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**INDIGENCE TO INDEPENDENCE:**

The Development of Social Policy in New Zealand For People With  
Learning Disabilities

A thesis presented in partial fulfilment of the requirements

for the degree

of Master of Social Work

at Massey University

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1995

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## **ABSTRACT**

This study traces the development of social policy in New Zealand for people with learning disabilities. The study examines the social influences and the outcomes of past social policies which have shaped the development of an increasingly explicit social policy for disabled people. Integral to this analysis is a consideration of the impact of these policies upon the family.

This study suggests that social policy, in establishing services which have moved people with learning disabilities progressively towards independence, has required a concomitant role of the family that has increasingly involved them in the lives of their dependants.

Social policy for people whose learning capacity is impaired reflects society's movement towards an understanding of the condition as a "learning disability"<sup>1</sup>. The study examines the changes in societal perceptions of learning disabled people which been fundamental in the construction of social policy, partnering changes in philosophies of care that in turn have shaped the nature of service delivery. Notions of deviancy, sickness, difference and partnership underpinned the development of social

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<sup>1</sup> The terms that recognise an impairment in intellectual functioning are subject to ongoing debate amongst the disabled community. Since this thesis was commenced, the term "intellectual disability" has returned to use alongside "learning disability". The term "intellectual disability" reflects disabled people's intent to have their disability recognised as a valid part of self. The term "learning disability" arises out of the notion of difference, which includes such 'otherness' as impaired intellectual functioning, within its continuum. The term "learning difficulty" extends this continuum further. The forms which recognise an impairment in intellectual functioning have moved to increasingly positive modes, removing the stigma associated with other labels such as "mentally retarded".

policy, as it related to people with learning disabilities, from the 1840s.

Services to people with learning disabilities have been delivered by both the State and the voluntary sector. The study contrasts the role of the State as a major service provider through the health, education and welfare sectors with the role established by voluntary agencies. A discussion of the development of service provision to people with learning disabilities provides an understanding of the changing relationship between the State and voluntary sectors.

Ideologies of 'welfare' underpinned the provision of services through the period of this study and were themselves influenced by the wider political and economic environment. Laissez-faire ideologies in the settlement period of the nineteenth century, fabian socialism in the 1930s and libertarian ideologies in the 1980s are discussed as they relate to the formation of social policy for people with learning disabilities. The State's changing role in providing for the welfare needs of its citizens, including those with learning disabilities, is discussed against this background.

The outcomes of past policies have been a major influence in the development of current social policy. Current policies are likely in their own turn to influence the nature of future social policy and services to those with learning disabilities. Some consideration is given to the implications they might hold for families who have dependants with learning disabilities, and for people with learning disabilities themselves.

## **ACKNOWLEDGEMENTS**

In the preparation of this thesis, there are a number of people who deserve special thanks for their support and encouragement.

I have to acknowledge the support of my work colleagues, who saw little evidence of the research while it was in the preparatory stages but nevertheless maintained an interest in its progress.

IHC National Office made the library facilities available during weekends and holidays in order that I might have access to archival material, a convenience that was appreciated. Thanks are due especially to Liz McGibbon for her prompt responses to my sometimes harassed requests for information and interloans.

Ruth Anderson and Martin Sullivan, who as my tutors helped guide the focus of the research and offered constructive comments through the draft stages, are also due my thanks.

Finally, to friends and family who have in various ways encouraged me through this experience, my gratitude for your understanding, patience and support.

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## CHAPTER ONE

### **INTRODUCTION**

In New Zealand today people with learning disabilities are to be found in many places in the community involved in the same sorts of activities which for most of us, constitute our everyday lives. Many live at home with their families. Children attend their local school where they are included in classroom programmes and join in the school's extra-curricular activities. Younger children enrol at kindergartens or playcentres, learning from activities in the same way as their peers. Other adults live semi-independently with people like themselves in ordinary homes in residential neighbourhoods, often near their families. Some travel to paid, full-time employment. Others have part-time jobs, complementing their time in employment with recreational pursuits. Yet others attend courses at tertiary institutions or take part in job-training programmes. In addition to these Monday-to-Friday occupations, many have other interests which involve them in local community activities.

But the situation described above has not always been the way people with learning disabilities lived their lives. In New Zealand, as in other Western countries, these people were subject to society's changing ideas about them and the way they were looked after. European society once regarded people with learning disabilities as being very different from themselves. This thesis traces the way society's ideas have changed, the

social influences responsible for these changes and the way society provided for those with learning disabilities, both by way of social policy and service provision, from the early European settlement of New Zealand. In an attempt to understand the impact of changing social policy for these people and their families, each chapter constructs a vignette which might be the experience of those, who in this study, have had no 'voice'. In doing so, I have taken the role of an advocate for people with learning disabilities, as someone who works in their environment. As part of the overall intent of this thesis, each chapter examines the evidence in support of the argument that as social policy has moved people with learning disabilities towards independence, the family has become increasingly involved in the lives of those of its members who have learning disabilities.

One purpose of this study of policy development for people with learning disabilities is to consider, in the light of past policy outcomes, some possible consequences of present policy initiatives for this group of disabled people. The first seven chapters of this thesis involve an analysis and discussion of past social policy and service provision, and is therefore retrospective in focus. Chapters Eight and Nine are a discussion of social policy that is still 'in the making'. My intention in these latter chapters is simply to raise some of the issues relevant to current policy, identify some of the debates and review possible trends and outcomes of present policy and provision for consumers.

The second chapter of this thesis examines the concept of learning disability, and traces how society's understanding of people with learning disabilities changed as new concepts were constructed from new knowledge of its nature. The chapter outlines these changing concepts in terms of the legal, medical, social and political paradigms that underpinned social policy and philosophies of care. This provides a theoretical background to the following chapters which discuss in more detail the way these different perspectives influenced service provision in New Zealand for people with learning disabilities.

Chapter Three looks at New Zealand colonial society and the welfare provisions available to those, such as families with disabled dependants, who found themselves in need. The family's vital role in caring for dependants with a learning disability is described against this background. But many families were unable to provide for family members who were dependant or incapacitated, and the chapter discusses the beginnings of State provision to these citizens, some of whom had learning disabilities. The State's interest in the mentally impaired arose out of a concern for law and order. The 1846 Ordinance which made provision for the mentally impaired, was an early social policy to care for a 'problem' group.

Chapter Four describes the growth of institutional care for people who were mentally impaired, especially after the abolition of provincial governments in 1876. "Lunatics" and "idiots" were cared for in asylums, and later in mental hospitals and mental deficiency colonies. The 'sane' in

society ensured they were well protected from elements they perceived as 'deviant'. But by the late nineteenth century, the State had become concerned about the growing numbers being placed in asylum care, largely because of worsening economic and social conditions. The State responded by tightening entitlement to charitable aid in an effort to promote individualism and self-reliance in the population. The "degenerate", those who were both physically and mentally disabled, were a particular focus of these social reforms which were prompted by the emergence of Social Darwinist ideologies.

By the turn of the century, the "degenerate" had come to mean the "mentally deficient". Eugenic influences considered the "feebleminded" in particular, to be those responsible for society's ills. Legislation enacted in the early twentieth century was a response to these fears. The policy of segregated care for the "mentally defective" in institutions continued, but now as a means of limiting the effect of their heredity on the fabric of wider society.

Chapter Five discusses the contrasting social policies which began to emerge from the 1920s for the "feebleminded". The Department of Education had begun to educate some of these slow learners who had stayed at home with their families. Children in the care of the Mental Hygiene Division of the Department of Health simply remained hospitalised.

They were regarded as the more "degenerate" because their disabilities were more profound. The passing of the 1938 Social Security legislation

heightened the difference between these social policies. Children in institutions were excluded from any benefits of the Welfare State. Parents recognised the injustice of this situation, but were prevented from further action by the outbreak of the Second World War.

Chapter Six reviews the social influences that began to emerge after the Second World War that created an environment of change for people with learning disabilities. Eugenic beliefs had been repudiated. People with learning disabilities wanted recognition of their rights as human beings and as equal citizens in society. Doubts were being cast on the value of institutional care, and parents world-wide were advocating for services in the community as an alternative to institutional care. In New Zealand, a small group of parents set about forming an organisation that began pressing the Government for services in the community for their children who were in institutional care. As the IHCPA, they initiated a process that would have far-reaching implications for these persons with learning disabilities. They began by petitioning the Government of the day for a review of services to the "mentally deficient". The review eventually endorsed existing policies of institutional care, and left voluntary groups such as themselves, to provide the services in the community.

Chapter Seven follows the efforts of the IHCPA to challenge existing Government policy through their own provision of services in the community for people with learning disabilities. The organisation had the support of a growing body of professional opinion as it set about

was not until the 1970s when the philosophy of "normalisation" had become a significant influence overseas, together with mounting internal criticism from those in the field and the increasing expense of institutional care, that there were major policy changes. Some of the more able people with learning disabilities were moved out of institutions to live and work in the community, and children began to be integrated into the regular education system. Legislative changes supported these initiatives towards community care.

Chapter Eight outlines the rise of a self-advocacy movement amongst those with learning disabilities who had moved out of institutional care and into community services. From small beginnings, these people learned to speak out on issues that concerned them and stand up for rights that were now theirs. People with learning disabilities were wanting to influence the services they received, and enhance their quality of life.

Chapter Nine considers the influence of 'new' political and economic theory on service provisions to people with learning disabilities in the 1990s. Disabled people wanted to influence the policies providing them services. The Government believed it could meet their demands for an improved quality of life by transferring to the market, the State's responsibility for health and welfare. They believed that by restructuring the Welfare State and introducing competition between service providers, the choices available to individuals would be maximised. Libertarian ideologies, which had influenced the political and economic climate of the

late nineteenth century, re-emerged to become the basis of social policies that would emphasise social efficiency rather than social justice. Consideration is given to the implications of current policies for the families of disabled people and the possible outcomes for individuals with learning disabilities.

Families and people with learning disabilities have become a formative influence in the development of present social policy for those with learning disabilities. In the course of this thesis, other groups and individuals are identified as having been a significant influence on the policy-making process. The beliefs espoused by such interested people, expressed as particular ideologies and social philosophies, came to play a major role in the development of social policy and service provision for people in New Zealand with learning disabilities.

## CHAPTER TWO

**SOCIAL PERSPECTIVES OF LEARNING DISABILITY**

This chapter sets out to examine a concept central to this thesis, the concept of learning disability, and how the meaning of this concept has shifted over the period of social history under study as a result of new knowledge and changing social attitudes. Successive changes in social perceptions of people with learning disabilities introduced new philosophies of their care. These social philosophies in turn influenced social policy and the nature of services provided to people with a learning disability.

Central to the development of philosophical perspectives and principles of care for learning disabled people, are the concepts and definitions of "learning disability". As a concept, "learning disability" has undergone a number of significant changes in meaning since first being conceived as the inverse of intelligence. For much of the past, concepts of learning disability functioned to identify a group of people within society in ways that justified the special attention and social action they received (Sarason & Doris, 1979:11). These changing concepts are reflected in changing social philosophies of care. Concepts and social philosophies have been influenced by shifts in social attitudes, the persuasion of other academic disciplines, the impact of research results and new knowledge, the active concern of parent and consumer groups, and a recognition of the outcomes that particular social policies have had for learning disabled persons

themselves.

Successive changes in social philosophies of care for people who might be described as learning disabled, led to the eventual transfer of many from segregated institutions to a life in the community. However, the philosophies and policies which initiated this shift were not able to address the marginalisation and disempowerment these people experienced as a consequence of this transition. A social theory of disability which addresses these issues is considered essential to the construction of any future social policy for learning disabled people.

### **The Meaning of Learning Disability**

Learning disability is a concept, a concept that has to do with people. Learning disability is also about difference, a difference in the cognitive state of some people that is recognised by others. Learning disability makes the distinction between the limited intellectual capacity of individuals and society's understanding of these concepts of difference, concepts which are socially bound, influenced by time, place and societal values. The term learning disability seeks to remove the subjective moral and cultural value judgements which have permeated previous labels. Use of the term learning disability is an attempt to be inclusive and empowering of those whose learning abilities are more limited. As a function of social beliefs, learning disability has been a socially created concept.

### **Definitions of Learning Disability**

The shifting definitions of the concept of learning disability are themselves a

reflection of changing social influences. Terms such as “idiots”, “imbeciles” and the “feeble-minded” were terms once used to identify those society regarded as “mentally defective”. More recently, the concept has been termed “intellectual handicap”, “intellectual disability” and “learning difficulty”, terms that reflect increasingly positive and inclusive modes of definition. The notion of “disability” has been redefined more recently by disability groups to distinguish between physical impairment, and disability as the experience of society’s intransigence towards those with physical or mental impairment (Oliver,1990:11). There is further discussion of this change in meaning later in this chapter.

However, shifts in terminology have occurred over the time in which this thesis has been prepared. “Learning disability” is the term selected originally to describe the impairment of this group of people in preference to “intellectual disability”, to capture the distinction between social and medical models of the disability. The term emphasised the process (learning) rather than the faculty (intellectual), and involved the notion of capacity (dis-ability) rather than identifying an “impairment” or “handicap”. It was also the term preferred by one consumer group in New Zealand around this time (Independent People First,1994).

Since this decision to use the term “learning disability”, further debates within the disability community have resulted in “intellectual disability” becoming the term recognised as the one having more precise representation. Those within the disability movement now regard the term

“learning disabled” as referring to only those once described as “feble-minded”, and now mainstreamed in the education system. Use of the term “learning difficulty” is also problematic, as amongst the disabled population the term is regarded as more accurately describing those with an organic impairment who are for example, able to undertake higher education. The term “intellectual disability” is seen to be inclusive of all those whose intellect is in any way impaired, the “feble-minded”, as well as those once termed “idiots” and “imbeciles”. It also recognises the push by the disability movement for disabled people to ‘own’ their disability, to demand that society accept them as they are (Sullivan,1991:256). This shift from ‘inclusive’ terminology to terms that are ‘disability-specific’ is an issue currently under debate within the disability community. The terms ‘people with disabilities’ and ‘disabled people, both of which are used in this thesis, also form part of this debate.

For the purposes of this thesis, the term “learning disability” must be understood to apply to those represented above by the term “intellectually disabled”.

### The Concept of Learning Disability

Learning disability is a concept still commonly thought of as the inverse of intelligence. This perspective regards learning disability to be a condition present in some individuals. Influenced by the empirical tradition, this condition was supposedly able to be diagnosed, measured and identified as a less than ‘normal’ function, when compared with other individuals

(Bogdan & Taylor,1979:76-78; Sarason & Doris,1979:34). In these terms, learning disability is seen as a genetic endowment, a condition in which qualities are absolute and unalterable. But learning disability is a condition which is neither neutral nor value-free. Just as intelligence can be understood to develop from the active transaction between individual and external stimuli, so learning disability as a condition occurs in a social and cultural context. Learning disability is understood within the context of social structures, traditions and values (Sarason & Doris,1979:13,31,34; Bogdan & Taylor,1989:79). These social constructs in turn prescribe the social norms by which society perceives people with a learning disability to be disabled (Begab,1975:xi; Sarason & Doris,1979:29-38). Sarason and Doris have said that learning disability is:

A concept that describes and judges interactions of an individual, a social context, and the culturally determined values, traditions, and expectations that give shape and substance to that context at a particular time. (1979:17)

### Learning Disability as a Social Creation

The social norms that identify people as learning disabled are reflected again in the changing clinical and diagnostic definitions of learning disability (Bogdan & Taylor,1989:77,78; Mental Retardation,June,1994: 181). Learning disability is thus a condition that is not fixed and absolute. Society too, makes learning disability more obvious at certain points of an individual's lifespan. Learning disability is more easily recognisable in the years when education and employment are an important focus. But in

other circumstances, such as within a family or community environment, people with a learning disability can function quite adequately, despite their disability. There are also times when it is not possible to distinguish between a person with a learning disability, and a person with a disability of different origin, such as dementia in old age. However, this is not to lose sight of the fact that there is an element of impairment present, whether individuals are described as "lunatics" or "learning disabled". Social attitudes, rather than the progress of society, is that which creates learning disability.

#### Definitions as Labels

Definitions of learning disabled people as "lunatics", "idiots" or "mentally defective" are terms that are as much socially constructed descriptions of learning disability as legal definitions. To resist suggesting legal definitions as socially created labels the term "learning disability", although itself a socially created description, is used throughout the study.

Definitions however, direct attention to the specific characteristics of the groups they describe, encouraging negative stereotypes and prejudiced attitudes towards those whom they identify (Begab,1975:28; Bogdan & Taylor,1989:76,79). They are often offensive, depersonalising, and imply a moral and human inferiority (Oliver,1990:11). Thus people with learning disabilities were often labelled, denied rights and subjected to treatment and practices that those without any such label were protected against (Bogdan & Taylor,1989:76).

Wolfensberger suggests that there are commonalities in the perceptions that others have had of learning disabled people over culture, time and distance. Others have consistently seen people with learning disabilities as deviant. Thus labelled, the individual has responded to the expectations of deviancy and subsequently become subject to society's efforts to manage their behaviour. Society's strategies to manage this deviancy have influenced particular philosophies of care at different times (1972:13-25). Attempts to segregate deviant individuals, to reverse or prevent the presence of any deviant status, can be recognised in the legal, medical, social and political paradigms that established particular social policies for people with learning disabilities.

#### **Classification as a Means to Care: the legal model**

The reform of the British lunacy legislation of 1845 brought the field of mental health to the crossroads of change (Jones,1960:10). From there, three avenues of further reform were possible. Development could proceed along social and humanitarian lines with an emphasis on human relations. It might progress along medical lines to realise the advances in medical science in the treatment of those with both physical and mental disorders. Alternatively, reform might proceed along legal lines where the emphasis was on legal procedures, establishing safeguard upon safeguard to protect the sane from illegal detention (ibid:10).

The direction of further law reform became a cause for pressure groups that unequally influenced the course of this reform. The legal profession

had been an established institution for centuries, the practice of medicine was still earning itself a credible reputation, and social work and therapy were not to become professional occupations until the twentieth century. Jones suggests that it was therefore not surprising given the established status of the legal profession, that the legal approach had precedence at the time in influencing reforms to protect the 'sane' over the option of medical or social reform (1960:10).

Thus as a Crown Colony of Britain, New Zealand's legislation for the mentally impaired followed the legal precedents established by British law. From the time New Zealand gained the power to pass its own legislation, six major statutes have been passed for the mentally impaired. These statutes, enacted in 1846, 1868, 1882, 1911, 1969, and 1992, all legislated changes in some aspect of their care. Although the statutes were often amended, the major revisions required several years of preparation prior to becoming legislation, indicating the growing complexity of mental health law over time (Brunton,1985:71) and continuing changes in status for people with a mental impairment.

From the 1840s. New Zealand's mental health law has been an amalgam of colonial and imperial influences, indigenous and imported ideas. The 1846 Lunatics Ordinance which presents as a simple, practical, local response to the problems posed by the "lunatics" in the new colony was almost a replica of a similar statute passed in New South Wales in 1843. Its appearance in the colony can probably be attributed to Governor

Grey's arrival in New Zealand from South Australia in 1845 (Brunton,1985:71).

The 1868 legislation was modelled largely on the extensive and comprehensive provisions of the 1845-62 English lunacy law. As the foundation of all subsequent mental health law, the 1868 Act reflected the concepts, principles, assumptions and procedures of the early Victorian period in which the law had its genesis (Brunton,1985:71).

The 1911 Mental Deficiency Act also drew heavily on English precedents, and similar initiatives were also being introduced in the United States around this time (Bannerman Foster,1987:10; Davies,1959:50). The Act was modelled on the assumptions and recommendations of the 1908 Royal Commission on the Care and Control of the Feeble-Minded. It established a legal and administrative framework for the care and control of people with a mental impairment, those sustaining a psychiatric disorder or a "mental defect" (Mitchell & Mitchell,1985:15).

New Zealand's legislation also reflected the various phases of social and professional thinking about services to the mentally impaired. These can be identified in New Zealand legislation with respect to social control (1846,1911); State interventionism and the public conscience, wardship and saving the 'sane' (1868); differentiating between the mentally ill and the "mentally defective" (1911); eugenics and hospitalisation (1911,1928); (Brunton,1985:71).

The 1911 legislation introduced the principle of classifying patients

held under the Act according to their varying needs, differentiating between the mentally ill and those with a “mental defect” (Williams,1987:63). The “mentally defective”, and the mentally ill, had long been regarded as separate groups of people and the nature of these differences was now given legal recognition (Brunton,1985:73). Determination of “mental deficiency” became a matter for judicial attention and clinical expertise, and involved the correct identification of the objective signs of “mental deficiency” (Alaszewski & Ong,1991:13).

Appearances of “lunatic” and “idiot” persons before a judiciary had its origins in the fourteenth century statute 'de Praerogativa Regis'. This early English law recognised a distinction between mental illness and mental defect (at least amongst the nobility), making the wardship of “lunatics” and “idiots” a prerogative of the Crown and the care of their property a matter for State intervention. Whereas the property of “lunatics” had to be managed by the State and returned intact to its rightful owner upon their recovery, that of an “idiot” could be appropriated to the Crown, or appropriated to a guardian (Heaton-Ward,1977:1). A diagnosis of “lunacy” or “idiocy” under the 1911 Act in New Zealand meant a loss of individual rights, freedoms and a change in social status in exchange for shelter, protection and confinement. The 1868 Act and the 1911 Act included provisions whereby the Public Trust could manage the estates of the mentally impaired (Brunton,1985:72). The continuing inclusion of the mentally ill and the “mentally defective” under the same law has resulted in

lingering confusion in the minds of the general public as to the respective differences between the two (Heaton-Ward,1977:4).

Some links can be made between the "mentally defective" being recognised as a problem group and the move towards using legislation and institutions for the purposes of social control. This was a reflection of policies and practices in Britain. Law and order considerations in the new colony had underpinned the 1846 Lunatics Ordinance, which provided for the 'safe custody' of the "dangerously insane". The 1911 Act was concerned with social control of a different nature, intending to limit the procreative activities of "defective" women. Reception orders, introduced in the 1911 Act, became the means of detaining a "mentally defective" person in an institution (Brunton,1985:73,74).

Other procedures that became part of New Zealand law with the 1868 Act were designed to prevent the detention of the sane in private institutions, although ultimately only one private institution was ever allowed to be established. These procedures appeared in the 1911 Act as safeguards against admission of the sane to public institutions. Two medical certificates, together with a magistrate's order were to be part of the committal procedures. Licensing, inspection, registration, medical supervision, and Parliamentary oversight were to provide further safeguards. Detailed documentation of patient movements formed another protection against irregular practice, and the system of inspection was also extended to State hospitals (Brunton,1985:76,77).

Collective responsibility for the mentally impaired arose around the middle of the nineteenth century as much from humanitarian concerns as from the need to 'save' the sane. The emerging egalitarianism in the colony ensured distinctions between pauper and private patients were never incorporated into the asylum system (Department of Health,1975:13). The 1846 Lunatics Ordinances envisioned public sector provision for "lunatics".

Subsequent legislation, and increased State provision resulted in the development of the public health system into a separate State department from 1876. This system remained in place for the next century (Brunton,1985:78).

The 1911 Mental Defectives Act was a revision of the law to accommodate the prevailing intellectual and social concern to limit the effects of heredity in terms of the "mentally defective" on the wider community. The 1928 Amendment included further provisions intended to limit the procreative capacities of the "mentally defective". These were repealed in 1954, when eugenic concerns were no longer considered relevant. The 1911 Act also swept away the pejorative concept of the lunatic asylum in favour of a "mental hospital" model. Terms such as "asylum", "lunatic" "inmate" and "attendant" were replaced by "mental hospital", "patient" and "nurse". The term "mentally defective" became the means of classifying those once known as "idiots", "imbeciles" and "feebleminded" (Williams,1987:63).

The nineteenth-century legal basis to care of the mentally impaired

resulted in a mental health law which became long and intricate, providing for every known contingency in detail, and setting up elaborate procedures and structures that separated it from other health and welfare services. As Jones points out, from a legal point of view, the culmination of Victorian lunacy law was nearly perfect. Protection of the 'sane' from illegal detention was its main function (Jones,1972:181). But from medical and social perspectives, the lunacy law was to be an impediment to progress that remained in place for almost the first half of the twentieth century (Brunton, 1985:77; Jones,1972:181).

