Chapter Three
A Pathological Embodiment

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

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

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

. . . takes as the distinctive quality of man not that he must live in a material world . . . but that he does so according to a meaningful scheme of his own devising . . . It therefore takes as the decisive
quality of culture—as giving each mode of life the properties that characterize it—not that this culture must conform to material constraints but that it does so according to a definite symbolic scheme which is not the only one possible (Sahlins 1976: viii).

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

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

\(^1\) The central place that reason plays in traditional theoretical interpretations of culture, including structuralism, functionalism and historical materialism, is one that Sahlins elaborates on in his discussion of the mind as more than just a rational tool but also a symbolic and constitutive entity (Sahlins 1976: 58-67). I explore this more fully in chapter four when I analyse the central place of reason, rationality and intelligence in Western conceptions of normality and humanness.
conform to normative social practices, dispositions and modes of articulation and relatedness. These attitudes and interpretations give form to the institutional practices of training and management. The symbolic scheme of reason and normality thus informs and orders institutional practices. It also informs clinical interpretations and perceptions of intellectual disability. I include here both medicine and psychology, as well as the practices enshrined in special education, behavioural management and normalisation policies. The symbolic scheme of reason and normality therefore exists as the implicit ideology or cultural assumption upon which these practices and interpretations are based.

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

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

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

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

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

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

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mentally retarded they offered no explanation for this. They connected the seizures with febrile activity and noted that they occurred in conjunction with ear, nose and throat infections, but made no inferences from this. It was not until we came to Australia that the medical profession started offering more specific diagnoses, such as that of autism for my brother Stephen (although this was discounted by the professionals at Grosvenor despite my brother going to an Autistic school for two years in Sydney).

With regards to the cause, the “problem” was definitely considered to be congenital and/or hereditary. As quoted from the medical reports, it was thought to be an “inherited disorder . . . the true identity [of which] will be disclosed with the natural course of the disease” (25/5/67). Later it became a “metabolic disorder” (12/12/69), then “an unknown metabolic disorder of recessive inheritance” (24/2/75), and, “although no definite diagnosis of the family disease was made in spite of many investigations, [i]t is [now] believed to be possibly a congenital metabolic disorder, manifesting [as] developmental delay, epilepsy, depigmentation and unusual behaviour patterns” (10/7/97).

On reading through the medical records I gained a haphazard and at times contradictory history of the family, the occasional incorrect piece of information being incorporated within this general perception of a familial abnormality. Much more apparent than any inconsistency in these details, however, is the constant reinforcing of assessments and diagnoses. Various medical authorities from 1962 to the present medicine and psychology as to which discipline is best equipped to diagnose intellectual disability (Rose 1985: 131-8), the recent development of prenatal testing has reinforced the role of medicine as the primary source of the diagnosis of a foetus’ potential intellectual or physical disability. Consequently, a judgement of abnormality is now being made prior to any possible observation of behaviour.

It surprises me that nobody has investigated this connection. My family lived in northern England, in Newcastle Upon Tyne and Liverpool, between 1959 and 1965. Both cities were large, industrial, polluted environments and although there are suggestions that a number of intellectual disabilities are the consequence of environmental causes, such as lead poisoning or exposure to infectious diseases (Heaton-Ward 1978: 23-28), this has never been considered a possible cause of my siblings’ intellectual disabilities. Instead, researchers are convinced that a genetic, biochemical cause will eventually be discovered. This is the only avenue of research that they have pursued.
have drawn on this same historical material, just as they have utilised the same
diagnostic tools to classify my siblings as retarded. All the details of the family, however,
whether correct or incorrect, are dutifully added to the files in the hope that one day
some biomedical specialist might finally crack the code to the “diagnostic puzzle” that
my family represents. My own visit to the Disability Specialist Unit at Summer Hill in
July 1997 was noted in their files, as was the information I gave them regarding the
present situation of the family. When I spoke to the medical officer at the Unit about my
family and the research I was doing she told me that an “Adelaide enzyme” might yield
the final answer to my family history of intellectual disability. Pathologists in Adelaide
are researching the effect of missing enzymes on congenital metabolic disorders and she
believed that this fitted the particular peculiarities of my family’s medical history.\(^4\) In
fact, this was where the most recent research on my family was being done.

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

From Theology to Scientific Medicine

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

\(^4\) Developments in biochemistry and genetics have ascertained that amino acids
are the building blocks of life, being as they are the main constituent of proteins
and enzymes. Enzymes are a group of complex proteins (themselves made up
of chains of amino acids) which act as catalysts in biochemical reactions (Collins
English Dictionary).
the 4th century B.C.\textsuperscript{5} Hippocrates, however, did not distinguish between insanity and idiocy, and neither did Galen, whose writings on mania and melancholy influenced medical thought throughout the Roman world for over 1500 years (Judge 1987: 7; cf. Porter 1997).

