritating because, I mean, he knew I knew what he wanted. He knew that I would get it for him, and it just seemed to be a stupid thing to hang around waiting for this word to come which I knew he wouldn't say. Because if he wasn't going to say the word there was no way in the world he would say it. And you just couldn't force him.
Going back to Steve talking. If we were walking in the street [in England] and a car passed by, he might say grey car, or just grey, and I'd be so thrilled because he knew his colours and I'd be so thrilled that he'd said grey car. But if another car went past which was grey and I'd say "what colour's that Steve?", he would absolutely refuse to answer. We both knew that he knew but he wasn't going to say it. Why should he?

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

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

\(^{20}\) Part of Merleau-Ponty's (1962) phenomenological enterprise was an explicit critique of the overtly cognitive rendering of human nature and understanding, and an argument for knowledge as attainable through both the senses and the intellect. It is interesting that many writers on intellectual disability turn to phenomenology as a tool for interpreting the life experiences of such people (Atkins 1998; Bogdan & Taylor 1976, 1982; Goode 1980a, 1980b, 1990), although they tend to draw their inspiration from Alfred Schutz (1972 [1967]) rather than
speech (and literacy) is one of the primary cultural markers of normality in our society (Jenkins 1998b: 19). Definitions of intellectual disability have traditionally and consistently incorporated references to deficiencies in language ability and comprehension (Binet & Simon 1976 [1905]: 336-7; Connors & Donnellan 1993: 269; Howe 1976 [1848]: 45; Kanner 1944: 214; MacAndrew & Edgerton 1970; Pinel 1962 [1801]: 172; L. Wing 1996: 327). Language is considered to be that which connects ideas, knowledge, meaning and creativity. The mind is seen as the necessary tool for humans to convey meaning. Its capabilities are what define us as human and separate from animals. However, language is often conceived as if it were solely a vehicle for communicating preexisting notions and ideas, as though these exist as specific and identifiable entities in the world. Those who are perceived to be deficient in mental ability and linguistic competency are therefore often considered unable to communicate meaningfully at all.

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

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

Chapter One: Ethnographic Encounters I

page 41
However, it is not solely through the mediation of symbolic objects that my siblings attempted some form of communication and interaction with others. When Maryla is introduced to someone new she goes right up to them, looks them in the eye, and grabs hold of their arm as she says "hello", turning back to the person she is with to get some affirmation of her actions. While this is Maryla's familiar way of communicating and acknowledging another person's presence, it can often be responded to with apprehension and confusion by those who do not know her. Their lack of recognition of the meaning and intention in Maryla's actions and dispositions, and her inability to utilise accepted social modes of interaction, both linguistically and behaviourally, means that people often respond by not seeking any form of interaction and engagement at all.

Other intellectually disabled people I know will smell, stroke the skin, or touch the face of someone they meet. Sometimes they will avoid any contact whatsoever, while others will hit out or make noises from a distance (cf. D. Williams 1996: 45). For many intellectually disabled people such forms become their primary means of interacting with others. To engage with the world in such a way makes interaction and mutuality highly contextual. The symbolic systems that my siblings used were highly dependent on particular persons, objects and places. In this way they represent what Basil Bernstein has termed a "restricted code", a mode of communicating that is implicit, shared, general and contextual, and whose reference points are not transferable (Bernstein 1971: 143-148). As Bernstein elaborates: "The principles and meanings [of restricted codes] are embedded in local contexts, in local social relationships, practices, activities. To this extent they are relatively strongly related to a specific material base (Bernstein 1977: 193-194; author's emphasis)."
Stephen and Maryla had no need or capacity for communication in the form that we are socially accustomed to. While this limited their range of sociality within the wider social world, it did not prevent other forms of sociality emerging and existing within the confines of family life. It did not prevent us articulating a degree of mutuality and sociality across shared and mediated symbolic systems such as the jigsaw puzzles, books, blocks, and bits and pieces. This capacity for sociality means that forms of mutuality are able to be transferred to other social domains provided certain conditions are upheld.22 This requires acknowledging that there is a modality of symbolic life upon which sociality and mutuality can be built. It also requires the inclusion of objects and behaviours that are not normally utilised as means of engaging with others. Therefore, it is not a lack of desire or the capacity to communicate that necessarily marks one's relationship with intellectually disabled people, but a very different way of doing so. When I was a child it never occurred to me that Maryla, Stephen or Ursula should communicate with me in any other way. Growing up with them meant that I absorbed and assimilated their systems of signs and dispositional behaviours. Their dispositions carried a specific and interpretable valency due to their shared and intimate nature, and were accepted as meaningful and purposeful. They, and their actions, were an integral part of our mutual interdependence and shared sociality.