#### Classification as Social Control

Society's concern over those who might threaten its welfare and stability resulted in the introduction of philosophies of care for "mentally defective" people that were based on the belief that their disability was inherited. The special State provisions established by the 1911 Act for the care of "mentally defective" people, involved an institutional response (shaped by legal perspectives) to the problem of social deviancy as it was perceived to affect the progress of society. Those with "mental defects", who began to emerge as an identifiable group from the end of the 1880s<sup>2</sup>, were seen as being a threat to this progress eventuating. The intentions of the policy makers of this period reflected what Mitchell describes as a "blend of

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<sup>2</sup> As a result of the move towards achieved rather than ascribed characteristics as the basis of western society's value system, the "mentally deficient" emerged as a problem group from within a compulsory education system oriented towards training a skilled workforce; and by reason of the demand for skilled wage labour in a capitalist economy, excluded as a group from the workforce (Ayer & Alaszewski,1984:5; Chappell,1992:45; Kurtz,1981:15; Oliver,1990:27,28).

benevolent humanitarianism ... and the imposition of a hegemony over those who had the potential to disrupt the prevailing social order" (Mitchell,1987:27). Ostensibly, the legislation held a dual purpose, to protect society from deviant individuals and the individual from society. But for "mentally defective" people, the balance favoured the protection of society, and consideration of their rights was largely secondary (Todd,1967:11). While undoubtedly there would have been individuals who, for their own, and society's safety, required containment, the majority of "mentally defective" people might have remained at home in the community but for the concerned few committed to influencing the policy makers.

The resulting social policies that established segregated, long-term care in large institutions were intended to, and effectively did, separate "mentally defective" people from their families and the community for most of their lives. But from around the end of the 1930s, medical knowledge began to provide new perspectives on "mental deficiency".

### **Clinical Perspectives as a Means to Care: the medical model**

Medical perspectives on "mental deficiency" prompted society to move from an understanding of deviancy as an inherited characteristic to view it as a physiological disorder (Brechin & Swain,1989:42). Although the question of "mental deficiency" as an inherited characteristic had not been ruled out, other causes of the impairment were identified. Within the medical model, "mentally defective" people were treated as 'sick' and their 'problem', if it could be described as such, was perceived to be an individual one (ibid:42;

Chappell,1992:39). The medical model focused on functional impairment and involved medical professionals in determining this (Sullivan,1991:258).

The medicalisation of disability has a long history, associated with the establishment of a biomedical paradigm of health care, the rise in dominance of the medical profession and its place in the hegemony of capitalist society (Oliver,1990:51). The discoveries by science during the nineteenth century of micro-organisms as the cause of disease, led to the development of the "germ theory of illness and disease" (ibid:47). This new theory of "specific etiology" exempted individuals of responsibility for, or control over their condition, changing previous medical concepts of disease which had held the individual as responsible according to theological or metaphysical interpretations of cause (ibid:29; Stone,1985:91,93). These discoveries established a scientific knowledge basis which enhanced medicine as a modern profession.

Within the medical model, the problem of responding to disease and illness was approached as a highly interventionist and specific form of medical practice. Physicians became the experts to be consulted in managing illness (Jongbloed & Crichton,1990:26). They were involved in the development of new instruments and techniques (such as the stethoscope, the microscope and X-ray photography) which provided methods of examination that were independent of patient description, revolutionising medical diagnosis and care (Stone,1985:104). The biomedical paradigm of care and the development of new diagnostic

methods are also seen as emerging in direct response to the needs of developing capitalism. Individual able-bodiedness underpinned production and waged labour. Oliver explains that people such as "lunatics", who could not meet the demands of individual waged labour, became excluded from this production system. He suggests that the exclusion of "lunatics" from production came about as a result of the medical profession's focus on the body. Under capitalism, disability came to be seen as an 'individual' pathology (Oliver,1990:47).

Doctors were seen as gatekeepers in this system. They cared for workers and their families to ensure the maintenance of production. Disabled people, through their exclusion from the labour force became dependent on, and controlled by, a system of welfare that met their needs (Jongbloed & Crichton,1990:26; Oliver,1990:47). In England, such a system of welfare was established by the early Poor Laws (Stone,1985:34).

The new 'distributive' principle of waged labour provided for individuals able to work. The State undertook to 'distribute' to those unable to work, provided their incapacity to work was not their own fault. Those who were sick, "insane", "defective", aged or infirm thus had legitimate entitlement as the 'deserving poor' to such support. The difficult task for officials was to distinguish between the eligibility of those genuinely unable to work, and those feigning illness or disability as the means to State support. The emerging Poor Law, while seeking to limit access to distributions by the State, also sought to establish new means of validating the entitlement of

disabled individuals to this needs-based system of welfare (Oliver,1990:33; Stone,1985:18-34; Sullivan,1991:256).

Medical science was to resolve this predicament, providing the means of making “objective, bias-free representations of the disease process” (Stone,1985:105). New, objective medical techniques and practices could replace the judgements of magistrates, or local public and parish officials as the basis of eligibility for the distribution of relief (ibid:100-105). Clinical criteria offered a model of illness that could legitimate claims for social relief and create the administrative means of legitimating these claims (ibid:91,103).

Stone argues that within twentieth century capitalism, disability has become an important boundary category through which people are appropriated to either a work-based or needs-based system of distribution (Stone,1985:27). The separate disabled conditions recognised by early Poor Law policy were eventually merged for ease of administration. Medical science had provided the State with an administrative tool to establish eligibility to social relief. Disability determined this eligibility, with a focus on individual, functional impairment and ability to work (Oliver,1990:40; Stone,1985:55,103; Sullivan,1991:256).

The rise of the institution has been associated with the medicalisation of disability (Finkelstein,1981:61). As one of the groups of deserving poor, “lunatic” people without permanent homes or incomes began to move into the growing number of institutions, often asylums, which had emerged as a

means of social control during the industrial revolution. This segregation facilitated an associated growth of a range of specialist, professional workers (Finkelstein,1981:61; Oliver,1990:33,52). Medically conceived interpretations and solutions to the problems of impairment began to shape both social policy, and the lives of disabled people.

As a natural adjunct to the medical model, the new discipline of psychiatry medicalised the treatment of those whom society had deemed to be "lunatics". It created subdivisions between those with a seemingly permanent and untreatable lack of reason (the 'stupid') and those whose dementia might be more temporary and curable (the 'mad'). The clinical reification of 'stupidity' generated an interest in its etiology, character, treatment and classification (Dunne & McLoone,1988:44). From the 1920s, pre-existing institutional settings were translated into hospital environments, and services involved increasing numbers of nurses, occupational therapists, and physiotherapists (Oliver,1990:48). Psychology provided an adjunct to the medical model as it attempted to understand "mental deficiency" and provide solutions to resulting behavioural problems. Drug therapy was also a major form of 'intervention' or treatment for the management of behavioural problems. Doctors, as therapists instead of jailers, made decisions about the management of many aspects of the lives of "mentally deficient" people, who were now become patients instead of inmates (Brechtin & Swain,1989:43; Oliver,1990:52, Sullivan,1991:257).

Advances in medical science, while eradicating some disabling

conditions, also meant the survival of greater numbers of people who were "mentally defective". This facilitated the dominance of the medical model and strengthened the connection between "mentally defective" people and institutions. These connections were reinforced with the passing of the 1938 Social Security Act and the introduction of free medical care in New Zealand. Doctors, as a powerful, professional pressure group and the medical model had a major influence on the lives of those with physical and mental impairment. The medical perspective of their disability prevailed, at the expense of any independence and any control over decisions relating to their own lives (Brechin & Swain,1989:43; Oliver,1990:52).

"Mentally defective" people, according to the individual pathology associated with the medical model of disability, were either 'sick' or 'developmentally delayed' (Brechin & Swain,1989:43; Kurtz,1981:15). However, cures are not available for permanent physiological impairment such as "mental deficiency" and thus within the medical perspective, what is 'wrong' with an individual is likely to stay 'wrong' (Sameroff,1975 cited in Sarason & Doris,1979:22,23). Medical interventions based on the germ theory therefore became inappropriate, and the pattern of disease and disability shifted from acute forms requiring treatment, to largely chronic forms requiring only maintenance and rehabilitation (Oliver,1990:48). With the advent of the Welfare State, the medical profession as its gatekeepers, were authorised to examine and confirm individuals' status as "in-valid" before measures of financial and rehabilitative assistance could be

disbursed (Sullivan, 1991:257).

The medical interpretation of disability has been a major and continuing influence on social perceptions of disabled people and philosophies for their care. Medicine established the connection between disability, disease and individual pathology together with a focus on the degree of functional impairment. For "mentally defective" people, this was their intelligence. The advent of medical science and its supporting new technologies brought major improvements to the lives of many disabled people, but "mentally defective" people, like others with physical, sensory, or psychiatric disabilities, were not sick. Medical knowledge was often of little direct benefit to people with a "mental deficiency". The institutional environments in which these people were cared for, managed by medical professionals within the Department of Health, continued to be the means of keeping them segregated from society.

### **Community Care: the challenge to containment**

Social influences on the care of people with "intellectual handicaps" began to emerge from around the 1960s, in a social environment that was beginning to recognise the impact of pressure groups. These new perspectives became the means of challenging the basis and assumptions of social policies which supported segregated, institutional models of care. The focus of these new perspectives was the notion of deviancy on which such policies rested.

One of the earliest and most influential theoretical works were the

writings of Goffman. His four essays, Asylums (1961) questioned conventional understandings of the function of institutions of reform, suggesting that prisons and mental hospitals did not cure deviant behaviour, but perpetuated it. Such places gathered "marginal people into tightly segregated groups" and reinforced their sense of alienation from the rest of the community (Jones & Fowles, 1984:11). In Goffman's later work Stigma, he suggested that institutional experiences for "intellectually handicapped" people created both a stigma and a situation which "disqualified [them] from full social acceptance" (1963:preface,33).

Sociologists studying deviancy were suggesting too, that in practice differentiating between deviant and non-deviant behaviour was often difficult. Particular behaviours could be classified in different ways depending on societal reaction and the social context. This began to shift the focus of research from 'how much' deviance, disease or handicap existed in society to examine questions of 'how', and 'in what circumstances' did behaviour become described as deviant, and individuals labelled as such. Sociological researchers found substantive evidence of deviancy being created through the processes which described individuals as deviants (Alaszewski & Ong, 1991:14). These findings drew on the work of Szasz, who had argued that the concept of mental illness was a 'myth' which served to justify and perpetuate unwarranted diagnostic and custodial practices (Jones & Fowles, 1979:55; Sarason & Doris, 1979:29). Deviance then, was no longer considered an innate characteristic (inherited, in the

case of people with an “intellectual handicap”), but the result of social processes and social groups whose rules resulted in the labelling of those who infringed these, as offenders (Alaszewski & Ong,1991:13-15). These new understandings and attitudes towards ‘difference’ called for new models of care, and social policies, that would reverse the segregation experienced by people with an “intellectual handicap”. The principle of normalisation, embodying these social ideas, provided this framework and a new philosophy of care.

The social theory of normalisation originated in Scandinavia as a relatively simple, pragmatic alternative to institutional care (Chappell, 1992:35). An early definition described it as:

Making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society.  
(Nirje,1980:33)

The concept of normalisation is culture-specific. The cultural norms and patterns are those to which normalisation pertains and those to which the restoration, rehabilitation, and reintegration of “intellectually handicapped” people returning to the community, are ultimately linked (Wolfensberger, 1972:13).

Normalisation thus involves the adjustment of the social environment and the behaviours of deviant individuals, so that an individual’s lifestyle no longer bears any appearance of abnormality and identifies as closely to that of non-disabled peers as possible (Alaszewski & Ong,1991:17). The process

of normalisation uses the social norms that once identified "intellectually handicapped" people as "handicapped", as the means of removing the labels and stigma to include them again in the mainstream of society.

Normalisation is also underpinned by a value system, one relating to human rights. The civil rights movement in the United States during the 1960s was the catalyst that inspired parent and consumer groups to seek the establishment of citizenship rights for people with an "intellectual handicap", their right to a normal life. From the 1970s, people with an "intellectual handicap" began to want equality with other members of society, to treatment and opportunities that would not disadvantage them simply because they were "intellectually handicapped". Legislation, particularly in the United States, was moving to protect the rights of "intellectually handicapped" people rather than those of society. The new position of "intellectually handicapped" people meant they also experienced the risks and responsibilities, the frustrations, failures and rejections associated with normal living (Alaszewski & Ong,1991:15; Bannerman Foster,1987:13; Macdonald,1991:129).

Wolfensberger, who transferred the principle of normalisation to the United States, incorporated the substance of both the Danish and Swedish definitions of normalisation into the North American version for the purpose of theorising and radicalising the concept of normalisation (Chappell, 1992:36,43; Wolfensberger,1980:7,79). Normalisation was seen as both a goal and a process of practice. Wolfensberger developed the principle into a

meta-theory, with a wide range of applications in the human services and a number of important corollaries that affected both the development and evaluation of services and service systems for people with “intellectual handicaps”. Its aim was to provide “intellectually handicapped” people with socially valued conditions and roles, replacing the roles that prescribed them as deviants (Chappell,1992:43).

Out of the new sociologies of deviancy and concepts of normalisation, grew a conviction that institutions could never be altered sufficiently to provide an environment conducive to the growth and development of those who lived in them. The essentially custodial and abusive nature of these facilities prohibited any reform. Community settings were therefore seen as able to offer more appropriate and effective situations in which to implement principles and practices of normalisation for people with “intellectual disabilities” (Bannerman Foster,1987:13).

As social policy, corollaries of the normalisation principle became the basis of a wide range of community based services for “intellectually handicapped” people. Deinstitutionalisation saw people moved out of large institutions to live in small residential units in the community. Integration gave people with “intellectual handicaps” access to the same generic services in the community as the non-disabled, including mainstreaming into education services. Community care engaged the local community in their support networks (Ayer & Alaszewski,1984:64). Eventually, the goals of normalisation became synonymous with the goals of community care

(Chappell,1992:35).

Community care has since drawn criticism as a term that has imprecise meaning (Macdonald,1991:145,146). Conflicting objectives are bound up in policies labelled as community care. The concept has been applied in the development of separate practice models to serve the needs of clients, managers, professionals and the community, and while these models are not mutually exclusive, there is considerable variation in the purposes for which each is implemented (Dalley,1989:200). Community care policies also have major implications for women as the main providers of care within the family. This is especially so where there are disabled dependants, as the model of the traditional, nuclear family is the 'norm' implicit in normalisation (Baldwin & Glendinning,1983).

While there has been an overwhelming momentum of change prompted by policies derived from principles of normalisation, there is continued debate over the place of institutional care in the spectrum of services to people with learning disabilities. Some maintain that the rationale for institutional care has been challenged to the point where institutions themselves can now be regarded as 'the problem' (Alaszewski & Ong,1991:12). Others would suggest that not all learning disabled people may be equally suited to, or wish for, care in the community (Macdonald,1991:132). Institutions therefore have a limited role in caring for the more severely disabled, many of whom present other conditions or behaviours in addition to their learning disability (Bannerman Foster,

1987:14). The debate as to whether or not deinstitutionalisation should be 'total' appears to revolve around the issue of where people with profound and/or multiple learning disabilities can, and should, live. It appears to be a debate that may have lost sight of the right of learning disabled people to make choices of their own. Moreover, whose interests in the debate are actually being served (Bannerman Foster, 1987:16,137)? Of greater concern is whether community care will 'reinstitutionalise' those living in these community situations because wider economic constraints reduce access to resources.

Inadequacies in the principle of normalisation as a radical theory are now being identified, as much the result of criticisms by disabled people themselves as its failure to overturn the perspectives it challenged. Criticisms have been made of its "elegant simplicity and parsimony" (Perrin & Nirje, 1989:227), which have allowed the principle to be misinterpreted and misunderstood. Others have questioned the appropriateness of the core social values to which normalisation pertains (Robinson, 1989:248), the excessive emphasis on making learning disabled people more like "normal" people rather than their unconditional acceptance in society, and the lack of challenge to social systems and processes which prevent this (Perrin & Nirje, 1989:224-226). Further criticisms of normalisation have arisen from the perspectives developed by social theories of disability.

Although the debates will continue over specific aspects of community care, social policies based on the concept of community integration are

likely to remain those that are the predominant influence on the nature of the services for learning disabled people. The social philosophies which had established new dimensions of care for "intellectually handicapped" people became the means of expediting a new sociology of disability.

### **Towards A Social Theory of Disability**

The need for new ways of thinking about disability arose from a growing recognition that the existing perspectives were theoretically inadequate and the conceptualisation of disability therein, ultimately unhelpful to disabled people themselves (Abberley,1987; Chappell,1992; Oliver,1986;1990; Sullivan,1991). The need for a theory of disability which took cognisance of the experiences of disabled people and the political context in which they occurred, formed the substance of critiques of 'disablist' perspectives. These perspectives functioned to maintain discriminatory practices towards people with all forms of impairment. Critiques of 'disablist' perspectives provided the means towards constructing such a theory.

The work of Foucault became a source for these critiques. He was concerned with how the relationships of power operated to control both individuals and groups in society. Foucault suggests that "it is in discourse that power and knowledge are joined together" (1977:100). Discourse (the way ideas are thought about and acted on) focuses upon the actions of the 'body' and whether or not it conforms to certain 'norms' of society. Dominant discourses which establish these social boundaries introduce new ways of constructing social order, legitimating certain practices and

beliefs and implicitly, delegitimizing others (Foucault, 1978:24; Munford, 1994:276; Oliver, 1990:45; Turner, 1987:80). Jones and Fowles have suggested that in most societies this discourse was effectively a dynamic of exclusion which was nothing more than a conspiracy by the powerful against the powerless (1984:45). Foucault believes that the discourse which defined the boundaries of society in relation to 'madness' (unreason) could only be understood in relation to 'unmadness' (reason). Applied to disability, the notion of individual disability is possible therefore, only alongside notions of individual 'able' bodiedness (Oliver, 1990:47).

Disabled people themselves began the challenge to these disablist perspectives by re-defining disability, proposing instead a twofold classification:

Impairment as lacking part or all of a limb, or having a defective limb, organism, or mechanism of the body;

Disability the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (Union of Physically Impaired Against Segregation, (UPIAS), 1976:3-4 cited in Oliver, 1990:11)

The definition moves disability from being an individual pathology to site it within society and social organisations that discriminate, identifying "the cause, then, of disability [to be] ... social relationships" (Finkelstein, cited in Chappell, 1992:44). This was not to ignore the aspect of impairment, both physical and physiological, the social origins of which provided the means of developing a political theory of disability as oppression (Abberley, 1987).

Understood in this context, disability can be viewed as a set of beliefs

and ideas (an ideology) that justify and perpetuate the social mechanisms producing and reproducing the conditions of disadvantage (Oliver, 1990:43; Abberley, 1987:13). In Oliver's view, disability is an ideology that concurs with the individualistic nature of capitalist society, and is supported by peripheral ideologies of individualism that legitimate medical intervention and underpin social policy. As part of a hegemony of normality, able-bodiedness, and able-mindedness, such an ideology of individualism merely supports the adaptation of disabled people to society instead of changing the social mechanisms to effect their access to, and inclusion in it (Oliver, 1990:44,58; Sullivan, 1991: 260).

Defined in this way, disability is a particular form of social oppression. Learning disabled people experience this oppression in their day-to-day lives as economic, social and psychological disadvantage; as poverty, marginalisation and disempowerment. It is this social oppression that is responsible for 'disabling' people with impairment (Abberley, 1987; Chappell, 1992:46; Oliver, 1986:6; 1990:70). Sullivan, 1991:259).

But such an analysis of disability is not able to explain why disabled people are socially oppressed nor how they have come to be perceived as disabled. According to Abberley (1987:12), there is "a complex interaction of material and non-material factors" in the process of oppression. Ideas, beliefs and attitudes alone do not account for the oppression experienced by those with impairment, it is the material context in which these are shaped which does (Chappell, 1992:46). Idealist accounts of disability are

inadequate because they fail to “link the interpersonal relations with the material base upon which interactions take place” (Abberley,1987:14). A materialist analysis of social relationships identifies those economic, social and political structures which underpin the ideology of disability, as those that also create material and social disadvantage and oppression for disabled people (Chappell,1992:43; Sullivan,1991:259). Oliver develops such a materialist analysis of disability within a framework of historical materialism. He incorporates Finkelstein’s (1981) understanding of the origins of the abled-disabled relationship, and his own earlier work. Oliver suggests that the nature of disability in society can be understood only by considering the relationship between the type of economy, the size of the economic surplus and the values that influence the redistribution of this surplus amongst society (Oliver,1990:24-32). Oppression as an experience for disabled people results from the emergence of capitalism as a mode of production, their exclusion from the work process and a consequent change in societal perceptions of disabled people (ibid:44). Abberley argued that this oppression is neither natural or inevitable, for as Oliver establishes, disabled people have not always been treated as inferior in all societies over time (Abberley,1987:7; Oliver,1990:70). Abberley suggests there is a beneficiary of this state of affairs (1987:7). Oliver identifies this beneficiary as capitalism, in that:

Disabled people may perform an economic function as part of the reserve pool of labour and an ideological function in being maintained in their position of inferiority. (Oliver,1990:70)

Disability, like all other forms of oppression, is created by the "ablist" biases of mainstream society (Stone, 1985:26).

Sullivan describes Oliver's work as one of the most comprehensive and theoretically developed material analysis of disability to date (Sullivan, 1991:259). Although his analysis is a generalised consideration of disability, it has provided a sociological basis for other theorists developing critiques of aspects of impairment as disability. Chappell has focused on normalisation as the "dominant" paradigm in the field of learning disability, identifying three main inadequacies in its development as a social theory (1992:35). She challenges the central role of professionals and academics in the disability field. Their role, Chappell argues, is at the expense of learning disabled people themselves, whose views and concerns are too often assumed. Normalisation focuses on providing a theory which improves service quality, while at the same time legitimising the role, the control and authority of professionals in the lives of people with disabilities. Although the principle of normalisation strived to change existing structures, it failed to locate the experience of learning disabled people within a wider political framework (Chappell, 1992:40).

Chappell describes normalisation as functionalist in its assumptions. In its emphasis on consensus, shared values and goals, and partnership between users and providers to achieve service objectives, normalisation fails to provide an analysis of social conflict, inequality or the distribution of power. She points out that the goal of "independence" shared by users and

professionals, is likely to have different meanings for each group. Chappell claims normalisation has failed to recognise the power relationship between professionals and learning disabled people (1992:41,42).

Chappell's main criticism of normalisation is that it fails to provide a material analysis of learning disability. She submits that the principle of normalisation provides an idealist explanation of oppression and discrimination, locating the suggested cause of social relationships (the construction of disability) to be in the realm of ideas and attitudes that others have about learning disabled people. The refashioning of attitudes and values that normalisation seeks to do, fails to address either the material conditions that helped to shape them, or the oppression experienced by learning disabled people as a consequence of these material conditions. Critics of exponents of normalisation suggest the theory has overlooked the role of poverty as a major cause of disadvantage (Chappell,1992:46). Normalisation's limited focus does not allow questions such as "why people with learning disabilities require services, why they are excluded from the labour market and why poverty is a prerequisite of receiving services" to arise (ibid:47).

Normalisation is far from being the radical critique it claims to be. Chappell argues that its roots are remarkably similar to the perspectives it strives to overturn. Normalisation has provided a theory of services but not a theory of disability (1990:38,39). Disability issues in general, and learning disability in particular, Chappell suggests, are severely

undertheorised. While giving recognition to Oliver's work as progress towards a materialist theory of disability, she contends that for a rigorous theory of disability to emerge which begins to examine all disability in a materialist account, an analysis of normalisation must be included (1992:38,48). Chappell's sociological critique of normalisation has gone some distance towards establishing this possibility.

As Chappell suggests, Oliver's work is a generalised consideration of disability and he has not applied his arguments specifically to the area of learning disability. While recognising that learning disability is socially constructed, the idea that dismantling 'disablist' structures in society would remove 'disablement', raises some difficulties when applied to people with learning disabilities. Although the removal of 'disablist' structures would result in the inclusion of learning disabled people in many aspects of society, this inclusion would stop short of their full participation in the means of production in a capitalist society. Oliver's argument, while consistent with his theoretical notions, moves too far towards idealism. His analysis of disability however, has advanced a perspective which incorporates the experiences of disabled people themselves.