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

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

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incorporated the former theological rendering, or were directly engaged with ridding the person of their spiritual malady.\(^6\)

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

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

\(^7\) The methods of treatment and interpretation based on the notion that disease is part of the body has a history that of course dates back to early Greek and Roman theories of bile, blood, humours and the passions, as well as to their practices of immersion, surgery, purification, exorcism, and medication (Judge 1987: 9-10). However, as Roy Porter has pointed out, the Aristotelian-Galenic concept of disease was related to the notion of essences or substances which were themselves based on alchemical principles rather than on the laws and principles of matter. In the former rendering the body was believed to be affected by vital forces whereas in the latter it is assumed to function as a machine (Porter 1997: 203-215). Michel Foucault has argued that the shift that occurred in seventeenth century medicine was significant and radical because it resulted in the internalising of illness. Consequently, madness, as a specific type of illness, was no longer thought to be due to an external cause, or a social malady, but was believed to be caused by, and became an intrinsic part of, one's own body (Foucault 1995 [1961]; cf. Porter 1997: 242).
and the body, and, as Drew Leder argues in his essay on Descartes’ concept of
the body, this focus reduced the experience and interpretation of illness to a
functional and mechanical problem (Leder 1992: 3). It became fashionable to
break down the body into its constituent parts in order to better understand
the processes by which it operates and hopefully elucidate the laws of nature
that govern these processes. It was believed that this would make it possible to
treat disease through the manipulation, alteration, and later even the
reproduction, of these specific components (Leder 1992: 20-1).

The transformation in the scientific, philosophical and medical
interpretations of the universe not only altered the perception of the body and
illness; it also profoundly affected the way in which human beings were
conceptualised. F. Allan Hanson (1993) highlights the outcomes of this change
that:

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

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8 The essays in The Body in Medical Thought and Practice, edited by Drew Leder,
critique this Cartesian medical paradigm from both phenomenological and
sociopolitical perspectives, arguing that it does not take into consideration the
lived experience of illness, nor the political and social aspects of the power of
medicine to define and discipline the body (Leder 1992: 1-6). Leder, however,
does not ultimately challenge the "metaphysical paradigm" that informs
Cartesian medical perceptions of the body. Instead, Leder proposes the
relativisation of differing perspectives so that the framework is widened to
include phenomenological understandings of illness alongside the knowledge
of Cartesian medicine.
nature. All this began to change in the sixteenth and seventeenth centuries when, with the growth of a scientific world view, human beings lost their patina of divinity and were placed squarely within the realm of nature (Hanson 1993: 14-15).

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

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

This powerful combination of discourses of identity, morality and normality has had a profound effect on those who deviated from the norm, as Jenkins
It created an abnormal, incompetent identity; an identity which was indelibly imprinted on the body. As Davis elaborates:

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

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

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9 Although usually associated with the practices of Nazi Germany, eugenics was a highly respected and seemingly progressive scientific and social theory in the mid to late nineteenth century throughout much of the Western world, including Australia (Ashton 1995: 144-149; Davis 1995: 30-1). The movement is most readily associated with Francis Galton, who built upon Charles Darwin's theory of the evolutionary advantage of the fittest to argue that society, and indeed the human race, was ultimately perfectible and, with assistance, could undergo a process of progressive improvement.
Not only were humans incorporated into a materialist paradigm that therefore rendered their bodies as part of the laws and processes of nature, but some of the differences that distinguished people from one another, such as differences in intellectual capability, came to be considered as expressions of an inherently abnormal and unnatural body/mind/self.\(^{10}\) The result of such theorising is that people with an intellectual disability have come to be perceived as somehow less than fully human (Jenkins 1998b: 19; cf. Bogdan & Taylor 1998: 246; Branson & Miller 1989: 159; S. Taylor 1998b: 195-196). Their identity has been discredited (Goffman 1974 [1963]: 5). As Jenkins puts it:

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

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

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\(^{10}\) In the following chapters I explore in more detail the consequences of this theory of an abnormal mind/self on the institutional and clinical perception and treatment of intellectually disabled people. For the purposes of this chapter I focus more exclusively on the pathologisation of the body as abnormal.
capacity for human sociality. Competencies such as language are believed to represent this capacity, and are used to reinforce the symbolic scheme of reason and normality that has ordered and defined the institutional world of intellectual disability.