22 Much of the thesis will involve looking at the conditions that either support or undermine this capacity.
Shame, Incomprehension and Distance

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

It is not just strangers, however, who respond with uncertainty. When I interviewed my mother's sister, Christine,—who came out from Tanzania and stayed with my family for a few months in 1970—she told me that she remembered Maryla as "a very strange being" and added that: "As somebody who only meets her occasionally you can't get through at all." My mother commented that Peter, the youngest child in our family, was terrified of Maryla and Stephen when we came back from spending a year in Europe in 1973. Maryla and Stephen had lived in an institution for the 14 months that we were away and Peter was only two when we left. These responses make me realise how much of our wariness of intellectually disabled people, and an inability to relate to them, is due to unfamiliarity, and the difference that separates them
from others. Rather than being an attribute of non-kin relatedness, this separation and incomprehension is the consequence of a lack of mutual interdependence, interrelatedness and intimacy. It is the product of forms of relatedness that do not seek symbolic mediation and negotiation through a shared and highly particular environment. It is, moreover, the consequence of attributing to intellectually disabled people an incapacity for symbolic representation, mutuality and sociality; of assuming that their modes of articulation and engagement are inherently meaningless and asocial.

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

On hot summer days we would often follow the path of many other Sydney families and head to the coast, joining the snake-like crawl of traffic up Mona Vale Road to the northern beaches, or eastwards to Queenscliff. The smell of hot bitumen and exhaust fumes would add to the already oppressive heat of the day as we children squirmed in frustration in the back seat of the car. On arrival at the beach we would open up the doors to let in the cool ocean breeze and out would leap Stephen, understanding this as his moment to run free. He would take off in any direction, and even if there were other cars around
would always manage to expertly weave his way through them without seemingly being aware that the cars were even there. My mother would stay with the rest of us, my baby brother or sister on her hip, and my older brother would take off after Stephen, anxious to catch him before he disappeared from sight. My mother later told me that Stephen and Maryla would often both leap out of the car and take off, and that my father and Joseph would head after them, my brother chasing Stephen while my father pursued Maryla.

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

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

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

²³ Stephen’s ability to know the way home and to understand directions was with him from early childhood. My mother often tells the story of the time in England when she was at a local park with the four oldest children and Joseph walked into the metal ear of a play horse and cut his head open. A woman who
on the other hand, would start asking where my mother was. I remember now that these comments were not so much questions as statements. It would be more like: "Mummy coming back soon," or "Mummy just doing the shopping now, she just doing the shopping. Yes." Yet these statements were always said with the need for affirmation. If met with a negation there was likely to be uproar. The scenes emanating from our car were enough to keep most people at bay, as they either pretended to ignore what was going on or else looked over at us disapprovingly.

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

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

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

Chapter One: Ethnographic Encounters I
page 48
schooling that were unavailable in Perth at that time. The specialists whom we saw in May 1967 at the Mental Deficiency Diagnostic Centre at Grosvenor Hospital in Sydney had also emphasised the need to find "appropriate educational facilities" (12/7/67). Access to an Autistic School in Sydney, and to the Grosvenor specialists, were what brought us east across the Nullarbor Plain in our Holden station wagon in the summer of 1967-8.