The moves by disabled people to uphold their own experience of disability in society has resulted in a critical examination of existing concepts and accounts of disability. The political, social and economic context which constructs this experience of oppression for disabled people has become the focus of recent sociological critiques with the purpose of

developing a social theory of disability. As a basis for future social policy, such a theory would ensure the issue of disability made the “personal” “political” (Ballard,1994:296), and shift disability from being a personal trouble to becoming one of public issue (Borsay,1986:179).

## CHAPTER THREE

**FAMILY CARE OF PEOPLE WITH LEARNING DISABILITIES:****1840-1853**

Families who had dependants with learning disabilities in the period of early European settlement in New Zealand faced circumstances that required them, more than during any period since, to be responsible for the care and welfare of their own family members. There were few provisions, either State or voluntary, in New Zealand in the 1840s to support those unable to look after themselves. Families had to be self-reliant and self-sufficient to survive, and would thus have been totally responsible for the care of all dependants, including in all probability, a child with a learning disability.

**The Settlers**

Initially, the white settlers who came as immigrants were carefully selected by agents of the New Zealand Company to ensure a balanced 'frontier' society and achieve an adequate labour supply for the new colony (Graham,1990:54; Sutch,1966:12). But with the passage of time and unscrupulous agents in London who were ready to profit from the demand for new settlers to the colony, the new arrivals began to include "the old, the lame, the blind ... aged widows, young women with infants, others pregnant and without their husbands" (Sutch,1966:41). Each settler ship brought

others who needed to apply for "benevolent assistance" (ibid:55).

As the colony's population expanded in those early years, others were affected by the unforeseen circumstances of life. There were those who became sick, aged or "insane", injured or disabled through disease or accidents, others supporting families who were widowed or deserted (Tennant,1989:20). From the very beginning of New Zealand's history, individuals incapacitated in some way were part of the nation's social fabric.

### **Employment and Economic Conditions**

The need for food, shelter, clothing and employment occupied the immediate attention of new immigrants (Graham,1992:124). Most were labourers or tradesmen, dependent for their living on waged labour, but there was little employment to be found. The New Zealand Company made some effort to fulfill an undertaking made to its labourers who could find no work, to supply them with relief work and rations. But in 1844, the Company abandoned this form of assistance leaving many families with only private charity to turn to, or facing acute distress and starvation (Gardner,1992:61; Koopman-Boyden & Scott,1984:97,98; Tennant, 1989:11).

### **Poor Relief**

Private charity however, was almost non-existent, for the absence of an upper class meant there were few wealthy on whom the poor could rely for donations (Koopman-Boyden & Scott,1984:98). There seemed little sense of

collective responsibility for those who could not earn a living. The Imperial Government and the New Zealand Company formed the essential State apparatus during this period (Fairburn,1989:241), and it was to the Government that the immigrants turned when faced with destitution. In their view the Government had a responsibility to them. Along with the Company, it had encouraged and sometimes assisted immigrants to the new colony, and the immigrants now felt it should be supporting them (Tennant, 1989:12).

But the Government had no State-sanctioned system for the relief of poverty (Koopman-Boyden & Scott,1984:99). The poor law system was not wanted by the settlers, and neither did the colony have the infrastructure by which to implement it (Sutch,1966:44,45). In rejecting Britain's Poor Law system, there had almost been an inadvertent rejection of any Government obligation to support the destitute (ibid:98). The country's founders had failed to recognise that they were introducing a system of production and wage labour "which bred poverty, but omitted to make legal provision in the shape of a poor law for its relief" (Sutch,1966:22).

### **The 1846 Ordinances**

The Government however, was not concerned about such issues. The prevalent political ideology of this period was one of *laissez-faire* which considered the welfare of migrants to be primarily a function of the family (Koopman-Boyden & Scott,1984:100). Survival in this environment was a

big enough challenge for families who were able-bodied and independent. For families with a disabled family member, the challenge was much greater. Ernst (1991:77) has suggested Maori families with mentally ill family members cared for them within the whanau throughout these early years of white settlement. Fairburn (1989:165) maintains that they were able to rely on family and tribal networks for support in a way that pakeha families at this time, could not. Parallels can probably be drawn between the whanau's care of the mentally ill, and their care of those who were mentally impaired.

But it was becoming clear that some basic measures were necessary to relieve the poverty and destitution which now existed in the colony. To this end, in 1846, the colonial government passed three Ordinances that were the first State initiatives towards the welfare of the country's citizens. They were measures of different intent and provision, but were attempts to deal with the problem of those who were destitute.

The 1846 Destitute Persons' Ordinance affirmed in legislation the principle that the family, not the State, was responsible for the material welfare of those who had no means of support. In reality, the Ordinance had little effect. Many migrants were here without families to support them, and those with relatives found them often just as poor. The ideal of family responsibility which the Ordinance sought to establish, in fact remained little more than that (Koopman-Boyden & Scott, 1984:98; Sutch, 1969:51;

Tennant,1989:13).

The four State hospitals<sup>3</sup> were established from 1846 to meet the needs of the Maori, and sick and destitute Europeans (Tennant,1989:12). These State-funded institutions replicated Britain's poor law infirmaries rather than its system of 'voluntary', subscription hospitals. In becoming the means of distributing outdoor relief to the destitute, the hospitals adopted the functions of the poorhouses; the reverse of the situation in Britain, where the infirmaries were attached to the poorhouses (Sutch,1969:66). This "peculiar principle" of State-funded hospitals (Sutch,1966:47) established the limited beginnings of the public hospital system and a method of providing restricted, short-term welfare assistance to destitute settlers during the period of colonisation (Sutch,1966:48; Tennant,1989:12,13). Later, in the larger settlements, this relief was supplemented by limited assistance from a few private charities. Outside these settlements, poor relief would have been almost non-existent (Tennant,1989:14).

The 1846 Lunatics Ordinance was a response to the growing problem of law and order in the colony. It recognised mental impairment as one facet of this problem. The first case of "lunacy" had been recorded as early as 1842 (Brunton,1987:156). The Ordinance provided for the apprehension

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<sup>3</sup> These four hospitals in Auckland, Taranaki, Wanganui and Wellington were set up on the initiative of Governor Grey, who hoped to secure peaceful relations with the Maori people by offering them the benefits of civilisation -education, health and prosperity. The system was limited to the North Island because this was where most of the Maori population was concentrated (Department of Health,1975:12; Sutch,1960:51).

and safekeeping of dangerous “lunatics” and “idiots” and persons of “unsound mind” in a separate building, often a gaolhouse or hospital, while they were unable to remain safely at large (Brunton,1987:158; 1846 Ordinances). According to a more contemporary source, these terms were the nomenclature of the period, “lunatics” referring to the mentally ill, “idiots” to those with learning disabilities and those of “unsound mind” to the aged infirm (the senile) and the alcoholics (Jermyn,1951:2,3). The terms “imbecile” and “feebleminded” came into use with later legislation.

The provisions of the Ordinance were visionary for their time. In contrast to the organisation of the early public hospitals, the Lunatics Ordinance provided for a publicly-funded, colonial lunatic asylum available to persons of any social class (Brunton,1987:158; Department of Health, 1975:13; Tennant,1989:13; Williams,1987:5). In doing so, the State had accepted very early in its growth, a direct responsibility for one group of settlers in need of permanent care (Oliver,1988:12).

### **The Implications of the Ordinances for Families of People with Learning Disabilities**

Families in this new society had to be independent. The Destitute Persons' Ordinance expected them to assume the responsibility of care for all dependent family members (Koopman-Boyden & Scott,1984:98). However, settler families consisted of only immediate family members (Fairburn,1989:165). The kinship networks which the Ordinance envisaged

would support families in difficulties, were non-existent in the new colony. Friendship networks were also absent. In addition, communication between settlers and settlements during the first decade was minimal. Neighbourly visits were infrequent and isolation was a way of life (Fairburn,1989:169,195; Graham,1992:119; Sutch,1969:41). The families of those had learning disabled children cared for their own dependants. There were few others who would.

For women, their primary role of having children and establishing families was the means to the family's economic progress and prosperity. But alongside this, they were likely to have undertaken the burden of responsibility for the care of any disabled family members (Brookes, 1992:129), including those who had a learning disability. Families were productive economic units. Children made a significant material contribution from an early age to the family economy (Macdonald,1990:170). During these years older children performed vital roles as child minders, domestic helps, farm labourers or running errands (Graham,1990:59). It would be reasonable to suggest that some learning disabled children might have learned to do simple tasks of a similar nature.

It is also likely, given the consistent nature of a learning disability that a child with a learning disability would have placed certain constraints on the day-to-day life of the family, depending on the degree of disablement. With no formal education system in place, it is probable that any skills that

children may have acquired would have been related to the family's needs and lifestyle. This could reasonably mean that at best, some children with learning disabilities would have accomplished limited tasks and responsibilities, achieving a degree of integration with the surrounding community. For those whose disablement was more profound, the constant supervision of another family member (probably a sibling) would be required and with this, the likelihood of being contained in a locked room or separate building. Babies, and very probably learning disabled children, would have been given laudanum to keep them docile. With the passing of the 1846 Lunatics Ordinance there was the possibility, although rather remote for many, that difficult or dangerous family members could be contained in a local gaol or hospital ward.

While there is no evidence to suggest so, it could be reasonably assumed that the family's understanding and treatment of a child with a learning disability would be determined by parental attitudes and values rather than the sanction of wider society. A child would have been cared for in whatever manner the parents deemed appropriate.

Childbirth was dangerous, and infant life precarious. Most immigrant women sought assistance from older women who were skilled or experienced in childbirth, if they were available, around the time of delivery (Macdonald, 1990:166). Doctors were few and far between. Hospitals were for the destitute. If female relatives were available to act as midwives, they

attended the birth, ran the household and cared for any other children around the time of confinement. In the absence of other women, husbands delivered the babies (Graham,1990:62). Long or difficult labours and inexperienced assistance would have resulted in the births of learning disabled children into many families, if not in the death of mother or child. Severely disabled babies may have been as much at risk of dying as those who were illegitimate, suffocating through being smothered, or meeting starvation or neglect (ibid.72).

The physical and emotional demands from the sheer volume of work, often in the most basic conditions, were taxing to the fittest of women (Graham,1992:125). The combination of poor nutrition, constant childbearing over what could be a twenty-five year period of reproductive life, and a pregnancy late in this period were all factors that might have resulted in such a birth. It would be reasonable to assume that learning disabled children born into the circumstances which these families faced would have simply added to the strain, the stress, and labour-intensive nature of the work that was pioneering life for most families (Graham,1990:66).

### **The Implications for People with Learning Disabilities**

In reality, few were confined by the Lunatics Ordinance. Separate accommodation was not considered necessary, or practical in the early years of colonisation. Immigration barracks, old people's homes or other

converted buildings of a similar nature sufficed where there were no gaol houses or public hospitals (Brunton,1987:158). Alongside the "lunatics" were any variety of convicts, deserters, debtors, delinquents, prostitutes, "waifs" and "strays", "drunkards" and "vagabonds" (Brunton,1987:157; Ernst,1991:69; Williams,1987:3). The gaols would often have been overcrowded, and conditions unhealthy and insecure (Brunton,1987:157). Females were referred to hospitals, when and where possible (Brunton,1985:3). The 'safe custody' provided them by the State would seem as much for the safety and convenience of society as for their own protection.

### **The Consequences of the 1846 Ordinances**

The passing of the Ordinances in fact exacerbated the pressured situation in the gaols. While the authorities tried to keep to a minimum those accommodated in such places, the increasing numbers and the differing needs of those placed in custody, eventually created difficulties for both gaol officials and doctors (Jermyn,1951:42). "Lunatics" were not commonly regarded as criminals, but neither did they fit common perceptions of sickness, on the basis of which some were kept in hospitals (Brunton, 1987:157).

Prison officials resented the inconvenience created by the presence of "lunatics" in the gaols. Problems arose for the prisoners and the gaolers from non-classification, from violent behaviour and from overcrowding

(Brunton,1987:157; Williams,1987:3). Medical authorities trying to treat patients found conditions there unfavourable. They considered that the patients should be receiving treatment rather than simply being locked up. Hospital conditions were little better. They were grim and foreboding places seen to depress and disturb rather than provide a place of refuge for troubled minds (Brunton,1987:158; Williams,1987:3).

The increasing dissatisfaction with both the gaols and the hospitals as places of confinement for "lunatics" by all concerned, together with a growing humanitarian concern that they required special attention, brought about both a demand by the public and a determination by the authorities to see that "lunatics" were housed in separate accommodation (Jermyn,1951:52; Williams,1987:3). This came to pass with the formation of provincial government.

The initiatives set in place by the colonial government for the relief of poverty and destitution constitute what Tennant refers to as the "tentative manifestations" of government responsibility for welfare (1989:14). But they were balanced throughout by a stronger philosophy which stressed family responsibility and self-help as the means of coping with most circumstances in a colony where few relief provisions existed. The State's move to take responsibility for those who were in some way clearly mentally impaired, recognised some of the difficulties of caring for "lunatic" and "idiot" family members in early New Zealand society. As an early form of

social policy, the 1846 Lunatics Ordinance was a reflection too, of prevailing social beliefs that problem groups in society should be controlled by containing their members in secure situations.

The argument that greater independence for individuals with learning disabilities has required a greater involvement of the family in achieving this, is well illustrated by this period of early settlement. The State's support of families at this time was minimal. The inability of people with a learning disability to be completely self-reliant meant most families had little option but to assume full responsibility for the support and care of family members who had a learning disability, in this new settler society.

## CHAPTER FOUR

**INSTITUTIONALISATION: The Growth of Segregated Care**

The formation of provincial government in 1853 marked the beginning of a long period in New Zealand's social history during which institutions became the principal means of caring for the mentally impaired. While the period actually spanned more than one hundred years, this chapter is concerned with the years from 1853 to the end of the 1920s. During this time a combination of factors involving acts of legislation, the occupation of public office and particular social influences, brought about gradual changes to the nature of institutional care and the purposes for which institutions were established. Although people with learning disabilities and people with mental illnesses were recognised as two distinct groups, it was not until the end of this period legislation was passed that acknowledged their separate needs.

**The Establishment of Lunatic Asylums**

Provincial governments were charged by the colonial administration with the responsibility for hospitals, and by these same delegated powers they established asylums for the care of "lunatics" (Williams, 1987:5). They were administered, alongside the hospitals, as medical departments of provincial governments (Department of Health, 1975:13) and funded from provincial revenues.

The belief that those who were dangerous or disruptive to society should be removed and contained in institutions, was a solution to social problems which reflected nineteenth century attitudes and thinking as much as did the stigma that surrounded insanity (Ernst,1991:69,71; Graham,1992:137). To the European settlers of this era, asylums were the obvious means of dealing with lunacy in early New Zealand society (Brunton,1985:4; Haines & Abbott,1985:44). While the main purpose of the asylum was one of containment, there was concern that the patients within its confines receive humane and proper treatment (Williams,1987:5)

#### The 1868 Lunatics Act

Many of the "lunatics" in asylums would have been transferred from gaols and hospitals under the provisions of the 1846 Ordinance. Others would have been admitted by families or relatives seeking safe custody for their dependants. Under the 1868 Lunatics Act the term "lunatic" was to be construed to mean any "person idiot lunatic or of unsound mind and incapable of managing himself or his affairs" whether found to be so by examination or not (1868 Lunatics Act,clause3). This definition did little to restrict those admitted to asylums to the "lunatics" only. The legislation was more concerned with putting in place committal procedures and requirements for patient care. But from 1868, it reflected some central government policy for the care of "lunatics".

#### The Beginning of Asylum Care

The first asylum, built in Wellington in 1854, was followed by others in

Otago, Canterbury, Nelson, Auckland and Hokitika during the 1850s and 1860s when the immigrant population was expanding rapidly. These six institutions formed the basic network of the country's asylums, making plans for a single, central asylum for the whole country eventually unnecessary (Brunton,1987:159; Ernst,1991:71; Williams,1987:5).

These 'first generation' asylums were usually located on the fringes of settlements. This facilitated interaction between patients and the local community, and allowed for the element of agricultural self-sufficiency and community life that the treatment programmes required (Brunton,1987:162; Williams,1987:6). Centred around work, recreational and intellectual pursuits and regular church services, this focus led to a belief that such means could bring "lunatics" back to full health (Brunton,1987:161; Williams,1987:5). It was claimed that at Sunnyside, several "imbeciles" (those with more profound "mental defects") had benefitted from such programmes (Brunton,1987:161).

#### The Growth of Asylum Care

Once asylums opened, there was a steady increase in the number of people admitted (Appendices to the Journals of the House of Representatives, (AJHR),1873:H-23,3). Officials noted many inmates were sent to asylums so "that their relatives may be relieved of the trouble and expense of keeping them at home" (AJHR,1882:H-9,12).

Those in charge of asylums made numerous complaints about their institutions having become dumping grounds for the "flotsam and jetsam of

society" (AJHR,1887:H-9,2). Numbers of chronic, incurable, but harmless patients were admitted to asylums (AJHR,1881:H-13,2). Many of these were pauper "lunatics" who had no home, no relatives, and no friends to whom they could be discharged once they were 'cured' (AJHR,1882:H-9,12; Williams,1987:12). They were better suited, officials suggested, to refuge care (AJHR,1886:H-9,2). Others were admitted with "transient and comparatively trifling affections of the mind" (Fairburn,1989:164). Yet another group comprised the "imbeciles".

Observers who had made comparisons of the conditions in England at the time with those in New Zealand, noted that there was a much higher proportion of "idiots" admitted to asylums here than in England, where the more harmless would have been cared for at home (AJHR,1881:H-13,2). Oakley Hospital records indicate children as young as ten years of age were admitted to the asylum. They were admitted at an even younger age if they had become difficult or dangerous and a menace to their family (Oakley Hospital Records,1890-1910 cited in Haver,1967:10). This would suggest that families in New Zealand viewed asylum care differently from their counterparts in Britain.

The increasing numbers of "imbeciles" being admitted to asylums led to calls as early as 1882 that consideration be given to the establishment of a separate provision for these patients (AJHR,1882:H-9,10). It was to be another forty years before any moves were made to do so.

### Difficulties in Asylum Care

The physical conditions, the size and layout and quality of care varied greatly between institutions. There were constant references in reports to the Colonial Secretary of overcrowding in facilities that were often inadequate, decayed and neglected. These were conditions that did little to improve patient health (Ernst,1991:73; Williams,1987:10). Patients in Auckland's asylum were obliged to sleep on the floors of the day rooms and passages because of a lack of room in the dormitories (AJHR,1875:H-2,1).

Universal entitlement to asylum care meant all social classes were represented. Some basic segregation of patient types was usual. This was often achieved through the architecture of the building. The "lunatics" were segregated from those with other social problems, the men from the women, and the unmanageable patients from the docile and refined (Brunton,1985:3; 1987:159). The admission of 'inebriates' presented a constant frustration for officials, some being sent "straight from the ships" to the asylum on arrival in the colony (AJHR,1879:H-4,2). However, after the 1882 Lunatics Act was passed, they were supposed to be kept separate from the "lunatic" patients (Brookes,1987:172). The 1882 Lunatics Act also tightened the definition of "insanity" in an effort to restrict the latitude with which this "elastic" term was applied (1882 Lunatics Act,clause 2; AJHR,1881:H-13,2).

Differences in asylum conditions and the difficulties associated with patient care precluded the possibility at this stage of establishing a uniform

standard of care within asylums, but the need had been recognised. The Report of the 1871 Joint Parliamentary Committee upon Lunatic Asylums recommended that a suitably qualified medical officer from Great Britain, experienced in the treatment of the insane, be appointed to supervise and control of the colony's asylums. The Committee had been established by a group of politically active medical doctors, who wished to make the medical profession not only responsible for State asylums (achieved through the 1868 Lunatics Act), but also the sole experts in the treatment of mental illness. Committee members encouraged the hope that medical (rather than lay) management of patient treatment would lead to improved patient recovery rates (Ernst,1991:74; Williams,1987:29).

#### The Groundswell of Change

The establishment of asylum care took place against a background of changing public attitudes towards these institutions (Brunton,1987:164). The abolition of provincial government in 1876 saw the colony's hospital and charitable aid reorganised and control of the asylums returned to central government. A lack of public enthusiasm (and private charity) for services to "lunatics", and the government's wish to maintain the discipline and control aspect of lunacy policy were two reasons behind this (Department of Health,1975:15; Ernst,1991:68,69; Tennant,1989:12; Williams,1987:28). Local authorities passed by-laws that denied hospital admission to those (such as "lunatics") whose care might be long-term or expensive (Dow,1991:51,52). Court orders committed "lunatics" to asylums

and not hospitals. Asylums therefore had no choice but to admit them (Brunton,1987:164; Williams,1987:28). This left the state with the "lunatics" as one of a number of 'residual' social problems for which it assumed responsibility (Ernst,1991:68). From these policies developed the parallel, but largely independent services for the mentally and physically ill (Department of Health,1969:14).

The increasing number of patients admitted to asylums with long-term, chronic or incurable illnesses was compounded by the effects of a long economic depression which had begun in 1865, and continued over the next thirty years (Brunton,1987:164; Ernst,1991:72; Sutch,1969:85). "Lunatics" became an economic burden to some families, with "an unusual proportion of idiot and imbecile children" being admitted to asylums during these years (AJHR,1887:H-9,2). Long-term care also took its toll. Families often had no choice but to admit dependants, and sometimes caregivers, into institutional care. As economic circumstances worsened, the population of older, single, male pauper "lunatics" in asylums also grew (Williams,1987:28).

The overcrowding increased over the remaining years of the century, as those admitted to asylums usually never left. The belief that medical management of asylums would increase patient cure rates was fading, and a sense of disillusionment prevailed (Brunton,1987:164,165). There was a return to custodial practices simply as a means of coping with patient numbers. Asylums became little more than goals (Brunton,1987:165;

Ernst,1991:72; Williams,1987:28). A report in 1877 to the Colonial Secretary on the Auckland asylum, described patient conditions as "deplorable", the system of treatment "neither curative or palliative", the patients with "neither occupation or amusement" and the great majority as "simply prisoners" (AJHR,1877:H-8,1).

Asylums had become associated in the public mind with incurability and the stigma of custodial care, but the most damaging shift in public attitude came as a result of the 'save the sane' campaign (Brunton,1987:164). The popular papers had begun publishing sensational stories from British sources, of violence and horror in asylums. The public reacted with hysteria and fear. The humanitarian concern for the inmates once present disappeared, overcome by public suspicion, self-protection and indifference. There was a demand for tighter security at asylums and community involvement in asylum activities lapsed, exacerbating the internal difficulties that were already present (Brunton,1987:164; Ernst,1991:72; Williams,1987:28). The reaction of the authorities in the face of an inimical public, was to build higher walls around existing asylums and situate the 'second generation' of asylums in rural areas away from population centres (Williams,1987:29). Rural or semi-rural locations were regarded as the solution for a number of problem groups in society around the turn of the century (Tennant,1989:54). It was this segregated, insulated, institutional environment that later provided the architects of social change with the potential for achieving their objectives over the next

fifty years.

### **The Reorganisation of Hospital Services**

The years between 1876 and 1885 were marked by attempts to organise and rationalise provincial hospital services into a national system of health and welfare provisions to the colony (Graham,1992:136; Tennant,1989:22). Central government had already assumed responsibility for asylums, and established the administration and financing of provincial asylums as a Department of State in 1876. The reorganisation also put in place the recommendation of the 1871 Joint Committee, establishing an Inspector of Lunatic Asylums as the permanent head of this new Lunatic Asylums Department (Department of Health,1975:15; Ernst,1991:74; Tennant, 1989:40). In 1880, with the establishment of a Department of Hospitals and Charitable Institutions, the inspectorate role was extended to include both hospitals and lunatic asylums. It was intended that the asylum inspectorate have seniority over that of the hospitals, because those appointed as Inspectors all had considerable experience in the care of "lunatics" in asylums (Department of Health,1975:16; Tennant,1989:40). The role of Inspector was to have a significant influence on the development of asylum care through the particular incumbents appointed.