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

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

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

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

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

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

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

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

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12 In their discussion of the everyday lives of institutionalised profoundly mentally retarded people, Craig MacAndrew and Robert Edgerton also argue that such people provide interesting material for the study of "both the nature of man and the nature of culture-bearing animals" due to their being "on the threshold between man and not-man" (MacAndrew & Edgerton 1970: 28).
scientific empiricism (Binet & Simon 1976 [1905]: 335). They claimed that the French physician Jean-Etienne Dominique Esquirol (who was a student of Philippe Pinel's) first clearly distinguished idiocy as a specific medical condition, and that he based his classification on the centrality and power of speech which is often lacking in such people (Binet & Simon 1976 [1905]: 336). On noting the difference between idiocy and insanity, Esquirol wrote in 1832 that:

Idiocy is not a malady, it is a state in which the faculties are never manifested, or have never developed sufficiently for the idiot to acquire the knowledge which other individuals of his age receive when placed in the same environment. Idiocy begins either with life, or during the period which precedes the complete development of the affective and intellectual faculties; idiots are what they must remain during the entire course of their lives. Everything in the idiot reveals an organism either arrested or of imperfect development . . . Insanity and idiocy differ essentially, or else the principles of all classification are illusions. Insanity, like mania or mono-mania does not commence before puberty . . . Insanity may be cured; one can conceive the possibility of suspending the symptoms; there is a diminution, or privation of the forces necessary to exercise the faculties, but the faculties still exist . . . The insane man is deprived of possessions which he formerly enjoyed; he is a rich man become poor; the idiot has always been in misery and want. The state of the insane may vary, that of the idiot remains always the same. The one conserves much of the appearance of the complete man, the other retains many traits of infancy. In one case as in the other, there are no sensations or practically none; but the insane man shows in his organisation and also in his intelligence something of his past perfection; the
idiot is such as he has always been, he is all that he can ever be relative to his primitive organisation (Esquirol; cited in Binet and Simon 1976 [1905]: 336-7).

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

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

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

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13 Foucault (1995 [1961]: 264-265) critiques historical interpretations of the perception and treatment of madness as a teleological progression towards greater humanitarian practices. Rather than liberating the mad, Foucault argues that the interpretation and treatment of madness since the seventeenth century has actually led to greater constraint and surveillance (Foucault 1995 [1961]: 241-278). The cause and treatment of madness ultimately came to reside within the self, such that treatment required greater self-surveillance, moral control, and an acceptance of self-responsibility.
mental asylums at Biçêtre and Salpêtrière in Paris, Pinel was in a position to apply his practical methods of treatment and, through detailed observations and records of the inmates, set about the task of creating a nosology of insanity and idiocy. He was also aghast at the chaotic intermingling of idiots and the insane, and went about separating them physically as well as categorically.14

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

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

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

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

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

Séguiin maintained Itard's "sensationalist" methodology but further elaborated and refined his methods and applied them to the training of idiots. Séguiin believed that it was the method that was at fault, not the person. While accepting Pinel and Itard's prognosis that idiocy was an essentially incurable malady, Séguiin challenged their assessment that such people were also inherently untrainable (Rose 1985: 37). He accepted the condition as an abnormality, but not as fixed. Consequently, Séguiin became the first to acknowledge that idiots could learn and develop, as long as they had the correct and appropriate training.
Drawing on Locke's theory of a connecting or intermediary link between the senses and ideas, Séguin believed that there existed within all people "an intelligent reflecting power that, seizing the notions of external objects as furnished by the senses, reasons upon them and produces ideas" (Barr 1904: 34). Séguin believed that the senses were the doorway to the mind. Therefore the anomaly which creates the condition known as idiocy had to occur in the functioning of the senses. Rather than relentlessly repeating sensory stimulation, as Itard had done, Séguin deduced that the permanent impression of these stimuli required the comparison, selection and increasing complexity of tasks (Talbot 1967: 186). The senses must be stimulated one by one, and in conjunction with the other senses and parts of the body, so that "correct objective impressions" might eventually reach the mind (Séguin 1976b [1879]: 163-6). And, as with other philosophical and medical interpretations of the Enlightenment, this process was deemed to be a natural extension of the laws of Nature (Séguin 1976c [1880]: 174; Rose 1985: 29-30). Therefore, not only were idiots unnatural and abnormal, but the laws of nature provided the guide that would help transform this abnormality into something more normal.

Séguin termed his attempts to alter the mind of the idiot through sensory stimulation the "psycho-physiological method" (Séguin 1976b [1879]; Séguin 1976c [1880]). This method marked the first medical/psychological/educational intervention into the lives of idiots; the overriding aim being to socialise and civilise them, to make them "normal". Séguin's methodology was inherently based on treatment and training, and relied upon assimilation and conformity to a norm. As such, it was founded on the principle of producing sets of dispositional behaviour which would correlate with socially recognisable and acceptable systems of communication and meaning. Even at its original moment, therefore, the treatment of idiocy was based on the transformation of "incorrect" and "abnormal" sensory impressions and behaviours into "correct"
and "normal" ones. It took as already problematic and dubious the nature of an intellectually disabled person’s humanity, and sought to transform this abnormal nature by making it conform to pre-established notions of what normal human nature should be. It assumed that human nature is a pre-cultural fact, and not the product of the symbolic scheme of reason and normality that identifies a particular range of meaning systems with "being human". This is not to deny that there are very real and tangible "material constraints" that make intellectually disabled people different, but that, as Sahlins has put it, as a culture we have conformed to these constraints "according to a definite symbolic scheme which is not the only one possible" (Sahlins 1976: viii). Competencies which are perceived as cultural deficits are used as proof of a deficient human nature (Jenkins 1998b: 19).

