

INTELLECTUAL DISABILITY and SOCIETY

Barbara Field

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Abstract

The aim of this thesis is to outline the story of intellectual disability from a medical perspective as experienced by the author during more than 40 years working in the NSW Health system. Most of the writing over the last 30 years is from a sociological perspective after the idea of normalization changed the philosophy of care, and medical perspectives have been largely absent. The first chapter provides an introduction and historical background to the concept of intellectual disability. The story over the centuries is one of parallels and conflicts in the medical and sociological discourses. The second chapter examines the representation of intellectual disability both in the symbolic sense in art, literature and film, and the political sense as advocacy and human rights and the effect of the social rights discourse on processes of inclusion and exclusion. The third chapter is an account of the history of intellectual disability in NSW, Australia since colonization, and the impact of the social rights movement on changes of policy and provision of services. The conclusion looks at the future and the structure of the Ideal Society. The thread, which runs throughout these aspects of intellectual disability and unites the themes, is that of changing discourses. New discourses emerge as others are silenced and the same discourse can also have different meanings at different times in history. The ideas were presented as papers at international meetings of the International Association for the Scientific Study of Intellectual Disability (IASSID):

Foucault's Power Knowledge Model applied to Genetic Screening. (Helsinki 1996);

Intellectual Disability in Literature and Film. (Seattle 2000);

Prejudice and Identity in Intellectual Disability. (Montpellier 2004);

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CHAPTER 1.

INTELLECTUAL DISABILITY in WORLD HISTORY

Disability is a paradox

Summary:

This chapter reviews the recorded history of intellectual disability and the changing attitudes in the eras of innocence, classical thought, enlightenment and progress.

Discussion centres on the interactions and conflict between the medical and social models, and examines, in particular, the work of Michel Foucault and Roy Porter who wrote on the history of madness. Finally, the discourses of intellectual disability are outlined.

1.1. INTRODUCTION

Events in history are recorded traditionally in a time-line and eras or ages are constructed to reflect attitudes of the time. Intellectual disability has existed since the earliest records. Initially, events such as drought, flood, disease and poverty, and later, war and economic fluctuations would have been significant factors in the provision of care. Scientific, medical and technological advances and economic rationalism balanced by Human Rights Legislation and the Rights of Disabled Persons have become major issues in the modern world. The social rights movement sought to shift the perception of the intellectually disabled from the object of the medical discourse to subjects of the political discourse in relation to issues surrounding care and acceptance of the disabled.

The story is complex. An early history of intellectual disability¹ describes evolving attitudes and services for the intellectually disabled from the pre-Scientific to the

Scientific Era, implying that there was a positive move towards acceptance by the community. The study ends in the 1970s with the concept of “normalization”, which is certainly the high point in the concept of the integration of the intellectually disabled into the community. The application of the principles of normalization continued through the succeeding decades in promoting acceptance in the community; however, advances in technology, which began around this time, gave rise to the idea that certain disabling conditions could be detected and avoided by genetic diagnosis. The conflict between the bio-medical model and the psychosocial model of care began in earnest. Practices that describe inclusion or exclusion of the intellectually disabled are evident from earliest cultures. Eras of abandonment, confinement and exclusion prevail, followed by a gradual change, with reform in education then a return to segregation, sterilization and even genocide in the early-twentieth century in the context of the Holocaust. Social and legal reforms in the mid-twentieth century led to deinstitutionalization and community living, and genetic screening became recognized in pregnancy with the option of termination of a child likely to have a disability.

1.2 THE STORY OVER TIME

The following is a chronology, part of which is necessarily speculative, of the events in history that relate to the intellectually disabled and their place in society.

Prehistoric Tribes

Evidence of the existence of disability and illness in prehistoric times comes from archeological and medical records documenting skeletal abnormalities or growth disorders characteristic of certain syndromes. Excavation of burial sites has shown that a number of tribes maintained and protected individuals with dwarfism, hydrocephalus and

anencephaly. Studies combining archeology, anthropology and ethnography provide clues about social attitudes. While it may be possible, however, to make some assumptions about social exclusion or inclusion from the content and location of burial sites, further conclusions are uncertain. It is not possible to determine whether people in the past felt compassion for the disabled or indeed whether this concept was irrelevant, as the disability may have been considered simply as part of the individual or the result of an external force. Hubert² writes, “Burial in the family vault may be the result of relief, guilt, the desire to make amends, to restore wholeness to the family and the wish to remember or forget.” Any society, including the earliest tribes, contains people who are less capable or disabled. The practice of infanticide appears to have been accepted as early as hominid man two million years ago; presumably as a means of ensuring survival of others.³ We do not know when ideas such as moral responsibility to the race rather than the individual, or religious ideas of the sanctity of life arose; nevertheless, the issues of fitness to survive and meet the demands of society are the forerunners of the debate about prenatal screening for disease and selective termination in the modern world.⁴

The pre-Scientific era has been termed an era of innocence, uncomplicated by the ethical issues of the modern world, with physical survival the essential goal. Prehistoric man endured hardship, lack of food and physical trauma in addition to the disorders that modern man suffers — tumours, infections and disorders of foetal growth. It is presumed that seriously deformed infants did not survive long and those who did would have great difficulty with a nomadic lifestyle. The life span of individuals with severe disabilities, such as spastic quadriplegia and congenital heart disease, would be short, as they would succumb to infection, pneumonia, or prolonged seizures. It is difficult to speculate on the

life expectancy of those with lesser forms of disability such as microcephaly, hemiplegia or Down syndrome. There are discrepancies between the reports of widespread infanticide and the archeological evidence of care, love and acceptance of disabled individuals in pre-Christian society.⁵ Some maintain that the hunter/gatherer society had the resources and motivation to care for disabled members, and intellectually disabled individuals may have been successful peasants, fishermen, hunters or tribal dancers.⁶

Basic survival skills such as hunting, cultivating crops and finding water are group activities acquired by imitation of the elders of the tribe. Intellectual activities so valued in modern society may not have been essential to daily life. Perhaps early humans simply protected and cared for all the members of the group without discrimination. It is likely, however, that infanticide and abandonment of older and physically weaker members of the community did occur and this indicates an early tension between inclusion and exclusion. These observations are significant with respect to the modern world. Routine tasks were essential to existence and wellbeing in the past and suited the abilities of the intellectually disabled; but with increasing mechanization and technology these tasks have disappeared.

Near Eastern Cultures

Treatment of illness relied on herbs and spells in Mesopotamia and Egypt. The earliest known reference to intellectual disability and epilepsy is in a papyrus of ancient recipes from Thebes³ in 1552 BCE. The beginning of moral responsibility is seen in the codes and laws and the types of legislation enacted to protect the vulnerable. It is not clear how enforceable such laws were or if there was any punishment linked to discrimination, if infanticide or euthanasia were enforced or if people were punished or convicted of

murder of a disabled or senile person. There are political statements made by leaders of the time but they may not represent the majority opinion. Economic necessity and the welfare of the nation may have been the guiding principles. Codes such as that of Hammurabi⁶ from around 2500 BCE do not specifically refer to intellectual disability. This culture cared for children and records of “monstrology” have been found in clay tablets dating back to 2800 BCE and foetomancy (prophecy by means of foetuses) and teratology (divination based on the examination of abnormal births) was practiced. Priests dominated society, and belief in benevolent gods such as Osiris may have afforded protection for the disabled. This casts doubt on the practice of infanticide and human sacrifice. The culture and the need for menial workers in time of war and in building projects probably provided tasks for the mildly impaired of the lower classes, while wealthy families cared for their own. The Pentateuch collated in Palestine between 400 and 500 BCE laid down foundations for human existence in the Ten Commandments — the basis for Judaism, Christianity and Islam.

Greek and Roman Cultures

The time of Greek culture has been called the Classical Age — a culture of perfection of intelligence, physical strength and beauty. Platonic ideals were the basis for thought, and symmetry of the human body was regarded as the ultimate in beauty. Man was seen as rational and capable of reflective thought, responsibility and guilt. Although children were valued, infanticide was practised as a form of population control. Attitudes to the disabled were negative. Plato⁷ held that the mentally retarded and weak had little place in society. Aristotle wrote, “Let there be a law that no deformed child be reared”.⁸ Illness and health were naturalistic and reflected an imbalance or balance of the humours.

Hippocrates recognized that epilepsy was a disease of the brain and not divine, but he saw no prospect of treatment of the weak-minded.⁶ The Roman Empire saw fluctuations in inclusion and exclusion of the disabled in response to changes in government and economic factors. Augustus, and Livia his wife, were compassionate, and many children were in the care of the State or charitable organizations; abandoned newborn babies were fostered. The wealthy could care for family members but many disabled persons existed among the masses of poor and illiterate, or as slaves, or used as a source of amusement. Exposure or drowning of defective infants occurred, and by the first century BCE under Emperor Celsus, castration, or life in chains in dark cellars, was the lot of the mad, mentally retarded and epileptic. When Christianity began to exercise its influence, edicts were issued against infanticide and the mutilation and selling of children into slavery. Justinian indicated that guardians could be appointed to care for them. Healing was still based on herbs, magic and prayer. Medicine advanced with Galen (born 131 BCE) who laid the foundations for neurology; but he wrote: “Imbecility results from the rarefaction and diminution in quality of the animal spirits and from the coldness and humidity of the brain”.³

The Middle Ages

The Middle Ages has been called “the era of abandonment” in its response to disability.¹⁰ Due to the hardships created by wars, plagues and famine, the resources of the State, Church and charitable organizations in caring for the weak and needy were stretched. Superstition and fear of witchcraft led to persecution of the mad and disabled. The close links between the history of madness and that of the intellectually disabled resulted in overlap between the terms relating to madness. Plater in 1609⁹ referred to *mentis*

consternatis as disturbance of the mind, and to intellectual disability as *mentis imbecilitas*, feebleness of the mind. The words imbecile, moron, half-wit, dunce and feeble-minded were used to refer to cognitive deficiency; and the terms “idiot” and “fool,” which date in literature from the 1300s, indicated a different context. There was also confusion between the terms dementia and idiocy. (This will be discussed in Chapter 2.)

Some disabled were cared for by the family and worked alongside them in the fields as the economy relied on agriculture and there was a need for manual labour. Children were valued, and infanticide was not acceptable but thousands were exposed, abandoned or sold into slavery. This necessitated the establishment of orphanages and foundling homes³ where the intellectually disabled were regarded as “God’s peculiar care”. Poverty, plagues and tyranny of the times forced a wandering lifestyle on disabled adult individuals when the community could no longer offer food and shelter, and so began the spectre of the “wandering weak” and the “village idiot”. The intellectually disabled individual may have been cared for by a devoted mother or secluded and concealed within the family group, chained in a cellar or left to wander half-naked and half-starved along the roads, and teased by the rabble and mocked and pilloried in a time of cruelty. Foucault¹⁰ calls this phase *Stultifera Navis*. Madmen and the intellectually disabled were conveyed from town to town by boat (termed the Ship of Fools or *Narrenschiff*) and cast out of the village in the belief that they would find the reason they had lost. They led a wandering existence in the countryside alone, or perhaps entrusted to the care of a group under the protection of merchants or pilgrims. The Inquisition was a time of persecution of many groups including the intellectually disabled, and the

Reformation did not bring relief from the cruelty. Luther saw the disabled as changelings; to him they were merely a mass of flesh with no soul.³ Many were confined in a tower called “The Idiots Cage”, but some had guardians appointed, or families were given money to care for them. The village idiot could roam the countryside unmolested and partly a public responsibility; and in rural areas they toiled in the fields, were beggars or kept as companions.³

The Age of Reason

This Age has particular significance for the intellectually disabled because of the emphasis on individuality, learning and thought. People tended to become less preoccupied with religion and more with material things. Philosophy was concerned with the relationship between the body and the mind as described by Descartes,³ and medicine focused on anatomy and surgery. Although magic and sorcery still flourished, there was a growing interest in causes. Pare identified 13 causes, and Paracelsus recognized the association with cretinism.³ The Age of Enlightenment saw the beginning of science, but apart from the recognition of an age-related difference in idiocy, there was still little understanding of intellectual disability and the consensus was that it was unamenable to treatment. In England “houses of correction” were established in 1575, and in Europe

The Hopital General was founded in Paris in 1656. The mad and intellectually disabled were imprisoned for more than 150 years there. This era of confinement ended with the social reforms of Pinel and Tuke and the symbolic freeing of the lunatics from chains at the Bicetre in 1793.¹¹

The Age of Progress

The nineteenth century saw major reforms in classification, education and scientific explanations with regard to the intellectually disabled, but these were unfortunately not sustained. This fact was raised in the twentieth century in criticism of proposed social reforms.¹² Major changes to the policy of incarceration of the mad and the intellectually disabled began in response to the rise of science. There was recognition that there were different orders of madness, and the separation of the mad from the poor, the criminal and the sick led to the opening of a number of institutions for the insane, which were the precursors of asylums. Just as madness was seen as factual and a disease, and the mad as objects of science, there were moves to classify intellectual disability and identify degrees of severity with the goal of training for a productive existence. Pinel's early definition in his *Treatise on Insanity* in 1801 was of Ideotism as a "defective perception and recognizance of objects, a partial or total abolition of the intellectual and active faculties." This was replaced in 1846 by Seguin's approach,³ which cited four broad categories of decreasing severity: idiocy, imbecility, backwardness and simpleness. Langdon Down proposed an ethnic classification based on regression to stereotypical racial forms such as Mongoloid and Aztec. This idea reappeared in the twentieth century with the work of Cesare Lombardo and phrenology — the study of skull contour to determine certain personality traits such as criminality. The claim that Negro races were of lower intellect was based on anthropometry and studies of the phenotype of Aboriginal people.¹³ Down abandoned his early method and in 1866 proposed a classification based on aetiology with three major groups: congenital, developmental and accidental. In 1880, with the discovery of the tuberous sclerosis complex by Dauneville and the subsequent discovery

of other syndromes, it became clear that intellectual disability was not a single phenomenon but had multiple causes.¹³ At this time the intellectually disabled were accommodated in asylums run by reformers in education and training and a more positive attitude to intellectual disability prevailed. Schools and educational programming began in Paris. Binet proposed individual testing in 1895, based initially on mental age scores and later on IQ scores on a normal distribution curve, and these are still in use today.³

The Age of Prevention

The twentieth century has been termed the Age of Prevention. The first half of the century was an age of social control and prevention in a punitive sense: compulsory sterilization, segregation and institutionalization of the intellectually disabled culminated in genocide along with other groups in the Holocaust. As a result of these policies, the world became more aware of vulnerable groups and the need to provide protection and legislation to define human rights; but specific reference to the intellectually disabled was not made until later. The World Health Organization (1954) definition of disability was “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. These may be sensory, physical, psychological or intellectual impairment or a combination of any two or more.” The United Nations Convention refined the definition to “Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” The wording introduces a social dimension to intellectual disability. While a number can place an individual on a scale compared with others, the functional/adaptive skills and behaviours are the deficiencies that influence the way an

individual performs in life. As society raises the standards of mental and physical achievement and demands greater intellectual and athletic performance, it is necessary to refine the terms used. Educational reforms and legislation made schooling available to all people by the 1960s; however, many intellectually disabled people remained in government-funded institutions collocated with the mentally ill. The well-off could afford privately run facilities, but many families struggled to care for the intellectually disabled family member at home, with little financial or practical assistance in the form of respite or day programs. The major advance in this area of care came in the 1980s with deinstitutionalization and the closure of large residential facilities.¹⁴ The residents moved to group homes in the social rights movement, which urged normalization and the establishment and financing of day programs.¹⁵

Twentieth-century medicine made many discoveries in the area of aetiology and identification of syndromes associated with intellectual disability. The Human Genome Map was completed with the promise of prevention of disease and longevity. Better antenatal care, eradication of infectious disease in developed countries, and the avoidance of known teratogens decreased the risk of disabling conditions, but no therapeutic measures were found to be consistently effective in curing established intellectual disability. Parallel with the social rights movement in the 1970s was the beginning of prenatal diagnosis and screening for conditions such as spina bifida and Down syndrome, which offered the option of termination of an affected foetus. These programs were described as secondary prevention.

The Age of Risk Avoidance

This aspect of reproductive medicine progressed rapidly, and prenatal testing has become an option presented to women as routine obstetric care in many countries. The genetic basis of more conditions has been clarified and it is now possible to define carrier status and counsel non-conception, to select unaffected fertilized gametes for implantation or to use alternative donor procedures. Techniques to block the effect of adverse genes are proposed, and philosophic arguments are used to justify the duty of parents to have the best possible child as an obligation-termed procreative beneficence.¹⁶ Information and communication are freely available on the internet in the twenty-first century. Science promises health, longevity and the genetic means to minimize the risk of disabling illness, and reprises the Greek ideal of physical perfection. These changes suggest that we are now in an age of risk avoidance and in the contentious area of bio-politics, where economic management influences the interaction between social and political philosophy. This places society in a paradoxical position in relation to government policy.¹⁷

1.3 DISCUSSION

There are a number of characteristics which are unique to the story of intellectual disability, and which have a significant bearing on the views which society maintains concerning the intellectually disabled. The following is an account of some of these factors.

Intellectual disability as the “hidden” and “silent” disability

The study of intellectual disability involves a plethora of disciplines in the sciences and humanities, archaeology, palaeontology and palaeography, anthropology, sociology and comparative and transcultural psychology. Mythology, hermeneutics, aesthetics,

linguistics, metaphysics and philosophy, medicine, psychiatry and genetics all contribute to the story, which changes as discoveries are made, as treatment and technology methods improve and the values of mankind change. All these studies objectify the individual with intellectual disability. We can read archival texts and scientific papers, and analyse sociological data to obtain direct or indirect evidence and speculate, but one crucial element is missing: intellectually disabled individuals have had no voice in history. They have been unable to record their plight or reactions, and there has not been any single powerful advocate for recognition of their status or rights. There is, however, the role of advocacy, which will be discussed in Chapter 2.