### Charitable Aid

Hospitals retained a responsibility for the indigent with the formation of provincial governments in 1853, but from around this time, the relief provisions that they had established began to be supplemented by those of

voluntary charities. In the larger population centres, the efforts of charities to organise indoor provisions established Homes for the young, the old and deserted women and families. But this institutional care was expensive to maintain and even in the larger centres, outdoor relief in the form of food, rent and clothing in cash or kind, was more usually the norm (Tennant, 1989:14-19).

With the return to central government in 1876, local provision continued to meet the need for relief. From 1885, local charitable aid boards set up by central government administered outdoor relief through the hospitals and in addition, managed any private benevolent establishments within their districts (Department of Health, 1975:16; Oliver, 1988:15; Tennant, 1989:22). The poor and the destitute (including numbers of so-called "harmless imbeciles") turned to local charity as state-funded charitable aid became curtailed in the latter part of the century (Oliver, 1976:7).

#### The 1885 Hospitals and Charitable Institutions Act

The Act, which put in place an administrative foundation for hospitals, reflected the influence of Dr. G.W. Grabham who became Inspector of Lunatic Asylums in 1881. Dr. Grabham's belief in local management and voluntary and local finance provided a rationale by which Government could rid themselves of a hospital and charitable aid system they considered an economic burden (Department of Health, 1975:15,17).

The justification for change appeared to be the proliferation of local

hospitals throughout the country and their increasing cost to Government. Parochial rivalry was blamed for these increasing costs (Department of Health,1975:17). In the midst of a recession, private charity had apparently made a less than satisfactory contribution over a number of years to their funding. It was considered extravagant expenditure for a country in the midst of an economic depression that almost three-quarters of the finance required for local hospitals had to come from the State (Department of Health,1975:17; Dow,1991:47). The State's concern, Dr. Grabham believed, should be to provide for only the "deserving poor" (Department of Health,1975:17).

What is perhaps more revealing of the rationale behind these organisational changes is Dr. Grabham's allegation some months previously, that free hospital treatment at the expense of central government (i.e. through the failure of local hospitals to collect fees) was, to an alarming extent "pauperising" the population by taking away inducements for thrift (AJHR,1885:H-18b,1; Department of Health, 1975:17). This fear of anything which might "lessen the self-reliance of the people" and "foster a dependence on the public" (and thus become a threat to public morals) had been present throughout the colonial period (Dow,1991:52; Sutch,1966:47). However, the possibility that the Government's generosity might be encouraging such pauperisation, was of concern.

It was this fear of pauperisation which was behind the State's anxiety

over the burgeoning social problems and poverty evident in the colony in the late 1870s (Koopman-Boyden & Scott, 1984:101). The possibility of a permanent pauper class developing as consequence of the long economic depression had not escaped the country's leaders. This emerging social class according to some was "the same, distinctly murky, social pool from which was fished the population of asylums and charitable institutions" (Tennant, 1989:23,40). The population of such places was considered to be large enough. Dr. Grabham had cautioned his superiors of the dangers inherent in admission policies to institutions which were too free (Dow, 1991:51). He had noted a rapid increase in asylum populations owing to "the strong tendency ... to throw every case that can be brought within the general definition of insanity off the local rates onto the general taxation of the colony" (AJHR, 1894:H-7,1).

### **The Influence of Dr. Duncan MacGregor**

These warnings had been sounded in the writings of two prominent Otago men from the mid-1870s, Robert Stout a politician, and Dr. Duncan MacGregor, then Professor of Mental and Moral Philosophy and Political Economy at the University of Otago. Both had taken a keen interest in the concerns expressed in Britain about urban poverty and the "casual" poor. As supporters of Social Darwinism, they found in its theories, solutions to what they believed was the imminent pauperisation of the colony (Fleming, 1981:11; Tennant, 1989:23). MacGregor's beliefs in particular, were to influence State provisions for the destitute through into the next century.

### Social Darwinism

In 1859, Charles Darwin published his theory of evolution (Bowlby,1960:339). It was a theory of biological change based on genetic principles describing the survival of all living things through the process of 'natural selection'. Herbert Spencer, in the early 1860s, began the development of a single, natural law that would unify all the sciences (Wiltshire,1978:66). His hypothesis involved Lamarckian concepts which suggested characteristics such as poverty were inherited, and that evolutionary 'progress' occurred through the 'survival of the fittest'. He integrated Darwinist notions of 'natural selection' alongside his own ideas (ibid:66,68,69).

While Darwin applied his evolutionary theory only to the realm of nature, Spencer believed that the evolutionary process could also be applied to society, as the means of its progress. Spencer saw a beneficent social evolution in which nature, rather than philanthropic intervention, purged the world of misery (Wiltshire,1978:50,69,197). Spencer believed society advanced when its fittest members (the resourceful and hardworking) increased in number, and the "unfit" were allowed to die out. The struggle for survival was the means whereby the fittest survived, hardship being the essential ingredient in this process. Spencer did not see it as the State's role to mitigate and ease the circumstances which would bring about social 'progress' (ibid:200,225).

Social Darwinism became the fundamental principle which shaped

MacGregor's views on poverty in New Zealand, as they were expressed in his series of articles in 1876. His own early experiences, and his conversance with both the 1834 Poor Law in Britain and the harsh Scottish Poor Law, would have influenced the rigorous and uncompromising views he held towards "social undesirables" (Chilton, 1968:147; Tennant, 1989:44).

During the time MacGregor occupied a Chair of Mental and Moral Science at Otago University, he introduced a number of his students to the tenets of social Darwinism. Though his views were not shared universally, some of the students who adopted his convictions were later to occupy positions of considerable influence in the leadership of the colony (Chilton, 1968:146; Tennant, 1989:23,44).

#### MacGregor's Social Darwinism

MacGregor believed that the colonisation of New Zealand had involved a form of "natural selection" by which the worst aspects of poverty in the Old World had been avoided (MacGregor, 1876:316). He saw the growth of a pauper class, due in his view, to Vogel's immigration policies of the 1870s, contaminating this 'new' society and creating a heavy tax burden for the State (AJHR, 1895:H-22,2; Chilton, 1968,147; Oliver, 1976:6; Tennant, 1989:46). According to his social Darwinist thinking, poverty was an individual, moral failing (Tennant, 1989:23). He therefore described paupers as part of the group in society deemed to be "unfit". He regarded charity given indiscriminately to the "unfit" as misapplied philanthropy (Fleming, 1981:5). It was almost inevitable that distinctions between the

“fit” and the “unfit” would be drawn along social and economic lines (ibid:82).

MacGregor believed that the pauperisation of the people could be prevented if strenuous disciplinary measures were applied, measures which would provide the deserving poor with only the bare minimum of relief (AJHR,1888:H-9,3; Chilton,1968:147; Oliver,1976:8; Tennant,1989:23). Assistance that was too generous would merely confirm the “undeserving” (the reluctant able), and the “degenerate” (the hopeless) in their reliance on charitable relief. MacGregor believed that part of the solution lay in a return to a degree of individualism and policies of laissez-faire (Fleming,1981:6; MacGregor,1876: 319).

MacGregor's appointment to Otago University gave him opportunity to substantiate his beliefs. Between 1871 and 1876, he held a concurrent term as medical officer of the Otago Lunatic Asylum. (Tennant,1979:35; 1989:44). At the time of his appointment as Inspector of Hospitals in 1886 during the last year of Stout's premiership, MacGregor's views were already widely known and made him a natural successor to Grabham in the role of Inspector (Chilton,1968:145; Tennant,1989:23). MacGregor, in what has been described as “his self-appointed role as guardian of the public purse” (Dow,1991:52), began his term in office by recommending stringent controls on public money, charitable aid, to prevent further pauperisation of the people (Chilton,1968:147; Oliver,1976:8). Too much State assistance he announced, threatened to “dry up the springs of voluntary charity” (AJHR,

1887:H-19,1; Dow,1991:52). It was MacGregor's intention to make relief as unattractive as possible. The able-bodied he felt should not be entitled to relief at all, the "deserving" poor were to be assisted only minimally, and the "undeserving" poor were to be excluded altogether (Oliver,1988:15; Tennant, 1989:98). He publicised the gravity of the problem through his annual reports to Parliament (Tennant,1979:35).

#### MacGregor's Attempts to Introduce Reform

Within three years of his appointment to the Inspectorate, MacGregor had shaped legislation which he hoped would reform charitable aid provision. As the 1889 Hospital and Charitable Aid Bill, it was an attempt to introduce clear principles for the administration of charitable relief according to the most rigorous principles of benevolence (Oliver,1988:15). The legislation was as much an expression of MacGregor's own beliefs, as the means of implementing the "new philanthropy" that he had noted emerging in welfare reforms overseas (AJHR,1897:H-22,1; Oliver,1976:10; Tennant,1989:46).

The Hospital and Charitable Aid Bill attempted to classify the poor according to deservedness. At one end of the spectrum, MacGregor advocated total State support for neglected, destitute children, whom he believed educable and worthy of investment), and pensions for the worthy aged (Chilton,1968:159,160; Tennant,1989:46). Degrees of moral worth separated those found at the other end of this spectrum. The deserving, "casual" poor (which included the "lunatics") were to be supported solely by charity or local administration, while the "undeserving" poor would be

placed in State refuges where they would be made to work (Oliver,1976:8; Tennant,1989:87).

MacGregor was attempting to realise the beliefs he had once expressed to rid the country of pauperism, that "hopeless drunkards, hopeless criminals, and hopeless paupers ... be made to work for their support, and deprived of liberty until they die, in order to prevent their injuring society either by their crimes or by having children to inherit their curse" (MacGregor,1876:320). But the Bill never became law. Local resistance to its other provisions effectively ensured its demise (Tennant,1989:33).

MacGregor's coercive intentions regarding the categories of "deserving" and "undeserving" poor were attempts to direct charitable aid administration towards meeting his own policy objectives. As an application of the principles of laissez-faire, such objectives weighed more heavily towards social control, discipline and efficiency than towards humanitarianism and social justice (Oliver,1979:26,32; Tennant,1979:37). The theme of classification would re-emerge as an important aspect of the care of the mentally impaired. But MacGregor, unshaken in his belief in social Darwinism, continued his crusade through the final years of the last century to warn anyone who would listen, of the perils of pauperism (Oliver,1976:8). Despite his unpopularity, he had become a powerful and important influence in policy-making through this period of New Zealand's social history.

### **The Influence of Eugenic Theories**

MacGregor had hoped the economies he could make in charitable aid would provide the means to develop the function of lunatic asylums beyond their 'catch all' function (Oliver,1976:4,7). Although many of the colony's existing asylums had grown, MacGregor continued to be concerned about the "terrible" overcrowding. The need for a suitable refuge for the "idiots" and "imbeciles" had become urgent (AJHR,1897b:H-7,1; Williams,1989:44). He blamed the problem of overcrowding on an admission system that was bound to accept all "lunatic" patients, whether there was accommodation for them or not (AJHR,1890:H-12,1; AJHR,1891:H-2,1; Tennant,1989:47).

But privately it seems, MacGregor was accepting that despite his most strenuous legislative and administrative efforts, Social Darwinism had failed to purge the "social organism" of its ills (Fleming,1981:5). Although he had been loudly critical of "lavish and indiscriminate, outdoor relief" which he saw as "subsidised propagation of the unfit" (AJHR,1898:H-22,4), it was eugenicists' fears which highlighted for him the realisation that the "unfit" reproduced prolifically and were costly to support (Fleming,1981:4). The solutions offered by eugenic thinking appeared to MacGregor to be a more effective means of dealing with those in society who were seen to be its downfall.

### Eugenic Theory

The theory of eugenics originated in the 1860s as another theory of those based on the primacy of heredity. Ascribed to Sir Francis Galton, it was

based on Mendelian principles which understood human characteristics (including mental retardation) to be genetically transmitted. Galton proposed that by systematic effort, the human race could be improved by limiting the fertility of the "unfit" and encouraging the productivity of the fit (Davies,1959:33; Simmons,1982:51). Eugenists believed a lack of moral self-control by the "unfit" meant that they were multiplying more rapidly than the 'superior' classes, who were limiting their families. The rate at which this was occurring was threatening to undermine the physical and moral qualities of a society some suspected was, at the same time, being populated by England's cast-offs and overrun by the prolific hordes of Asia (Fleming,1981:12; Mitchell,1987:31; Simmons,1982:50). Eugenic interest in the "unfit" was an expression of wider socio-political concerns about maintaining order and stability in a time of social change (Fleming,1981:9,77).

Those regarded as the "unfit" included "the criminal, the insane, the imbecile, the feeble in mind, the diseased at birth, the deformed, the deaf, the blind etc." (Fleming,1981:3). By eliminating their fertility, and increasing the birthrate amongst the fit, eugenists aimed at the gradual extinction of this "defective" and deviant group of people, thereby ensuring the ultimate prosperity and progress of society (Fleming,1981:78; Olssen,1981:4,6).

Eugenic thinking, described as a "refined" form of social Darwinism (Fleming,1981:5) did contain certain differences from its progenitor.

Eugenists realised that natural selection as the result of individual responsibility and laissez-faire policies was no longer feasible. Rational selection was needed. This implied that although "social defectives" might have a right to live, it did not mean that they had the right to create a future generation to whom they could pass on their 'tarnished' heredity. Segregation for life, sterilisation and restrictive marriage laws were to be the means of preventing this. However, these strategies required the intervention of the State and a measure of social solidarity to implement them. The politicians, doctors, scientists, academics and educationalists who subscribed to eugenic beliefs, were those in positions of influence able to facilitate the introduction of such 'social engineering' through social policies of the period.

#### Early Eugenic Influences in New Zealand

Eugenic arguments spread to New Zealand from America and England from the turn of the century. As the basis of official thinking, evidence of its influence can be found in reports, recommendations and legislation of the period. But the general public shared little of officialdom's concern about the fertility of the "unfit". Indeed, public opinion finally rejected eugenic solutions to the problem (Coney, 1993:71; Fleming, 1981:39,72).

MacGregor continued his attacks on the county's system of outdoor relief but, unable to implement legislative changes to curtail charitable aid, he had begun to move the focus of public attention to the social "defectives" who were recipients of this aid. In his annual report of 1897, he cited the

example of a “defective” half-imbecile girl and her five illegitimate children by different fathers, who were all supported by charitable aid, to highlight what he saw as the country’s “weak sentimentalism” towards the issue of poverty (AJHR, 1897b:H-7,1). MacGregor believed that these “degenerates” should be prevented from procreating. Otherwise, he claimed their continued accumulation would threaten the whole fabric of society (AJHR, 1898:H-22,7).

The eugenic movement in New Zealand received further impetus with the publication in 1903 of W.A. Chapple’s The Fertility of the Unfit. Chapple, a politician and surgeon, blamed the alarming increase in pauperism, insanity and crime on breeding amongst “defective” stock (Chapple, 1903:xv,6,7). The differential birth rate and pauperising charitable aid exacerbated this problem (ibid:65,79). State intervention was needed to limit the procreation of the “defectives” and ultimately extinguish their lineage. True to eugenic tenets, it was those with mental, moral and physical deformities unable or unwilling to support themselves, who were the focus of his measures (ibid.xii). “Defective” women, and the wives of “defective” men were those who qualified for the surgical solutions he proposed (ibid:120).

The founding of The Society for Promoting the Health of Women and Children by Dr. Truby King in 1907 was an attempt to deal with the roots of degeneracy. The lack of self-control, seen to be a characteristic of all social “defectives” and the cause of most of society’s ills, would be overcome by a

return to domesticity and 'scientific' methods of feeding and training children (Oliver,1976:9). King believed discipline and control were the means to improve the nation's health (Olssen,1981:4). Thus he hoped "the main supplies of population for our asylums, hospitals, benevolent institutions, gaols and slums would be cut off at the sources" (Truby King, cited in Olssen,1981:6).

In 1910, eugenists formed the Eugenist Education Society to advance their beliefs. Those with an interest in eugenics were a prestigious and influential group in society at the time. The Society's membership included a number of leading politicians. Their interest in eugenics promoted its cause and the Society in turn, gained prestige from the politicians' involvement (Fleming,1981:27,28). Fleming suggests that there was an optimism surrounding eugenics in this country that was due to New Zealand's established status as a leader in the field of social legislation. As the State had already involved itself in health and welfare issues, eugenists saw their proposals to limit the procreation and marriage of social "defectives" as a natural extension of the State's present responsibilities. State paternalism, rather than individual responsibility, was to solve the problem of degeneracy.

Degeneracy however, was about to be re-defined. Reports from overseas such as the 1908 Royal Commission in Britain, had begun linking the newly discovered problem of the "feebleminded" with the "defectives",

the "unfit", and the "degenerates"<sup>4</sup> of society (Simmons,1982:54). What had once been regarded as criminal or social degeneracy, was now explained in terms of mental deficiency. "Feeble-mindedness" suddenly became the mother of crime, pauperism and degeneracy (Davies,1959:46; Simmons,1982:51). Distinctions between organic disability and social deviancy became blurred. Labels such as "morally insane", "moral imbeciles", "criminal imbeciles" or "defective delinquents" became interchangeable, but all indicated the supposed absence of a functioning moral faculty (Gelb,1987:248,249). As a result, eugenisists began to turn their attention to all the mentally impaired.

Aside from the particular interest of eugenists, there was also widespread humanitarian concern about the welfare of the mentally impaired in the country's overcrowded asylums. The lack of a classification system and treatment facilities, particularly for patients who were curable, was a concern to professionals, politicians and members of the community (Fleming,1981:28,72; Watson et al.,1985:47). Of the inmates at Seacliff in 1885, for instance, women made up just over a third of the asylum inmates, and most of the male inmates were unskilled labourers (Brookes,1987:173). By 1912, Maori were amongst those being admitted to Porirua Asylum (Ernst,1991:76).

The development of specialist care for the "mentally defective" in

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<sup>4</sup> The development and application of the intelligence test by Binet in the early 1900s discovered many in society previously unrecognised as "mentally defective". Studies of their families gave substance to the notion that "mental deficiency" was inherited.

institutions became a convenient means by which the State could deal with the myth of the menace of the "feeble-minded". Containing the "feeble-minded" in institutions would prevent the "transmission of mental defect by heredity" but more importantly, limit the numbers of those who were seen to be the cause of most of society's ills (Fleming,1981:32; Simmons,1982:50,59).

### **A Legal Model of Care**

#### The 1911 Mental Deficiency Act

The 1911 legislation was the first Act to recognise that the "mentally defective" were a specific group of people with a chronic defect, whose needs were different from those of the mentally ill (Brunton,1985:4; Mitchell & Mitchell,1985:15). Many of the Act's provisions were a recognition of the need for more humane and enlightened treatment of the mentally impaired (Fleming,1981:31), but eugenic concerns overshadowed all its provisions.

The term "mental defective" described many of those already in mental hospitals. The Act introduced other terms which classified the "mentally defective" as persons of "unsound mind" or "mentally infirm", "idiots", "imbeciles", "feeble-minded", "epileptics" (with or without an associated "mental deficiency") and "persons socially defective". The Act's other provisions could be extended if necessary, to include others who were proved to be socially "defective" in eugenic terms (New Zealand Parliamentary Debates,(NZPD),1911,Vol.155:301). Those classified as "mentally defective" were to be provided care in mental hospitals, where

many already were, although some of the "feeble-minded" were legally allowed to continue living at home. All were the responsibility of the Director-General of Mental Defectives (Mitchell & Mitchell, 1985:18).

The extension of the State's province over the social "defectives" was evidence of increasing concerns on the part of eugenicists about "feeble-minded" women (Simmons, 1982:58). This group, described as "persons who suffer from mental deficiency associated with anti-social conduct" were those who might "by reason of mental deficiency and conduct require supervision for their own protection or in the public interest" (Mental Defectives Act, 1911:s2). Two other clauses of a eugenic nature were included in the legislation. One stated that the sexes in institutions had to be kept separate (s47), and the other made carnal knowledge of a female under its care as a mental defective, an indictable offence for any person, including a husband (Mental Defectives Act, 1911:s127). The legislation of such wide statutory powers was the State's means of limiting the fecundity of female "mental defectives" (Fleming, 1981:31). Although eugenicists had called for the sterilisation of the "mentally and morally defective" (Chapple, 1903:116), the legislation adopted segregation as the preferred option (Mitchell & Mitchell, 1985:18).

#### The 1922 Report of the Committee of the Board of Health

Eugenicist concerns that "feeble-minded" women would procreate, and thereby transmit a "mental defect" to another generation, were not laid to rest by the 1911 legislation. By 1922, the Board of Health had appointed a

committee to investigate the “menace” of venereal disease. Eugenist submissions to the Committee laid much of the blame for the problem on a sub-stratum of promiscuous “mentally defective” or “morally imbecile” girls (AJHR,1922:H-31A,11,12). It was claimed that they either married and brought forth a new generation of defectives, who were then either a charge on the State or produced children who were, or themselves became “irresponsible sources of corruption and debauchery” in their communities (AJHR,1922:H-31A,21; Davies,1959:48; Beck, cited in Fleming,1981:34; Simmons,1982:58). The “mentally defective” were damned by the Committee as both the cause and the effect of venereal disease (Fleming,1981:5).

The Committee, seeking strategies to combat venereal disease, recommended eugenic solutions to the problem. They repeated Chapple’s call for the issue of marriage certificates, and recommended the registration and classification of all “mentally defective” persons so that they could be segregated into mental hospitals or special institutions, to be taught there or usefully employed (AJHR,1922:H-31A,21,22). During the same year, 1922, part of Nelson Hospital was set aside for the care of the profoundly “mentally defective”.

#### The 1924 Committee of Inquiry into Mental Defectives and Sexual Offenders

The recommendations of the 1922 Report did little to allay the hysteria in official circles surrounding “defective” females. The growing concern about promiscuous “defective” women, and the rise in sexual offences

committed by males pushed the Government a little further towards action. Most eugenicists saw a connection between these two social problems. The 1924 Committee of Inquiry had concerns that the:

Unrestricted multiplication of the feeble-minded members of the community is a most serious menace to the future welfare and happiness of the Dominion, and it is of the utmost importance that some means of meeting the peril should be adopted without delay. (AJHR,1925:H-31A,5)

The Committee set out to examine whether "the propagation of mental defect by mental defectives ... [could] be greatly checked, if not completely prevented" (AJHR,1925:H-31A,20). The Committee concluded that segregation and sterilisation were certain and complementary means of achieving this. The Committee claimed that:

Sterilisation is less drastic than segregation for life, and on the whole a much slighter interference with the rights of the individual, which are surely subordinate in such cases to the rights of the State. (AJHR,1925:H-31A,20)

The Committee also recommended the formation of a Eugenics Board, with whom "mental defectives" who were not inmates of mental hospitals, could be registered (AJHR,1925:H-31A,17). This authority would also have the power to make sterilisation a condition of release from institutions under its control, or from its register. Marriage, and carnal knowledge of a person on the register would remain an indictable offence and a new category, the "moral imbecile", omitted from the 1911 Act, was to be included in a planned amendment to the Mental Defectives Act (AJHR,1925:H-31A,15,17).

### The 1928 Mental Defectives Amendment Act

The Government appeared reluctant to implement the recommendations made by either Committee. Sensing public opinion might not be ready for such changes and aware too, of a growing disquiet with eugenic notions, the planned amendment was delayed another four years (Fleming, 1981:47,49). These doubts were the substance of later opposition to eugenic notions (ibid:43-55). When the Mental Defectives Amendment was eventually introduced, the clauses of a eugenic nature drew most opposition.

The Committee's recommendations concerning the establishment of a special Board, and the provision of institutions for the care and training of "mentally deficient" children, were enacted (Mitchell & Mitchell, 1985:24). Templeton Farm was established for the purpose of caring and training "mentally deficient" children the following year. But the clauses that prohibited marriage for those registered with the Eugenic Board and allowed for their sterilisation, were defeated and withdrawn during the debate stages of the Bill. The clause which sought to change the definition of a "mentally defective" person to include the group referred to in the 1911 Act as the "socially defective" and by the 1924 Committee as the "moral imbeciles", was the most controversial. Although strongly opposed by a number of groups (refer pp 106-107), this clause was part of the legislation which finally became law (Fleming, 1981:50-58; Mental Defectives Amendment Act, 1928:s7).