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

15 The interpretation, perception and treatment of intellectually disabled people has many parallels with the history of racism, especially in relation to the experience of indigenous peoples. Indigenous people were originally thought to be the evolutionary remnants of our early human ancestors and as such on the inevitable path to extinction. When they defied this prognosis indigenous people were then encouraged, often forcibly, to assimilate to the dominant culture. Nowadays, despite the rhetoric of indigenous rights and self-determination, the onus for mediation, negotiation and change is always on indigenous people. Aside from issues of domination and power, the problems encountered in post/colonial encounters with indigenous cultures have been exacerbated by the enforced interaction of cultures that are based on entirely different symbolic schemes. In the case of the engagement of indigenous cultures with post/industrialised societies, this difference is embedded in both
dispositions that conform to recognisable and normative values. As a mode of engagement such practices and attitudes have nothing to do with mediating differences. They lack the mutuality and necessity for negotiation that underpins sociality and intimate relations, and ignore the fact that intellectually disabled people can engage in relations of interdependence; that they can engage with others as they are as part of a joint commitment (Carrithers 1992: 11).

The Causes of Idiocy

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

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

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

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

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

18 In fact, the first anthropological excursions into the world of intellectual disability supported and provided evidence for these phrenological interpretations. Physical anthropologists with an interest in the evolution and variability of the human species initially sought to measure the anthropomorphic range of human variability. This eventually led to a concern with what is "normal" in human nature rather than with variations, and this "norm" was then used as the marker from which differences were measured and interpreted (Gleason 1989: 89-90; Hanson 1993).
While phrenological practices played a prominent role in early scientific interpretations of mental disorders, and stimulated further research into the anatomy and function of the brain and nervous system, they are now considered rather clumsy proto-scientific attempts at describing these conditions (Judge 1987: 8). Yet the present inclination to account for these disorders in genetic, organic or biochemical terms can just as readily be interpreted as a more refined method of correlating physical attributes with a comparably deficient social being. Whereas the methodology has changed, the theoretical assumptions have not. There is still a pathologising of intellectual disability that renders people as fundamentally abnormal in both the body and in the gamut of social dispositions. Despite changes in the methods used to assess and diagnose intellectual disability, the practice of noting physical characteristics, including measurements and descriptions of the cranium, remained common practice throughout the 1960s and 1970s. This is evidenced in the reports on my siblings.

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Medical assessments of Maryla, Stephen and Ursula always began with an appraisal of their physical appearance, mobility and behaviour. On the whole they were considered to be attractive looking children, although their “unusual gait” was constantly referred to as an indication of their retardation. More specifically, however, physicians in England and Australia used phrenological evidence as part of their assessments, one of them commenting that my sister’s “head circumference was 19.5” [inches] and . . . that she had a rather odd shaped head, having a broad forehead, widely set eyes and a flat occiput” (10/2/65). Maryla is in fact very Polish looking, inheriting this appearance from my father’s side of the family. My other sister, Ursula, was thought “not to resemble either parent” and it was noted that she had a “prominent forehead, nose and right eyebrow” (25/5/67). An examination of Stephen at the same time noted that he “had a normal shaped head—51 cm. [in] diameter. His palate was
high arched and his ears, nose and eyes were normal. Dermatoglyphic pattern was normal on the hands. He had 4 areas of depigmentation over the posterior aspect of his torso—just above the sacro-iliac crest. There was syndactyly of [the] 2nd and 3rd toes of both feet and he walked with an unsteady gait stooped forward. Tendon reflexes were grossly exaggerated” (25/5/67).

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

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

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19 The use of post-mortem examinations to determine a connection between the body’s organs and the person’s disability is common practice, as Grace Woods has pointed out (Woods 1983: 48).
they have limited but specific social competencies, the focus is on a deficient being who not only becomes pathologically embodied as abnormal, but must be trained and normalised in order to become part of social life.