It is by listening to the voices of the intellectually disabled and hearing of their experiences in society that better empathy and understanding can be achieved. Intellectual disability is not only the “silent” disability; it is also “hidden”. There is no distinct physical marker, and in the past many individuals were lost amidst the vast numbers of disadvantaged people in work houses with the destitute, housed with the terminally ill and designated “incurable”, confined in asylums with the mad or locked in prisons with criminals. Their silence and invisibility contribute to the difficulty in documenting their history. Recent autobiographies and biographical films of adults with intellectual disability, autism, Aspergers and cerebral palsy have provided some insight into the realities of life with a disability. The perspective on disability is, of necessity, from “above”, without understanding the reality “below”. This is perhaps the reason for the plethora of disciplines involved, each with its own perspective.

Intellectual disability as paradox

Disability can be seen as a paradox¹⁸: the impairment occurs at the level of the person, but the process of disablement is influenced by both the capacity of the person and the capacity of society to support people with diverse needs and abilities. Both aspects need to be addressed; not only the individual and his capabilities, but also the environment in which he lives. This could provide a unifying process for integration, but instead it has activated conflict between two approaches to research and services: the medical model and the sociological model, and heightened awareness of processes of inclusion and exclusion, which are identifiable in the history of intellectual disability.

Medicine objectifies the individual; the medical gaze focuses on the patient to determine diagnosis and cause, and devise cures or preventive strategies. Sociologists return the person to his environment and note the background influences that inform the attitudes of society; and determine the shape and scope of services that are appropriate and just for the intellectually disabled.

The tension between medical and sociological models

The tension between the medical and sociological models is reflected in competition between medical and sociological models in political and economic terms, and as a worldview. The bio-medical interest is in classifying and eliminating disease, and the sociological approach is to promote acceptance and integration in the community. The common goal of each is to create a more functional and better society. The compassionate society is faced with this conflict and faces the question whether the two models can be reconciled.

Practices of exclusion and inclusion of the intellectually disabled throughout time have been justified on both social and medical grounds. Exclusion has often occurred in response to economic hardship, but when man realizes the situation, his conscience is aroused, he recognizes a moral responsibility to protect the weak and the balance returns to inclusion. The practice of infanticide³ in primitive cultures was justified by the survival of the group. Later political edicts ordered castration and condoned abandonment and infanticide of disabled infants as a form of population control. Confinement by incarceration, seclusion, segregation or institutionalization was political, and judicial policies were justified as protection for society and carried out by lay and medical authorities. Social control by sterilization and abortion, eugenics and genocide, and genetic screening for disease, with the option of selective termination, were medical both in origin and implementation. Prenatal diagnosis and selective termination for the benefit of society has social, ethical and medical implications.

The history of the medical model

The earliest medical response to the intellectually disabled 400 years BCE was indifference from Hippocrates.³ He believed the disabled were less than human and no cure was possible. Galen³ was interested in the phenomenon, but he too could see no cure. Later, belief in an external cause such as demonic possession identified the affected person as blameless, and exorcism and herbal treatments were offered. However, fear remained. Late-seventeenth century lower class medicine was based on magical, astrological and faith or folk healing that provided belief systems that gave meaning to suffering and allowed the person to live as he and his family wished.¹¹ The change to a more recognizable medical model occurred with the anatomical revolution, which

objectified man via dissection and experimentation. This process began to erode the belief in the sanctity of the body, a divine creator and the brain as the seat of the soul.¹⁹ The eighteenth century saw commercialized medicine of pills and potions; and doctors and apothecaries who interpreted diagnostic signs. Hospitals became synonymous with jails and punishment. The individual could be deprived of liberty and autonomy, and medical and lay superintendents again responded to intellectual disability with indifference or punitive measures. The nineteenth and early-twentieth centuries saw the power of the bio-medical/psychiatric model in decision-making that influenced institutional care policies of sterilization, segregation and chemical restraint, and more radical measures such as eugenics. The later part of twentieth-century medicine was characterized by major advances in genetic technology and reproductive options, and the mapping of the human genome. The application of this knowledge further objectified the disabled, and the identification of syndromes associated with genetic anomalies was followed by the option of termination if the child was affected. Parallel with these advances was the push for normalization, the social rights movement for inclusion, and legislation to protect the rights of the disabled. The medical model today relies on a well-defined sequence of procedures: to obtain and evaluate the history of a disease, examine the signs, investigate physiological changes, determine causes, define and institute treatment, and finally cure, eliminate and prevent recurrence of disease.

The sociological model, aims for social valorization by increased individual and collective awareness of the range of diversity, and emphasizes the need for compassion

and responsibility to determine future directions. It has been questioned whether medicine can claim intellectual disability as part of medical history,¹⁹ or whether it belongs in sociological history.

There has been undoubted intrusion of medical and scientific knowledge into the life of the intellectually disabled from earliest times. The early responses were negative: indifference, then concealment and punishment. It was not until the intervention of social reformers that positive changes were effected with education, training programs, social rights and integration policies, which came from non-medical professional groups.

Two episodes have striking parallels with the story of intellectual disability, and they too illustrate the conflict between the medical and sociological models. One is the history of infectious disease control and the other is the history of madness. The first fits the medical model; the second the sociological model. Medicine changed the course of both. The history of intellectual disability is taking a different path due to advances in genetic technology. The identification of infectious agents and antibiotic treatment are clearly part of medicine, but there is a strong case for the story of madness and intellectual disability to be viewed as part of sociological history. Social historians use the history of madness as the example of medicine appropriating a condition for its own ends. The antipsychiatry movement opposed the use of electro convulsive therapy and medication in favour of “talking” therapies, but did not succeed in overthrowing medical control of mental illness.²⁰ The basis of this change was the concept that mental illness was a social construct.²¹ The principle of normalization in intellectual disability was based on a similar concept: that it is society that places restrictions on the disabled person. Critics of the medicalization of care proposed a new philosophy of social

valorization,¹⁵ which led to the dissolution of many of the established support services. The medical care of madness and intellectual disability was taken over by social reformers, with both positive and negative consequences.

Defenders of the history of Public Health²² point out that the issues are not simply medical but encompass a broad range of historical fields both past and present: political, cultural, legal and economic. Analysis of Public Health policies lies both within and beyond the framework of medical history, and this may be the best way to view the history of intellectual disability. Each event is “meant to happen” even though each is seen to be socially constituted. Anderson²³ identifies the importance of spatial patterning in colonial history (which is relevant to Australia) and the fact that science is embedded in society’s social relations.

The analogy with infectious disease

The standard practices of infectious disease control in public health policy²² have a strange similarity to those used in the management of the intellectually disabled. While some practices seem inappropriate and punitive when considered by modern day standards, and in the light of advances in Human Rights Law, many of the strategies were implemented in times of economic stress, with inadequate consideration for human rights, and in response to public outcry and fear. Clarifications of causes and better management methods have contributed to greater understanding, but madness, infectious disease and intellectual disability in the twenty-first century still arouse strong reactions in the public sphere. Modern day controversies exist about the prevalence of depression, teenage suicide, alcoholism, drug abuse and the scarcity of mental health services. Outbreaks of influenza, typhoid fever, cholera and HIV/AIDS are constantly in the news, as are reports

of discrimination, abuse, and limited educational and vocational choices for the disabled. The similarities between the three groups begin with early beliefs and healing practices. Madness, infectious disease and “feeble-mindedness” were all thought to be due to evil spirits or possession by demons or miasmas,¹¹ or the effect on pregnant women of seeing wild animals. Exorcisms or trephining the skull to release the evil forces were accepted practices, as well as the use of herbs and natural treatment and the application of heat or fomentations or cold immersion. Affected individuals were vulnerable to coercion, and isolation or segregation of groups was easy to achieve. Isolation was designed to prevent spread of the disease in the case of plague or leprosy, but for the mad and feeble-minded the strategy was a reaction to the threat of violence and fear of the unknown. It was designed to protect society rather than for the protection of the affected individual, which could be effected by simple confinement and provision of care, food and shelter. Services were supplied by the State, and later, as the burden grew, by charitable or religious organizations motivated by moral duty to care for the vulnerable members of society, rather than culturally coded notions of fitness or isolation of non-productive members of society to cleanse the population. This was an early concept of social and political policy.²⁴ Pre-emption by isolation of the healthy carrier in infectious disease has its parallel in the identification of biological markers; and in both instances is open to misuse. The authority to segregate by quarantine for the public benefit in epidemics has fewer ethical implications than institutionalization, isolation from community activities in group homes and special schools or reproductive control by sterilization or elimination by termination or non-conception. There is a vast difference between the elimination of bacteria or viruses for smallpox or HIV/AIDS and the elimination of an individual with

Fragile X or haemophilia. The manipulation of genes to block their expression is still far in the future of genetics; and in any case many conditions are multifactorial and polygenic. Nature herself contributes to equilibrium by spontaneous mutations, and this suggests that many conditions will persist regardless of attempts to remove them. It is a matter of coming to terms with this reality. The history of intellectual disability has returned to the domain of medicine with the introduction of genetic diagnosis.

Worboys,²⁵ in considering Germ Theory, says that the actual identification of the infectious agent is not in itself the significant factor: rather it is the reaction of society. When intellectual disability is identified in a child, the diagnosis has an initial effect in the reaction of the immediate and extended family, then in the circle of contacts and the surrounding community to determine the life pattern for the affected individual. The provision of services rests mainly with the government. The reaction of fear and lack of understanding of the disease process, and misguided methods of containment, was a feature of colonial medicine.²⁵ These analogies with infectious disease are described as the “menacization of the intellectually disabled”.²⁶

The analogy with madness

The history of madness also has parallels in both medical and sociological aspects with the history of intellectual disability. Intellectual disability was included in the early classification of madness and on this basis both groups were confined in the same facilities for centuries and subjected to the same laws and to the same “cures”. The mad and feeble-minded were seen as religious or mystical phenomena possessed by demons, and they were allowed to roam free or were cared for by family, or concealed within the family group; food and shelter were provided if economic circumstances allowed. Life

was hard and aimless. When the era of confinement began, the intellectually disabled became part of the group known as “incurables”. While the mad were intermittently afflicted and would occasionally respond to primitive measures and could return to their family, the intellectually disabled did not, and the two groups continued to be housed together. Modern psychiatry identified the bio-chemical basis for psychotic disorders and provided treatments, but the claims of bio-chemical cause and cure for mental illness are disputed to this day. Structural genetic or biochemical errors and preventable diseases such as rubella are associated with intellectual disability and individuals respond successfully to training but treatment is not yet available to them. It is at this point that the histories of madness and intellectual disability appear to diverge.

Foucault

The history of madness was evaluated in sociological terms by Michel Foucault in his thesis *Folie et Deraison*,¹⁰ published in an abridged form in 1965 as *Madness and Civilization*.²⁰ This moved the story of madness from a medical narrative to a socially constructed phenomenon. His ideas caused a major shift in the way society viewed and interpreted history. He emphasized the power of knowledge in political terms, and redefined man as an object of science. He provided a detailed and empathic account of the story of madness from the end of the Middle Ages to the mid-twentieth century, which the story of the intellectually disabled lacks. He begins with the disappearance of leprosy and the empty leprosariums in Europe, England and Scotland. The disease disappeared as the result of segregation and cessation of contact with the Eastern sources of infection. The containment houses became derelict or filled with incurables and madmen. The stigma attached to the leper, that God was punishing him for the iniquities

of the world yet he could still remain in the Grace of God in social exclusion, would be assigned to other groups. There are parallels for the mad and feeble-minded when they were banished from society to lead a life of existential wandering. He relates that, in the late-Middle Ages, the figure of the madman becomes ambiguous and evokes threats and derision. The character of the Fool, Idiot and Simpleton in farce and satires was no longer familiar and ridiculous, but served as the harbinger of truth. The incarceration that occurred in the seventeenth and eighteenth centuries had no hope of freedom or rehabilitation. The feeble-minded were shut away with the mad, as they lacked ability to acquire working skills during an economic crisis that affected the whole western world. The cruelty and restraint of the Dark Ages returned with imprisonment in manacles, irons and straight-jackets. A landmark date for Europe was when the Hopital General was founded in Paris in 1656. Foucault describes the event as an administrative reorganization of several existing establishments housing the poor and unemployed, prisoners and the insane. It was not a medical establishment but a semi-judicial structure — “a police matter”. The directors appointed a doctor at a salary of 1000 livres per year. There was no concern for curing the sick; rather the prevention of “mendicancy and idleness as a source of all disorders.” The repressive function had the added use of giving work to those who were confined, and thus contributing to the prosperity of all. The Age of Confinement ended with the recognition that there were different orders of madness. The separation of the mad from the poor, the criminal, and the sick began when a number of institutions for the insane were opened. These were the precursors of asylums but lacked the reforming attitudes of the eighteenth century. The harshness of confinement changed, and restrictions were lifted as liberty came to be regarded as a right to be protected.

The divisions that Foucault saw in the treatment of the mad are easily fitted to the history of the intellectually disabled. The world of the seventeenth century was strangely hospitable to madness and feeble-mindedness, which were seen as religious or philosophical phenomena. The era of confinement was repeated in institutionalization, which was a prolonged period until the actions of educational reformers and social rights activists. His ideas are Eurocentric and reflect the attitudes of the French who were influenced by the concerns that led to the Revolution; and as a philosopher he searched for deeper interpretations of disordered thought when he saw the power of religion as a moral enterprise in the old confinement of the mad, the criminal and the disabled. His works led to the re-evaluation of attitudes to the shifting profiles of social power. He saw social norms not only as constraints or a source of power, but as productive forces.²⁷ Foucault's writings¹⁷ reinforce the view that power is augmented by knowledge, and that economic factors are at the forefront of decisions about health care often overruling ethical considerations. He died in 1984 at the dawn of the rise of genetic technology, but his words have a resonance to the examination of medical priorities today.

Critics of Foucault

Foucault's critics regard some of his statements as too sweeping²⁸ and say that he offers "a vision of history as the triumph of evil forces", while others see his pessimism as stemming from a realistic appreciation of the fact that change in history never springs from gratuitous acts of good: all change has its reasons and all modes of rationality involve structures of power.²⁹ Porter, in *Madness A Brief History* (2002),¹¹ records essentially British patterns of behaviour and the ideologies and institutional forms of the "houses of correction". He is less critical in his evaluation of the history of madness as he

focuses on the transitions from the reliance on magical and astrological and faith-healing practices by “wise women”, to the era of the infirmary run by medical staff. He feels that increasing emphasis on knowledge of the body discredited taboos of the mind, soul and self; but this led finally to the time of disillusionment with medical practice. He describes three phases in the history of madness as demonic possession, the asylum, and the antipsychiatry movement. These phases correspond in the story of the intellectually disabled with demonic possession, institutionalization and the social rights movement. He embraces both the medical and cultural models and refers to “social historians of medicine”.¹⁹ He sees the history of medicine as related in the sixties as the unproblematic chronicle of how dreadful diseases had been conquered by “great doctors.” Then came two major changes: the advent of new diseases such as HIV/AIDS, and a more critical public attitude to the medical profession. Medicine today is entering the era of chronic illness and ageing in a narcissistic population seeking to retain youth and postpone death. Porter distinguishes between the attitudes of medical and social historians. The medical historian seeks to identify disease and find cures, to provide answers, determine causes and devise preventive strategies that, in the case of intellectual disability, is to identify syndromes and gene abnormalities — a process that objectifies and loses sight of the person. In contrast, the social historian describes man within his environment, and examines the effect of major world events and political and economic factors that have shaped policies and laws.

The evolution of the sociological model

The impetus to shift the history of intellectual disability from a medical to a social model came from the bio-political model of Foucault and the idea of *social construct*. Madness

and intellectual disability are based on the concept of norms. The mad do not conform to the behavioural norms of society, and the abilities of the intellectually disabled are below the required number of standard deviations expected on a normal distribution curve of the population. Life decisions are made on this basis. Szasz further expanded the term “social construct”.²¹ Madness and intellectual disability were re-evaluated as socially constructed conditions, with the implication that they had no other basis. Rosenberg³⁰ rejects the idea that illness is a social construct, but suggests that a disease is a sequence and does not exist until we have agreed that it does by perceiving, naming and responding to it. He adds that because scientific models have replaced the humanistic connotations of “social”, the terms sociological and cultural should be replaced by the concept of a “frame”. The metaphor of a compartment implies ideas, which enclose and restrict, that is relevant to the intellectually disabled individual whose social role is restricted because the options and opportunities available to him are limited by the perceptions of society. Cooter³¹ agrees that the term “frame” emphasizes the relation of biological events and the individual and collective experience and perception, but feels that history has rendered the frame superfluous. He questions the validity of using medicine as an analytical tool for the history of society because of the socio-political context. The changing philosophy of medicine renders it unsuitable as a tool for social analysis for two essential reasons: medicine is about power, and medical ethics is becoming secondary to medical economics. In the modern world, decisions about beginning and end of life decisions are based to some extent on cost, and the question is put: “should unproductive dependent people be born and maintained by society?”

Despite ongoing opposition to treatment and the views of the antipsychiatry movement, the history of madness was changed by the psychiatry revolution. It removed the perception of demonic possession and established credible bio-chemical causation. The search for causes and treatment for intellectual disability has been less successful and this realization fuelled the trend against the medical model and towards social integration.