Those who subscribed to eugenic views were an elitist minority. The public were generally apathetic to the issues that concerned the eugenicists (Fleming, 1981:71,72). Some groups expressed their disagreement, and the arguments they raised in opposition to the 1928 legislation became the basis of more substantial challenges to eugenic beliefs from the 1930s. In fact, no register was ever compiled by the Eugenics Board, and the Board ceased to function after 1928 due to a lack of co-operation between the Education and Mental Hospital Departments (Winterbourn, 1944:62,71). The 1928 Act was the last legislation of a eugenic nature concerning the "mentally defective", and its other provisions remained in effect until new legislation was passed in 1954. Although concerns about "degeneracy" had been present from the mid-1870s, it was the eugenicists who identified the "feeble-minded" "mentally defective" as the deviants responsible for most of society's evils. Overseas, institutional care had become an established, but unsuccessful means of attempting to reform the lives of "deviant" individuals, including the "mentally defective" (Gollay et al., 1978:8). Asylums in New Zealand functioned briefly as the means of 'curing' "lunatics" but once this was seen to have failed, the institutions simply became dumping grounds for large numbers of "mentally defective" people deemed by a few to be a threat to society. In New Zealand, eugenicists enjoyed some success in influencing the Government of the period to adopt a eugenic policy in areas of health, welfare and education. Their arguments merely added weight to existing policies of providing for the "mentally

defective” in large, isolated, institutions.

### **The Implications of Legislation for Families of People with Learning Disabilities**

Although institutions were home to many people with learning disabilities during the second half of the nineteenth century, there were always some who, with the support of their family, were able to remain at home. Most found some form of casual employment, and were regarded as a familiar part of the community.

But for the families of others with learning disabilities, institutions would have offered an expedient solution to the difficulties of care. While distance might have made access to institutions difficult, it would have also provided reason for many families not to visit. For many inmates, the institution became the only home and family they knew.

Many families would have dealt with dangerous or disruptive behaviour or profound impairment until they could no longer cope, when asylum admission would have been sought. Such disturbing behaviour would have been more than just inconvenient. As with the behaviour of the mentally ill, it would have tested family members to their limits. Women would have borne responsibility for these dependant family members (Brookes, 1992:131). Perhaps with the passage of time, some families would have wider kinship networks that would have been able to care for mentally impaired dependants at home. However, the reports indicated, that many of these individuals were simply left in asylum care.

It is likely that families themselves would have shared the ostracism associated with the stigma of "lunacy" and asylum care. Social attitudes in colonial society towards the learning disabled reflected a lack of understanding of learning disability as much as a fear of the behaviour. For women in particular, the birth of a learning disabled child was a matter of shame and guilt (Dybwad,1990:26). Religious attitudes of the time saw mental impairment as a consequence of the 'sins of the fathers'. Eugenic notions reinforced it as a consequence of genetic inheritance (Whitehead, 1992:53; Winterbourn,1944:27). Either way, the family were subject to scrutiny, the implication being that the parents themselves were somehow "defective" and therefore unable to provide the care and control for their "defective" child. This justified the long-term removal of many dependants with a learning disability from what was regarded as the damaging influence and environment of the home (Ayer & Alaszewski,1984:8-12).

The 1911 legislation had made it illegal to care for a person with a learning disability within their own family. The Act provided for the "oversight, care or control" of a learning disabled person in an institution "for his own good" (Mental Defective Act,1911:s2). However, it was more usually for the benefit of society or their families that they were placed in care, and the individual's interests were the last to be considered. Once admitted, people with a learning disability became absorbed in the daily life of the institutional community, many perhaps never seeing their families again.

From the late 1920s, institutional care became the preferred option of care for the learning disabled. Emphasis was placed on the overwhelming burden and disruptive influence of a child with a learning disability on family life. Mothers were discouraged from seeing their newborn infants who were placed, like older children, in institutional care. Mothers were told then to forget they had ever had the child (Gollay et al.,1978:10).

On the other hand, it was never intended that all the “feble-minded” be segregated into institutions (AJHR,1925:H-31A,21). Some families were allowed to care for these dependants at home. However, families who chose to do so received no assistance, as it was thought that any support might encourage others to follow their example. Those who did care for “feble-minded” dependents at home, cared for them in the confines of their property. Some families hid their dependants from relatives and sometimes withdrew from community life altogether (Mathews,1973:146).

### **The Implications for People with Learning Disabilities**

From the turn of the century, legislation was no longer aimed at just care and containment, but at protecting society from the perceived effects of those who were identified as the learning disabled. Following such a diagnosis, a person with a learning disability would be sent to live in a large institution, separated from their families and the mainstream of society, where they were detained under supervision often for the rest of their lives (Ayer & Alaszewski,1984:12; Bannerman Foster,1987:10; Davies,1959:50). Diagnosed as such, people with a learning disability became labelled and

stigmatised.

The legislation for people with a learning disability was enacted with little regard for their rights. There was no means of challenging the diagnosis of "socially" or "mentally" "defective". Neither was there a system of review. Once a decision was made to diagnose a person as learning disabled, the individual was likely to move into institutional care for life. Until 1928, learning disabled women lost the right to marry and to have children and, once admitted to asylums, they were routinely sterilised. The rights of society took precedence over the rights of these individuals.

For those placed in institutional care, the conditions that they experienced were dehumanising and created overdependency. The cycle of daily life would have been one of predictable, regimented routines amongst familiar faces set in drab, and often run-down, prison-like surroundings. The learning disabled patients were regarded as indentured servants in order to reduce operational costs. Institutional care would have provided the bare necessities of life and inmates would rarely have had luxuries to enjoy (Central Regional Health Authority, 1995:6,7). Cleanliness, fresh air and a basic diet would have comprised the essentials of wellbeing. But contagious illnesses claimed the lives of many inmates. Life expectancy was not long (Morrison, 1976:94). Privacy and personal space would have been at a minimum, and there was little room for the expression of personal taste or individual interests. Institutional life lacked meaningful relationships and individuals developed little sense of personal identity (Scheerenberger,

1976:62,63).

With the passing of the 1911 Mental defectives Act the already burgeoning population of asylums would have become even bigger. Some classification of patients according to the provisions of the Act, would have occurred at this point. There would have still been many who engaged in behaviour that was disruptive to other inmates. As the different genders were segregated, it would have been only on special occasions when the population of the whole institution came together. And attached to most institutions would have been a graveyard, testimony to the fact that many never left the isolated, custodial, environment of the institution.

The philosophy of care which segregated the learning disabled into institutions was, in reality, a social policy that fulfilled society's agenda of removing those from its mainstream who might prove a threat to its social stability. Leading individuals in society who espoused social Darwinist and eugenic ideologies had a major influence, collectively, on the formation of legislation and social policies for people who were learning disabled.

By the early 1920s, the care of those with learning disabilities had become a large and expensive State activity (Oliver,1976:11). The philosophy shifted focus from around the 1940s when it was found the learning disabled were not the menace to society they had been thought, and segregation as a means of control was proving ineffective (Bannerman Foster,1987:11). Eugenic notions had lost their credibility. The role of institutions was redefined. They became part of a 'total programme' for

people who were learning disabled, with an emphasis on training within the established custodial model. Their purpose was to meet the basic needs of life for the individual, shelter them from the demands of a competitive society, and relieve society, and more particularly their families, of the burden of dealing with the learning disabled (Gollay et al.,1978:10). It was this philosophy that guided service provision for those with learning disabilities over the next forty years.

The argument that families were increasingly involved in the affairs of their learning disabled dependants as they moved towards independence, finds no substance from the events of this period. Rather, the argument is proven in the negative. The absence of any services, save the State asylums, together with the impact of eugenic fears meant many people with learning disabilities were sent into institutional care for life. Denied the opportunity of living independently in the community, their families did not have to take responsibility for, nor have any involvement in, the lives of these dependants who once, were family members.

## CHAPTER FIVE

**SERVICE DEVELOPMENT: State Initiatives and State****Control**

The majority of people diagnosed as “mentally defective” continued to be provided services in institutional settings throughout the 1930s and 1940s. These State institutions grew in size and number as more people with learning disabilities were admitted into institutional care. But while some of those classified as “feebleminded” lived in institutions, many remained in the community to become the concern of the Education Department, whose philosophy and practices concerning the “feebleminded” were different from those of the Mental Hygiene Division of the Department of Health. The enactment of the 1938 Social Security legislation began to sharpen the differences between these two approaches to the care of people who were “mentally defective”. However, the policies of both Departments of State continued side by side, and unchanged, until after the end of the Second World War.

From the beginning of the twentieth century, the Government had implemented legislation that reflected two different approaches to “mentally defective” people. Eugenic concerns were prompting legislation implying that all “mentally defective” people should be living in the Mental Health

Department's institutions. At the same time, legislation was being passed allowing the Department of Education to establish special schools, classes and centres for the "feble-minded" in the community.

### **Policy and Practices in Education**

Since the Education Act of 1877, the "feble-minded" had access, along with other children of primary school age, to free, secular schooling although there were provisions which exempted their compulsory attendance on the grounds of "temporary permanent infirmity" (Mitchell & Mitchell, 1985:7). Indications were that many "feble-minded" children did attend school. It was the presence of children over eight years old in infant classes, noted in some early official returns, which prompted administrators to investigate the nature of "feble-mindedness" (Winterbourn, 1944:20).

As New Zealand society became increasingly industrialised and the education system was required to produce a more skilled and socialised workforce, standards of achievement became an important aspect of education (Olssen, 1981:20). The pressure grew to establish a special education system for those whose disabilities were less obvious than the disabilities of the blind and deaf, for whom provision had already been made from the 1880s<sup>5</sup> (Mitchell, 1987:31). This pressure came from teachers and school inspectors, who believed that the separate grouping of

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<sup>5</sup> Special schools were established for those with sensory disabilities much earlier than for children who were "mentally defective". The Sumner Institution for the Deaf and Dumb (now Van Asch College), was opened in 1880, the Jubilee Institute for the Blind (now Homai College), in 1890.

“feebleminded” children would allow them to learn at their own pace, and afford the more able pupils better opportunities to learn. In 1899, discretionary powers were given to headmasters to implement such strategies (Winterbourn, 1944:21-26).

#### Special Schools and Special Classes.

Separate services for the “feebleminded” were not realised until after 1907, when Hogben, the Inspector-General of Schools returned from Europe and the United States with new ideas about provisions for the mentally subnormal. These were eventually incorporated into the 1914 Education Act, which contained the requirement that all “feebleminded” children be provided an education, either in a special school or in special classes, which the Act established (Mitchell & Mitchell, 1985:15,19). Otekaieke, in Otago (later known as Campbell Park School), was opened by the Education Department in 1908 as a residential school for “feebleminded” boys. In 1916, a second special school (later called Salisbury School) was established in Richmond, Near Nelson, for “feebleminded” girls. These residential schools, which also accepted “children” referred from the Child Welfare Branch of the Department, were intended to provide a secure environment and re-training for “educable” children who had been removed from their homes because of anti-social conduct (ibid:37). “Children” remained until twenty-one years of age. If necessary, they could be detained still longer by order of a magistrate (ibid:59).

Both schools were located in rural areas of the South Island, some

distance from the communities with whom reintegration was supposed to subsequently occur, making the appropriateness of such a location questionable (ibid:38,42). But Campbell Park and Salisbury were established during the period in New Zealand's history when, as a response to the wider concerns about degeneracy, a proliferation of institutions (usually situated in rural situations) emerged as the means of dealing with the control and welfare of its problem groups.

Although there was strong pressure to establish other such schools, these institutions were ultimately the only two special schools ever established by the Education Department (Winterbourn,1944:40,52). The Department moved instead, albeit slowly, to establish special classes attached to ordinary schools to cater for the needs of "educable" children whose home environments were judged to be more satisfactory than those of children sent to the special schools (Mitchell & Mitchell,1985:23; Winterbourn,1944:37). These policies were a reflection of eugenic notions that held parents to be directly responsible for the "mental deficiency" of their children. The first special class established was at Auckland Normal School, in 1917. By the early 1940s, around a thousand children were being educated in either special schools or special classes (Winterbourn, 1944:39,55).

Both the Education Acts of 1910 and 1914, and the Mental Defectives Act of 1911 detailed the categories of "defectives" who came under their respective jurisdiction. The legislation attempted to establish a clearer

responsibility for “educable” and “uneducable” “defectives”, making the Education Department responsible for educating “feeble-minded” minors, and the Mental Hygiene Division of the Department of Health for the care of “idiots” and “imbeciles”, although in practice some overlapping occurred (Winterbourn,1944:308,309). Until 1929 and the opening of Templeton Farm, this meant “uneducable” children were committed to one of the mental hospitals around the country. However, many parents preferred to keep them at home. The 1911 Mental Defectives Act created the legal means of transferring responsibility between Departments for those not under their jurisdiction, but living under their care. The 1928 Mental Defectives Amendment Act detailed further means of co-operation between the two Departments in carrying out their joint functions (ibid:48,59,60).

Philosophies of education engendered attitudes amongst educationalists towards the “feeble-minded” that contrasted sharply with those of professionals in the Mental Health Department. In 1927, the Department of Education established a special education policy for “defective” children based on three principles: an agreement that segregation be avoided where possible, recognition that parents were unwilling to part with their children and should not have to do so unless it were absolutely necessary, and a realisation that widespread provision of residential schools would be costly (Ilalio,1972:29). The provisions subsequently established by the Department of Education for “feeble-minded” children reflected these principles.

### Centres for School Leavers

It was educationalists, as members of the New Zealand Educational Institute (NZEI) who, in 1929, suggested separate day schools be provided for the children of "low-grade" ability in large centres, as both "educable" and "uneducable" children were appearing in special classes. The two special schools were not able to admit all those needing placement, and parents were often unwilling to send their children away to these Departmental schools. The Minister of Education rejected the NZEI's suggestion. But in 1936 (with a change of Government), occupation centres modelled on the Auckland example, were approved by the Department for both Dunedin and Christchurch (Winterbourn, 1944:48,49). These centres catered for about forty "children" up to the age of twenty-one, providing some academic work and a range of activities that developed children's physical and social skills. Each centre had a large degree of autonomy in how it operated and the activities offered (Department of Education, 1953:11; Winterbourn, 1944:287,294). Parents however, were excluded from the committees of these centres since they were considered by many to be "as backward as their children" (Anyon Papers,<sup>6</sup> 1949a, 1971).

As early as 1926, the NZEI had recognised that some provision also

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<sup>6</sup> The Anyon Papers are the early records of the IHCPA covering the years 1949-1974. The period in which Mrs Anyon was Hon. Secretary, 1949-1954, is the most fully documented. Official records after 1974 are stored now in commercial archives.

needed to be made for special-class children as they completed their schooling. Several 'after-care' schemes were subsequently established by the Department to provide assistance and guidance to these pupils from the time they left school, until they reached twenty-one (Winterbourn,1944:49,50). Thus at the end of the 1920s, additional provisions for the "low-grade subnormals" were being developed in the population centres where they were needed. Admission to these services was later restricted, but the policy which established them provided parents whose children were in mental deficiency colonies, with an alternative service model. Parents were later to use this precedent in their efforts to secure changes in the Mental Hygiene Division's services for their more profoundly "defective" children, those who were once described as "idiots" and "imbeciles".

### **Policy and Practices in the Mental Hygiene Division**

The State had provided care in asylums and mental hospitals for many of the "mentally defective" until the 1920s, when some separate provision was introduced. Nelson Mental Hospital was established in 1922 to provide for those "mental defectives" who were described as "idiots" and "imbeciles". Templeton Farm School was established in 1929 to cater for those placed, unsuitably, in mental hospitals and for whom special schools were not appropriate, but who were nevertheless "capable of being trained to some degree in manual work" (Winterbourn,1944:301). These institutions were the responsibility of the Mental Hygiene Division of the Department of

Health. Medical models influenced the nature of care therein, despite the fact that "mentally defective" people were not sick.

Templeton's site was originally designated to be an extension of Sunnyside Mental Hospital. But at the direction of the then Director of Mental Health, Dr. T.G. Gray, the facility was appropriated for the use of the "mentally deficient", and the first villa was occupied shortly after it was built in 1928 (Shephard,1979:3). Gray, a committed eugenicist, had returned from a study tour of Britain, Europe and the United States impressed by Mental Deficiency Colonies as the means of providing for the group described above. As a result of his report to Parliament the 1928 Mental Defectives Amendment Act was introduced, a requirement of which was that certain of the mental hospitals be reserved solely for the care and training of the "mentally defective" (Fleming,1981:48; Shephard,1979:3).

Templeton's first inmates were selected from amongst the "lower-grade subnormals" attending the two special schools, Salisbury and Campbell Park, or transferred out of mental hospitals. Consistent with the philosophy of the time, all activities were segregated and accommodation was allocated according to approximate mental ages and behaviour of the patients. Groups of fifty were housed in each villa. Some attempt was made to separate the adult patients from the children, but staff shortages meant older patients often looked after younger ones. Sometimes they were occupied with activities (such as the 'school') which were inappropriate to their needs, or just left unsupervised (Winterbourn,1944:301-315). The

'training' focus was occupational and tasks related largely to the maintenance of the institutions. Boys were involved in gardening, farm work, carpentry and upholstery, boot making, painting, and canvaswork. The girls did kitchen, laundry and domestic duties, sewing and knitting (AJHR,1934:H-7,1; Shephard,1979:2; Department of Education,1953:9).

Templeton's resources were never adequate to meet the demand for placements. The initial 28 patients in one villas in 1929 grew to 200 in 1934, and 384 patients in 8 villas in 1944 (Shephard,1979:3; Winterbourn, 1944:302). A few were able to find jobs and leave Templeton but most never left the institution. It was their home for life (Winterbourn,1944:301,315). Through its 'occupational' focus, Templeton grew to be a self-sufficient community made the more necessary by its segregated, custodial function as an institution for the "mentally deficient".

There was growing pressure from parents to establish a similar institution in the North Island, but lack of funding during the 1930s and the onset of the Second World War delayed these plans (AJHR,1935:7,3; AJHR,1945:H-7,2). In 1944, the Department of Health took over the vacated Air Force Training Base near Levin for a second institution, thereby fulfilling their stated intention of establishing "separate institutional accommodation for these defective children from the Mental Hospitals proper" (AJHR,1934:H-7,1). In 1945, 42 male patients from Templeton (and 38 females in 1947) were transferred to Levin Farm. What transferred with them, were the practices characterising a large and impersonal mental

deficiency colony (Ilalio,1972:34,37; Shephard,1979:6).

Two Homes of Compassion provided the only alternative to State care during this period, but the numbers they were able to accommodate were in fact very small (Department of Education,1953:10).

### **The 1938 Social Security Act**

The Social Security Act of 1938 developed out of the history and ideology of the Labour Party and the social dislocation many experienced during the depression (Oliver,1976:19). The Act established a "non-contributory, universal, comprehensive and adequate" social security scheme whose benefits were to be provided by the State as the right of each citizen (ibid:19). Benefits (both cash and medical) were designed to safeguard the people of New Zealand against disablement arising from certain life-cycle crises, and provide "such other benefits as may be necessary to maintain and promote the health and general welfare of the community" (Social Security Act,1938:65 cited in Koopman-Boyden & Scott,1984:123). The Act represented a marked shift in responsibility for assistance in such crises from the family to the State.

P. Fraser, who was Deputy Prime Minister of the first Labour Government, was also Labour's first Minister of Education. Consulting closely with the New Zealand Educational Institute in 1935 over the nature of future education policy, he promoted the concept that "the child had a natural right to an education". In his report of 1939, Fraser declared that:

Every person, whether his level of academic ability, whether he be rich or poor, whether he live in town or country, has a right as a

free citizen, to a free education of the kind for which he is fitted, and to the fullest extent of his powers. (AJHR,1939:E-1;2,3)

Policy reform was based on the principle of 'equality of opportunity' (Sutch, 1966:261,262).

The 1938 Social Security Act also paved the way for free and comprehensive medical care (Koopman-Boyden & Scott,1984:127). This reinforced the position of the medical profession as a prominent and powerful group in society. In the decade following the election of the first Labour Government, the State was able to mobilise a substantial portion of its economic resources to secure "socially desirable ends" for its citizens (Oliver,1976:24).

As taxpayers, many parents of people who were "mentally defective" saw the injustices of this situation. While families with "non-defective" school-aged children were able to have access to education and health care benefits in the community, children whose learning "defectiveness" was moderate or profound had no choice but to live in mental deficiency colonies, or mental hospitals if the colonies were full. "Feebleminded" children might attend a special class if they lived in an urban area, or otherwise be sent to the South Island to live for a number of years at a special school. Recognition of the rights of "mentally defective" citizens had failed to move in keeping with the policies of previous governments, that had moved to meet some of the welfare needs of wider society. The 1938 Social Security legislation had the effect of further marginalising people who

were “mentally deficient” living in institutions while tacitly supporting those who lived at home with their families.

### **The Implications of Legislation for Families of People with Learning Disabilities**

Although there was no new legislation passed after the late 1920s that directly involved people with a learning disability, the statutes enacted in the eugenic period were to leave a legacy which continued through the next two decades, until new legislation was passed in the mid-1950s.

The two mental deficiency colonies became large, isolated, custodial institutions with limited resources compared with those available to the physically ill in hospitals. Despite being managed by medical professionals, the institutions had no resident medical or dental practitioners, something parents later requested when making submissions to the Consultative Committee in 1951. Neither were there physiotherapists, occupational therapists, speech therapists, clinical psychologists or social workers (Anyon Papers, 1951). The 1928 Mental Defectives Amendment Act established psychological clinics as part of the provision for the learning disabled, but the services of psychologists were oriented to the education system rather than to the mental deficiency colonies.

Gradually, there was a shift in the numbers admitted to mental colonies and hospitals. By 1959, only a third of those classified as learning disabled were in special institutions, the rest were in mental hospitals around the country. A significant proportion (39%) of those admitted to

these institutions were the "feebleminded", many of whom were children (British Medical Association's (BMA) Report, 1959:4, 18).

Within these institutions, the large number of patients and inadequate staffing meant the standard of care and attention they received was a source of concern to parents. In mental hospitals, children shared wards with mentally disturbed adults. In the mental deficiency colonies, early attempts to group the residents had failed. By the end of the 1940s, all age-groups and disabilities were associating together. Children on weekend leave with their family often arrived home with minor health problems which had been neglected because of a lack of medical attention. Clothing was frequently found to be missing, laundered incorrectly or mixed with that of other residents, causing parents constant extra expense in replacements (Anyon Papers, 1951). Parents' concerns were seen as interference by staff, who were often antagonistic to their interest.

Families who placed dependants in one of the mental deficiency colonies found the distance and cost involved in travelling to visit them, in Christchurch or Levin, prohibitive of maintaining any contact, let alone regular contact (Anyon Papers, 1951). Institutions expanded to meet the demand for services, but inevitably they became overcrowded. Waiting lists grew, and it could be years before a vacancy arose. Parents were faced with the alternative of sending their child to a mental institution or keeping them at home, which many preferred to do. Often they had no choice. Children were placed in institutional care of necessity because families were no

longer able to cope. Some parents later removed their children because they considered the conditions to be so inadequate and unsatisfactory (Anyon Papers, 1951).

But the alternative, caring for dependent "children" at home, was a strain that over many years took its own toll on family life. There was nowhere available to take children with learning disabilities in an emergency or to provide families with badly needed relief care. Parents were often worn out with the constant physical and mental demands of caregiving. They became prisoners in their own homes. Those parents who were ageing had no assurances about the future for their dependants, except that these adult "children" would have to be admitted to a mental hospital when they reached middle age because there was nowhere and no one to care for them.

Despite being wards of the state, and despite so many with a classification of "feebleminded", the "uneducable" in mental deficiency colonies had no opportunity for an education except at Nelson Hospital, who employed a teacher. The institutions had no educational equipment and few organised activities that might provide the patients with intellectual stimulation or interest. "Educable" children on the other hand, were able to attend special classes or schools until they reached school leaving age, when they could join one of the four occupation centres (or groups) which were the only facilities available to cater for the needs. Country children simply missed out altogether. Some parents were able to afford private

tuition or speech therapy, but most children carried speech impediments into adult life. These parents were aware too, that other parents were not required to outlay such expense in the course of a normal child's education.