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

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

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

22 The terms used to describe these differences of degree in idiocy vary between different people. Jules Voison's symptomatic description of idiocy was divided into complete idiocy, incomplete idiocy, imbecility and mental debility, whilst Bourneville classified the state of idiocy into complete idiocy, profound idiocy, imbecility proper, slight imbecility or intellectual retardation, mental instability, and moral imbecility (Binet & Simon 1976 [1905]: 338-341). The term feeble-minded was in fact an American term that was adopted by the English in the 1860s to designate those who were the least mentally afflicted and the most capable of reasoning (Digby 1996: 2). There were, and still are, ongoing debates over whether there is a difference of degree between these gradations, or whether they are indicative of absolute differences in type, especially when it comes to those "borderline" cases of mild mental retardation or feeble-mindedness (Simonoff et al. 1996: 260). A whole class of people were also labelled "moral imbeciles", and the usual debates over whether this was a congenital, hereditary, or environmental condition prevailed. Alcoholics,
a sensory disorder, "disturbances of brain power . . . [or] simply nerve lesions in the narrowed sense of the term", as Pinel, Esquirol and Séguin had argued. Down claimed that idiocy and imbecility "were profound diseases involving almost every organ and system of organs in the body" (Down, cited in Miller 1996: 363). Down's contribution to the medical research on idiocy was a scientific and clinical distinction thoroughly embedded in the organic matter of the person. Research into Down's syndrome in the 1950s only served to strengthen this original interpretation of a specificity in typology by exposing an extra chromosome as the common feature of all people with Down's syndrome (Porter 1997: 587-8).

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

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

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

In 1846 Edouard Séguin described a condition which he termed "furfuraceous idiocy" and it was this condition that Down later termed "Mongoloid" (Porter 1997: 587). Cretinism was another common term for describing intellectually disabled people (Judge 1987: 39). It had been used by Felix Platter in the late sixteenth century to describe a specific condition identified by a short stature and protruding tongue, features which made it easy to confuse it with what was later called Down's syndrome (Judge 1987: 39; Porter 1997: 196-7). Cretinism is actually a specific type of intellectual disability now known as hypothyroidism and was common in Switzerland in the nineteenth century due to low levels of iodine in the water supply (Judge 1987: 39; Porter 1997: 196-7). Along with Down's syndrome it was one of the first types of intellectual disability to be extensively researched as a disease (Judge 1987: 39).
broad nose, protruding tongue and round face that were common to these people, Down identified them as belonging to a particular class of idiots. However, more than just being a descriptive term, it also incorporated Down's initial theoretical conviction that such people represented an atavistic regression to a "lower race". Through a similarity in facial features, and particularly the epicanthic fold, Down associated these "Mongoloids" with people from Mongolia. There were also other forms of idiocy that represented throwbacks to other "races", including Ethiopian or Negroid, and Malay or American Indian (Borthwick 1996: 404-406; Judge 1987: 42-43; Kanner 1967: 167; Miller 1996: 367). Down later rejected these racial associations, arguing instead that aetiology was the most suitable means for classifying, treating and diagnosing types of idiocy. He based this classification on organic and pathological distinctions between congenital, developmental and accidental causes of idiocy, associating these with epilepsy or microcephaly, onset in puberty, and injury or illness respectively (Kanner 1967: 167-8). Down classified "Mongolian idiocy" as a congenital disorder and associated it with tuberculosis in the parents (Miller 1996: 368).

However, despite Down’s rejection, the connection between idiocy, race and degeneracy had been made. As Anne Digby points out, the "diagnostic significance of physical aspects of mental defect [were] revealingly termed the 'stigmata of degeneration'" (Digby 1996: 8). Degenerationist arguments were based on both moral and evolutionary principles, incorporating references to lifestyle and behaviour as much as to the supposed potential of the human race to regress to an earlier human type. The atavistic argument was based on the "theory of recapitulation", a theory which postulated that the "higher human races had passed through and developed beyond the stages now represented by the existing civilisations of the lower races" (Borthwick 1996: 405). In such a theory, idiots were perceived as a throwback or reversion to our human
ancestors; ancestors who were contemporaneously represented by other "races" such as Mongolian, Malay and Ethiopian. These "racial" groups were inherently assumed to be at an earlier evolutionary developmental stage to Caucasians; socially, morally, intellectually and physically (Borthwick 1996; Miller 1996: 368).

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

These consciously manufactured tales of lost beginnings and tragic ends are doubly fascinating in that scientists came from around the world to observe these "ethnological curiosities". They then used spurious information generated by the freak shows to classify people within the greater scheme of human variation and evolution. Bogdan notes that John Langdon Down had as one of his categories of idiocy the "Aztec type", and that both Shuttleworth and Ireland referred to these "Aztecs" in their own diagnoses and classifications (Bogdan 1986: 125). What is most interesting with regards to the increasing medicalisation of intellectual disability, however, is the fact that after the turn of
the twentieth century these "freaks" were often accompanied by a nurse rather than an attendant when performing in the shows (Bogdan 1986: 124). They were now not only ethnological curiosities, and representative of the missing link between humans and animals, they were also medical abnormalities.  