Disillusionment with inadequate services for care of the intellectually disabled in the community has influenced attitudes toward prenatal screening and termination as a form of prevention. This, in effect, returns the focus to the medical model. The advances in DNA diagnostic methods in medicine objectify and separate further categories of people. The history of humanity has been changed, and the diversity of man is no longer viewed as a spectrum, which has existed throughout the centuries. The conflict between the medical and social models in the provision of services for the intellectually disabled will be discussed in Chapter 3, with special attention to changes in policy in NSW in the period 1980 to 2010.

The discourses of intellectual disability

The term *discourse* is now widely used in sociological studies.²⁶ It has particular relevance to intellectual disability in history because it describes both the beliefs about the causes of certain conditions, and knowledge that has emerged over time, and the reactions that they evoke in society. This interaction between knowledge and response informs the complex processes of integration and rejection by society.

Both positive and negative discourses can be traced throughout history. The beginning and end of an era are often hard to recognize, but major precipitating factors for the discourses of exclusion or inclusion are identifiable. It is accepted that discourses

can change or produce different meanings at different times in history (p285).²⁶ New discourses echo old ones, and traces of past discourses persist and can appear in different forms. They act to protect society. Foucault uses a medical metaphor to describe some of the rituals that are used to protect the social body as “remedies”, such as segregation of the sick, monitoring of contagions, and exclusion of delinquents. The elimination of hostile elements, formerly by the supplice (public torture and execution), is replaced by the methods of asepsis, criminalization, eugenics and quarantining of “degenerates”.³² The discourse of elimination is the strongest negative discourse promoting exclusion. It was originally motivated by the instinct for survival, when man was at the mercy of the environment and all his energy was directed to the search for food and shelter and escape from predators to ensure the survival of the group. Infanticide was practiced for the continued existence of the group and was not based on individual decision. In later times abandonment was the practice. Natural events such as drought, flood disease famine and poverty had catastrophic effects in the ancient and modern world. Disasters, wars, ethnic conflicts and economic fluctuations influenced the distribution of wealth, and disadvantaged the supply of resources and provision of services for the weaker members of society: the old, newborn and young children; the sick and the disabled. Survival of the fittest has added meaning under adverse conditions.

In later times, Darwin’s evolutionary theory of a hierarchy of beings reinforced the discourse of exclusion by elimination. This form of social Darwinism is, to some extent, being used in the current debate about screening and termination. The disabled were seen as lesser beings and not contributing to the progress of society. Social indictment and

“genetic alarm” at the supposed inherited basis of disability led to active punitive measures of control such as sterilization, genocide, ethnic cleansing and eugenics.

The sixteenth and seventeenth centuries were dominated by discourses of concealment and confinement. The motivations were disgust and fear of contamination by association, economic factors and punitive policies of control and restraint based on the presumed moral degeneracy of the disabled, and the supposed positive intervention of forced productive work. The taint of criminality, immorality and uncontrolled behaviour associated with madness and intellectual disability, led to passive punitive discourses of imprisonment, institutionalization or concealment.

The background discourse to these measures was demonization, which persists today but in a weaker form than originally. The menacization of the intellectually disabled has its origins in medieval times due to fear and ignorance when man was ruled by superstition and fear of the unknown. Malformed people were seen as evil and their appearance as portents of disaster, as well as the threat of violent behaviour, stigmatization of the family and the emotional and financial burdens of dependency. Later, with greater knowledge of anatomy, the idea of the sacrosanct nature of the human body, the deformed and intellectually disabled became the “other”. Freud’s concept of *self* reinforced this view,³ and as many menial tasks disappeared with mechanization and computerization, the productivity of people with limited abilities declined, and they became more marginalized and dependent.

The Greek notion of bodily perfection and Platonic ideals reinforces exclusion of the intellectually disabled⁷ as does the concept of mind and intellect that arose in the seventeenth century.³ Superior cognitive skills, learning, literacy and numeracy, and

planning could lead to the acquisition of land and wealth. The intellectually disabled were more easily recognizable and seen as an impediment to progress. It is this discourse that underlies the idea of the moral imperative to have the “best possible child”.

Positive discourses, which embrace a philosophy of compassion and inclusion, were much less evident in early times, despite some considerations of human rights. A sense of moral responsibility emerged and was confirmed by Christian belief in mercy, and equality in the eyes of God. The Enlightenment brought optimism for the potential of all mankind. The rise of secularism led to a decline in the numbers of people involved in religious orders and charitable work and a decrease in the availability of help for the weak and poor.

It was not until collective guilt about the genocide of World War II forced a re-evaluation of moral values that the Universal Declaration of Human Rights was made in 1948. Covenants for civil, political, economic, social and cultural rights followed in 1966. The next positive discourse in the history of the intellectually disabled, and the most powerful, was the social rights movement. This began in the 1980s at a time when humanitarian issues came to public attention and society was ready for change.

The evolution of Human Rights legislation, and the origins of the social rights movement will be discussed in Chapter 2.

1.4 CONCLUSION

Religious, political, economic, intellectual and social forces “frame” the narrative of intellectual disability, but society sees and judges the consequences as a lack of capability to fulfil family, work and social obligations. The increasing complexity of everyday life and the disappearance in Western culture of many menial tasks with industrialization and

computer control, render the intellectually disabled redundant as far as productivity, work and contribution to the advancement of society are concerned. There has been a change from accommodating disability: as something contained within the range of normal; to rejection: as a deficiency lying outside the normal range and therefore pathological, as identified by the refinements in medical diagnosis and knowledge of genetic patterns. Current bio-medical practices allow identification of those who do not meet certain standards of capability or conform to the behaviours and beliefs defined as normal by society. Intellectual disability is an unchanging natural phenomenon.²⁶ Members of this group deserve protection and respect as part of every society, rather than discrimination in the modern world, which places emphasis on conformity and productivity.

The way individuals with intellectual disability are represented reflects and influences the attitudes of society. This will be discussed in Chapter 2.

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CHAPTER 2.

REPRESENTATION and INTELLECTUAL DISABILITY

To be themselves among others

Summary:

This chapter looks at two forms of representation of intellectual disability: the symbolic representation in art and literature, and political representation in advocacy and legislation. The main themes identified in literature and film are the fool, the village idiot, the mystic or prophet, and the monster or demon. Discussion centres on the significance of the terms “scapegoat” and medical stigma, and the prejudice that derogatory images promote. Political representation encompasses advocacy, the social rights movement, inclusion and exclusion, and human rights.

2.1 INTRODUCTION

The first use of the term *representation* can be understood in an artistic sense as the symbolic portrayal of the characteristics and behaviours of an individual. Images in art and literature are enduring records that both reflect and influence the thoughts and values of the culture from which they originate: by this means it is possible to see the intellectually disabled through the eyes of society over the centuries. The second use of the term *representation* is in reference to the welfare and rights of the intellectually disabled as advocacy: the attempt to present and meet the needs and thoughts of a group, and so benefit the individual. Political activism and legislation for the rights of the disabled have been decades in the planning and slow to reach fruition. Implementation of those rights is proving difficult. The intellectually disabled ask only “to be themselves

among others”¹; but they are at risk of losing a place in a rapidly progressing world. People of varying capabilities and characteristics form the spectrum of human existence. How they are viewed by others and supported by society helps to determine their role in life. Many of the distorted views that persist in modern society about human imperfections have their origins in the past and are based on superstition and unwarranted fear. These prejudices cannot be attributed solely to medical theory, as many powerful political and social influences operate in the world today. Reports of violent or antisocial behaviour and descriptions of unkempt and disturbing appearance promote a negative view of the intellectually disabled in the mind of readers and viewers and reinforce the sense of alienation from society. The social rights movement hoped that, with deinstitutionalization and community living, the visible presence of the intellectually disabled in society would enhance their acceptance, but this hope has only partially been realized. Stereotypes that arose centuries ago continue to be reproduced and do little to foster a sense of moral responsibility and compassion in society or to promote the acceptance of diversity. Symbolic and political representations of the intellectually disabled are forces that interact with the culture and beliefs of society in determining the discourses of disability. A discourse,² or episteme, is based on language, knowledge and power, and it is the power/knowledge dyad that intervenes between words and actions and determines what is said or left unsaid.³

2.2 THE SYMBOLIC REPRESENTATION OF INTELLECTUAL DISABILITY

Man has attempted to represent himself and others, and events and aspects of his existence since prehistoric times. Cave drawing and storytelling, then paintings, carvings, sculpture and epic verse and poetry did this initially. Representation in the modern world

is by static image in photo and moving images in film and television. These forms can be interpreted as true representation: either symbolic or narrative. The meaning of the images is a composite of the thoughts of the artist and viewer, or the writer and reader; memory of the past, experience of the present and vision of the future.

Painting and Sculpture

The earliest images of primitive man depicted scenes of his everyday existence, but there was little indication of disease. The Classical Greek ideal and preoccupation with physical perfection are reflected in statues and in later iconic sculptures such as Michelangelo's *David*. Medieval images of madness and disability appear in the paintings of Hieronymus Bosch (1450-1516) and Pieter Brueghel the Elder (1528-1569) of the Netherlands. The grouping of the mad, the destitute and the feeble-minded was common, and the tortured faces show dysmorphic facial patterns; and individuals with stunted growth and misshapen limbs. Peasants, fools, demons, and monstrous creatures interact in everyday life in the village. These scenes appear in Breughel's *The Cripples* (1568) and *The Fight between Carnival and Lent* (1559)⁴; Bosch's *Cripples, Fools and Beggars* and *Ship of Fools*, refers to the *Narrenschiff*.⁵ Pierre Gringoire (fifteenth and sixteenth centuries) depicts many types at the *Feast of Fools* at the Mardi Gras in Les Halles.⁶ Natural monstrosities or "lunar births" such as hydrocephalic and anencephalic infants were thought to be the result of unnatural influences and strange occurrences that were portents of disaster. These are portrayed by Levinus Lemnius in the sixteenth century as *The Secret Miracles of Nature*,⁶ and by Ambrose Pare (1573) in *The Origins of Monsters*.⁶ Some images have religious symbolism,⁷ with the fool as moral overseer of the Church; while religious art shows compassion with benevolent figures welcoming and

blessing the weak and disabled: such as a priest blessing an epileptic (seventeenth century), Christ healing the sick, and *John Donaldson* a poor idiot who, living in the eighteenth century, who made it his habit to walk before funeral processions in Edinburgh. A nineteenth-century print shows pilgrims in Gheel at the medieval healing shrine for the insane and mentally defective.⁷ Nineteenth- and twentieth-century representations of the intellectually disabled reflect the increasing medicalization of disability as they document the physical characteristics of different syndromes. Portraits and photographs of family units and ancestors were valuable in the study of inherited disease. The first pictorial illustration of a person with Down syndrome was in 1876.⁸ An acknowledgement of disability as an ever-present phenomenon was the display in 2005 on the fourth plinth in Trafalgar Square, London, of a sculpture by Marc Quinn of the pregnant Allison Lapper, who suffered limb deformities as a result of exposure to thalidomide *in utero*.

Architecture

There is a strong symbolic significance in the architecture and location of places of confinement of the intellectually disabled.³ The architectural features of buildings used to isolate different groups over the centuries have been repeated in modern structures so that they resemble the monastic hospices, leprosaria and pesthouses used to quarantine the sick and indigent, lepers and plague victims. Prisons, workhouses and disused institutions such as army barracks were used as temporary housing but new buildings were constructed with the exterior and interior characteristics of churches and monasteries, and were located in remote areas close to a river for ease of transportation for the protection of society. This isolation reinforced the idea of the need for seclusion and the potential

for violence. The need for supervision was repeated in the dormitory-style wards and day-rooms, with a central observation station echoing the panopticon of Bentham.⁷ This atmosphere of incarceration and the punitive attitude of staff, as well as the large size of institutions and the large number of intellectually disabled housed in overcrowded, bleak and unsanitary conditions, were major objections which led to the push for deinstitutionalization. The forbidding outer façade of the Hospital of Bethlehem (Bedlam) at Moorfields,⁷ built in 1675-6 just north of London, which housed the mad and the feeble-minded, bears a chilling similarity to the façade of Tarban Creek Hospital at Gladesville in Sydney, which was built in 1878 to house the insane and idiots.

Literature and Film

Individuals are subject to many formative influences in life; some subtle and learnt through parenting or experience; others overt. Priests and learned men had access to books and pamphlets, but as the skill of reading was taught, these and reports of discoveries (new ideas such as evolution), and reports of scientific societies became available to all. In the modern world, communication by the media is one of the most powerful influences in shaping attitudes and prejudices through newspaper and magazine reports, television, film and literature. The intellectually disabled are frequently portrayed in a demeaning and negative light.

The individual alienated from society and portrayals of “difference” are major themes. The reason for the “difference” may not be clear, but the outcast who says or does what should be said or done is often one who expresses what others are too constrained to do, and fear within themselves. The simple person may be just that one who lacks the inhibition or social conditioning to prevent the representation of truth.

The character Boo Radley in Harper Lee's novel *To Kill a Mockingbird*⁹ is a mystery in many ways. He is a recluse in the family home. Boo may be intellectually disabled, autistic or emotionally damaged — the reader does not know. At the end of the novel he returns to seclusion; as Scout, the child narrator, says: "I never saw him again." He has the features of the intellectually disabled individual in literature. He is "a malevolent phantom", described as six-and-a-half feet tall with a long, jagged scar across his face, hollow cheeks, wide mouth, yellow and rotten teeth, and grey popped, colourless eyes and feathery, dead, thin hair. He is a threatening ghost-like figure who tries to relate to the children by leaving small gifts in a tree trunk. He rescues Scout in an encounter that ends in the murder of a townsman threatening her harm. It is not clear whether Boo is the murderer; Atticus, the lawyer and father of Scout, chooses not to pursue this. Both Boo and Tom, the young black man with a withered arm accused of rape, are symbols of the destructive forces of prejudice and racial hatred.

A gentle portrayal for children of an intellectually disabled character as an object of love and nurturing is "The bear of little brain" found in the series *Winnie the Pooh*,¹⁰ by A.A. Milne, and published in 1929 in Britain. He is an example to children of the lesson of tolerance. The modern example is the American movie *ET*,¹¹ in which an alien, seen through the eyes of children, becomes their friend; while adults see him only as an object for scientific investigation.

Themes

There are recurring themes in the portrayal of the intellectually disabled, and different interpretations of the terms used in literature to describe the intellectually disabled individual.

The *Fool* in early plays has a role in providing commentary on the issues of the times, but the true innocent is the *Village Idiot* who is part of the community, yet may be patronized and mocked; even tormented. He is infantilized, inefficient and ridiculous. The *Holy Fool*, by contrast, is a mystic and prophet, who returns as the modern superhero. The *Monster* of the Middle Ages returns as a criminal: violent, unpredictable and less than human.

Different interpretations of terms are used over time, in literature, to describe the intellectually disabled individual.

The Fool

The term “Fool” appears in the Book of Proverbs and the Book of Psalms,¹² and is defined as one who “despises wisdom and instruction.” A “fool” is one who does not know or has forgotten God; and so “foolish” equates with “Godless”. The First Epistle of St Paul to the Corinthians has a different meaning of “foolishness” to describe those who are wise in God but who forgo earthly values; this is the basis for the Holy Fool.

One of the earliest English language references is in Chaucer’s *The Canterbury Tales*¹³ (1386), where the word “ydyot” is used: “What, wenestow make an ydyot of oure dame?” This instance refers to an individual who is “deficient in reasoning powers” and accused of hiding the keys to the coffer doors. In 1393 William Langland in *Visions of Piers the Plowman*¹⁴ wrote:

Moneyless they walk
Wilt to good wil, witless, mery wyde contrye
Right as Peter date and Paul, some that they preete rat.

The mad and the feeble-minded were grouped together in the sixteenth century, and there was an overlap between terms relating to intellectual disability and madness: *mentis imbecilitas* referred to feebleness of the mind and *mentis consternatis* to disturbance of the mind. The words imbecile, moron, half-wit and feeble-minded relate to cognitive deficiency, but the terms “idiot” and “fool” were used in different contexts. Formal definitions¹⁵ of these terms are:

Idiot: a person without learning; an ignorant uneducated man; a simple man; a clown; or a person so deficient in mental or intellectual faculty as to be incapable of ordinary acts of reasoning or rational conduct. The term is applied to one permanently so afflicted, as distinguished from one who is temporarily insane, or “out of his wits”, and who either has lucid intervals, or may be expected to recover his reason.

Fool: one deficient in judgement or sense; one who acts or behaves stupidly; a silly person; a simpleton, or one who is deficient in, or destitute of, reason or intellect; a weak-minded or idiotic person.

The two terms are interchangeable by the older legal authorities, where an idiot is defined as one congenitally deficient in reasoning powers: “a natural fool.” Swinburne’s description in *Testaments*¹⁶ (1590) lists the skills that were lacking in his character:

An Idiote, or naturall foole is he, who not withstanding he bee of lawfull age, yet he is so witlesse, that he can not number to twentie, nor can tell what age he is of, nor knoweth who is his father, or mother, not is able to answer to any such easie question.