### **The Implications for People with Learning Disabilities**

Children with a learning disability who were placed in an institution at a young age were deprived of a family environment and family relationships from a very early stage of their development. Young children were required to leave the security of a family life to face the uncertainties of living amongst several hundred strangers, all with like disablement, in circumstances which could be lonely and frightening. Their emotional and psychological development was dependent on the numerous staff who took the place of their parents, a situation which could only adversely affect the development of secure and healthy personalities. Visits from family or weekends at home were infrequent and significant relationships were formed with those who lived within the institution, peers or older patients.

The lack of organised activity, either educational or occupational, meant that many were often bored. Although some joined work groups, these could not cater for all patients. The resulting loss of stimulation meant a deterioration in both their physical and mental health, which parents believed a family environment could have prevented (Anyon Papers, 1953g).

Parents became increasingly concerned about the conditions in institutions (Anyon Papers, 1953g). But there was little that could be

immediately changed. The advent of the Second World War meant issues to do with the care of learning disabled people were low on the Government's list of priorities. Parents' challenges to change the conditions and quality of care in institutions would have to wait for a more suitable and sympathetic social environment. It was the post-war period, and the emergence of new ideas, attitudes and social movements that would provide the catalyst for change.

The argument that as social policy moved people with a learning disability towards independence, families were increasingly involved in their support begins to find some grounds in this period. The different policies and provisions established in the 1920s for the "feebleminded" and the benefits delivered by the welfare state to its other citizens in the 1930s, quickened the attention and concern of some parents to the inherent injustice of these circumstances. Their "mentally defective" children had no option but to remain in institutional care, a situation which these parents considered to be unsatisfactory.

## CHAPTER SIX

**TOWARDS ADVOCACY: Parents on Behalf of People with  
Learning Disabilities**

In the years following the end of the Second World War, there emerged simultaneously in a number of countries throughout the industrialised world, voluntary, parent-based organisations which began to challenge both public attitudes and the nature of services provided to learning disabled people (Dybwad,1990:26). These organisations arose spontaneously in countries that were widely separated by both distance and culture, and in the services they were able to provide (ibid:26). The goal of these parent-based groups was always "to provide, procure or improve services and opportunities" to achieve a better life for their learning disabled dependants (Dybwad,1963:283). In New Zealand, a few parents of children with learning disabilities met in 1949 to form the IHCPA. Acting initially as a pressure group to secure changes in State provisions for their children, the Association found itself having to provide those services it had originally sought from Government.

There was no one phenomenon to which the rise of these social movements could be attributed (Whitehead,1992:47). But a major influence towards these nascent changes was the discrediting of the eugenic movement. In New Zealand, opposition to its tenets had gathered in a

number of quarters with the passing of the 1928 Mental Defectives Amendment Act. There were those in academic circles who had argued that the scientific basis of eugenics might be flawed. Some questioned the accuracy of statistics relating to the suggested increase in the prevalence of mental deficiency. Yet others claimed psychology, and a better care system, held the solution to mental health problems rather than eugenics (Fleming, 1981:43,49,52,55). The sterilisation clauses had drawn moral objections, from Roman Catholics on religious grounds and from others fearing sterilisation would lead to increased promiscuity (ibid:46,52,55). The Labour Opposition had attacked the Bill for its eugenic solutions to poverty and the class bias implicit therein (ibid:52). Others pointed out that "defective" offspring were sometimes born of 'respectable' stock, a certain challenge to eugenic theory for those who wished it to serve as the basis for policy development (ibid:45,83). Some had argued that the segregation of all "mental defectives" could not be done in sufficient numbers to be effective, and would prove too costly to implement anyway (ibid:46) (refer p 81).

These objections were eclipsed in the latter part of the 1940s by world condemnation of the Nazi's use of eugenics as the ultimate solution for a number of minority groups. The realisation that such potential was inherent in the arguments used earlier in the century to justify the incarceration and sterilisation of many learning disabled people, shocked

other Western nations. This, together with the horrifying discoveries about concentration camps (seen as “monstrous” institutions), saw a new acceptance and support of those with learning disabilities amongst society (Simmons,1982:158).

It also prompted a critical re-examination of the premises on which eugenics was based. A return to the studies of the “Jukes” and “Kallikak” families used to support eugenics theory, found fault with the methods and conclusions of the original research (Davies,1959:84). New research was establishing a variety of causes of “mental deficiency” other than inheritance (ibid:86,88). The widely held belief that the “mentally defective” reproduced more prolifically than other groups in society was also disputed (ibid:89). Educationalists had begun to find that many of those considered to be “feebleminded” in fact were often of normal intelligence, but disadvantaged by their poor socio-economic background (Gollay et al.,1978:12). Disproved and discredited, eugenic theory became redundant as the basis of policy and planning for educating and caring for the “mentally defective”.

In the wake of these events, there emerged three strong social movements that were to reshape public attitudes and opinion in relation to people with learning disabilities. One had to do with human and civil rights, another with citizenship rights and citizen welfare and the third was the anti-institution movement.

The issue of human rights arose in a number of countries after the Second World War, most prominently in the United States. Black soldiers found that while their war effort was recognised, most faced inequality, segregation and poverty on their return home. These circumstances were the experience of most black Americans, who began the battle for equality in the courts and later in the streets (Whitehead,1992:48). The black civil rights movement became a model for other oppressed minority groups during the 1960s and early 1970s. Many young men returned home from the Second World War with physical disabilities, followed by a more articulate group from Korea and Vietnam, with clear ideas about a future role as part of society (ibid:48). Along with the physically disabled, women, indigenous groups and the dispossessed, those with learning disabilities were attempting to establish their identity and rights within the mainstream of American life (Bannerman Foster,1987:13).

Learning disabled people however, needed others to champion their cause. Few, if any, were directly involved in the inception of their support organisations (Whitehead,1992:48). Parents, family members, and a few professionals in the mental health and education fields with some concerned members of the public formed the small, self-help groups that challenged the state of existing provisions for those with learning disabilities. They encountered indifference from the public, and resistance

from professional groups who regarded the care of learning disabled people as their own (Casely,1985:99).

Parents began demanding greater support for dependants with learning disabilities, whether they were in institutions or the community (Gollay et al.,1978:11). Where learning disabled people had been segregated into institutional care and excluded from the community, groups lobbied for access to educational facilities and services in the community. Where services did not exist, parents set about establishing their own programmes and activities (Dybwad,1990:26,27). This was the pattern in most countries which were part of this global phenomenon (Dybwad,1990:26,27; Wolfensberger,1973:7).

The issue of citizenship rights was associated with the social reforms which occurred in a number of Western countries in the aftermath of the Second World War. The generation which had experienced the deprivations and social injustices of the Depression in the 1930s, and witnessed the atrocities of the Second World War understood the need for safeguards to prevent such occurrences happening again (Whitehead,1992:51). Such safeguards were to involve a political recognition of all human beings as individuals in their own right, each worthy of the same dignity and respect afforded to others (ibid.51). For the first time, it became possible to argue that learning disabled people too, should be afforded the rights and privileges given to other members of society (Simmons,1982:158).

Associated with the validation of individual rights came the notion of a collective social responsibility, organised by the State, to ensure that each citizen's right and ability to participate in their society was both protected and strengthened (Whitehead,1992:51).

In New Zealand, the Welfare State emerged earlier than the Second World War. The 1935 Labour Government passed the legislation towards the end of its three-year term. The legislation had little direct benefit for people with learning disabilities, except for the introduction of the Invalid's pension in 1936. But amongst parent-groups it created a realisation that while citizenship for most members of New Zealand society had established the right to a range of social services, learning disabled people continued to be denied both citizenship rights and access to the benefits of the Welfare State enjoyed by their peers. Such perceived injustice was the motivation for parents to begin demanding changes in the services provided by government for their learning disabled dependants, as a right owed to them as taxpayers, and to their dependants as citizens of a post-war society.

There was yet another shift of opinion which became a significant influence for change in official attitudes towards those with learning disabilities. Parent-groups had already begun to question the relative benefits of institutional care for their learning disabled dependants, and to look for alternatives in the community (Gollay et al.,1978:11). The

challenge to find an alternative model of care was then taken up at a theoretical level, by the sociologists.

In the reconstruction of society after the Second World War, there had been an acceptance of the notion that the various functions and institutions of a society worked together as part of a cohesive whole. These assumptions fed into the dominant force in sociology during the 1950s, structural-functionalist theory, which assumed for example, that if something existed it did so to maintain and preserve society. In this conservative, paternalistic approach to understanding the nature of society, issues such as learning disability were seen as part of the picture of society as a cohesive entity (Whitehead,1992:49).

Sociologists from the 1960s (for example, Dexter in 1964, and Mercer in 1973), began to challenge these traditional and institutional approaches which influenced society's understanding of problem groups (Whitehead,1992:50). They looked at how and why some people were defined as learning disabled, and what effect this had on their subsequent behaviour. They concluded that care in institutions in fact created and reinforced the notion of difference for learning disabled people (Alaszewski,1988:9).

From another perspective, questions began to be raised after the outrage over concentration camps, about the function of institutions and effect of institutional care on people such as those with learning disabilities.

Researchers such as Bowlby in the 1950s and Goffman and Tizard in the 1960s were beginning to note the debilitating and damaging effects of institutional life on various groups that lived in institutions. Bowlby was one of the earliest to observe the effects of maternal deprivation and institutional life on normal children who were orphaned (1952:129). Lady Allen of Hurtwood exposed the unimaginative and depersonalising conditions in childrens' homes. Baritone (1959), a British psychiatrist, found that many long-stay patients in mental hospitals suffered from two diseases; one relating to their admission and a second created by their stay in the institution (Alaszewski,1988:7,8). Goffman (1961), suggested that such an analysis was not limited just to institutions concerned with controlling social deviance, but could be applied to a wide range of institutions in society. His work challenged the conventional wisdom about the function of institutions such as mental hospitals in society.

Research such as that carried out by Dr. Tizard was beginning to find that the physical, emotional and educational development of children with learning disabilities was affected negatively by being cared for in institutions. These were intrinsically dehumanising and depersonalising environments (Tizard,1964:83). Other studies found the anxiety inherent in children being separated from parents, to have a profoundly adverse effect on various critical areas of their development (Scheerenberger,1976:19-52). Large-scale institutions, which had once been seen as the solution to caring

for the “mentally defective”, now came to be regarded as the source of the problem they had been attempting to solve (Alaszewski, 1988:8).

Alongside the emergence of these post-war influences, there developed new strategies to realise the purposes of these social movements. Mutual self-help groups grew rapidly as the means of meeting the individual needs of member persons, across a wide range of human and social needs (Loney, 1981:302,303). These self-help groups had the potential to become pressure-groups, each with its own political agenda and ready to influence the policy-making process to achieve its own objectives. Individually, each of these social influences, the human rights movement, the movement to gain citizen rights and welfare and the anti-institution movement, were influences for change. Together, they were to provide the context in which the concept of normalisation would later emerge.

Wolfensberger (1973), later examined the development of parent self-help groups for people with learning disabilities. He found that in spite of national differences in the patterning of services and of voluntary associations, these associations “evolved in ways that show[ed] amazing similarity to each other” (1973:5). He suggested that there was a systematic and predictable regularity in the evolvment of these associations, and drew on social and organisational psychology to explain the dynamics of this growth (ibid:5). The development of voluntary associations, he suggested, occurred in three stages.

The initial stage involved a small group of parents forming a local association which would, under its charismatic leader, enlarge and eventually join with other groups to form a national organisation (Wolfensberger,1973:5). Often they were parents of young children, concerned with developing quasi-educational and developmental programmes because their children were excluded from the services provided by the regular school system. They sought support from the group, or solutions to the problems they faced. These services were often the only kind in place for many years, until increased demand forced expansion and development, and eventually secured public funding (ibid:8).

The second stage of associational growth resulted from the successes achieved in the earlier phase, and was taken up with “obtaining” services (or the funding for services) rather than “providing” them. An unintended consequence of success at this stage of development was the formalisation of the association. Leadership became more bureaucratic as services were professionalised and a service ‘empire’ grew (Wolfensberger,1973:6,9).

Wolfensberger expected few associations to realise the third stage of associational growth. He suggested that if, and when associations did achieve their major objectives, their role must then be, simultaneously, to maximise the rights of those with learning disabilities and ensure its own purpose, relevance and renewal was maintained (Wolfensberger,1973:23). The focus would shift from “obtaining” services to a role of advocacy,

ensuring services adapted, and that their quality was monitored and safeguards were implemented to protect the rights of learning disabled people (ibid:23,24). Wolfensberger suggested that his study of associational growth could offer helpful insights into the nature and dynamics of organisational change in associations such as those providing services for people with learning disabilities (ibid:43).

In New Zealand, the formation of the Intellectually Handicapped Children's Parents' Association in 1949 captured some of the earlier characteristics Wolfensberger described. The parents who initiated the challenge to the government and community for a change of public attitudes, provisions and policies on behalf of their learning disabled dependants, could not have known the magnitude of the task they faced. They were simply convinced of the need to relieve families of their distress, of the justice of their cause and believed that their efforts were on behalf of those who had few rights (Mathews,1973:154).

### **The Intellectually Handicapped Children's Parents' Association**

The IHCPA was an organisation of parents who believed that the State institutions which provided for their "mentally defective" children were unsatisfactory, and that the lack of support and constructive advice from professionals concerning their care was unhelpful and frustrating. As members of the public, they were surrounded by those who held their children in fear or felt them an uncomfortable fact of life. The public

preferred them, as the professionals did, to be living out of sight in institutions. One parent described it thus:

At birth the family doctor usually discouraged the mother from even seeing the baby or taking it home from hospital. If a parent retained the child at home, little or no services were provided to help mother or family....Professional workers in the field at this time felt an obligation in the interests of the family or the community to discourage any decision of the mother to care for the mentally retarded at home or even maintain contact when placed in a state home. Such actions by the parent were felt to create stress in other members of the family....Professional workers' opinions, both educational and medical seemed to be that the mentally retarded had little or no potential or rights, and that all that could be done...was to house and feed the intellectually handicapped member until death, such care to be in large institutions away from the community. (Mathews,1973:146)

These parents wanted changes. They saw an education system providing for "mentally defective" children in the community, and believed that parents who wanted to keep their children at home had the right to similar services. They felt that the isolation, stress and hardship they experienced in bringing up a child with a "mental deficiency" would be considerably reduced were the state to provide them the proper support services. They believed that their children would enjoy a better quality of life living with their families than in an institution (Riseborough,1986:51). As a group, these were parents with a particular experience of life who set out to influence the political process for the benefit of their children. The Welfare State, already providing other assistance to families, established the

ideological and materialist basis for these parents to argue their case for change.

### Parent Activism

The small group of Wellington parents who formed the IHCPA were concerned initially with the education issues. They were parents who had chosen to keep their children at home and found the education system unwilling to admit their children, most of whom had moderate mental "deficiencies". Frustrated at this situation, the parents formed a local organisation to begin a campaign to secure an educational facility for their children in the Wellington area (Munro, 1987:189).

The experiences of the Anyon family were to prove an important influence in this campaign. They had a son with Down's syndrome who had been refused enrolment in the local special class, and instead was accepted into the After-Care Association's programme. M. Anyon became highly involved in the Association, but eventually it failed to meet her expectations. She hoped to persuade the After-Care Association to provide the younger children attending the centre with an education, instead of just minding them (Anyon Papers, 1951a). Unable to achieve her own objectives through this organisation, M. Anyon resigned her responsibilities and initiated the first meetings of the IHCPA.

M. Anyon's attempts to bring changes to After-Care foreshadowed her later efforts through the IHCPA to gain alternative services in the

community for “mentally defective” children. For the Anyons had a vision: to motivate parents to organise themselves into an association that would champion the rights of “mentally defective” people, and their families. They were the driving force behind the formation of the IHCPA and travelled the length and breadth of the country, separately and together, often at their own expense and at considerable sacrifice of time, effort and money, to achieve this goal (Casely,1985:101).

Hal and Margaret Anyon worked as a team. Their skills were very different but always complementary. “Hal was ... an artisan, she was ... [an] eloquent [speaker] ... a competent person” (Clark,1986). Her most valuable asset as far as the early IHCPA was concerned, was her knowledge of the workings of Government and how to lobby, derived from her experience as a Ministerial Secretary prior to her marriage. The tenacity with which they stuck to their original vision often made them unpopular with those who stood in their way (Clark,1986; Sontag,1993:54). Others have since paid tribute to their moral courage and complete devotion to the cause which they espoused (Botting,1972:2). In the words of one woman who knew and worked with them, “I think they were born for this one culminating thing of setting up an organisation” (Clark,1986). The Anyons provided the initial impetus for a small group of parents to form a pressure-group that subsequently grew to become a powerful influence on policy-making for people with “intellectual handicaps”.

### Strategies to Establish an Occupation Centre

M. Anyon's resignation from After-Care focused her efforts on securing an occupation centre in Wellington. Between 1947 and 1949, M. Anyon led a campaign to persuade the education authorities of the need for such a facility. She made links with parents involved in other Occupation Centres, and later visited these centres to see what aspects of their programmes would be suitable for a facility in Wellington. Both she and her husband, along with other parents, maintained a persistent correspondence with the Minister of Education, the Department of Education and the Wellington Education Board requesting such a centre for Wellington<sup>7</sup>.

In to this parent pressure, the Minister of Education wrote on 12 August 1948 stating that the Wellington Education Board was endeavouring to establish an occupation centre (Anyon Papers, 1948), but it was another year (July, 1949) before the Government confirmed it was making available to the Board one of its properties in Oriental Bay for the proposed centre, to be ready by October of that same year.

The exchange of correspondence between M. Anyon and various public officials reveals the strategies she employed to achieve her objectives.

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<sup>7</sup> Efforts have been made to locate the Department of Health files relevant to this period from the National Archives. The file marked 'IHC Policy 1954-64' although listed as having been transferred from the Department of Health, is not able to be found. The developments for people with learning disabilities, as seen through the eyes of the IHCPA, are therefore not able to be substantiated in this study. However, this does not prevent raising the critical question as to what the Department of Health's position in regard to people with learning disabilities was, during this period.

Having secured an initial commitment from Government for the centre, M. Anyon turned her attention to other related concerns. She was anxious to secure an assurance from the Minister of Education that in future, legislation might be passed ensuring parent representation on the committees of Occupation Centres. Her own experiences, and those of other parents with children attending Occupation Centres convinced her that if parents were not represented on school committees, they had little influence on the programme or activities offered. The Minister indicated legislation on such matters was a little premature, but that her concerns had been noted (Anyon Papers, 1949a).

As a means of achieving parent representation on the Committee of the new Occupation Centre, M. Anyon asked the Chairman of the Wellington Education Board for a list of names of prospective pupils for the centre, from whom such representatives might be chosen (Anyon Papers, 1949b). Along with the names of sixteen children, came the Minister's agreement that parents would be allowed representation on the Committee (Anyon Papers, 1949c). Parents' rights to have an input into their children's education had been recognised. Persistence and determination were the means by which the Anyons made their vision a reality.

#### The Inception of the IHCPA

The Occupation Centre was not ready in October, and it was over a year since it had been promised to the parents. The Anyons, frustrated at the

delays, thought the education authorities might be moved to action if the pressure came from a group of interested parents, rather than just themselves. Hence M. Anyon organised the first meeting of what would become the IHCPA, for 25 October, 1949. Parents from sixteen families responded to the newspaper advertisements (Anyon Papers,1970). They were parents of children with a wide range of "mental deficiency" some of whom would qualify for the new centre. Non-parents and the press were excluded from this first initial meeting to allow for parents to share their concerns freely and privately.

This meeting agreed to form an association, and an interim committee of four was set up with H. Anyon as chairman and M. Anyon as secretary-treasurer. At a further meeting a month later, the parents agreed on a constitution and the Intellectually Handicapped Children's Parents' Association was formed. The Association's constitution was a clear statement of its aims and objectives, and how it should be run. The term "intellectually handicapped" was adopted to describe those who had been previously referred to as "mentally deficient", "idiots" and "imbeciles". Full membership of the Association in 1949 was restricted to "parents", including legal guardians. Non-parents could become associate members, but could not hold office or vote. "The Association was to be a voice for parents; in opposition to professional, official, and public opinion where necessary" (Riseborough,1986:62). The Anyon's experience of the latter

group ensured non-parents were given no chance to dominate policy making.

The constitution set out the “objects” of the Association, aims which were remarkably far-sighted, comprehensive and ambitious for a small group of parents in 1949. The main aim of the Association was “to promote the physical, educational, economic, and social welfare of intellectually handicapped children” (Anyon Papers,1949d). The specific objectives identified were largely to do with the establishment of support and services to parents and children, objectives which have changed little over subsequent years (Anyon Papers,1949d; Casely,1985:101). The constitution also laid down the rules and regulations by which the Association was to be run, foreseeing the formation of other branches and a national executive even before their inception.

As a pressure-group, the Association’s initial success in securing a commitment from the Government was due largely to M. Anyon’s leadership skills, her knowledge of the organisation of government and the direct contact she established with the Minister and Departmental officials concerned. This informal relationship with the representatives of Government was formalised with the inception of the IHCPA.

#### The New Organisation Becomes Involved

Following the inaugural meeting of the IHCPA, M. Anyon set about publicising the new Association and its aims amongst Ministers of the

Crown, Departmental Heads, local Members of Parliament, newspapers, broadcasters, and a number of professional organisations likely to have an interest in the new Association (Anyon Papers, 1950a). She lobbied her own Member of Parliament to amend the party's education policy to include "special provisions" for the education and treatment of "backward" children (Anyon Papers, 1949e). Another of her self-appointed tasks was to find the funding to purchase equipment for the new Occupation Centre (Anyon Papers, 1950b).

The Association was also keen to hold discussions with the incoming National Government about the delays in the readiness of the Oriental Bay site. In the meantime however, opposition had emerged from the residents of the area over the use of the building as an Occupation Centre. They were concerned at the presence of such children in their neighbourhood, rather than somewhere else. Despite pressure from the parents worried they would lose the premises, the Government finally decided against the development of the property and began to seek another.

Temporary premises opened at the Basin Reserve on 23 May 1950 in physical conditions that were far from satisfactory. A teacher appointed by the Board taught the children games and handcrafts. The parents, who had campaigned for a school, wanted their children to receive some education. Their continued protests resulted in the teacher's transfer a year later (Anyon Papers, 1950c). Frustrated with the situation and the Board's

lack of progress, M. Anyon invited P. Fraser, the Leader of the Opposition, to visit the centre in July. He subsequently brought the matter to the attention of Parliament, and the debate which followed raised for the first time the whole issue of what to 'do' with the "intellectually handicapped" (NZPD, Vol.289,1950:837-848). The Minister of Education confirmed that there were plans in place for a new, purpose-built Occupation Centre, which was finally opened in September, 1952.

Throughout these developments, M. Anyon's strategy was to ensure that the activities and concerns of the IHCPA were kept before the attention of the particular ministers and officials concerned. Some, such as P. Fraser and W. Nash, and H. Ross (Minister of Social Welfare, and Women and Children) showed a particular interest and sympathy in the work of the Association. In February 1950, H. Ross visited the families of some Wellington members, and was able to support their plea for a school during the debate in the House (Anyon Papers,1950d; NZPD,Vol.289,1950:847-848). M. Anyon was always careful to acknowledge and appreciate the efforts of those who had been involved in helping achieve their goals. She believed that the Association's representations were effective because there were no "middlemen" between it and the Departments concerned (Anyon Papers,1951b). M. Anyon was later to comment:

It must be remembered that we had no precedent for our claims, no literature, no knowledge of other countries' work, no trained people, no departmental and practically no political anxiety to assist, no money, no relief in our own homes. We had no

occupation centres, no short stay homes, and institutions as they were then were deplorable, from our point of view, without accommodation for any increased demand. We had to explain at every turn what we meant by an intellectually handicapped child. (Anyon Papers,1970)

As a pressure-group, the IHCPA had pushed the issue of the care of the "intellectually handicapped" on to the political agenda. The leadership of the IHCPA exploited this new political awareness, one which crossed political party boundaries, as a means of realising the Association's objectives. At the same time the organisation moved to ensure their concerns were taken up at the more formal level of the political process, through the parliamentary system.