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

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

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25 In his book *Freaks: We who are not as others*, Daniel Mannix argues that circuses and freak shows actually provided the people who performed in them with an independent source of income. Due to growing moral outrage over the exploitative nature of the shows, however, they disappeared, and as a consequence the former performers were institutionalised and/or became entirely dependent on public welfare (Mannix 1990).
intellectual disability, interpreting it as an entirely organic disease (Digby 1996: 8). The medical interpretation constituted intellectually disabled people's differences as abnormal and pathological and grounded these within the physical. Medical science did more than just operate as a tool for categorising and classifying aberrations from the norm, it also had a significant and influential effect on those who were subject to its practices (cf. Conrad & Schneider 1985: 17; Zola 1972). As Foucault put it, a person who was "simple minded" came to be "a pure object of medicine and knowledge—an object to be shut away till the end of his life . . . but also one to be made known to the world of learning through a detailed analysis" (Foucault 1984: 31-2). Such people became objects of knowledge rather than subjects in their own right. Their differences were constituted as absolutely different. They were different "not because they were like us, only damaged, but because they were intact and complete specimens of a lesser order of being" (Borthwick 1996: 406). And, as

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

**Heredity, Degeneracy and Morality**

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

27 The combination of heredity and immorality as one of the primary causes of idiocy continued to be accepted as fact well into the late nineteenth and early twentieth centuries, as shown by Richard Dugdale's 1877 study of the "Juke" family, and Henry Goddard's 1912 study of the "Kallikaks" (Dugdale 1976 [1877]; Judge 1987: 49; Miller 1996: 366). Such accounts of the inherited degeneracy of idiocy and feeble-mindedness across a number of generations, and the association of these conditions with asocial, immoral and criminal behaviour, only added fuel to the eugenics scare that swept across North America and Europe in the 1920s (Judge 1987: 49; Wolfensberger 1977: 123). The prevention of this cycle of degeneration was thought to require the most stringent measures, including sterilisation, institutionalisation and the prevention of marriage or sexual relations between intellectually disabled people (Scheerenberger 1986: 61-2; cf. Charlesworth 1989: 82-3; Dugdale 1976...
Despite the controversy and uncertainty surrounding the process of heredity in the nineteenth century, physicians continued accumulating data that suggested hereditary illnesses or diseases were the cause of certain conditions such as idiocy (Porter 1997: 587). William Wentworth Ireland, an American physician with an interest in the diagnosis and classification of idiocy, had strongly encouraged physicians as early as 1882 to note familial traits of epilepsy, idiocy and neurosis, and suggested that idiocy was the defect most likely to be inherited and was not just the result of sinful living (Ireland 1976 [1882]: 250). In 1904, Martin Barr, Chief Physician at the Pennsylvania Training School for Feeble-Minded Children, felt confident proclaiming that heredity was a proven law, and believed that it was one's social duty to preserve the integrity of society through understanding and thus preventing the continued "pernicious" inheritance of idiocy (Barr 1904: 123). There still remains a moral obligation on the part of parents to reduce the number of children who are born with intellectual or other disabilities.

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

[1877]; Radford 1991; Rhodes 1993; Smith & Polloway 1993). These practices were legalised in many states of the United States of America in the 1930s (Judge 1987: 48-9). And, as Sabagh and Edgerton (1962) have documented, in North America in the 1950s it was a requirement that intellectually disabled people be sterilised before being released from mental institutions and returning to the community. While such practices are no longer accepted as legitimate ways of dealing with intellectually disabled people, and despite recent discussions over their rights to a sexual life (Held 1992; Rhodes 1993), intellectually disabled women are still being forcibly sterilised and/or prevented from having a menstrual cycle (Smith 1996, 1997a; Sweet 1997; Trumble 1997). One of the people I worked with, a woman in her late twenties, had a hysterectomy when she was fourteen and was going through early menopause at the time of my fieldwork.
implications for future children”, noting that my mother was a Roman Catholic and therefore probably did not use contraception (12/7/67). Dr R—the female doctor in Perth who became the ‘case manager’ for my family during the time that we lived there—responded to this comment on contraception by the doctors at Grosvenor saying that she had spoken to my mother and stressed the “imperative” need for contraception due to the family circumstances. Dr R was greatly relieved that my mother had already “sought the advice of a broad minded priest” and was taking the “pill”. “Thank goodness” she writes (24/7/67). One of the psychiatrists in Perth also wrote to her colleague prior to our forthcoming move to Sydney in the hope that “people will be able to accept them as they are and not feel too outraged at these good Catholics who have filled the world with such oddities” (30/10/67).

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

In the hope of discerning this biological cause the medical professionals sought to discover whether there were any traces of a “familial disease” in earlier generations of my family. A “family and contact” history had been taken at the Alder Hay Children’s Hospital in Liverpool and this was added to by those at Grosvenor. It was noted that,
apart from the problems affecting the immediate family, a maternal great uncle had suffered from convulsions until the age of five, and that one of his daughters was epileptic; that a paternal uncle was mentally ill; that my mother’s cousin had TB and that her paternal grandmother had also had TB.\textsuperscript{28} It was also remarked upon that my own father may have had convulsions in childhood, and was slow to begin speaking—although this was considered unreliable evidence—and that my paternal great uncle was epileptic and possibly schizophrenic. My parents, however, were considered to be “healthy” (9/5/66). A slightly later family medical history suggests that there may have been “a background of epilepsy or degenerative brain disease, or even schizophrenia” on my father’s side of the family and that my mother has “two cousins who had epilepsy” (19/5/67).\textsuperscript{29}

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

\textsuperscript{28} It is interesting to note that tuberculosis was one of the diseases that John Langdon Down singled out as a particular cause of idiocy.