Shakespeare’s¹⁷ fools do not lack wits; in fact many are the wise advisors and fit the category of “Holy Fool”, having greater insight to situations than the one to whom he answers. The fool in *King Lear* and Feste in *Twelfth Night* are clearly “wise fools” to

entertain the master; while Sir Andrew Aguecheek is a proper simpleton. The meaning is clear in *All's Well that Ends Well* (1601):

he was whipt for getting the Shrieues fool with child
A dumb innocent that could not say him nay.¹⁷

Faulkner¹⁸ used a quote from *Macbeth* (1605) as the title of his novel narrated by an intellectually disabled man:

Life's a tale
Told by an idiot, full of sound and fury
Signifying nothing.¹⁷

Fools were kept as playthings at court and feature as part of the life of European nobility.⁷ Professional fools flourished in society. Deformed, dwarfed or crippled individuals were kept for luck and amusement and to avert the evil eye — they were considered to be symbolic of the weaknesses and vices of society.⁷

The Village Idiot

The most common image of the village idiot is that of an individual cared for at home by a loving mother as a child, but as an adult is a recognized identity in the community. His family shelters and feeds him or he is given scraps of food by others. He is unproductive and spends his days wandering in the community. He starved to death in times of famine or was cast adrift to wander the highways as an eternal child, an object of pity and ridicule.⁷

Erving Goffman wrote in *Stigma*¹⁹ (1963):

the village idiot in early times had a clearly defined role in village life, while of limited capacity he or she performed certain clownish functions, even while denied the respect accorded fully fledged members. He serves as a mascot although qualified in certain ways to be a normal member he has a special role as a symbol of the group. This individual ceases to play the social distance game, approaching and being approached at will. He is often the focus of attention that welds others into a participating circle

around him, even while it strips him of some of the status of participant ... only one person in the group is needed, further adding to the burden of the community.

Wordsworth's²⁰ poem *The Idiot Boy* (1798) uses the term in its original context: Johnny, "He's not so wise as some folks be", is sent on the Pony by his mother to fetch the doctor for a sick neighbour. He has not completed the set task but is unconcerned and simply "burrs" and laughs aloud when he is found.

Sir John Mills played the village idiot in the David Lean film *Ryan's Daughter*.²¹ His clownish functions included insatiable curiosity and an eye for scandal; a facial grimace and dysmorphic features; a hunchback with uneven gait and a withered arm. The film showed that life was far from easy for this man. Although he willingly conveyed messages, he was ridiculed and assaulted by louts and ignored by others.

The term has a flippant and ironic tone when used in the twentieth century by English writers such as TS Eliot²² in *The Cocktail Party* (1930):

They kept him rather quiet,
He was feeble minded
He was only harmless....
They had to find an island for him where there were no bats

The policy of confinement is revealed in Nancy Mitford's novel *Love in a Cold Climate*²³ (1949): "What a monstrous thing it was to let the Skilton village idiot out again..."

The term *village idiot* has entered the modern vernacular and is used frequently as an insult to describe someone who makes sweeping, incorrect statements. It has achieved widespread use in politics. The phrase "somewhere in Texas a village has lost its idiot" was used to describe George W Bush, along with the term "global village idiot".²⁴

The novels of Charles Dickens²⁵ contain many characters of limited intellectual ability. They are often loved and supported within the family circle, as are Barnaby in *Barnaby Rudge*, Maggie in *Little Dorrit*, and Mr. Dick in *David Copperfield*. Dickens uses deformity and ugliness as an indicator of evil in his descriptions of physical disability and frailty to arouse compassion and sympathy with characters such as Tiny Tim in *A Christmas Carol*. Smike in *Nicholas Nickleby*²⁶ has qualities that arouse sympathy because of his deprivation and the mystery of his spirituality. The first description of him focuses on his inappropriate attire: “a skeleton suit, such as usually put on very little boys ... a very large pair of boots ... too patched and tattered for a beggar”, and “a look so dispirited and hopeless.” Smike lacks skills in life and learning. His childhood was abusive and he is emotionally damaged. He improves a little in the course of the tale, with love and attention, but remains “a timid broken spirited creature” on the periphery of the family. Others refer to him disparagingly as “imbecile” and “in danger of becoming silly”. He is welcomed into the family circle but wastes away. His presence becomes increasingly remote and ghostly, and it is not until after his death that his true relationship of cousin to Nicholas becomes known. The closing words of the book indicate that Smike is now a mythical being. His memory is treasured; and his grave, situated within the grounds of the family estate, is a site of worship. Smike assumes an ethereal quality, and a religious element suggests that he is soon to journey to another world. This quality is also a key element in the next theme.

The Holy Fool

The religious element and a quality of not belonging to this world is key to this theme.

The early religious interpretation of the intellectually disabled was as special children of

God, implying a communication or closeness to God and having His protection. There were also those known as Holy Fools who had a supernatural quality and a divine aura. They were valued as eternal innocents whose preoccupation with religious matters made them incapable of everyday tasks and also incapable of committing evil.²⁷ Epilepsy was termed the “sacred” disease, and it is suggested that the “changeling” of folklore – the strange child who is silent and remote and takes the place of a normal infant – may have had what is now recognized as autism.²⁸

Grove²⁹ also refers to the mischievous quality of the archetype or trickster in traditional “Jack” tales of the boy who gets things wrong or is clumsy or lazy, as a picture of intellectual disability, with the over-literal interpretation of situations as an autistic trait. The darker side in Celtic tales is the marginalized and voiceless shadow of the “other”, and the ugly giant who is noisy and clumsy and easily tricked. The term Holy Fool originated in Egypt³⁰ and reappeared in the Middle Ages to describe a prophet in whom simplicity is wisdom. The derivation *juro divyi* is from the Greek *yurod* “mad stupid”, and *salos* “simple stupid”, which have the same overlap as the early English usage. There is the added dimension of special purpose and insight into the future. He tells the truth disguised under a fool’s appearance and behaviour, while he wanders unkempt, wearing dirty torn clothing or almost naked. The outward disgusting appearance conceals an inner religious power. He appears preoccupied and remote and pretends he is mad to save his soul and the souls of others. He is possessed by demons and fights them on behalf of others. The Russian Holy Fool of the eighteenth century was a spiritual mystic until a secular variant. “Ivan the Fool” appeared as a hero in the struggle between Good and Evil. Dostoevsky then used the image to emphasize the evils

of materialism in nineteenth-century Russian society. The concept has religious, folkloric, literary and political significance. The thread runs from the early allegories, which revealed the weaknesses and vices of society, to the professional fool at court who served the same purpose; to Shakespeare's literary fools who are fictional characters who provide commentary on aspects of the action of the play and society without fear of reprisal to the author.

The image of the Holy Fool returns in a different form in the film *Being There*.³¹ Chauncy the gardener (Peter Sellers) has been shut away and his life experience is of plants. He leaves his secluded existence and ventures into the world after his protector dies. His simple gardening aphorisms are interpreted as metaphors with political significance, and he becomes an advisor to the American President. He walks on water in the final scene as a religious allusion.

The character Mr. Tanakama in *Kafka on the Shore*³² by Haruki Murakami has been exposed to mysterious extra-terrestrial rays, and is mystical and meditates in a coma-like state about the significance of life and death, and then drifts into his final sleep. This theme has a new dimension in modern representation: that of *superhero*, and is personified in the character *Forest Gump*,³³ who embodies the secular equivalent in the cult of the superhero or celebrity. He fights the discrimination faced by the intellectually disabled and overcomes the recognized barriers of exclusion from school, bullying and ridicule. He moves into fantasy when he discards his callipers and wins a running race. Clever uses of superimposed images make him a celebrity, a military hero, advisor and philosopher: "Life is like a box of chocolates. You never know what you are going to get." A less flamboyant character is the single father in *I am Sam*.³⁴ He presents a positive

image in his fight for the right to continue to care for his bright little daughter; but he is a stereotype of intellectual disability with his simple work tasks in the diner, and his repetitive mannerisms and speech.

The Monster

There is an association between the mystic and the portrayal of the intellectually disabled as a monster: a less than human figure who is violent and a threat not only to the safety of others but to the wellbeing, equanimity and lifestyle of those around him. Those who offer comment on society are rarely censored or punished, but the innocent who says what others dare not or acts on impulse through lack of inhibition, shows the dark side of human nature and his repressed feelings may emerge as violence and sexuality for which he must bear the consequences. The film *Slingblade*³⁵ is a violent and stereotypical portrayal of an intellectually disabled man who has been released from an asylum and commits murder.

Lennie Small in *Of Mice and Men*³⁶ (1937) combines the elements of simplicity interpreting the materialism and evil in the world and the violence of his uncontrolled reactions. His description shows many of the stereotypes of intellectual disability that were applied to Boo Radley⁹: “A huge man, shapeless of face, with large pale eyes and wide sloping shoulders. He walked heavily, dragging his feet a little, the way a bear drags his paws. His arms did not swing at his sides and hung loosely”³⁶ (p8). He shouts, is impulsive and gullible and “too dumb to take care of himself”³⁶ (p39). There is an escalating atmosphere of dread as Lenny’s obsessions control him; he murders Curley’s wife and runs to the creek; psychotic fantasies overwhelm him and George shoots him like a sick animal.

The monster image stems from the pre-Christian belief in portents and the idea of demonic possession as the cause of madness and intellectual disability in the Middle Ages. The aura surrounding this image is fear and superstition; this is the image of a subhuman creature and an object of dread. The term “moral monster” has been used to describe the perpetrators of atrocities and injustices in history, and this lack of integrity and potential for cruelty is implied in relation to the intellectually disabled. Monsters of early civilizations were mythical creatures part-man part-animal, who roamed freely among villagers at festivals. Biological monsters were objects of curiosity to Aristotle and Michel Montaigne wrote an essay on the horror of a monstrous child.⁷ Anatomical deformities were said to be against nature until the French academy initiated the study of teratology and related deformities to events in the womb.⁶

Shildrick³⁷ describes her mixed emotions at the sight of an exhibition of photographs of foetal and infant monsters in Dublin Still Life. She draws parallels with carnival freak shows of the nineteenth century that encouraged revulsion, ridicule and dehumanization of the deformed with reality TV shows, which she terms “enfreakment of corporeal extremes in a society obsessed with the ideals of body habitus.” The common factors are the fear of “otherness” and contamination by a scapegoat who needs to be cast out from society. The question “what is it to be a person?” arose with early efforts to create man. The clay man, “The Golem”, appears in biblical references and with Erasmus Darwin who attempted to animate an inert substance with galvanism. Mary Shelley’s novel *Frankenstein*,³⁸ published in 1816, describes a creature fashioned from many parts by man not God; and who lacks an essential part of human nature. She was inspired by galvanism and by her fears that her unborn child would be stillborn or a monster. The

literary monster lacks a certain moral quality and so is regarded as less than human. His outward appearance is frightening, and his communication and emotional responses are limited. Charlotte Bronte in *Villette* (1853)³⁹ describes “a poor deformed, imbecile pupil a sort of cretin, her poor mind like her body was warped: its propensity was to evil.” It was only a few years later that evolutionary theory⁴⁰ introduced the idea of a hierarchy of living organisms.

The idea that science can modify nature is a theme in the film *Charly*,⁴¹ when an intellectually disabled man competes with Algernon the mouse to complete puzzles. His increase in skills is not sustained; he does become a genius, but then gradually deteriorates. Recently, in *Splice*,⁴² two scientists try to create a being from two creatures by combining their DNA. The modern version of a monster that is part-human part-machine influenced by lay knowledge of bio-medical variations, organ transplantation and cloning. In such a representation, Man has become a machine that can be modified to a dysfunctional biological agent in a post-human stage of evolution as a cyborg intent on destroying the world. These ideas seem as irrational as the fears of medieval villagers who saw demons as portents of the end of the world.

The second half of the twentieth century saw the positive influence of policies of Inclusion, integration, normalization and acceptance, and the change in portrayal of the intellectually disabled; whereas previously, intellectually disabled characters were incidental or identified solely because of their disability and limitations. A series of biographical films were made with a central character who has an intellectual disability: *Best Boy* and the sequel *Best Man*⁴³; *Bill*⁴⁴ with Mickey Rooney, and *The Other Sister*,⁴⁵ where characters face the challenges of everyday life and relationships. In *Shower*,⁴⁶ an

elderly Chinese man cares for his disabled son; and *The Eighth Day*⁴⁷ tells the story of a friendship between a man and a boy with Down syndrome. There were minor characters in TV series: David in *Heartbeat*,⁴⁸ and Benny in *LA Law*,⁴⁹ who represented the return to the village idiot model.

Finally, there are examples of films in which apparent attempts at social inclusion go awry. There is the strange film by the Danish director Lars van Trier, *The Idiots*,⁵⁰ made in 1998, which satirizes normalization as a group of adults pretend to be intellectually disabled to test the reactions of society. The film *Ringer*,⁵¹ made in 2005, was acknowledged to have gone beyond satire to bad taste when, in order to win a bet, a group pretending to be intellectually disabled athletes enter the Special Olympics. Another American film, *Tropic Thunder*,⁵² was regarded as so insensitive that disability groups called for a boycott due to bullying of a character called “Simple Jack”, and use of the term “retard”.

There is little acceptance of children with intellectual disability or Down syndrome in the novels of the twenty-first century such as Zoe Heller’s *Notes on a Scandal*,⁵³ where reference is made to the child as “a court Jester”, in a reprise of the Fool. Sylvia Townsend Warner (2003) returns to the solution of confinement in *The Music at Long Verney*⁵⁴: “Her second boy was found to be a Mongol and had to be put away in a very special and exclusive institution”; and secrecy and abandonment is the answer in Kim Edwards 2005 novel *The Memory Keeper’s Daughter*,⁵⁵ where one of twins has Down syndrome, is given away and her existence is kept secret. Thoughts of murder of the child are not unusual, as in Helen Garner’s 1984 novella *The Children’s Bach*.⁵⁶ Despair, and the wish for the child to die, overwhelm the parents in the 1967 play *A Day in the life of*

*Joe Egg*⁵⁷ by English playwright Peter Nichols. Anxiety and fear and the risk of the responsibility for a disabled child are emotions that recur in twenty-first-century novels; for instance, there is reference to the limitations of prenatal testing. One of the most disturbing is in *We need to talk about Kevin*⁵⁸ (2003), by Lionel Shriver, when the mother refers to “a common or garden moron” being detected, but not her homicidal son.

2.3 DISCUSSION

Symbolic representation of intellectual disability in art, literature and film focuses on the characteristics of the individual. The needs and rights of the group are the concerns of the political representation.

The role of stigmatization

The examples in novels plays and films of images and words used to describe the intellectually disabled often objectify, demean and present a negative, confused picture of their role in society.

The representations range from the incompetent yet lovable father Sam,³⁴ to the satire of Chauncy³¹ the gardener as political advisor to the President of the United States of America. Forrest Gump³³ rises from village idiot to superhero and celebrity, but he remains “The ideal citizen for the modern world — a perfect idiot.”³³ Reactions range from scorn and ridicule, bitterness at the very existence of such a person, to disgust at one who cannot communicate and is ugly, unclean and unkempt in appearance and potentially violent. These portrayals are designed to alienate and to emphasize difference, lack of conformity and the deficient skills of the intellectually disabled individual. All of these responses reinforce fear and exclusion.

The themes of the past still exist: the unproductive village idiot who is unable to perform the ordinary tasks of living, a holy fool who has unnatural powers (whether they are for good or evil), or the unpredictable, violent monster who does not understand the rules of society. Wolfensberger,⁵⁹ in an early chapter of his work on normalization, describes historical roles that relate to “deviancy” in reference to intellectual disability. He lists the various roles of the deviant individual as: a subhuman or diseased organism who is an object of ridicule, a menace, an unspeakable object of dread, an object of pity, a holy innocent, or an eternal child. Elements of all these terms are found in the representation of intellectual disability in literature and film.

The term “deviancy”, which was in use in the 1960s as a psychiatric term, is regarded as derogatory by current standards, and is often replaced by the term “scapegoat”, which is no less discriminatory. It leads to stigmatization and lays blame without cause; but the role of the scapegoat has an important function in maintaining the balance of society. By casting him out the community is cleansed.¹⁹

Szasz⁶⁰ drew parallels between psychiatry and the persecution of witches, and claimed that institutional psychiatry replaced religion as the justification for oppression. He saw a unifying theme of the “scapegoat” in the persecution of various groups throughout the centuries, and the function of the role in the moral metabolism of society.⁶⁰ He maintained that social man fears “the other” and tries to destroy him; but paradoxically he needs “the other” and if need be he creates him; so that, by invalidating the other as evil, he may confirm himself as “good”. In addition, Cocks³ points out that social devaluation serves many purposes. Since the rise of materialistic service systems,

there are economic and political gains to be made based on the maintenance of a society whose members are not accorded equal value.

Szasz⁶⁰ also refers to the manufacture of medical stigma in reference to madness. A process of stigmatization, which enables laws to be made to afford protection from the mad as malefactors, justifies destroying them because they are destroying the fabric of society. He suggests that the mad were simply those who did not conform to the behavioural standards of society. Intellectual disability bears the same stigma. It is seen as an imperfection; but the process of medical stigmatization has shifted to genetic disease. The implication that a genetic anomaly is something to be declared; and policies written and acted upon to eliminate it has shifted the focus from the individual to the group.

The evolution of political rights

Political representation is concerned with the welfare and rights of the intellectually disabled as a group, and as a secondary effect it benefits the individual. It involves not only legislation but the efforts of advocates, activists and the social rights movement – workers who direct their work to protecting the rights of the intellectually disabled – and in the planning, funding and implementation of services to promote inclusion in society and participation in the mainstream of life.