#### The IHCPA's Submission to Parliament

The Association's first 'Dominion' conference in April 1950 drew parents from several regions around the country. The conference considered it a matter of urgency to form branches in other areas, especially the main centres, to gain support in establishing schools, Occupation Centres, and short-stay "cottage homes" for their children (Anyon Papers,1950e). To spearhead such moves, the Wellington-based members of the New Zealand Committee had prepared a petition asking the Government to set up a committee to inquire into the needs of "intellectually handicapped" people and their families. It was hoped to gain about 5,000 signatures in its support through the Association (Anyon Papers,1950f).

The petition asked that a special committee, to include specialists representing Education and Health Departments as well as parents, be set up to:

1. Inquire into and formulate proposals to remedy the anomaly which denies to the handicapped child the educational, health, and other social amenities enjoyed by the normal child.
2. Inquire into and formulate proposals to remedy the lack of suitable homes for these children.
3. Formulate proposals to stimulate the search, medical and social and otherwise, so that a comprehensive scheme may be provided to meet the needs of all these children throughout their lives. (Anyon Papers, 1950g)

The petition, with 3,294 signatures was presented to Parliament by J.R. Hanan, on 2 August, 1950. Representatives of the Association went before a Select Committee of the House to give evidence relating to the petition on 31 October, 1950.

The parents wanted a 'Care of Children' Committee to be set up that would undertake to "meet regularly to co-ordinate the needs of the children ... and ... administration of all services connected with the children" (Anyon Papers, 1950h). The parents had identified the need for particular services for families, and outlined the types of educational facilities they believed were needed. Representatives of the Mental Health Division, who also appeared before the Select Committee, supported the status quo suggesting "any long-term residential provision for the mentally deficient is best done by means of the colony type of institution ... such as Templeton and Levin, with accommodation for say, five hundred to a thousand beds". In their

view, medical administration was considered necessary, and any similar institutions were thought to be uneconomical (NZPD, Vol. 292, 1950:3917).

Clearly differing philosophies of care for “intellectually handicapped” people were emerging before the Select Committee. The Association wanted services provided in the community to support families caring for “intellectually handicapped” children at home. The Department of Health believed such children were best provided for in institutions. The Select Committee of the House recommended that the petition “be referred to the Government for most favourable consideration” (Anyon Papers, 1950i). As a pressure-group, the IHCPA had mobilised its membership to ensure its concerns reached the policy-making arena.

#### The 1952 Consultative Committee of Inquiry

The Government’s consideration was slow to eventuate. It was almost a year before the Consultative Committee of Inquiry’s terms of reference were drafted and its members appointed by the Ministers of Health and Education. The Consultative Committee was to consider the existing facilities provided for two groups of “intellectually handicapped” children, those between the ages of five and eighteen, and those over the age of eighteen, making recommendations concerning both groups of children. Additional terms of reference required them to carry out a census of the numbers of “intellectually handicapped”, to inquire into their places of

residence, their education and means of their training (Department of Education, 1953:1).

The Consultative Committee, announced by the Prime Minister on 31 August, 1951 was to be chaired by Dr. R.S. Aitken of Otago University and included representatives from Child Health, Mental Hygiene and Education Departments, but no parents. Parents had been previously given an assurance by the Minister of Education that they would be represented (Anyon Papers, 1951c). The IHCPA responded immediately, challenging "the suitability of the committee" and suggesting a "better-balanced" one which would include a parent, a social worker but no representative of the Mental Hygiene Division (Anyon Papers, 1951d). In making the Committee a Departmental one, the parents felt:

The Government has drawn an iron curtain of restraint across the way of parents who already have made a tremendous effort to find a way out of their difficulties. (Anyon Papers, 1951e)

The Minister of Health would not concede to a parent representative, believing they could not act impartially as both advocates and judges. The Association reasoned the same would be true of Departmental representatives. But the Minister of Education was willing to consider the inclusion of a woman social worker, and made an additional appointment accordingly (Anyon Papers, 1951f). The Committee was to hear submissions "in camera", due to the private and confidential nature of much of the

evidence given. Nevertheless, the Committee undertook to make its findings public (Anyon Papers, 1952a).

The New Zealand Committee of the IHCPA finally decided to accept the Government's terms as to the composition and conduct of the Consultative Committee, directing its energies instead towards co-ordinating the preparation of submissions by branches, and by its own Committee (Anyon Papers, 1951g).

#### The IHCPA's Submission to the Consultative Committee

In February, 1952 the Consultative Committee began moving through the country hearing submissions from representatives of IHCPA's branches and other bodies, visiting mental hospitals, mental deficiency colonies, occupation centres and groups, special classes and schools as they went. The New Zealand Committee of the IHCPA made its submission once the Consultative Committee returned to Wellington in June.

The forty-three page submission which M. Anyon had prepared and presented in evidence to the Consultative Committee, was a summation of parents' views of the present services provided and of those they believed were needed for their children. It presented the Committee with a parent perspective of the issues being discussed. It began by suggesting that the children:

Have an equal right to the help of the amenities which the normal child enjoys...and a share of any public funds which are available.  
(Anyon Papers, 1951h)

The submission identified apathy and lack of responsibility amongst the Departments concerned as one of the main reasons for the absence of suitable facilities (ibid). This left the children excluded from anything other than institutional care, if this was even available. There was criticism throughout the submission (supported by anecdotal evidence from parents) of the care provided in the two mental deficiency colonies, and by implication, of the Mental Hygiene Division whose responsibility these institutions were (Anyon Papers,1951i). Parents had found that once children were admitted to these institutions they made little progress, either mentally or physically (Anyon Papers,1951j). The New Zealand Committee wanted improvements in these institutions and instead of any further extensions, they requested "cottage homes" and "emergency homes" be established (Anyon Papers,1951k). They also asked that the responsibility for these institutions be transferred to a sub-department comprising Health, Welfare, Education and Mental Hygiene representatives (Anyon Papers, 1951l). The submission reiterated calls for occupation centres to be established, and for the "intellectually handicapped" living at home to have free speech therapy and access to the health camps (Anyon Papers,1951m). Parents wanted the welfare of their children, not the cost, to be the Government's first consideration in determining how the "intellectually handicapped" were to be provided for.

It was eight months between the Consultative Committee's hearings and the Government's release of its findings. Before the Committee met, the IHCPA's President had expressed the hope that:

A definite, sound, progressive and comprehensive plan will be implemented by the Government to support the Committee's findings....We are sure that this [extensive evidence] will play a large part in enabling the Committee to reach its decisions. (Anyon Papers, 1952b)

Some five months later the President was being a little less optimistic, stating that although:

The Association expects the Government to provide all the facilities required...where the report...makes no recommendation for action by the Government...then the Association must pursue its own course in the matter. (Anyon Papers, 1952c)

The future role of the Association was very much dependent on the recommendations made by the Consultative Committee.

#### The Consultative Committees Report

The Minister of Education made the Consultative Committee's report available in February, 1953. The New Zealand Committee suggested that all branches familiarise themselves with the report because:

It will no doubt become a code of reference on which all Governments in future will lean. All subsequent requests by the I.H.C.P.A. will be weighed against what is already recommended in the report. (Anyon Papers, 1953a)

The Consultative Committee had dismissed the IHCPA's arguments against institutional care, and rejected their requests for the development of alternative services (Department of Education, 1953:23,32,33). Although

admitting that conditions in institutions needed improving (ibid:23), the Committee concluded "... the only satisfactory policy is the provision of good residential institutions, well equipped and well staffed, for the great majority of imbecile children ... and parents to place their children therein at about the age of 5" (ibid:24). The Committee did concede that "... many homes are better than an institution" but that it was "sound to argue that a really good institution may be better than most homes" (ibid:23).

The Committee claimed the motive behind maintaining large institutions was "partly economic ... but largely humanitarian" (ibid:28), but elsewhere stated the "considerations of cost and staffing make a large institution the only practicable one" (ibid:26). They were to remain under the management of the Mental Hygiene Division of the Department of Health (ibid:26). The provision of community care was to be left to voluntary bodies such as the IHCPA (ibid:34).

With few adjustments, the Consultative Committee's report simply maintained the existing state of affairs. The report appears somewhat patronising in places towards parents and the IHCPA. For example, the Committee had dismissed the parent's arguments against institutional care on the grounds that parents might have had a "distorted" picture of mental hospitals or mental deficiency colonies (ibid:23). They spoke of the effects of the IHCPA's "propaganda" (ibid:35) and had been "touched" to hear intelligent parents concede institutional care might have been preferable for

their child (ibid:24). The Consultative Committee's view of family life with an "intellectually handicapped" child was a stereotyped one (Sontag,1993:62). One might conclude that there was some inherent bias to the Committee's deliberations, but both the Committee and the Health Department officials briefing them appeared ignorant of the advances being made overseas in this field.

The New Zealand Committee of the IHCPA, dismayed with the contents of the report, outlined its specific criticisms of the ten recommendations made by the Consultative Committee in a circular to Branch Committees (Anyon Papers,1953b). These were to be discussed in more detail, along with the Association's policy for the future, at its forthcoming conference. In his annual report to the Association, the President spoke of his concern that the original requests for a 'Care of Children Committee', and for co-operation with the parents had been disregarded (Anyon Papers,1953c). Other parents remembered the contrast between the "tremendous achievement" and "triumph" at the Consultative Committee being set up and the "horror, and anger ... and hurt" they felt on finding the Aitken report's recommendations were so conservative (Clark,1986).

Both the Minister of Education, R. Algie, and the Minister of Health, J. Marshall, had been invited to address the conference. Their Departments had accepted the report, and the Ministers' comments reflected official thinking. R. Algie displayed a sympathetic understanding of the issues. He

expressed his Department's continuing commitment to training the "educable" "handicapped" child and indicated that while the report would be the basis of further development, he would seek the Association's views on its contents before the Ministers established it as policy (Anyon Papers, 1953d). J. Marshall expressed the hope that the recommendations relevant to his Department would be implemented as policy as soon as possible, although he did not accept the need for reducing the size of the institutions (Anyon Papers, 1953e). As the basis for future policy, the report did little to resolve the two differing approaches to "intellectually handicapped" people which each Department had been implementing over the last fifty years. The Department of Health maintained a belief in care within large institutions, while the Department of Education was making some provision for children with a learning disability the community.

#### The IHCPA's Response to the Report

Despite the New Zealand Committee's objections to much of the report, the conference of the IHCPA accepted the majority of its recommendations, directing that:

The incoming N.Z. Committee...work with the Government to implement the Report of the Consultative Committee. (Anyon Papers, 1953f)

Delegates seemed resigned that the Association's role would have to change. It would be they, instead of Government, who would be providing the new services. In fact, the IHCPA was already providing services in a small way.

In 1951 they established occupation groups for small numbers of school-aged children, with some Department of Education funding. The challenge ahead was service provision on a much larger scale.

The New Zealand Committee therefore presented the conference with some proposals as to the direction of its "future policy" (Anyon Papers, 1953f). The Committee was concerned that branches "target the most essential policy items" first (and particularly those attracting Government subsidies), but not at the risk of over-committing themselves, or losing sight of the essential reason for the Association's existence (ibid). It was sound advice, but branches later made their own decisions as to those services most essential to their needs. Although the organisation as a pressure-group had not achieved the changes in policy they had hoped for, they had nevertheless raised political awareness of the issues surrounding the care of children with "intellectual handicaps". Its role as pressure-group would continue alongside its new role as a service provider, until their objectives were achieved.

Through political means, parents had sought to challenge the establishments, both medical and educational, that provided services to people with learning disabilities. They wanted some accountability from medical and educational professionals in terms of the range of services available and the quality of care that was provided. The Anyons were instrumental in bringing this movement for change together as a formal

organisation. However, the parents and their organisation had in effect, lost the first round of the challenge to introduce changes in the nature of care for people with a learning disability.

H. and M. Anyon stepped down from the New Zealand Committee in 1954. There were changes being voted in to the constitution with which they did not agree and family commitments had begun to conflict with the increasing demands made of their time, as the Association grew. One parent believed that "... there is no doubt that the government was very relieved when they [the Anyons] pulled out ..." (Clark,1986). But they had guided the fledgling Association in its role as a new pressure-group through its crucial formative years.

The Consultative Committee's report ensured official policy in the early 1950s for those with learning disabilities remained largely unchanged. Their recommendation to continue funding the care of people with a learning disability in institutions nudged the IHCPA reluctantly, but resolutely, towards implementing the community provisions they had hoped the Government would introduce. In effect, they had taken policy development and implementation into their own hands.

The argument that families of people with learning disabilities became increasingly involved in their affairs as they moved towards greater independence, begins to be substantiated by the developments during this period. Parents, on behalf of family members who had learning disabilities,

began the campaign to move them out of institutional care and lobby for the development of services and social policies which would support them living with their families, in the community.

## CHAPTER SEVEN

**DEINSTITUTIONALISATION: The Development of Services in  
the Community**

The Consultative Committee's recommendation that institutional care remain official policy for learning disabled people, was a policy which was beginning to be overturned in a number of countries overseas in favour of services in the community. In providing the services they had originally sought from Government, the IHCPA were introducing these community-based alternatives. The implementation of these new ideas, together with a change in thinking amongst the medical profession began a momentum of change around the 1950s. This change saw a policy of "community-based services" for people with "intellectual handicaps", provided initially by voluntary agencies, sanctioned by the Government. Its success led to a review in the early 1970s of the Department of Health's own policies of institutional care, with the result that many "intellectually handicapped" people left the psychopaedic hospitals to live with support, in the community.

**The Influence of Overseas Professional Opinion**

With the release of the Consultative Committee's report, the Association turned to similar organisations and professionals working in the field of

mental deficiency overseas, for comment on its recommendations. It was concerned specifically with the Department of Health's intended policy of increasing the size of institutions rather than introducing "cottage homes" and "decentralisation" which it had wanted. The opinions of these distinguished overseas "experts" formed part of the Association's second submission, invited by the Ministers of Education and Health, on the Consultative Committee's report (Anyon Papers, 1953h). Their opinions reflected current thinking on aspects of service development to "mentally defective" children, and were the Association's means of trying to convince the Government that ideas such as they supported, were already functioning in countries overseas.

One professional living overseas who had a particular interest in the developments occurring here was a New Zealander, Dr. J.U.L. Tizard. As a single individual influencing the policy-making process at this time, his opinions were to add considerable weight to the IHCPA's arguments for policy changes to the care of people with "intellectual handicaps".

Dr. Tizard found the Consultative Committee's report to be "a disappointing document". He expressed serious doubts about the recommendation that children as young as five should be placed in institutions, and believed the report had ignored the possibility of providing adequate community assistance to parents caring for children at home. Dr. Tizard's own policy was one of not placing children in mental deficiency institutions, where it could be avoided. Recent research indicated that

there were damaging effects on young children placed in institutional care. Furthermore, Dr. Tizard believed there was a possibility for further emotional and intellectual development for “imbecile children” whose social and emotional needs were met within their home environment. He thought that the Consultative Committee had dismissed this possibility too lightly. In adopting a policy of institutional care for all “mentally defective” children, they had adopted a policy which because of costs, would never be fully implemented anyway.

Dr. Tizard suggested some immediate strategies for the Association: that they press for more facilities to be made available to support parents who kept their children at home (parents were, after all, saving the Government money by keeping them at home), and press for smaller institutions to be set up in the vicinities of parents' places of residence. Parent contact, he believed, was ultimately more important than the size of the institution (Anyon Papers, 1953i). Dr. Tizard's ideas about the care of the “mentally defective” acknowledged the needs of children and their families rather than any so-called ‘advantages’ of institutional care.

#### The World Health Organisation's Report

Encouraged by Dr. Tizard's response, the Association invited him to speak at their 1954 conference. His address, read in his absence, was a critical comparison of the Consultative Committee's report with the relevant sections of the report of the Joint Expert Committee of the World Health Organisation (WHO), (Anyon Papers, 1953j). Dr. Tizard found fault with the

fact that the Consultative Committee had based their assessment of the numbers and needs of the "mentally subnormal" in New Zealand on a British report (the Wood Report<sup>8</sup>) which by 1951, was out of date and inaccurate. He rejected the Consultative Committee's adoption of "comprehensive colonies" as the principal form of residential care in New Zealand. Dr. Tizard favoured the WHO's Joint Expert Committee's recommendation of home care "unless the subnormality is severe, or ... the child in the home is likely to bring about serious maladjustment or dislocation of other aspects of family life" (WHO Report, 1954:16). The Association felt it had at last found "expert" professional opinion to support its own arguments against institutional care.

Dr. Tizard considered the question of institutional care to be more complex than merely a decision about the size of the institution, or whether or not children should be placed there. Parents first needed to make what was essentially a philosophical decision: whether in fact they wanted these children all to be "sent away" or to remain in the community. Such a decision depended largely on the facilities available to them. The WHO Joint Expert Committee had advocated that:

Substantial monetary grants should be made available to the parents of handicapped children who live at home; that there should be nursery schools and occupation centres provided for them as a matter of right; that it should be easy to place children into institutions or holiday homes for short periods; that there should be available adequate specialist assistance, and domestic

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<sup>8</sup> The Mental Deficiency Committee of the Board of Education conducted an official inquiry into the number and means of caring for "mental defectives" in England. Known as the Wood Committee, their report was published in 1929.

assistance for the parents and families of defective children living in the community. (ibid:16)

These were services the Association was attempting to lobby for and establish, so that parents could make the choice to keep their children at home. The WHO Report noted that services such as these were expensive, but that "even generous financial and practical assistance to parents is still cheaper than hospital care" (ibid:16). This was later to become a significant factor in favour of policies of community care.

Where institutional care was necessary, the Joint Expert Committee recommended the institutions be small units, with sufficient staff to provide children satisfactory parental substitutes, providing the conditions "which allow children full development, both physical and emotional and intellectual" (WHO Report,1954:32). Patients were to be separated according to age and the degree of handicap. The institutions should be located close to other specialist medical facilities, providing the opportunity for research and teaching, and be within easy travelling distance for parents so they could maintain contact with their children (ibid:32). The WHO Committee's recommendations were almost identical to those the Association had made to the Consultative Committee some three years earlier.

The Joint Expert Committee also recommended that the development of services to the "subnormal", in either the health or education field, occur within existing general services. This extended the concept of 'normality'

towards the "subnormal", and made access to specialist services easier for parents. The Joint Expert Committee also recommended the family, rather than the "subnormal" child, become the focus of health and welfare services (WHO, 1954:41,42). Both these recommendations had captured the concept of community-based services which began to develop in the next decade.

The World Health Organisation's report, and Dr. Tizard's contribution by way of comment and discussion of its ideas and recommendations, helped the IHCPA clarify its thinking concerning the role of institutional care and the importance of services for those families whose children lived at home. Such "expert" opinion had validated the Association's arguments against total institutional care, but advanced the realisation that however adequate the services to families might be, institutions would always exist to care for some "intellectually handicapped" people who could not live at home. But the WHO's Report as "expert" opinion, did little to shift Department of Health officials from their belief in institutions as the best means of caring for these children.

### **Pressure from the IHCPA**

The Association's role was determined now by the WHO Report and Dr. Tizard's opinions as much as the outcome of the Consultative Committee's report. It was committed to providing the services it believed its families required, and the most urgent need was for short-stay homes to provide families with relief care.

The Wellington branch was one of the first to establish a short-stay

facility. It had been offered a property which was ideal for this purpose, but was too expensive for their means. Again, because of the Branch's proximity to the seat of Government, a direct approach was made to the Prime Minister for financial assistance to secure its purchase (Anyon Papers,1953k). The Government did not respond to this request. Instead an "anonymous benefactor" purchased the property and returned it to the branch for use as the short-stay facility they wanted (Anyon Papers,1953l).

The Government though, was not able to ignore the setting-up of these short-stay homes. The Wellington project had received much local publicity, and in seeking financial assistance from the Government for this and other short-stay homes, the Association had made the point that the State's costs were reduced when parents chose to care for their children at home (Anyon Papers,1953m). Perhaps some of the arguments advanced by the IHCPA were beginning to have some influence, because in March, 1954 the Minister of Health, J. Marshall, announced that the Government had decided to assist the Association's efforts to establish its short-stay homes. Cabinet had approved both a capital subsidy and a capitation subsidy, thereby contributing to the capital outlay and running costs involved (Anyon Papers,1954a). Although the Association would still have to raise the balance of funds, they considered the granting of this assistance to be a real breakthrough.

But the Government was not intending the establishment of short-stay homes to create any precedents. Short-stays were to be limited to eight

weeks, thereby ensuring the Association did not take advantage of their gain and extend these facilities into long-term residences. Under the then current legislation (the 1911 Mental Defectives Act) these short-stay homes were in fact illegal, a situation which lasted another six months until new legislation was passed and the anomaly corrected. During this time, predictably, the IHCPA attempted to persuade the Government that the Amendment should extend the period of stay for up to twelve weeks, and allow the establishment of hostels (Anyon Papers,1954b). Dr. Lewis, Director of the Mental Hygiene Division, refused to make any changes. He declared "the principle of providing hostels is not regarded as a sound one" and wished the Association to advise its branches accordingly (Anyon Papers,1954c). Special licenses would be issued for the two hostels already in existence, but no others would be contemplated (ibid).

The attempt by the IHCPA to alter the Amendment was a direct lobby on their part, as a pressure-group, to influence the mind of the policy makers. Botting, the President of the New Zealand Committee at the time, commented later that it was never the Association's intention to supplant the Department of Health, but that they still met opposition and frustration at almost every step they took (1972:6).

Dr. Lewis' decision met with a similar implacable response of the opposite point of view from the New Zealand Committee, who stated their conviction that there was a "permanent need" for hostels as an alternative to institutional care (Anyon Papers,1954d). Some of the Wellington

members, being unable to persuade the Association to do so, presented a private petition to Parliament calling for the Government to confirm its commitment to those sections of the Consultative Committee's report, and the WHO's Report, which supported the Association's objectives (Anyon Papers, 1954e). The Association (and the petitioners) had wanted to secure these changes as part of the impending amendments to the Mental Defectives Act. The New Zealand Committee had gone to some lengths to advise and encourage branches in making submissions to effect this, but in the event the Bill was rushed through its first reading with little opportunity for consultation or discussion (Anyon Papers, 1954f). In this instance, the two opposing factions in the debate over short-stay homes (the IHCPA and the Department of Health) had used the parliamentary process as the means of attempting to secure their own particular policy objectives.

#### The 1954 Mental Health Amendment Act

The new legislation, introduced to Parliament as the Mental Defectives Amendment Bill, became law on 30 September, 1954. It included a new legal term, "intellectually handicapped person" to replace "mental defective", and correspondingly a new title to the act, "The Mental Health Amendment Act". It introduced the concessions approved by Dr. Lewis, otherwise there were no changes. The intention of the legislation was as the Director of Mental Hygiene had outlined, and the policy of caring for those with an "intellectual handicap" in State institutions, remained for the meantime, unchanged (Anyon Papers, 1954g). Botting was to comment later that the

Department of Health's resistance to change protected the IHCPA which, as a new organisation, was unaware of the magnitude of the task it was proposing to undertake (Botting,1972:7).

#### The 1957 Mental Health Amendment Act

Shortly after the Amendment was passed, the New Zealand Council of the IHCPA met to discuss its future policy on short-stay homes and hostels. It expressed its "grave concern and disapproval" of the shortcomings and omissions of the Act, and considered the Government should be prepared to redraft the amendment so that it encouraged the growth of the Association's facilities in its various branches (Anyon Papers,1954h).

In line with this resolution, the meeting decided short-stay homes should be established in each branch. Although such a policy committed branches to purchasing property, these homes could also accommodate other activities and still qualify for short-stay subsidies. Such a strategy ensured a network of facilities was in place which could also be used as short-stay homes, were there to be a change in legislation.

Almost a year after presenting their petition, the parents were called before the Public Health Committee to present their case. The petitioners told the Public Health Committee they believed that:

The law should be amended to allow private approved organisations...to set up private homes for our children, and to receive every possible consideration and assistance to do so.  
(Anyon Papers,1954i)

The delay in hearing the petition had meant it was too late to influence the

1954 Mental Health Amendment. But it became the means of bringing the IHCPA, through the deliberations of the Public Health Committee, one step closer to securing their objectives: "cottage homes" and hostels for adults instead of care in large institutions.