\textsuperscript{29} On discussing these matters with my mother I discovered that some of the details of this information were incorrect, although there were incidences of epilepsy, retardation, mental illness and tuberculosis in the family.
epilepsy seems to be a constant thread in the family history. There is no consanguinity” (17/6/88).

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

The Road to Genetics

The earliest mention of genetics as the possible source of my family’s particular circumstances was in 1966, when the senior physician at Walkersgate Hospital in Newcastle Upon Tyne wrote to Dr R in Perth saying that “It certainly sounds a very
queer family history and perhaps this is of genetic background” (16/5/66). Urine tests had been performed to determine the “normality” of amino acids ever since we lived in Liverpool but at that time genetic testing was still in its infancy. Although much was made of the inherited nature of the “disease” it was not until the mid 1970s that the first specific genetic tests were done on all of us children. I could find no records of these tests, however, and only have vague memories of the strange and clinical nature of the examination. I remember that it was inexplicably disconcerting to be having my genes tested for some familial disorder, and that my parents were equally anxious and distressed at the possible implications of these tests. The progress report from Grosvenor in 1975 did, however, comment on the “recessive inheritance” of this “unknown metabolic disorder”. This diagnosis was repeated verbatim in 1986 for Maryla in a psychological report at Stockton, and the most recent tests that she has had are all genetically related enzyme tests.

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

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The metamorphosis from sin to genetics as a primary cause of intellectual disability places the breach of morality and normality both beyond and within the self. The soul, no longer a consideration of medical science, has now
become the genetic code of the person, and it is this that is blamed when a person transgresses the boundaries of "normality". Despite the conviction for over a century that inherited causes could and would be discovered for specific diseases and disabilities, no studies had been able to prove that this was actually the case. Interestingly, the final proof for the hereditary nature of certain diseases and disorders came through genetic research into Down's syndrome (Porter 1997: 587).

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

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30 E. J. Yoxen has pointed out that the early "Mendelian geneticists" faced considerable criticism from their professional peers in the early twentieth century because their theories were not acceptable to contemporary notions of evolution and variation. Because of this, the field of genetics developed mostly within disciplines focusing on plant and animal breeding, disciplines devoted to the study of the general principles of heredity rather than with problems of variation. It was not until the 1930s that the relevance of earlier studies of potentially inherited abnormalities began to influence the biomedical fields in terms of aetiological reasoning (Yoxen 1982: 146-7).
the 'true' nature of the deviant behaviour, one could prevent or, more likely, control it closer to its source” (Conrad & Schneider 1985: 25).31

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

31 For Conrad and Schneider, deviance is a socially meaningful construct representing "human judgements of conditions that exist in the natural world" (Conrad & Schneider 1985: 31). Through their social constructionist and symbolic interactionist approach, Conrad and Schneider sought to understand the "meanings we attribute to different behaviour" (Conrad & Schneider 1985: 20). Following Howard Becker's 1960s theory of labelling, Conrad and Schneider considered the stigma attached to such designations as deviant, especially the effect it can have on a person's behaviour and identity, and how others perceive and treat such a person (Conrad & Schneider 1985: 20). However, due to their commitment to sociological interpretations of the nature of labelling, the authors never considered the actual lived realities of the people in question—the alcoholics, the mad, or the pro-abortionists. Just as clinical specialists remain beyond the boundary of abnormality that they themselves perpetuate and reinforce, Conrad and Schneider also do not enter the lives of the people they write about as subjects engaged in a continual process of interaction with these medically ascribed labels, identities and attributes. They criticise the designations that medicine creates, but remain just as much outsiders when it comes to really engaging with difference.
... developments in medical technology will reveal that those whose condition is presently due to unknown causes, especially those with mild intellectual impairments, will eventually be found to have biomedical causes for their cognitive and adaptive impairments (Bregman & Hodapp 1991: 707).

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

It is not so much that genetic interpretations of intellectual disability are a false assessment. It is rather the implication that as an abnormality it must be erased. The Human Genome Project is the latest development in this field. As Tom Wilkie comments, its primary aim after mapping and analysing each of the 3 billion "letters" within the DNA sequence will be to treat the "mistakes", "disorders" or "errors" of nature that produce diseases, defects and disabilities.
It appears that Descartes’ machine-body is being manipulated and "corrected" at ever more particular levels. The interpretations might have narrowed to specific diseases, germs, genes and enzymes, as Luchins remarks (1989: 593), but the perception of abnormality as an integral part of an intellectually disabled person's identity has been sustained, and the stress on prevention is still integral to this judgement.