*The United Nations Universal Declaration of Human Rights*⁶¹ was made in 1948, but specific mention of the intellectually disabled was not made until the *Declaration of the Rights of Mentally Retarded Persons* in 1971,⁶² which read: “The mentally retarded person has to the maximum degree of feasibility the same rights as other human beings.” It has been claimed this type of statement emphasizes “the otherness” of the intellectually

disabled and defines them as a group.³ This is the same criticism which has been levelled at normalization. *The Declaration of the Rights of Disabled People* was proclaimed in 1975.⁶³ *The International Year of the Disabled* was declared in 1981, and *The World Program of Action* (WPA) concerning disabled persons began in 1983.⁶⁴ *Standard Rules on the equalization of opportunities for Persons with Disabilities*⁶⁵ were adopted in 1994'; but it was not until 2006 that the United Nations Convention agreed on *The Rights of Persons with Disabilities*.⁶⁶

This point marks legislative inclusion of the intellectually disabled; but the interactions between the law and politics, religion and ethics have direct bearing on the rights of the disabled; not only to participate in society but to have the right to exist. It has been observed, however, that "Human Rights involve much more than what is covered by legislation".⁶⁷ Cycles of alienation and oppression of certain groups continued throughout the centuries in response to the desire for power and political and economic forces. Dependency is interpreted as an economic threat, and not as motivation for compassion and responsibility for those who need care. Some groups have disappeared completely, and customs and ideals are lost forever. After a radical shift in cultural values or the emergence of a changed understanding, a group may find acceptance and merge back into the mainstream of society. If the group survives, it may remain apart from the centre of life activities: outcast, lacking status and power, and unable to change this situation. There are many examples: the isolation of lepers¹⁶; and the persecution of witches in medieval times⁶⁷ are cited as examples in the social histories of madness.

Advocacy

The traditional role of advocacy is to plead on behalf of and to support,⁶⁸ but in sociological terms it is the attempt to present and meet the needs and thoughts of an individual or group that is thought to be disadvantaged or oppressed. Groups and organizations are involved now; and political activists lobby for change. There are contentious issues, including the problem of the internal politics of intellectual disability.⁶⁹

The earliest advocates for the intellectually disabled were “the gentle voices”²⁷ that sought humanity specifically for the intellectually disabled: urging compassion for the weak and dependent amidst brutality and confinement. They were seldom heeded in their own time: Zoroaster, for whom concern for others was a cardinal principle; and Confucius who made specific reference “to be gentle, to be kind and to help those of weak mind”. The first of Buddha’s five moral precepts is “No man shall kill a living creature.” Religious orders have played a role from early times in caring for the poor, the weak and ill, in establishing charitable refuges, and sought a way of life based on love, mercy and equality. The teachings of Jesus are that healing is based on faith, He sought to dispel the idea of demonic influences. Mohamed, to whom Gabriel revealed the text of the Koran, said: “Give not unto those who are weak of understanding the substance which God hath appointed you to preserve for them: but maintain them thereout, and clothe and speak kindly unto them.”²⁷ Early social and educational reformers sought recognition for the cause of the intellectually disabled with Church and political figures, but met with opposition or indifference and found it hard to find philanthropists. Families and carers have formed groups and organizations to recognize and discuss publicly the issues

through the dissemination of information and publication of studies. Political activism has led to drafts, planning and validation of government policies, which are ratified by legislation. Responsibility for implementation, monitoring and funding is delegated to local authorities. An additional dimension is for the intellectually disabled to be involved in governance of organizations that were mainly run by non-disabled persons. Rights-based language introduced a number of terms to the new managerial/business model of services, such as “consumer participation and consultation, empowerment and stakeholders⁶⁹ (p132). Two distinct types of patronage/partnership organizations emerged: the consumerist/self-help model concerned with service delivery and run on social justice principles; and the economic/parliamentary organizations that focused on political activism through lobbying and research.

A significant feature of rights-based language is the use of the term *discourse*³ to describe themes, events and beliefs surrounding the history of intellectual disability, and in this role a discourse becomes an integral part of representation.

The context for intellectual disability is that a discourse arises from language, knowledge and power, which surround and describe the group.³ Discourses play a central role in creating knowledge and legitimizing attitudes, and contain within them much that is unspoken. They intervene between words and actions, and determine what is said, or left unsaid.³ Language itself must be analyzed in order to understand culture and society. Indifference or the use of derogatory terms such as “idiot” and negative images of dishevelled, unclean individuals misrepresent the intellectually disabled and are another form of exclusion, albeit at the lower end of the spectrum. Words and images create false knowledge that interacts with cultural traditions, spiritual and ethical beliefs (about which

actions are right or wrong), assumptions about the meaning of life, and the value of a person with an intellectual disability.

The complexity of the interactions has been likened to the threads, and configurations and warps of theories, definitions and assumptions, and understandings of intellectual disability; wefts of values and beliefs against the Judeo Christian ethic, and socio-political background.⁷⁰

The Origins of the Social Rights Movement

The most significant positive discourse and influence for change in the role of the intellectually disabled in society was based on the normalization principle formulated by the Swedish scholar Bengt Nirje, which addressed the issue of the basic humanity of people with an intellectual disability, and which had been denied them.⁷¹ He was influenced by Niels Erik-Bank Mikkelsen who had been the driving force for Danish law for mentally retarded citizens in 1959. The preamble to this law reads: “to let the mentally retarded obtain an existence as close to normal as possible”. The original normalization was the acceptance of persons with an intellectual disability of their handicap; offering them the same opportunities as other citizens. It was basically a humanistic approach. Nirje emphasized freedom of choice and recognition of a person’s integrity.

Wolfensberger⁵⁹ had a different approach based on the sociology of deviance. He focused on normative means to establish normal behaviour. His reformulation implied both a process and a goal, and was culture-specific to north-western America. He stressed the importance of conformity and “passing”, and the need for people to deny and hide their deviancy. This approach appealed to carers, had a major impact on service

provision, and led to deinstitutionalization and the development of instruments to evaluate human services quantitatively. He developed a new approach to normalization in 1983.⁷² Termed the *theory of social role valorization*, it emphasized the concept of deviant groups obtaining valued roles in society.

Inclusion and Exclusion

Much of the social rights discourse about the intellectually disabled centres on the terms “inclusion and exclusion”⁷³ from the activities that we regard as part of everyday life. This is the result of the wording of the principle of normalization, viz: “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.”⁵⁹

In order for exclusion or inclusion to occur, there must be a clearly defined group who are denied or afforded opportunities. There are types and degrees of exclusion⁷⁴ ranging from semantic exclusion and the use of terms that could be seen as derogatory, or simply by identifying the intellectual disabled as a discrete group instead of part of the spectrum of human diversity.

In order to illustrate the complexity and potential controversy behind the discourses of exclusion and inclusion, I propose to examine two examples at opposite ends of the spectrum of exclusion: the issue of infanticide and the debate about prenatal testing; and the denial of access to activities within the community.

Infanticide

The practice of infanticide is termed profound exclusion, along with other forms of elimination such as eugenics, abortion or abandonment and social control by sterilization, segregation by confinement, incarceration, seclusion or institutionalization. Primitive and

nomadic tribes unable to rear and nourish ill babies and multiple births are thought to have practiced infanticide as a means to preserve the health and progress of the tribe.²⁷ The decision usually rested with the leader. Researchers⁷⁵ extend the practice to other cultures including the Australian Aborigines and Mandarin Chinese. Greek and Roman civilizations issued edicts about abandoning defective children; yet some wealthy families elected to care for the family member, so no law was enforced. Rose⁷⁶ softens this attitude by saying that Aristotle's words may actually suggest that although exposure was a practice known to all, infanticide was not actually a practice. Singer, on the other hand, says that infanticide was not merely permitted but, in certain circumstances, deemed morally obligatory. Not to kill a deformed or sickly infant was often regarded as wrong, and infanticide was probably the first, and in several societies the only, form of population control. He asks "who should live and who should die?"⁷⁷ and proposes, as in ancient time, that some people do not deserve to live or some are less than human. This debate continues now in the contentious issue of screening for genetic disease. The arguments centre not only on religious belief about the sanctity of life and secular values about the avoidance of suffering, but also the philosophical questions of the greater good to mankind, individual choice, and the concept of self and justification for the devaluing of existence of disabled people.⁷⁸

Prenatal testing is offered to women in Western society as an option in obstetric care. The choice can be promoted as a routine and desirable part of pregnancy care, and termination of a pregnancy is usually offered if significant problems are identified. The religious view of the sanctity of life is set against the view that abortion is a form of contraception, and population control is morally desirable in accordance with the

principle of procreative beneficence.⁷⁹ Selecting the best child of all possible children one should have is seen as a positive and generous act that helps to avoid certain genetic features regarded as adverse to the progress of society. It is considered plausible to assert that genetic screening is morally neutral,⁸⁰ as it is an investigative process to determine genetic features. The next step, which is termination, is done in order to reduce the incidence of conditions associated with disability. This is a decision made by an individual to whom the choice must be available.

Somerville⁸¹ questions that reproductives is the new eugenics, and she rejects the opinion that eugenics is practiced only when a choice is made about a group or class of people. She claims that it is sophistry to say that an individual choice about the nature of one's child is not a eugenic decision.⁸¹ The situation is further complicated by recent court rulings relating to "wrongful life", where parents claimed damages because information or testing was withheld and a disabled child was born. In these cases it was determined that it was discriminatory not to inform parents of the options. A further complicating factor is that Australia does not have legislation covering termination of an abnormal foetus.

At the other end of the spectrum of exclusion is technical exclusion.⁷⁴ The term describes the denial of rights to access facilities and activities in the community, such as education, employment and recreation services. This denial extends to practices of community living in the form of dependent care in geographical isolation. These activities have been the focus of the disability rights movement for social inclusion. The movement demands radical changes in social policy and the difficult task of implementing and maintaining them. These changes mirror the shift from the medical

model to models where power does not lie with the professionals. The ideal is the empowerment of the individual who desires inclusion; but in reality it is self-determination for the families.⁸² Many of the changes have been met with opposition from the community, but the major difficulties have been in management of services and the inadequacy of funding. Even those who favoured the philosophy and the implementation of the changes feel that it is time to move beyond normalization because it fails to recognize the intrinsic humanness of the intellectually disabled.⁷¹

The impact which normalization and the social rights movement had on the provision of services for the intellectually disabled in NSW will be discussed further in the next chapter.

2.4 CONCLUSION

The symbolic representation of the intellectually disabled has been negative and demeaning and has reinforced prejudice, which in the traditional definition is “injury, detriment or damage caused to a person by judgment or action in which his rights are disregarded” (p1569).⁶⁸

Some redress has been made by political representation, but although the rights of the intellectually disabled are set out in law, more is needed to present the image of individuals with intellectual disability as an integral part of society and not as “the other” or an alienated group.

Reinders wrote “without people who have sufficient moral character to care, rights can do little to sustain the mentally disabled and their families. People can be forced to comply, but they cannot be forced to care.”⁶⁷ This statement will be considered in the next chapter in relation to the just society of the future.

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CHAPTER 3.

INTELLECTUAL DISABILITY in NSW AUSTRALIA

You cannot make people care

Summary:

This chapter looks at intellectual disability in NSW since the colony was established in 1788, and outlines the eras and the changes in care after the medical model was replaced by a community care model. Discussion centres round the features unique to NSW and the search for a model of a just society.

3.1 INTRODUCTION

The history of intellectual disability in Australia has the same patterns of exclusion and inclusion that have been evident in Europe and Britain throughout the centuries. Services for the mentally ill and the intellectually disabled in NSW were linked in their administration and provision of funding until the 1980s. The process of “disciplinary normalization” and imposition of social order by concealing the group in remote locations was replaced at this time by the social rights model of community living in group homes. The accelerated process of deinstitutionalization which took place at this time in Britain and Australia escalated the conflict between the bio-medical and psychosocial models. Competing philosophies of service became a destructive force in availability of funds for provision of comprehensive care, and many were left without adequate support or accommodation. There were a number of issues other than competition for funding. There was debate about centralized versus decentralized service

structures, exclusion versus inclusion in relation to access to the community, and ethical questions of social rights and the right to exist.

The ideologies and institutional forms, which shaped the background of welfare, health, law and education, were transported to Australia from England and Europe along with the convicts and settlers. These patterns of care were maintained despite the fact that they had been found to be inefficient and were not adapted to suit the new environment and the vastly different population. Well-motivated reformers found it difficult to negotiate with government authorities, and philanthropists were not as numerous or as amenable to providing funds as in Britain. Many of the early decisions about the care of the intellectually disabled made by government bodies were motivated by economic concerns rather than the urge to reform, or for the protection of society or the affected individuals. There was little input from the population-at-large as government was mainly autocratic, and the concept of the individual as consumer (either as the carer or individual concerned) was unknown. It is only in later years that welfare groups and advocates for the disabled, including parents, carers and church groups, have had any influence on policy. Intellectually disabled individuals like the mentally ill and poverty stricken of the eighteenth century, have been the object of punitive policies. They have had no voice in decision-making; although token gestures have been towards inclusion in future planning, the choice of the individual is not always considered.

3.2 THE FIRST 100 YEARS IN NSW, 1788-1881

The colony and the people

European settlement in Australia began in late January 1788 with the arrival of the eleven ships of the First Fleet at Sydney Cove. The first settlers in Sydney consisted of 586 male

and 191 female convicts, and their 13 children, 252 marines, some of whom had wives and children; and 20 officials and 210 seamen of the Royal Navy.¹ The numbers are uncertain but it appears that during the hazardous voyage there were stillbirths and child deaths among the free and convict families; at least 6 children were born to convict women during the trip, of whom 4 survived.² The people subjected to forcible transportation from England were mainly English and Irish; some of whom were citizens who lived a vagrant existence or were inmates of asylums. They had committed minor crimes related to poverty such as theft of food and clothing, prostitution and more serious offences such as assault and robbery. There were, no doubt, some individuals with intellectual disability in the group, and women with borderline personality disorder found in female prison inmates. Similarly, the male prisoners may have had conditions that predispose to learning disabilities. The potential existed for these individuals to have children with disabilities from both a genetic and environmental viewpoint. There was poor maternal nutrition, high alcohol intake of raw spirits, no antenatal care or supervision during labour and delivery, and the infants were exposed to infections such as meningitis, childhood exanthemata, trauma and malnutrition.

The colony had punitive, corrective and protective functions, and which philosophy prevailed depended largely on the personality of the Governor. The humanitarian influence of charities and religious groups was denied, and British law was observed as it is today. Little attention was given to alternative policies other than those in England, and there were few innovative or rehabilitation programs.

The Governors and the advocates

Governor Arthur Phillip, the first governor of the penal settlement in NSW in 1788, had absolute power of the Crown over lunatics and idiots, and his commission entailed their care. He governed as a military autocracy with the Crown's prerogative in Chancery. The convicts were sentenced to transportation at the Old Bailey Court in London, and English individuals were confined for the well-being of the community and the preservation of personal estates, rather than for their own protection. The power of the Church was limited initially by order of the authorities. Only the Anglican Church of England was established in the colony in 1788. This was evidently a strategy from the UK experience to maintain the power of the Crown. It was not until the 1800s that Catholic, Presbyterian, Methodist, Congregational, Lutheran and Baptist groups arose.³

Philip Gidley King was commandant of the penal station in Norfolk Island from 1788 to 1790 and Lieutenant Governor from 1791 to 1790. He had a more humanitarian attitude to his charges and made provision for abandoned and orphaned children of convict women by opening a residential institution for female orphans and two day-schools on Norfolk Island.

The Reverend Richard Johnson, the first chaplain of the colony, reported concern about the increasing numbers of neglected and destitute children living without parental support, who were roaming the streets of Parramatta and Sydney. They were the offspring of convict women and soldiers, sailors or male convicts.⁴ This was a brief era of abandonment of children and it is unlikely that babies with problems survived the harsh conditions. Attitudes to child health and welfare at this time differed from the modern day. Infant mortality was high and childhood illness was often fatal as medical

knowledge and treatment methods were lacking. When King took office as Governor of NSW in 1800, he approached this problem based on his memories of the Georgian Houses of Refugee and Foundling Homes in the UK. The model was that of Coram Foundling Hospital, which opened in 1739 in Bloomsbury. The number of children requiring care at this time in the UK was so great that a lottery system was used to allocate places. In England the practice was that babies were put out to nurse until the age of four and then returned to the workhouse. Boys were later apprenticed to a master and girls were trained for servant duties in the houses of the wealthy.⁵ A similar scarcity of places existed in facilities that were opened in NSW, and later training often depended on the promise of local residents to provide a position for a child.

The orphan schools and other institutions

The Female Orphan School was opened in Sydney in August 1801 for girls 5-8 years. This became The Female School of Industry in 1826. Governor Lachlan Macquarie opened the Male Orphan School for boys 7-10 years in June 1818 on the corner of George and Bridge Streets in central Sydney. This later moved to Bonnyrigg and remained there until 1844.

There were curriculum guidelines for training and education of the “4Rs”, industrial and religious training with the aim of a degree of plain education, and instruction to achieve a sense of moral and religious duty. The goal for these children, as existed in the UK, was apprenticeship for boys and placement as domestic servants in established households for girls. The children were required to meet the criteria of health, and ability to learn a trade in order to be eligible for entry. This excluded many children with chronic illness.⁶ There was little knowledge or interest in intellectual disability at this time;

formal evaluation of skills did not begin until the early 1900s. Admission records⁷ to these facilities are sparse in detail, but there are occasional comments written beside the registration such as “a cripple from a fall from a swing aged five”, “child unable to give an intelligent statement”, and “measles aged three”; or “physically imperfect children”, “child subject to fits”, and “bad eyes”. There is no mention of children with severe disability until Richard Sadleir the Superintendent of the Male Orphan School Hospital refers in a letter dated January 1831 to “two cripples received in that state”.⁴ The mortality rate was high in the barracks-like accommodation. Child mortality rates were extremely high at this time: 18.7% of children died in infancy and 27.4% did not survive past five years of age. There were also three government-run institutions³: the Roman Catholic Orphan School at Waverley House (1836); the Protestant Orphan School, and the Female School of Industry. The aim of these facilities was to provide “a suitable degree of plain education and instruction to achieve a sense of moral and religious duty.” Boys were trained as mechanics and farmers, and girls as house servants. Private philanthropy ran Durands Alley, a series of boarding houses for the poor in central Sydney. The Society for the Relief of Destitute Children was formed in 1852 and established three voluntary organizations: the Randwick Asylum (1858), which later became Ormond House; The Ragged School Movement (1860); and The Lisgar Training School for Girls (1843).⁴

Child welfare reformers such as Renwick and Guillame were concerned at the plight of children in overcrowded dormitory-style sleeping quarters that allowed the spread of disease. They established a system of “boarding out” with families in the 1870s and 80s, which was the forerunner of the foster parent system. They also promoted the

family principle of institutional care in cottage houses for crippled and invalid children and, later, children regarded as “feeble minded”. The first residential school specifically for intellectually disabled children was established in Newcastle in 1871 on Shepherd’s Hill, the site of the military barracks that had previously housed the Girls Industrial School for delinquent girls. Between 1900 and 1914 there were increasing numbers of “mentally defective” children in specialized residential care at the Home for Cripples and the Raymond Terrace Home for “feeble minded boys”. Conflict arose around the term “feeble-minded” and many residents were classified as “mentally weak” without medical examination or IQ testing. An assumed association persisted between mental deficiency and delinquency in boys, and sexual depravity in girls. IQ testing was at first haphazard but became central to the suitability of a child for foster placement as it was found that 90% of mentally normal children were successfully placed in foster care while only 45% of those who showed “mental abnormality” succeeded.