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

Nowadays, with advances in prenatal genetic testing, parents who are potential carriers of any "disorder", or women who are at "risk" of having a disabled child, are encouraged to seek genetic counselling. Amniocenteses, ultrasounds, urine tests and even the traditional family tree are used to predict the genetic traits that might be passed on to one's child, and specially trained genetic counsellors interpret these tests and inform clients of any such potential
In relation to reproduction, parents are encouraged not to continue with a pregnancy if there is evidence that the foetus is in any "serious" way abnormal. This includes such conditions as Fragile-X and Down’s syndrome. Despite not knowing what the cause was, my parents were also strongly encouraged not to continue having children. Consequently, the moral weight of guilt, shame and blame still resides with the parents, who are made to take responsibility for the "choice" of reproducing an intellectually disabled child. As E. J. Yoxen comments:

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

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

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32 Yoxen has also argued that genetics as a discipline developed within the restraining power of other biomedical interpretations of disease and abnormality such that "the phenomena with which genetics works are intellectual constructs" (Yoxen 1982: 145; cf. Charlesworth 1989: 90; Rapp 1988). This interpretation, while acknowledging that "many of the phenomena of genetic disease are grounded in material reality" (Yoxen 1982: 144), propounds the theoretical position that all phenomena are cultural or social constructions. As such, any perception of disability involves the projection of cultural and social meanings onto the material or person under observation. While Yoxen challenges the overtly deterministic interpretations of a biomedical approach, his idealist approach does not take into consideration the way in which such observations and perceptions become part of a persons lived reality. For him the process remains one way, whereas in fact it is the interrelationship of an individual’s biomedical make-up with their being and experience in the world that creates a person’s lived reality.
raises concerning human life. But as Ruth Chadwick (1992: 119) points out, despite the problematic use of such terms as defect or handicap in the field of genetics, the moral role of geneticists is still fundamentally to replace “faulty parts” and repair any genetic defect.

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

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

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

Chapter Three: A Pathological Embodiment

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

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

My parents were considered “difficult” because they challenged the interpretations of the medical profession and would read up on the medical literature when given any possible diagnosis. The doctors at Grosvenor “gained the impression that though a definite label would be a help to them in some ways (and what they tried very hard to provoke us into giving) it would also add fuel to their well-established mechanisms of denial of their children’s condition . . . Our impression was that part of the reason for their ‘shopping around’ . . . for opinions and advice (which seems to have been very ably given in the past) springs from their understandable difficulties in facing the tragic facts of their children’s handicaps, apart from the realities of lack of appropriate educational facilities” (12/7/67).
The stigma attached to such a diagnosis was barely considered. The implicit blame attributed to my parents for having more children despite their family histories—with incidences of intellectual disability and epilepsy on my mother’s side and mental illness on my father’s—the possible congenital recessive disorder that they had supposedly passed onto their children, and the status of retardation as an abnormality that must be eliminated, managed, treated and institutionalised, all contributed to their anxiety and unwillingness to accept this definitive diagnosis. What did such a diagnosis say about who they were, let alone what their children were? The diagnosis was a final cut, a separation that put their children on one side of a divide, with themselves somehow straddling the gulf that separated their children as intellectually disabled from others in the community. It categorised their children as unfit for human social life, and assumed that they had no capacity for culture and sociality. My parents had given birth to a difference that was considered an aberration of normality, manifesting as a deficiency in social and intellectual capabilities, and the doctors wondered why my parents were so “difficult”! Such attributes are considered the most advanced and definitive human capabilities in our society and their children had been given close to zero on their score cards.

My own distress at reading the medical records resonated with my parents’ responses. It is not so much that I too am implicated in this possible familial disorder, but that I, like all of my family, knew Maryla, Stephen and Ursula as human beings; as cultural beings; as integral and participating members within the sociality and mutuality that constituted our family life. Like the rest of us, my intellectually disabled siblings, albeit within their own limitations, existed within and helped to create the symbolic systems that operated as the medium through which we not only made sense of our shared environment but through which we communicated and related to one another. Despite limitations to this mutual engagement, and their tendency to revolve around very particular social idioms, symbolic practices and dispositions such as the jigsaw pieces and bits and pieces, our interactions with one another through such
objects were a way of meaningfully and purposefully engaging within our shared social world. We did not separate, isolate or strip my siblings bare of vestiges of human sociality. We did not perceive them as the medical anomalies they were constituted as being. And yet, the medical interpretation has had a profound effect on my siblings’ experiences, increasing in intensity the more they moved outside the intimate and essentially closed world of the family and into the public social world of medicine, education, and, ultimately, the institution where two of them went to live. The practices and attitudes that my siblings have been subject to are similar to the treatment given to residents of Xanadu and the group homes. Their everyday regime embodied forms of institutional practice shaped by the legacy of medical science. This legacy includes the symbolic scheme of reason and normality that still informs the field of intellectual disability.