The Care of Adults: Prisons and Asylums

Intellectually disabled adults were recognized more for behaviour disorder or inability to function independently, and either remained within the family or were admitted to infirm and destitute asylums. Committal to these institutions was by jury of 12 good and lawful men chosen by the services of a clergyman and a landholder.⁸ The system in the UK was maintained by the generosity of wealthy benefactors and there were some families who fulfilled this role in the colony. The Benevolent Society was founded in Sydney by Edward Smith Hall in 1813 and cared for the poor, aged and infirm in a facility on the site of Central Railway Station from 1821.

Male convicts who re-offended were placed in custody in Parramatta Goal, and women in the Female Factory, also at Parramatta. Corrective facilities were for the protection of free society and to provide a working class for the rich settlers, with farm work for men and laundry and sewing as occupations for women. The aim of the administration was to settle the new country with active productivity and to cultivate the land. In the early days it was to the economic advantage of the community that existence in an institution implied working and earning one's keep. It was thought that idleness promoted moral degeneracy and was the cause of crime, so productivity implied moral rehabilitation. The tasks were menial, and literacy and numeracy in this population were rare, so it is possible that the intellectually disabled were well integrated, provided with poor quality food and shelter, but subjected to harsh treatment. The Female Factory at Parramatta housed many women and children in conditions that were crowded and with poor sanitation. The women had been found guilty of crimes from murder to petty theft or for leaving the family to which they were bonded. The mortality of children was reported to be very high. Female criminals were later housed at Darlinghurst Goal, and in 1907 in Long Bay at the State reformatory for females.

The first mental asylum⁹ was established in 1811 at Castle Hill on government-owned land originally cleared for agricultural settlement. There was a lay superintendent responsible to the Governor. This system of administration followed the example of the UK where medical control was not established until the 1880s. The asylum existed until 1825 when the buildings became rundown and the facility was moved to the courthouse at Liverpool and known as the Liverpool Asylum. Conditions in the asylums were only marginally less punitive than those in prisons, and there was mounting criticism of the

inhumane system and the problem of overcrowding. The response to this was that the new Tarban Creek Asylum was opened. Twenty-eight female patients from Liverpool and 11 women from the Female Factory at Parramatta were transferred to the new site; and 46 male patients arrived in February 1839 making a total of 85. This number had risen to 135 by 1841. Four inmates, 3 male 1 female, were described as having “idiocy or imbecility (congenital)”. GW, aged 26, was described as “an idiot, a difficult person, liable to paroxysms of anger”, and his brother DW, aged 25, as “another violent idiot, often filthily disposed”, while WH, aged 32 was termed “a deformed idiot, occasionally violent.”

Administration was the responsibility of a Mr Digby who answered to Reverend Samuel Marsden. The medical care of the inmates rested with Dr Thomas Lee who answered to the Principal Surgeon, Wentworth. An inquiry into the conditions resulted in the appointment of Dr Francis Campbell as Superintendent in 1848. There were 489 inmates (311 male and 178 female) at the time. The majority had diagnoses of insanity, mania or melancholia; 3 females had epilepsy; 4 patients (1 female) were described as having “idiocy or imbecility (congenital)”. Case notes made by Dr Campbell, which are highly regarded as descriptions of the patients under the category “Aments and Dements”, include two of the original patients admitted in 1838.⁸ They were: CB, aged 39 “an idiot ... her life is an unruffled stream ... characterized by the same blank uniformity today which distinguished her in infancy”; GW aged 35 “a congenital idiot in habit, manners and intelligence, about equal to a child of 2 years”, described as having a head circumference of 17 inches; MF, aged 17, admitted in 1844, arrived from Ireland 2 years

earlier “from the disproportionate size of his head, I am inclined to believe he was born an idiot or became one shortly after his birth from hydrocephalus.”

During this time there was a feeling that institutionalization was beneficial as it offered group interaction rather than isolation, and avoided possible abuse from unwilling carers. The provision of education and programs for the intellectually disabled appears to have faded, and the idea of threat and the association of madness and intellectual disability with criminality and moral degeneracy were reinforced by association.

The story of the intellectually disabled in NSW in the period up to 1880 is closely aligned with that of the mentally ill, and is resonant with the era of confinement in Europe and Britain.

3.3 THE SECOND ONE HUNDRED YEARS, 1880-1980

Asylums and Mental Hospitals

There were six Inspectors General of the Insane spanning a period of 85 years from 1876. The first, Dr Frederick Norton Manning, was a man of stature who envisioned combining the Public Health and Lunacy Departments of the Colonial Secretary’s Department into one integrated service, but this was not achieved until 1942. His successor, Dr Eric Sinclair, built on his predecessor’s vision and changed the name of the position to Inspector General of Mental Hospitals in 1918. During his tenure, asylums changed from pseudo-prisons in which the insane were incarcerated, to hospitals where active treatment replaced care by restraint.¹⁰ Despite efforts to improve conditions, the site at Tarban Creek remained overcrowded as a mental hospital housing psychiatric and intellectually disabled adult patients. Later it was renamed Gladesville Hospital and a division was created, linked by a tunnel under Victoria Road to form Riverglade, which was

designated for the intellectually disabled. It consisted of some wards and cottages in the grounds leading down to Parramatta River. Riverglade closed in 1999 when the last patients moved to group homes or were transferred to Macquarie Hospital (formerly North Ryde Psychiatric Centre) as the institutions were closed. The land was sold to a developer and is now a private residential complex.

The Parramatta Asylum was expanded in the 1860s and remains as Cumberland Hospital, which houses facilities for the acutely and chronically mentally ill. Proposals were made in the 1990s to establish a small unit designated for the care of the intellectually disabled with a dual diagnosis of mental illness or challenging behaviour. The plan was unsuccessful despite the fact that it was clear that these patients were disadvantaged by management in overstretched community mental health services and the inexperience of staff in dealing with the specific needs of the intellectually disabled; as a result they often ended up in police custody.

The Newcastle Asylum was established in the premises of the military barracks at Watt Street in 1872 as a central institution for “idiots and imbeciles” to which patients could be transferred from the unsatisfactory accommodation at Parramatta and Gladesville. Rabbit Island (Peat Island and later Milson Island) in the Hawkesbury River, and the Quarantine Station at Stockton, were established in 1911 to house “adult mental defectives” when Watt Street was inadequate. Stockton Hospital housed both children and adults until the closure in 1999 under the Richmond Scheme.

The Lunacy Department acquired the site of a disused orphan school at Ermington in Western Sydney in 1888. This later became Rydalmere Hospital. The patients were described as chronic cases of dementia and a large proportion of “adult mental

defectives". North Ryde Psychiatric Hospital (later Macquarie Hospital) was established to house large numbers of intellectually disabled patients. Cottages in the grounds were used as group homes to offer respite and permanent care. Nearby, the Anglican Church ran Crowle as a residential facility, school and workshop. Group homes for men and women with intellectual disability in the Ryde area were run by the Sisters of Mercy.

The Callan Park site was purchased in 1873 and combined with Broughton Hall to become Rozelle Hospital. Both were essentially psychiatric facilities with a small number of intellectually disabled patients. The Royal Commission into Callan Park in 1961 discovered many intellectually disabled people in the back wards of other mental hospitals and in country centres such as Bloomfield in Orange and Kenmore at Goulburn.

Facilities for children

Dr Alan Jennings¹¹ established a ward for emotionally ill children in 1959, and then a unit for 20 mentally retarded boys at North Ryde Psychiatric Unit. This was designed to show the advantages of having a much higher than usual ratio of nursing staff to patients. He also opened a ward for severely mentally handicapped children under two years; many also had physical disabilities. The staff had a positive and caring attitude.

Dr Jennings was the first Director for the Mentally Handicapped in the NSW Department of Health from 1964 to 1973. Due to his efforts, there was progress in the provision of special facilities for children with disabilities. He advised the Department of Health to buy Renwick Hospital in Summer Hill to establish the first Diagnostic Unit for Retarded Children at Grosvenor Hospital in 1965. Residential facilities were also onsite. Further residential accommodation was opened at Parramatta at the old King's School site, allowing closure of Milson Island. Marsden Hospital opened in June 1969, and

Collaroy Convalescent Home transferred there to become an annex. There were a number of privately owned facilities for babies such as Matron Eaton's Babies Home at Wentworth Falls, Greystanes at Leura, St Anthony's at Ashfield, and Allowah at Dundas.

Government funded units included the unit for babies and young infants at Watt Street, Newcastle, and later the Carlton Unit at Grosvenor Hospital, Summer Hill, and John Williams at Wahroonga, an annex of the Children's Hospital, Camperdown. The buildings at Summer Hill and Wahroonga were donated specifically for the care of the disabled. The Intellectual Disability Unit at North Ryde, then called the Lachlan Centre, expanded to two wards for 30 boys and girls with physical and intellectual disabilities. Staff included a psychologist and a Program Co-ordinator, and a school was established in the grounds. Psychiatry registrars were based at the Macquarie Hospital as well as a medical superintendent and mental health nurses with special training and expertise in dealing with the problems specific to intellectual disability.

Restructuring took place in 1975 under Commonwealth Community Health reforms and the unit became part of the Metropolitan North Region of the Department of Health based at Chatswood. The Community Support Team remained in the grounds of Macquarie Hospital. Several other cottages became residential accommodation for adult intellectually disabled patients. These services were structured and run on the medical model. There were well established and co-ordinated educational facilities and long overdue reforms to the law to provide guardianship and protection; educational reforms were planned (personal communication Margaret Anderson 2010).

Guardianship, protection and care

The Governor of the colony was given the authority to exercise the Crown's powers over lunatics and idiots until the establishment of the Supreme Court in 1823, when the Crown's prerogative in Chancery was delegated to the jurisdiction of the court, which could then appoint guardians for the purpose of protecting property⁹ (p4). There were, in Law, two grades of mental incapacity: madness of a defined period (*non compos mentis*), and idiocy (*a navitate*). The policies in the UK under these categories were of institutionalization for mentally retarded children, with Church- or charity-run residential schools for education and care. Adults entered asylums as protection from abuse and mistreatment or neglect by parents and guardians. The Lunacy Act of 12th December 1843 is "An Act to make provision for the safe custody of, and prevention of offences by, persons dangerously insane; and for the care and maintenance of persons of unsound mind."

In NSW, children and adults were committed on Schedule to residential institutions to the care of the Master for Lunacy, under the Inebriates Act (1900), with a diagnosis of congenital idiocy, imbecile, cretin, mongolism, ament or mental defect. Part 9 wardship of children without parental care was replaced by The Guardianship Act of 1987, for the medical control of lunacy was not established in the early years; a lay superintendent was in charge of asylums and he was responsible to the Governor. It was not until the 1830s in the UK that lunacy became a medical concern. The change came later in the late-1840s in NSW when a doctor replaced the lay superintendent of Tarban Creek asylum (later Gladesville/Riverglade complex). The superintendents of facilities for the intellectually handicapped were, in general, trained in psychiatry, and assessment centres were linked

administratively to hospital services and funded by Health until the Richmond Enquiry (1983) and separation of mental health from intellectual disability. Asylums were crowded and the lack of organized activities and staff trained to deal with challenging behaviours, meant that residents were not taught to complete menial tasks . They did not undergo the “moral rehabilitation” which was promised to the community. The early part of the twentieth century was dominated by ideas of segregation and sterilization of the intellectually handicapped who were seen as a threat to society.

The ideas of training and education were ignored. The Mental Defectives Act (1930) stated that the mentally retarded were to be treated as patients not criminals. Parents and advocates critical of structured confinement began to establish community facilities under the Aid Retarded Persons Association of NSW, but Scheduling under the Mental Health Act (1958) could be made by doctors at the request of families. Concerned professionals formed the Australian Group for the Scientific Study of Mental Deficiency (AGSSOMD) in 1960 and addressed the issues of education, training, socialization and rehabilitation.

Families wishing to ensure the future care of relatives could make provision in wills, and also had access to the now defunct Orphans Trust, later The Protected Estates Act (1983). The Public Guardian could be appointed for management of financial matters. The Decisions made by the Guardianship Tribunal and NSW Trustee and Guardian Act 2009 can be appealed under the Administrative Decisions Tribunal Act (1997).

Educational reforms

Greater understanding of mental retardation had been growing in Europe since the 1830s (influenced by Seguin and Esquirol) and behavioural classifications gave way to the concept of individual testing with Binet in 1895.¹² Specific interest in children with intellectual disability began in NSW with two medical practitioners and social reformers who were presidents of the Benevolent Society: Arthur Renwick and Charles Mackellar.³ The latter returned from overseas in 1913 and published a comparative study of the treatment of mental defectiveness in children, where psychological measurement and interventions were advocated as a means of dealing with child welfare problems. Specialized residential care for the mentally defective was seen as a solution; but the cost was prohibitive. This was a time of social Darwinism, and eugenics and improvements in educational facilities did not begin until the 1950s. Mental Age Scores were replaced by IQ testing based on a normal distribution curve of intelligence within the population, as determined by a standardized test of verbal comprehension, perceptual reasoning, working memory and processing speed.

The terms Intellectual Disability, Learning Disability and Developmental Delay which is appropriate for children under 5 are used in the NSW Education system today.¹

The old term Mental Retardation was still being used in the Manual of Psychiatric Disorders DSM IV 2005,¹⁴ which states:

The essential feature of Mental Retardation is significant subaverage intellectual functioning (Criterion A) and is accompanied by significant limitations in adaptive functioning in at least two of the skill areas: communication, self care, home living, social/interpersonal skills, use of community services, self direction functional academic skills, work, leisure, health and safety (Criterion B).

Criterion A is a number that places the individual on a scale. Criterion B describes functional/adaptive skills and behaviours (i.e. the deficiencies that influence the way an individual performs in life).

The range of normal intelligence is set at 80 to 120; the mean set at 100. A score below 70 (2 standard deviations below the mean) is said to indicate subaverage intellectual functioning, and further classification of the degree of disability is mild (50-55 to 70); moderate (35-40 to 50-55); severe (20-25 to 35-40); and profound (below 20-25).

These figures are determined by an approved individual test of intelligence. The three categories are considered in the educational placement of children in NSW schools, but allocation of funding is based on support needs and Disability Criteria in recognition of the complex nature of intellectual disability and the associated problems,

On the basis of this distribution curve, 3% of the population are intellectually disabled and there is some confirmation of this method of evaluation in the results of the 2008 Census, which identified 3% of the population as fitting this category.

The allocation of funding by the Department of School Education for children with special needs is reviewed and changed frequently. Disability Criteria are based on six categories of disability: autism, intellectual disability, physical disability, speech and language disorder and hearing and visual impairment. Schools for the intellectually disabled were established in the 1920s in NSW; although some church or privately owned facilities for the deaf and blind existed as early as the 1860s. Glenfield Park Special School was established in 1927 as a residential and education facility.

More severely intellectually handicapped children and adults were usually accommodated within mental hospitals, or in some cases in separate colonies run by State Psychiatric Services. A number of hospital schools existed, as well as privately funded facilities. There was a policy of education or instruction in special schools for those with an IQ above 55 and therefore deemed capable of living within the family. The policy of integration was approved in 1964, and by the 1970s the State government had taken over the role. Metropolitan State schools had special classes, and two institutions for State Wards: Brush Farm Infants Home and Watt Street and Stockton in Newcastle, had school facilities attached. Many of the State wards had conditions such as Down syndrome and Fragile X and were surrendered by their families because of difficulties coping with problem behaviour. There are currently 106 special schools (SSP) in NSW; 58 of these cater for students with intellectual disability, and there are 70 integrated support classes (IM) for students with mild intellectual disability; each class has a capacity for 15 pupils (personal communication Ivy Green 2011).

Post School options funding was instituted in 1991 to allow transition to an educational program, work placement or community access program for young adults leaving school.

The Social Issues Committee of the Legislative Council of NSW is currently reviewing services for children with additional and/or complex needs, and their families, during transition between stages of education.

While Guardianship and Educational reforms proceeded slowly, major changes occurred in the provision of medical care and accommodation for the intellectually disabled as a result of the social rights movement.

3.4 THE PAST 30 YEARS, 1980-2010

Existing services

In 1980 there were major residential institutions designated Fifth Schedule Health Department facilities and located in Metropolitan Sydney and country areas, which housed intellectually disabled adults. There were units at North Ryde Psychiatric Hospital; the Riverglade unit at Gladesville (formerly Tarban Creek); Rozelle, Cumberland and Rydalmere Hospitals housed mentally ill patients as well. Marsden was designated for children, but many of the original residents from 1969 remained. There were also Kenmore in Goulburn, Bloomfield in Orange, Peat and Milsom Islands in the Hawkesbury area, Morisset Hospital near Wyong; in Newcastle Stockton, Watt Street, and Raymond Terrace Unit. All patients were held on schedule from the Master for Lunacy under the Inebriates Act.

There was one major assessment centre: Grosvenor Hospital at Summer Hill, which was supra-regional and saw patients from the whole of NSW. Assessment centres were attached to the two major paediatric hospitals: the Royal Alexandra Hospital for Children at Camperdown had Layton Street Clinic, and the Prince of Wales Hospital at Randwick had Tumbatin Clinic. Laurel House at Parramatta opened in 1981 to provide assessment services to Western Sydney. These facilities were administered, structured and run on the medical model. Co-ordinated education and training programs were in place, and the importance of reforms in education and training were recognized. Further programs were planned with the Department of Education.

1980-2000: Promises made for the future

A variety of positive changes in the position of the intellectually handicapped were predicted during the last two decades of the twentieth century. A report tabled in 1980, which canvassed the opinions of a group of significant figures in the field of retardation in Australia, outlined the optimistic views that the medical model would be superseded by a psycho-social-education approach. Doctors and nurses would be replaced by carers trained in the 'new' philosophy of care.⁹ There would be a positive change towards acceptance by the community as a result of community education, public relations work, citizen advocacy and a greater presence of the disabled within the community. This change required special facilities and the provision and co-ordination of services run by the State governments. There was a planned closure of large institutions and purchase of smaller locally run residential group homes for short and long term care, with parental input for short term care.¹⁵

The reforms were met with enthusiasm from younger workers but, as is often the case, those who had been involved in the area were more circumspect. There were professionals in the UK¹⁶ and locally¹⁷ who saw the changes as problematic, and expressed doubts from the outset. It was felt that optimism about the changes was misplaced, just as the reforms of asylums and early schools were seen as solutions to problems at the time; they had now become a dark chapter in the history of the intellectually disabled. It was feared that the same cycle of repression would occur and that deinstitutionalization and the closure of major institutions with inadequate planning and availability of finance would place the burden of care back on families who were unable or unwilling to accept the responsibility.

In 1982 the NSW government announced an inquiry and in 1983 the results were released as the Richmond Report.¹⁸ It recommended major reforms in the care of the intellectually disabled. A similar process had begun in the UK with an inquiry published in 1979 as the Jay Report,¹⁷ with a vision of a new non-medical caring profession for the mentally handicapped. In 1981 the UK Tory government announced its commitment to community care. The outcome was disappointing: controversy over the expenditure resulted in a fragmented policy, with care being provided mainly by families. The closure of large hospitals proceeded, but by 1987 the optimism had faded and the closure of institutions was suspended. A more prolonged but equally disappointing outcome was to occur in NSW.

The following is an account of the changes that occurred in services for the intellectually disabled when the new policy of normalization and deinstitutionalization caused the existing model of care to be superseded by a psychosocial model.

The bureaucratic processes

One of the key recommendations of the Richmond Report¹⁸ was the separation of Mental Health and Developmental Disability Services. A major program of deinstitutionalization and the formation of Group Homes, Community Integration programs and Community Support Teams were proposed for the intellectually disabled.

Similar initiatives were proposed to increase the role of Community Mental Health Services. Funding was provided for both through the Department of Health. Progress of these initiatives was monitored by The Handicapped Persons Programs Review (1985) and The Ministerial Implementation Committee on Mental Health and Developmental

Disability (1988), resulting in The Commonwealth Disability Services and Guardianship Act (1989), which recommended a policy of inclusion.

Developmental Disability Services were transferred from the Department of Health to the Department of Family and Community Services (FACS) in NSW on 1st July 1989. The portfolio of the Minister for FACS, Virginia Chadwick, was greatly enhanced as there was a considerable increase in services and funding in her control. The Minister welcomed the change and promised autonomy and separate management of funds for the intellectually disabled. All major policy changes were now dictated by non-medical advisors whose guiding principle was normalization and the abolition of the “sickness model”.

Changes

A number of changes were made to ensure that the psycho/social/educational model was maintained over the bio-medical model; and as a result the health care needs of intellectually disabled adults received less attention. Medical care was no longer seen as the responsibility of the community care model, and patients were referred to general practitioners who were often reluctant to undertake review and management of the extremely complex medical problems that were beyond the scope of general practice. The limited time frame for consultation did not suit the management of patients who had communication difficulty and could not provide a history. Detailed past information about past medical history was often not available as no ongoing medical files were compiled. Patients with challenging behaviours or dual diagnoses of intellectual disability and mental health problems were referred to overcrowded psychiatry units, which relied on psychotropic and neuroleptic medication regimes over more effective but time

consuming behaviour modification programs. Many specialized clinics which had run in the institutions were closed, and physicians with long experience in management of intellectually disabled adults were no longer available. Despite representations by the Australian Salaried Medical Officers Federation (ASMOF) to the Health Department, funding or salaries for medical staff were not allocated after the transfer to FACS, and funds originally for this purpose were diverted to other projects and non-medical positions.

Research focused on social aspects and the process of deinstitutionalization. A number of pamphlets were produced for staff training purposes such as *Community Living Programs* (1987) and *Guidelines for the Operation of Community Living Programs for Persons with Disabilities* (1990). House staff were trained to devise Individual Program Plans (IPP). The report of the Working Party of the Council of Social Welfare Ministers was released in October 1990 and titled *Framework for the Funding and Operation of Disability Services*. It was obvious at this stage, to those working with the intellectually disabled, that the category of disability was being expanded and the needs of the developmentally disabled were being absorbed into a generic policy statement. The types of disability now covered the aged and chronically ill. The service was now called the Department of Aging Disability and Home Care (DADHC). Some Community Support Teams were collocated with DOCS services and there was overlap of casework. There were plans to locate all services in multilevel office facilities so that families had easier access to the offices of Centrelink, DOCS and DADHC.

In 1991, the Commonwealth State and Territory governments agreed to changes in the administration of disability services to be implemented by 1993. The agreement had

been reviewed several times, but it was clear that changes were planned when the January 1991 FACS document *Roles and Responsibilities* was followed in February 1991 by a document, *Suggestions for Change*, which was released by the Disability Council of NSW. A change of Minister from Robert Webster to Jim Longley heralded the 1991-2 strategic organizational restructure to help the department to consolidate.

A new area management model was constructed. Care and Protection was expanded to include Child Protection and Substitute Care, guardianship and advocacy, crisis support, community support and family support. The Community Service dollar was being spread very thinly and Developmental Disability Services were a low priority. The essence of the Commonwealth/State agreement was that the Commonwealth would administer funding for employment services and the States and Territories would administer funding for accommodation and other support services. Responsibility for administration of advocacy and research activities was to be shared; whereas previously, the Commonwealth had provided direct funding to a wide range of services. Each State now has its own legislation to complement the Disability Services Act and all services must meet the Disability Services Standards minimum which demand enhanced operating requirements for government and funded non-government disability service providers. A new Director General of the NSW Department of Community Services, David Marchant, was appointed, and area models, each with a separate new management were constructed in seven areas of Sydney. This created a top-heavy management system and more lines of middle management were appointed to address problems. Management positions were filled by staff with no previous experience in administration. Some disciplines such as therapy were informed that there was no upward career path other than in management.

This left gaps in service delivery. Experienced frontline workers were hard to find, and essential positions in social work, occupational, speech and physiotherapy remained vacant.

Rising concerns

Concern about service delivery was voiced from several areas, and dissatisfaction with administrative decisions and funding allocation became political controversies. The deficiencies in the process were analyzed in the 2000 publication *Promises Promises*,¹⁷ which describes the disillusionment and frustration of families, consumers and advocates due to forestalled promises, uncertain progress and the persistent sense of alienation. It became clear after a time that the new area management structure had so diluted the service that the original core structure of the community support teams could not be replicated in the smaller teams. Workers felt isolated from the central advisory system and lacked education and support. Rising rents for the new units forced relocation and amalgamation to shared office space, with other services justified as “one stop shopping”; but collocation with Care and Protection, Social Security and Justice and Parole services proved to be inappropriate. Ease of access, wheelchair ramps and parking restrictions were problems. Many felt that they could not maintain the quality of service that professionals in the larger centralized diagnosis and assessment teams had used as best practice. The appointment of senior therapy positions to supervise staff and a senior psychology advisor, did not meet the needs of staff and many resigned. The service became increasingly fragmented with Behaviour Management Teams functioning separately. A change was made to Age Based Teams: Early Childhood (0-5 years); School age (6-18); and Adult (18+), and so continuity of family care was lost. The

caseworker model was abandoned. Families were required to phone a central intake line to request a new service because each case was “closed” after an “occasion of service”. This augmented the number of service deliveries but disadvantaged non-English speaking families, those of limited ability or education in times of crisis; and those who wanted to be independent or did not like to appear to be demanding or not coping. The effect was that many families ceased to access services completely. The focus was on management systems and “occasions of service” rather than continuity of care for families needing support or in distress, which had been the philosophy of care held by dedicated workers.

Services that had previously focused on the moderately and severely disabled and provided continuity of care through early childhood, school age, adolescence and adulthood now extended to the mildly delayed group. This is a much larger population presenting a whole new range of difficulties such as school placement and support, behavioural issues and encounters with the law, open employment, independent accommodation and relationship and parenting issues; but extra staff or training were not provided to deal with these problems. Requests to meet the needs of the aged and provide home care were escalating and funding was limited.

As deinstitutionalization proceeded rapidly, problems arose in group homes. Staff were originally trained workers from the institutions and they were experienced in behaviour management and programs of daily living skills for residents. As the number of houses increased and the problems of integration and behaviour management escalated, staff left and were replaced by junior untrained staff working part-time on relief rosters.

There was an increasing demedicalization and deprofessionalization of staff involved in the provision of care in the name of normalization and the move away from the sickness model. Group homes were run on the hotel model rather than an educational model. The prediction that there would be greater community acceptance of the developmentally disabled because of greater visibility proved to be unfounded as disruptive behaviours within the homes and in the community caused complaints and alarm. Tenders were called for the running of services such as group homes and day programs and family support, with funding provided by DADHC. Many non-government organizations (NGOs) submitted the lowest tenders, but they had no concept of the complexity and labour-intensive nature of the work or the level of staff expertise and training required. Access to respite was severely curtailed with the closure of the large residential institutions, and respite beds in group homes were blocked by families leaving their disabled adult relative for long periods, sometimes even permanently, due to inability to cope at home. Many families had been on “high priority” waiting lists for years but permanent places were no longer being offered, except to those who were homeless or had an elderly parent or carer. University-based courses for nurses and trainees in Developmental Disability were abolished, and the ranking and pay scales for nurses working with community teams were scaled down. Nurses were no longer available in group homes caring for fragile residents with special needs such as oxygen therapy for heart failure in Down syndrome patients, or gastrostomy feeds and epilepsy management.

As the focus of the community teams was on integration, and a policy of non-medical care was adopted by DADHC, many psychologists and specialists in psychiatry,

general medicine, rehabilitation, neurology and gastroenterology who valued input from experienced staff found it increasingly difficult to maintain care. Medical and surgical services attached to residential sites were closed, and staff advised to take patients to local hospital emergency departments. Doctors and nurses were no longer employed at diagnostic and assessment centres, so comprehensive medical reports were not compiled for adults. Group homes approached local general practitioners to provide ongoing care for the residents of houses, but it was sometimes difficult to find a group practice willing to do so. Refusal was based on such discriminatory grounds as not wanting the patients sitting in the waiting room for fear they would upset other patients. There was unwillingness to do home visits or to spend time attempting to communicate with difficult or non-verbal patients, general lack of interest or lack of expertise in dealing with such medically complex patients with epilepsy, eating disorders, visual, hearing and behaviour problems, all within the framework of a short consultation time.

Behaviourally disturbed patients were relocated from the psychiatric institutions where they had lived perhaps for 30 years, but no formal liaison with acute psychiatric units was established to provide advice to group home staff or facilitate admission in a crisis situation. The police were reluctant to intervene or to arrest intellectually disabled individuals. Despite many and lengthy negotiations no provision for special facilities for patients with mental illness or challenging behaviours has been achieved.

The optimistic feeling of the 1980s had now disappeared and the problems that some had predicted were realized. The terms normalization, deinstitutionalization, education for children with special needs, integration and community access appeared in

government policy documents, but planning and implementation of services was fragmented with frequent changes of direction and restructuring.

Financial provision has always been crucial in determining the availability of services. Both initial and recurrent funding was restricted, particularly with changes of government. Cut-backs and non-implementation of recommended changes were frequent, despite the sale of land and institutions and estates willed to the State specifically for use as facilities for the intellectually disabled.

Rather than enhancing the image of the intellectually disabled by greater visibility, some communities were not ready to accept the close proximity of individuals with challenging behaviours. Predictions that expectations of easy integration were unrealistic were confirmed, and parents who had grown used to the cloistered care of their family members were threatened by others assuming the carer role. They expressed concerns about the increased freedom, safety and quality of care in the group homes. Nevertheless, the demand for places in group homes far exceeded availability; as funding was restricted and institutions no longer offered respite care, the burden of care was returned to the families.

Proposed solutions

Concerns about the quality of medical care provided to intellectually disabled patients were raised at meetings of the Association of Doctors in Developmental Disability (ADIDD) at a committee level, and alternatives were put forward in joint consultations with the Health Department. Representations were made as early as 1992 for some parts of Developmental Disability Services to return to the Health Department but this was not

to happen for 13 years, by which time many positions had gone due to financial cutbacks; links to therapists, social workers and residential support staff were lost.

In 1997, the Centre for Developmental Disability Studies (CSDDS)¹⁹ was established at Ryde. The Director, Professor Trevor Parmenter, was appointed to the academic staff at Sydney University. He had extensive knowledge, experience and expertise in the area. The mission statement was to create and disseminate knowledge that could improve the lives of people with developmental disabilities. His task was to design and develop research, teaching and clinical practice to inform policy and practices that impact on people who have developmental disabilities. Funding came from the process of deinstitutionalization and DADHC-allocated funds from the now vacant medical officer positions formerly attached to major assessment centres and residential units. The staff and research projects at CSDDS focus on social aspects of care of the intellectually disabled and on community awareness. They also evaluate policy and assessment of support needs and advise the government on proposed changes. This follows the predictions made in 1980 that the medical model of service delivery would give way to a psycho-social-education approach. A doctor was later appointed to carry out research in several areas, including a clinical trial of drugs in dementia, health problems such as osteoporosis, and eating disorders. A medical outpatient clinic was attached to the unit staffed by general practitioners with an interest in developmental disability in adults, and links to rehabilitation services were maintained by appointment of a rehabilitation specialist. A postgraduate program co-sponsored by the Centre and Faculty of Health Sciences at the University of Sydney was also established and is open to all disciplines.

The pendulum swings back

In July 1999 further negotiations were begun with DADHC for transfer of funds and services back to NSW Health in order for clear lines of responsibility for medical care to be defined. It was not until July 2005 that the remaining medical, nursing and psychology staff were transferred back. Medical services funded by the Health Department previously located in community premises, moved to outpatient clinics of the Department of Rehabilitation Medicine at Westmead Hospital. Interest in and support for the sub-specialty continued from the Faculty of Rehabilitation Medicine, with plans for a teaching module in the training course. A Rehabilitation Registrar funded by DADHC was attached to the Leichhardt assessment team for a short period. Specialized clinics were established for neurology, dysphagia and physical disability, and liaison with psychiatry. Attendance at a major public hospital facilitates access to consultation with other specialists as required. This also allows investigations such as XRays and blood tests to be completed at one visit. Day-only admissions with special care and urgent admission can be facilitated. Communication with local practitioners is an important function of these consultative clinics to optimize care and maintain the individual's right to access the doctor of choice and provide access to Comprehensive Care Plans, Chronic Disease Management Plans and Palliative Care funding. The local doctor can use the extended consultation fee for these applications and also visit the group homes, which have experienced nursing staff, for intensive medical and palliative care.

The problems in the group homes continued, although the Disability Services Act (2006) established clear guidelines for accommodation and respite services, which were run by non-government agencies and supervised by DADHC. There was lack of equity,

and pressure on behalf of certain residents by advocates and families resulted in ministerial letters and threats of legal action. Frequent changes in management continued, and the Department has undergone restructure at two-year intervals. Currently, it is named Aging Disability and Home Care (ADHC). The policy of May 2009 was called “Brighter Futures”. The Standing Committee on Social Issues of the NSW Legislative Assembly held an inquiry into services provided or funded by ADHC, which was released in November 2010 (Report 44), detailing 55 recommendations. No government response has yet been made.

The story of intellectual disability in NSW has followed the patterns observed in the UK both in the early days of the colony and in the later indecision about funding and policies such as deinstitutionalization. This resulted in the return of care to the responsibility of families. Examination of the situation was essential for future planning, and it is appropriate to examine programs and innovations in other countries.

Parallels and differences with the USA experience

The story of intellectual disability in the USA²⁰ bears interesting comparison with the Australian experience. English colonization in the USA began more than 180 years earlier than NSW. Family units were strong and were the first line of responsibility for the intellectually disabled. They could seek relief from poverty — a tradition in accordance with England's Poor Law of the practice of local responsibility. Later, community support, family, religious and medical resources were gradually linked. People with mental illness, however, were treated differently and were more likely to be removed from their homes and placed in houses of correction. There was the issue of slavery, which created the precedent of social stratification and discrimination against a

minority group. The issues regarding social obligation to protect the intellectually disabled were raised as early as 1637 with the first petition for guardianship for Benoni Buck,²⁰ who had severe intellectual disability. The case was referred to the Court of Wards and Liveries in Jamestown, Virginia.²¹ The first institution for the intellectually disabled opened in 1848. Poverty and unemployment following the Civil War in 1861 made funding difficult, and by 1880 training schools became custodial institutions. There was growth in the number of large institutions, with 25 existing in the USA in 1904; amongst 171 identified in a worldwide survey.²⁰

Intelligence testing was introduced in 1912 by Henry Goddard to diagnose intellectual disability and determine educability, but the negative consequences were that it was applied at points of entry to the USA to support class bias against immigration and to reinforce racial bias against poor, black Americans.²⁰

People with intellectual disability were thought to have an incurable disease and to be socially deviant and a menace. The eugenics movement of the early-twentieth century emphasized inheritability, criminality and the “downgrading of the species”, and advocated segregation and sterilization of the intellectually disabled.²⁰ Unemployment and poverty in the 1930s during the Depression contributed to overcrowding in institutions, and there was no government funding for support of the disabled. Research into causes and prevention, and foster care plans, proceeded slowly. The creation of the National Institute for Mental Health in 1946 resulted in increased services for the mentally ill, but not specifically for the intellectually disabled until the National Association for Retarded Children (NARC) organized by parents in the 1950s insisted on remedial programs.²⁰

In 1961, President Kennedy (who had a personal interest in the area as his sister had an intellectual disability) appointed a Panel on Mental Retardation, the recommendations of which were included by Congress in Public Law.²¹ The principle of normalization followed in 1969, and national programs now oversee the specialties involved in research, prevention, community services, education and civil rights. There was a struggle to introduce the controversial Universal Health Care Plan that now exists under the Obama administration, and the global recession affected funding. An evaluation of policies in 2007 claims partial success in the arena of intellectual disability in that “most Americans living with significant intellectual disabilities receive Medicaid, the dominant and often only payer for key services”²¹ (p106).

The lesson from the American story is that the intellectually disabled need a powerful political advocate who recognizes the need for a central advisory body, and policies devised by professionals for a co-ordinated plan of care. Adequate funding for provision of services is essential.

3.5 DISCUSSION

It was evident by 2008 that a radical re-evaluation of policy was necessary in Australia in order to resolve the disorganization of services. The inadequacy of provision of care for the intellectually disabled had resulted in part from the conflicting philosophies of the medical and social models and different priorities of the portfolios of Health and Community Services, and funding shared between State and Federal governments.

The plan for a National Disability Strategy²² indicates a change in the philosophy of care of the disabled in Australia. The new scheme necessitates a return to the identification of types and degrees of disability that exist in the population, and the

unique needs of each group. This should not imply a process of objectification and alienation, which is the major criticism of the medical model, but should result in a plan for each individual to be integrated in society. It is hoped that this will satisfy the ideals of proponents of both the social rights and the medical model. There is agreement that people with an intellectual disability, in particular, have unique, complex medical and social needs. The basic human rights of the intellectually disabled should be observed, but many factors needed to be considered in providing comprehensive care. It was acknowledged that involvement of families and support for them to care for a disabled family member were vital. Group home living has cut off some individuals from their family circle. Poorly funded day programs, lack of transport and restricted opportunities for community participation and recreational activities are all forms of exclusion.

Health professionals saw that the gaps and deficiencies in services, and the manner in which they are funded and delivered were part of the overall deficiencies in the public health system. The conflict in philosophies of care between the medical and social models, however, created confusion in the minds of policy makers and resulted in competition for funding.

One of the major decisions to be made is the style of management that is most appropriate to the new strategy. There is agreement that the social rights model of service provision has gone too far and is to the detriment of those requiring care.¹⁷ The most vocal and educated advocates succeed in obtaining services for a small number of disabled people, while those whose families are unable to negotiate the red tape of service allocation and provision miss out.

Each model of care has its critics.¹⁷ It is claimed that the family or supportive community model is maternalistic and infantilizing; while the custodial model is paternalistic, punitive, cruel and inhuman. Both have the negative consequences of patronizing benevolence, overprotection and pity. The medical model is described as coercive and judgemental, focused on “illness”, and seeking a cure or prevention. The charity model fails to encourage independence and the opportunity to participate and progress. The custodial model uses excessive control by confinement, cruelty and punishment, and does not facilitate enablement or freedom to live within society. The managerial model, which emerged from normalization, sees disability as negative and a personal tragedy. The self-advocacy model requires skills in human interaction and the ability to negotiate the bureaucracy and obstacles in government agencies. The intellectually disabled individual is objectified and weakened in all these models and subjected to discrimination. There is the implication that something exists that is to be pitied or changed, cured or eliminated, rather than accepted as part of society. The powerful parental figure, whether the government, the Law, the doctor or the manager, remains dominant.

Parmenter²³ agrees that it is time to move forward from normalization, which means “making available to the mentally retarded patterns and conditions of everyday life as close as possible to the norms and patterns of mainstream society” (p277). The way forward is to incorporate, in future planning, provision for the disabled on the basis of equality. The Disability Policy Framework for Australia²² has as its statement of plan that “all people with disability would be entitled to an appropriate whole of life suite of services and support” (p29).

The re-evaluation process in Australia

The indecision at both State and Commonwealth level about how to address the problems of organization, management and funding of Disability Services was revealed in the series of investigations made during 2008-2010. A Discussion Paper compiled as a result of calls for submissions in August 2008, prior to the National Disability Strategy Consultation Report, was released as “Shut Out: The Experience of People with Disabilities and their Families in Australia”.²⁴ This was followed in September 2009 by the release of “The Way Forward. A New Disability Policy Framework for Australia”, which acknowledged “high levels of unmet need for disability services”²⁵ (p2), and proposed replacing the welfare model with a three-pillar policy of a comprehensive National Disability Insurance Scheme, a strong income support system, and a range of measures to enable private contributions.

The plan for the future

In November 2009 the Disability Council of NSW announced that the Productivity Commission would investigate the feasibility of new approaches for funding and delivering long-term disability care and support, and report to government in July 2011. The press release stated that “The Commonwealth and State and Territory governments have adopted a bold vision for the National Disability Strategy — an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.” The wording is reminiscent of the mantra of the social rights movement. It also states, however, that under the National Disability Agreement, funding will be allocated for specialist disability services including supported accommodation, respite and home care. After a delay of 6 months the NSW State government called for proposals for a

Specialized Clinical Pilot for People with an Intellectual Disability: a multidisciplinary medical and therapy service model identical to that which existed in 1980 and which was abandoned under the social rights philosophy.

There was immediate criticism and debate about the feasibility of a National Disability Scheme. The major problem identified was the cost of the plan and where the funds would be found. In the climate of economic rationalism, the government clearly was looking to the private sector for funding, and to increased productivity from the disabled. A greater contribution from philanthropists is likely to require generosity and respect for the cause from secular and religious charitable organizations. Substantial support and extensive training programs are required to integrate the disabled in the workplace.

The difficulty specific to the intellectually disabled in this plan is one that occurred when disability services were transferred to a community services model, which included all types of disability: namely, that the intellectually disabled became lost among the overwhelming numbers in other dependent groups.

The report of the Standing Council was released in July 2011.²² Planning and consultation were initially estimated to take seven years, with a projected date for implementation of 2018; but this may be revised and brought forward to 2013. Despite the criticisms listed above, the optimistic view is that Australia is entering an era of change in the philosophy of care and the provision and delivery of services to the disabled, and that the government will lead the way in this. Australia is a young, economically stable, tolerant country and has now the opportunity to set the standard for

care of the intellectually disabled, but there are many factors to be considered: some specific to our culture and others that are universal.

The Australian way

The attitude of the Australian community to the intellectually disabled and to social issues in general is tolerant. Australia is known as “the land of the fair go”, but coupled with this is an apathy — a feeling that it is not a problem for the ordinary citizen to consider. It was hoped that deinstitutionalization and a greater and visible presence in the community, combined with education and advocacy, would foster greater acceptance and a feeling of responsibility for the quality of life and welfare of the intellectually disabled; but evidence of success is limited.

There are no earlier studies with which to measure attitude change but a study in 2002²⁶ designed to identify agents of change, indicated that older people, those with less education and people without personal experience, are less positive in attitude. Younger people, with a focus on the future, people with higher educational attainment, and those with a prior knowledge of people with intellectual disability, are more likely to express the most positive attitudes. They are more likely to support integration, rights and empowerment of people with intellectual disability than the general population. Exposure to people with an intellectual disability may have had a positive effect. Many of the staff of disability services have a family member with a disability and their involvement is a direct result of personal experience of the difficulties faced by individuals and their families.

Australia as a multicultural society has the model of the family unit and loyalties to the extended family. Emphasis on care within the family is especially characteristic of

Italian, Middle Eastern, Asian, Mediterranean and Greek cultures. Australia has many affluent Asian and Western families with aspirations for higher education, financial independence and material wealth. These families may sometimes hold negative attitudes toward dependence and unemployment. The recent influx of families from areas of famine, and war-torn countries such as Afghanistan, Sudan, Iran and Iraq, has introduced family units that may have a child disabled by adverse perinatal events, untreated infection or malnutrition in infancy.

The tendency to indifference or selective inattention to the intellectually disabled may lie in the belief that the government should take responsibility and provide adequate care for the disabled. More recently there has been widespread dissatisfaction with many government services, fuelled by media programs informed by activists and consumers and aimed at highlighting deficiencies.¹⁷ Current affairs reports about the unavailability of accommodation and services such as respite, day programs and equipment for the disabled have provoked discussion about whether prospective parents take these factors into consideration when testing the status of the foetus during pregnancy and considering whether to continue or terminate a pregnancy.

Overview of the history of intellectual disability in NSW

There are specific characteristics of the colony which influenced Australian attitudes to intellectual disability: the early colony in NSW was unique because of the background of the settlers and the style of government and enforcement of the law. The extreme poverty, lifestyle and isolation from extended family, and the origins of the convict population contributed to the instability of the family unit. The early punitive policies of the governors and exclusion of the religious component of care limited the option of care by

family with support from charity, which was the custom in the UK and Europe. Concern was expressed by more humane governors, but this was largely ignored by authorities in the UK which led to delays in the implementation of change. The weak and disabled were virtually ignored, and infant mortality was high. There was a type of exclusion by neglect.

The philanthropy of wealthy families and persistence of social reformers led to the establishment of the Orphan Schools based on work-training designed for a productive life; but this was only available to a small group and not effective for the intellectually disabled.

The brief period of abandonment and neglect was followed by a long period of punitive confinement in prison for males, and work factories for women. The discourse of concealment and exclusion continued in asylums and institutions for two centuries. Positive ideas about reforms in education, assessment methods and models for accommodation took time to reach our shores. World events of the past such as the Great Depression, the eugenics movement and events of World War II, had great impact in Europe and the UK, but to lesser degree in NSW. The social rights movement, however, was quickly accepted and brought rapid positive change as new models of community care were used and institutions were closed.

The discourses of today

History shows that separate discourses can co-exist by complementing or opposing one another. Society today is confronted by two discourses with different philosophies with regard to disabling medical conditions. Both claim a moral obligation as the basis for decisions regarding the disabled.

The social rights movement, based on principles of inclusion and normalization of the intellectually disabled, had its origin in the philosophical position that argued that it is not the individual who is deviant but the deviancy of society that is responsible for discrimination against the intellectually disabled. This placed responsibility on society for its actions. This discourse has persisted for more than four decades in heightening conflict with the medical discourse. The latter revived with the genetic revolution, which has changed the perception of disease prevention via prenatal diagnosis for foetal abnormalities. The medical discourse suggested a moral imperative of “procreative beneficence”. Both discourses are thought to make a beneficial contribution to society, but they also have unintended consequences and there is no guarantee that the government will face the issues raised by either philosophical position. The outcome depends on government decisions to influence the attitudes of citizens. Both movements place extensive demands on resources if they are to be implemented, and finance must be available to back the rhetoric. This intensifies the debate about the paradoxical relationship of society to government²⁷ and the suggested “remedies” that have been deemed likely to protect the social body.²⁸ Reinders points out that the discourse of economic rationalism is now heard above all others in the management of services for the disabled.²⁹ It can be argued that greater weight should be given to positive discourses to inform economic and political decisions, the formulation of social policy, and the social contract between government and service provider.

Cultures vary with respect to improvements in the care of the intellectually disabled, especially those with fewer economic resources. The model of care of the intellectually disabled in Scandinavian countries has been a return to the village

responsibility.³⁰ This is also happening in South Africa with the establishment of farming communities and craft centres.³¹

Current changes in Australia provide an opportunity to consider which model of care will provide the best life for the intellectually disabled within acknowledged resource constraints. Three aspects, which are interdependent, require re-evaluation: the first is the practical level of management and hands-on delivery of services. As outlined before, the previous models have defects, but by integrating positive discourses of inclusion a more effective method is possible. It is more difficult to effect radical change in the two other aspects: the political level of planning and finance, which is dependent on government policies; and the most vital — the attitude and value system of society regarding the responsibility of caring for the intellectually disabled.

Styles of government and care of the disabled

Debate about a just model of government began with the earliest records in the codes of Hammurabi (2500 BCE).¹² Plato (c.427-347 BCE)³² proposed a constitution with justice at its core, with political and philosophical power in the same hands. The philosophical divide in the seventeenth century rested between the conservatism of Hobbes³³ who had no faith in individual morality and felt that the care of the weak should be determined by government policy, and the liberalism of John Locke who relied on the individual as a moral agent and saw the care of the disadvantaged as the duty of private donors.³⁴

Hume assumed that morality is immanent in mankind; that we have a sixth sense to distinguish between virtue and vice.³⁴ Rousseau saw all humans as fundamentally equal and proposed a social contract based on the concept of the general will.³⁴

A policy of utilitarianism that balances resources and compares the actual needs of everyone affected is the principle underlying medical and biological practice and research today, but it is often said that this model of moral reasoning disadvantages the disabled.²⁹ Rawls³⁵ agreed, and suggested that utilitarianism imposed unfair disadvantages on minorities, including the unskilled. He proposed a hypothetical social contract theory by a method of *reflective equilibrium* to achieve a balance.

The attitude of society and care of the disabled

Rawls³⁶ refers to *Public Reason* as a force in determining justice and fairness. The interaction between general moral principles and individual reason can be improved by more balanced symbolic and political representation of the intellectually disabled, both as individuals and as a group. Society is aware that it is judged by the way it treats its most vulnerable members. The decent society recognizes and maintains basic human rights and provides adequate food and shelter, and protection from harm. It also acknowledges the duty of care and responsibility for the weak and vulnerable,³⁷ but these are less demanding goals than those of a just society as defined by Rawls.³⁵

Adam Smith³⁸ wrote:

If we believe that man is a moral and social animal not just driven by appetite, then science must go hand in hand with sympathy for the human condition. If we regard man as a moral agent with the sense of justice and goodness immanent in his nature we must also be aware that human goodness is not simply a matter of will or intention, but is vulnerable to the whims of fortune, and virtue, like a plant must be nurtured.

Perhaps in this 200 year old statement lies the answer to Reinders' statement that:

Without people who have sufficient character to care, rights can do little to sustain the mentally disabled and their families. People can be forced to comply, but they cannot be forced to care.³⁹

Rioux⁴⁰ states that “under the social formulations of disability, the moral principles that tend to be paramount are principles of justice including either the Rawlsian notion of justice as fairness or the notion of justice as equality.”

Virtue as the primary ethical concept, when added to the social justice theory of Rawls,³⁵ formed the basis of decision making for the evaluation of genetic research and its applications when UNESCO finalized the *Declaration on the Human Genome and Human Rights*,⁴¹ in 1997. The principles are justice, non-discrimination, diversity and autonomy, and informed decision making. Parmenter comments: “the essential element of the declaration resides in the balance it strikes between safeguarding respect for human rights and fundamental freedoms and the need to ensure freedom of research.”²³

3.6 CONCLUSION

The ideal society of the twenty-first century would achieve a balance between the goal of science to eliminate disability, and approach human perfection and the moral responsibility to provide care and a secure environment for all individuals regardless of their physical or intellectual limitations. This would require a shift from a utilitarian base to a justice base, using medical knowledge balanced by a sense of obligation.

The report on disability released by the World Health Organization in 2011 identifies the intellectually disabled as one of the most vulnerable groups in society.⁴² While it is the government that bears responsibility for those among us who are less capable, public attitude can modify decisions.

The caring society³⁷ supports and encourages others and is aware of the moral features of caring practices that are committed to the wellbeing of people who are dependent on the support of others: the young, the old, the less fortunate and the disabled,

and accords them respect. This requires compassion defined as voluntary behaviour intended for the benefit of others, which refers not only to individual behaviour, but also to the behaviour of institutions and governments. It can be innate but it also can be learned.

The sense of right and wrong for an individual appears in early infancy and is influenced by many factors throughout life. The ability to care is connected to our own experiences of nurture and to observation and contact with others.⁴³ As adults we learn to reject prejudice, acknowledge equality and accept diversity in mankind in order to consider disability as part of the human condition. While we are aware that human abilities and potential are vital to the survival and progress of man, it is true that a spectrum of abilities will continue to exist in every race. Citizens of an ideal society celebrate diversity and are willing participants in providing care. They acknowledge the benefits to society that are inherent in this behaviour.

There have been major changes in the area of human rights in the first decade of the twenty-first century. The rights of the disabled should not be lost in the plethora of social rights movements such as anticolonialism and anticapitalism that confront society today. Concern for human rights must remain both an ideal and a practical movement. The revolutionary nature of the modern concept of human rights is that it is a set of principles above the negotiated relationship between nation states and citizens.⁴⁴

This statement implies that society must move on and reach a higher standard of moral responsibility to achieve the balance that is the key to a just and compassionate society.

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