As a result of the many protests of parents and the Association, the Government was persuaded to make a further amendment to the Mental Health Act, and invited the IHCPA to submit its ideas before doing so (Anyon Papers, 1957a). The provisions of the second amendment extended the length of stay in short-stay homes from two to three months for children under eighteen, effectively making these homes, hostels, and allowed other private organisations and trusts to establish permanent homes for the "care and training of intellectually handicapped children over the age of fifteen" (Mental Health Amendment, 1957:s12). The Amendment, passed on 18 October, 1957 enabled the Rudolph Steiner Trust to establish Hohepa school for the "intellectually handicapped" near Napier, the Brotherhood of St John to open Marylands Special School for "feble-minded" boys in Christchurch and the Presbyterian Church to open a Home for subnormal women in Dunedin.

Both the 1954 and 1957 legislation can be attributed to the persistence of the IHCPA in pressing Government for the services they wanted. But official attitudes were slow to change, for at the same time, the Department of Health was pursuing plans to enlarge capacity at both its mental deficiency colonies, and to build a third. They believed that:

By and large...the intellectually handicapped are happier amongst their own. They enjoy a community life...achieved by residence in colonies much larger in size than is often contended. After years of experience, this Division still holds the view that the colony of 750 gives a much wider scope for these 'children' and a much happier environment than the restrictions imposed by a smaller one. (AJHR, 1956:H-31,32)

### **The Influence of Local Professional Opinion**

By the end of the 1950s, the Government's policy of caring for "intellectually handicapped" people in large institutions had come under attack from other doctors in the medical profession. There was increasing acceptance internationally of the superiority of community care over institutional care (Jack, 1986:85). The release of the WHO's Report began to influence medical opinion in New Zealand against the recommendations of the Consultative Committee, in favour of the policies detailed in the WHO's report. This change in medical opinion led some members of the New Zealand branch of the BMA, to set up a sub-committee to review the Mental Deficiency Services, in an "analysis of existing policy and the community's requirements" (BMA Report, 1959:1). It was their hope to influence "the general body of their own profession ... and all other interested professions, departments, associations and persons" to:

Halt...the building of large institutions for the mentally subnormal far removed from the homes of their parents, in favour of smaller units in the neighbourhood of urban areas, easy of access to those concerned, and that everything possible...be done to further their education (ibid:2)

The BMA's report, published in 1959, was highly critical of the Consultative Committee's report. Sir Charles Burns, Chairman of the sub-committee,

thought those interested in the mentally subnormal child should be:

Gravely concerned to find those in authority in this country and responsible for the planning for these children...seem determined to pursue the policy recommended in the Aitken report when these recommendations are based on outworn and outmoded ideas. (ibid:2)

The Aitken report, he wrote "... failed in its purpose because it took no cognisance of what was going on in the world elsewhere" (ibid:1). It astonished him to find the only overseas publication used in reference was the Wood Report, published in 1929.

The Burns Report detailed inadequacies in most of the State's services and damned many aspects of official policy as misguided (ibid:12-20,23). The sub-committee's findings throughout the report endorsed the directions in which the IHCPA were moving. "Extreme caution" they suggested "must surround any decision to place a child in an institution" (ibid:7). Such a decision "... is almost never taken in the interest of the child itself" (ibid:8). The Report recommended that institutional care at too early an age could be prevented if various measures were employed, measures which included the payment of extra allowances to mothers and foster mothers and the development of community services (ibid:8). The report suggested that where residential care was necessary, it be planned on "entirely new principles". Institutional care "should serve to relieve the family of their burden ... but not of their child" (ibid:8,9). The BMA had sought to challenge the Department of Health in an attempt to influence the policy-

making process on behalf of those who were "intellectually handicapped".

The BMA's report was welcomed by the Association. It was the second of some authority to endorse their arguments against care for the "intellectually handicapped" in large institutions. While the report did not halt the building of large institutions as its authors had hoped, it prompted the Mental Hygiene Division further towards accepting, though not encouraging, the idea of non-institutionally based support services provided by voluntary bodies, for some "intellectually handicapped" people.

### **The Influence of Philosophies of Normalisation**

The Association's resistance to institutionalisation as the means of caring for the "intellectually handicapped" preceded the emergence of any formal theories of normalisation. Members' beliefs that "intellectually handicapped" children were best cared for in their home environment, not in large institutions, was a conviction shared by growing numbers of parents and professionals concerned with the care of people with "intellectual handicaps", both in New Zealand and overseas. The State however, had established institutions as the means of caring for these children, and now had considerable resources committed to maintaining this policy. But the State had also begun to recognise that some "intellectually handicapped" people could live at home supported by community services. The philosophy of normalisation, which grew out of similar beliefs to those held by parents of the IHCPA, began to influence State provisions for "intellectually handicapped" people in New Zealand

from the late 1960s.

### Changes in the Mental Health Department

Attitudes amongst medical professionals in the Department of Health were beginning to change in the early 1960s. Mental deficiency colonies were renamed "psychopaedic"<sup>9</sup> hospitals and training schools, and in 1961 a further amendment to the Mental Health Act allowed for the informal admission of "mentally subnormal persons" as they were also called, to these hospitals. Certification was now not always necessary, and this enabled families to use the hospitals as short-stay facilities (Mitchell & Mitchell, 1985:56; IHChild, 1962, No.6:2,3). These were small changes, but were indicative of the major policy changes to occur in the mental health field.

### The 1969 Mental Health Act

Towards the end of the 1960s, a major revision of the mental health legislation became necessary to replace the 1911 Mental Health Act, and its several amendments. The main intent of the legislation was to facilitate the transfer of mental health services, including psychopaedic hospitals, from the Crown to local hospital boards (NZPD, 1969, Vol.360:8). It was realised that the divisions between mental and physical health which had existed for over one hundred years were obsolete, and these services should be

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<sup>9</sup> The term "psychopaedic", unique to New Zealand, was coined by Dr. Blake-Palmer, Director of Mental Health, with the help of the English Department of Victoria University in an attempt to distinguish between the mentally ill and the mentally retarded (Watson et al., 1985:48).

integrated within the overall health care system (Watson et al.,1985:48). The legislation included new classifications of “mental disorder” and detailed the provisions for informal admissions.

The Mental Health Bill was introduced to Parliament in 1967 and allowed to lapse so that members of the general public and interested organisations could make representations on its various provisions (NZPD,1969,Vol.360:14). The Intellectually Handicapped Children's Society's (IHCS), submission<sup>10</sup> again urged the Government to reconsider its policy of providing care for the “intellectually handicapped” in institutions in favour of providing the kind of community services already pioneered by the Society (Anyon Papers,1968).

But the final legislation contained no change in policy. The Department of Health was finding it more cost effective and efficient to add a psychopaedic unit to existing hospitals, than to build new, smaller units or new hospitals (IHChild,June,1969:24). The Department's policies earned the rebuke of Professor Tizard, who declared that for more than fifteen years, “world expert opinion” had consistently condemned the kind of accommodation the Department was building. He also disputed their arguments that larger institutions were cheaper to build and run. His

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<sup>10</sup> The IHCPA was renamed the Intellectually Handicapped Children's Society (IHCS) in 1962, and the New Zealand Society for the Intellectually Handicapped (Inc.), (also referred to as the Society, or IHC), in 1975. The changes dropped the word ‘Parents’ from the organisation's title in 1962, and the word ‘Children's’ from the title in 1975. These changes will be discussed further in a later chapter. In December 1994, the organisation became known as IHC New Zealand Incorporated, and is still commonly referred to as IHC.

experience in Britain had proved the opposite (ibid:4,24). Behind these differences of opinion were the divergent policies of the two main agencies involved in caring for the “intellectually handicapped”, the State and the IHCS, and the lack of any overall, co-ordinated planning of services to the “intellectually handicapped” (IHChild, March, 1969:26). This lack of co-operation in long-term planning became an increasing frustration to the Society. The IHCS sought, without success at this stage, to bring together representatives of the Departments of Health and Education in an effort to establish a basis for the development of comprehensive services to people with “intellectual handicaps” (IHChild, Vol.12, No.4: 17,18).

#### The Beginning of the End of Institutionalisation

Prior to transferring responsibility to local boards, the Department of Health undertook a review of its hospitals and related services. Their report noted the constant demand for psychopaedic beds and the “particularly heavy demand” for the admission of children five to fifteen years of age, hardly surprising given this was standard policy. While acknowledging the debate surrounding these issues, and other matters to do with the size, design and location of these institutions, the Department conceded that economic considerations were a significant influence in maintaining a policy of institutional care (Department of Health, 1969:100). The Department had however, bowed to outside opinion and were evaluating claims as to “the efficacy of small units” with a pilot project of a special group of small units at Tokanui Hospital (ibid:101).

The Health Department's entrenched policies on institutional care drew further criticism from the Royal Commission of Inquiry into Hospitals and Related Services, appointed by the Government in 1973. The Commission's report rejected the Department's current policies for the "mentally handicapped", policies which had been based on the Aitken Report, then already twenty years old. The Commission accepted the need for both institutional and community services, but believed there had been a "disproportionate emphasis" on care in large institutions. Policy, they suggested, needed to be reshaped so that the emphasis was on providing facilities in the community "to keep persons out of hospital and to provide the care they need in the community" (Royal Commission of Inquiry, 1973:14,15). The Commission of Inquiry believed the problem of "mental handicap" was one of 'welfare' rather than one of 'health': that people with a "mental handicap" were not sick (ibid:16). Amongst other things, the Commission recommended a comprehensive review of the "mentally handicapped" be undertaken to determine how many might be moved out of hospitals and back into their own homes, or into community placements. This review was carried out by the Department of Health in 1974. Patients in psychopaedic and psychiatric hospitals were surveyed to determine who could be cared for in the community, given the availability of suitable accommodation and support services. Of the 4,312 mentally subnormal in hospitals, 20% were under fifteen years of age. The survey found just over half the 897 children should remain in hospital, one third

could be moved into fully supervised homes, and around 5% able to live in units with some staffing. Similar distributions occurred for the remainder of patients, with a further 3% assessed as able to live fully independently (Jeffery & Booth, 1974:3-6).

The Commission's report was the third of some significance to find fault with the Department of Health's policies of care for the "mentally handicapped". As a consequence of their findings, the survey results, and financial constraints at the time, a moratorium was imposed on the building of further psychiatric and psychopaedic hospitals from 1974 (Watson et al., 1985:48). This became the turning point in the Department's thinking about care for "intellectually handicapped" people in institutions, and policy changed almost overnight. Other factors, such as the shock rise in oil prices in 1973, and the increasing relevance of the philosophy of normalisation could be credited with helping advance these policy changes.

The Deputy Director-General of Health wrote to Hospital Boards requesting they provide community housing for those currently in hospital or on waiting lists, for whom such housing was suitable (IHReview, Vol.14, No.3:13). The project was implemented the same year through the Community Care Programme, a joint venture between the Departments of Health, Social Welfare and the New Zealand Society for the Intellectually Handicapped (IHC). Hospital Boards, with funding provided by the Department of Health, constructed residential accommodation in the community and asked the Society to run this (IHReview, Vol.18, No.4:9;

IHReview, Vol. 17, No. 2: 13).

The Society accepted this responsibility without comment. To them the Department's change of policy represented:

An acceptance by Government of the principle we have advocated so long - that when accommodation as an alternative to the parental home is needed, for most intellectually handicapped such housing should not be in large hospitals, in many cases far away from their homes, but rather in small units in the community close to family and friends. (IHReview, Vol. 14, No. 3: 14)

The philosophy of normalisation for people with "intellectual handicaps" had finally been adopted by the State after some twenty years of lobbying by a pressure-group of parents.

### **Mainstreaming: Normalisation in Education**

Most children who were "intellectually handicapped" were not part of the State education system. They either lived in institutions and were therefore not the responsibility of the Department of Education, or attended occupation centres or groups once they were established by the IHCPA. To the Association these day-based facilities were only a beginning. Parents wanted their "intellectually handicapped" children to have access to the same educational facilities as normal children, and at the same cost: free.

In 1964, the Government introduced the first major revision of the Education Act since 1914. Free and appropriate education continued to be provided in the State's special schools for some "intellectually handicapped" school-aged children (Munro, 1983: 189). However, the Department of

Education retained the right to refuse enrolment of children below a certain level of ability. Special education provisions in the Act were permissive rather than mandatory (Milne & Brown,1983:40). Children living at home who were multiply or profoundly "handicapped", or who were in institutional care, were excluded. Under the terms of the Act, parents were then responsible for providing an education for these children, something parents of normal children were not required to do.

As philosophies of normalisation gained influence amongst parents and professionals in the 1970s and the rights of disabled people recognition from the 1980s, IHC began to campaign for development of the State education system. They wanted children with all degrees of "intellectual handicap" to be provided a free and appropriate education, in a facility established and maintained by the Department (IHReview,Vol.15,No.1:3,4).

This came with a commitment from the Department of Education to mainstream "intellectually handicapped" people into the education system. From the working principles for educating all "handicapped" people identified by the Department in their report to the Organisation for Economic Co-operation and Development examiners (OECD) in 1982, it was a short distance to the introduction of new policy (Department of Education, 1983:61). In April 1984, the Government announced its intentions concerning the education of children with severe "intellectual handicaps" (IHReview,Vol.22,No.3/4:6). From the following year, children enrolled in educational facilities provided by voluntary agencies would be transferred

and enrolled in special education facilities provided by the State, over a five year period. Legislation passed in 1989 gave all children with disabilities (including those in psychopaedic hospitals) entitlement to full inclusion in the State education system (Education Act, 1989; IHReview, Vol.23, No.2:1).

### Mainstreaming Pre-School Children

For younger children with "intellectual handicaps" the process of inclusion into the State education system followed a similar development. As early as 1971, it was recommended by the Committee of Inquiry into Pre-School Education that wherever possible children with less severe "handicaps" be accommodated in regular pre-school sessions. Others with "handicaps", able to adapt to ordinary pre-schools, were to be provided with additional support so that they could be included in small groups in the normal programme. The first of these groups was set up in 1973 (Mitchell, 1987:146). Gradually, in response to parent pressure, a wider range of "intellectually handicapped" children spent time in regular kindergartens. However, their full inclusion into the State system did not occur until after 1989. The Education Act made no provisions for those under five years of age. Hence the Society, along with other agencies, had to return to the political arena on behalf of those under five to negotiate their inclusion into the pre-school education system.

### **Community Care: Normalisation for People With "Intellectual Handicaps"**

The Community Care Programme began the transfer of hundreds of

“intellectually handicapped” people from psychopaedic and psychiatric hospitals into the community from the mid-1970s, prompting the development of related policy in support of these moves. The Disabled Persons Community Welfare Act, passed in 1975, made legal provision for disabled people to receive assistance through the Department of Social Welfare, outside of the benefit system, to enable them to live and work in the community (IHReview, Vol.15, No.1:14). One of the Act’s main provisions entitled parents caring for “intellectually handicapped” dependants at home to twenty-eight days relief care annually, from the burden of this responsibility.

Social Security legislation was also amended to assist the moves towards community care. In 1972, the age of entitlement to Invalid’s Benefit was lowered to fifteen years thus easing the financial burden for families supporting “intellectually handicapped” adults at home (Social Security Amendment Act, 1972:s10). In 1975, “intellectually handicapped” adults became eligible for a means-tested disability allowance to cover extra costs associated with the handicap (Social Security Amendment Act, 1975:s12), and in 1978, parents caring for a child with a serious “intellectual handicap” at home became eligible for a “handicapped” child allowance (Social Security Amendment Act, 1978:s39). These financial provisions were the kind of support parents had requested since the early 1950s. Successive reports had also recommended these services be established in the community as an alternative to institutional care.

Another proposal made by an earlier report developed in this environment of community care. The Board of Health's recommendation to establish multi-disciplinary assessment centres for all children with "handicaps", "to support and assist a family, not just an individual" (Board of Health, 1975:8), echoed the suggestion made by the WHO report of a "family" focus for health and welfare services (1954:42). This concept of a co-ordinated approach to supporting families in the management of an "intellectual handicap", became a model for other service provisions to families with dependants who were "intellectually handicapped".

During this period of development, other provisions were established under the auspices of IHC in the field of "intellectual handicaps". In the late 1960s, the Society established its own research body, later to become the Donald Beasley Institute to undertake the research it had always believed was necessary. Alongside this development, a Trusteeship Scheme was set up in 1967 to care for those left without family members. This later became the Personal Advocacy Trust. With the move towards community-based services, the organisation published its Philosophy and Policy document in 1979. It detailed the rights of people with an "intellectual handicap", and the nature of the services the organisation believed they were entitled to. These were years of rapid growth and through this period, the Society ensured those elected to its Presidency had the professional standing and skills necessary for the leadership of what had become a large welfare organisation.

The 1970s was the decade in which community-based services became established, and the 1980s the years in which the rights of disabled people began to gain recognition. The International Year of Disabled Persons in 1981 focused public attention on all people with disabilities, highlighting the need for their integration into the local community (Mitchell & Mitchell, 1985:83). The formation of the Disabled Persons Assembly in 1983 created a forum from which disabled people themselves began to press for recognition of their rights and challenge the social mechanisms which, for them, had become as disabling as their impairment. In 1988, new legislation was passed which recognised the rights of people with learning disabilities to legal protection in matters concerning their personal affairs as well as the management of their property (Protection of Personal and Property Rights Act, 1988). Not until 1993 in the enactment of the Human Rights legislation, did people with disabilities gain wider legal protection. Discrimination on the grounds of disability in the areas of employment, access to places and facilities, the provision of goods and services, housing and education became illegal (Human Rights Act, 1993). After nearly one hundred and fifty years of legislation which had subjected them to ostracism, segregation and separate service provisions, people with an "intellectual handicap" had finally won the right to be considered equally alongside others in society.

### **The Impact of Policies of Community Care**

To the State in the 1970s, community care policies were becoming an

attractive alternative to policies of institutional care, as much for the idea that they were cost-effective as for their philosophical basis. But as the demand for community-based placements grew, so did the cost to agencies providing the services. The funding accompanying those patients transferring from psychopaedic hospitals to community care programmes was proving to be inadequate. The notion that community care was less expensive than institutional care had become a rationale for the State to reduce its funding to the voluntary sector. The idea that community care was cheaper to provide was part of the argument against institutional care, but it has been proved since that community care is at least as costly to provide, if properly implemented (Craig & Mills, 1987:32).

As a major provider of services, IHC began to experience financial difficulties in the late 1970s until the Government agreed to increase its funding to the organisation. This was with the proviso that the Society become part of the Joint Planning Group, along with representatives of the Departments of Social Welfare, Health and Education, to "facilitate co-operation and co-ordination of services in the community for the intellectually handicapped" (IHReview, Vol.20, No.2, iii). This was the joint planning the Society had sought to introduce in the late 1960s. As a result of joining the Planning Group, IHC was to develop a close working relationship with government Departments concerned with the care of "intellectually handicapped" people.

Implicit in the Society's involvement in this group was a recognition by

Government of the organisation as a "major provider" of these services (ibid). It was recognition too, that in the area of the "intellectually handicapped" the Government's objectives could now be described as "the same" as the Society's (IHReview, Vol.20, No.3:1). It was also acceptance of the belief advanced earlier by Dr. Tizard and others, that the cost of institutional care far exceeded the cost of services provided in the community.

But the Government's increase in funding to the Society had come with a warning from the Minister of Social Welfare, not to expect further assistance. Welfare services were costing the Government as much as it could sustain, and he believed New Zealand was coming to a crossroads in the development of services for the "intellectually handicapped" (IHReview, Vol.20, No.3:1). The economic environment was changing and by the end of the 1980s, these crossroads had been reached.

Community care policies had been implemented in the 1970s with little analysis of the flow-on effects for service providers, or service users. Continuing financial difficulties in IHC resulted in a Government audit of its funding to the organisation, in 1985. It identified a number of problems in the long-term management and funding of those transferring from psychopaedic hospitals to organisations such as IHC. The audit found that two departments of State (Health and Social Welfare) were funding two separate agencies to service the intellectually handicapped in New Zealand (Report of the Controller and Auditor General, IHReview, Vol.24, No.2/3:26).

In order to resolve these problems, the report recommended that one consistent policy apply to all service providers, a single authority monitor and co-ordinate resources, and that there be a greater commitment to co-operation amongst those providing services to ensure the needs of people with "intellectual handicaps" were met. It suggested that those organisations which might be involved in transferring other "intellectually handicapped" people from psychopaedic hospitals, would need to be funded in a manner which allowed them to meet the demands placed on them. These recommendations became the basis of new policy initiatives, initiatives which reflected the growing influence of New Right philosophies, but which were expected to complete the process of normalisation for all people with "intellectual handicaps" who were still in institutional care.

### **The Implications of Legislation for Families of People with Learning Disabilities**

It can be reasonably argued caring for a learning disabled dependant in the community had been a long-standing practice for some families who had resisted moves to institutionalisation and chosen to keep their children at home. It would also be reasonable to suggest that the amendments to the mental health legislation in the 1950s and 1960s which established relief provisions for these families, simply acknowledged the demands involved in such care. But these changes in legislation also signalled the beginning of the end of segregation and institutionalisation for people who had a learning disability. Philosophies of normalisation introduced social policies which

actively supported their shift back into the community (Whitehead,1992:25).

Community care policies reflected a gradual recognition of the importance (instead of the rejection) of the family as the main source of support in caring for people with learning disabilities. Parents with a learning disabled child were no longer seen as responsible for the handicap. Heredity was regarded as just one of many factors which might be the 'cause' of a learning disability. It was an event which could happen within any family, without discrimination between class, culture, fortune or vocation (Ayer & Alaszewski,1984:26,27). The community too, became an essential source of support for families and the means of integrating children with learning disabilities into their neighbourhood (Alaszewski & Ong, 1991:22).

Parents whose children were returning from institutions to live in the community had pressed for these changes for years (Anyon Papers,1951i). But the prospect could still raise fears for these parents as to how their dependants would manage after perhaps years in a protected, sheltered environment (Central Regional Health Authority,1995:20-21). It was likely that there would be new skills to learn, new people to meet and new horizons to explore, most of which would be a positive experience for these adults. But parents might still hold fears for their dependants coming to harm in some way, or being taken advantage of. Services in community settings were subject to change in response to new ideas or funding

differences, often with consequences for people with a learning disability. Those whose parents were still alive or had siblings, were generally assured of someone to protect their best interests through these changes. For those who had no family, it would be reasonable to suggest that they had an advocate to act on their behalf.

For parents whose children had grown up in the local community and had never been admitted to an institution, there would have been fears and frustrations of a different kind. These parents coped with the extra demands of a child whose development was delayed, together with the normal pressures of family life. There may have been other family members or friends to share the caregiving. For families without immediate relatives nearby, support networks had to be developed amongst people in the community who were initially strangers to the family. It would be fair to say that this would have been an additional stress for a family who had a child with a learning disability.

Siblings needed parents' time and attention, parents needed time for each other and a learning disabled child always needed extra time and attention. The practical and emotional demands were constant, the challenges enormous but that the gains these children made, though often small, would have provided tremendous rewards for those involved.

Inclusion in the community demanded time, commitment and expense of families in order access service provisions. Parents played a key role along with professionals, in planning their children's developmental and

educational goals, often from birth. Given that the experience of caring for a child with a learning disability was a new one for most parents, this meant they were likely to face a bewildering array of professionals. These 'experts' were all concerned with some aspect of their child's progress, and parents would not always have the confidence of knowing whether they were receiving the best advice, or what choices to make. Parents were likely to turn for support to others who had trodden the same path and knew the pitfalls, the disappointments, and the progress that was possible for their children. Often parents became the experts on their child's handicap.

Parents had always faced fears about the future for their children. Institutional care had provided parents with some assurance that dependants would be cared for upon their death. Now there was no certainty as to who would fulfill this role. As with many aspects of community care, answers would have to be found for each child in each new set of circumstances.

### **The Implications for People with Learning Disabilities**

People with learning disabilities moving back into the community were no longer regarded as 'deviant'. They might be seen as 'different', but as equal members of society they were afforded the same rights, privileges and responsibilities as everybody else in the community (Alaszewski & Ong, 1991:17). Returning to the community meant they exchanged the security, the protection, and the disempowerment of institutional life for the choices, the freedoms and the risks associated with living in the community.

As equal members of society, learning disabled people might now want to vote in an election, go to the pub for a drink, stay out late at a nightclub, play sport in the weekends, enjoy a sexual relationship or marry and have a family. They would also have to put out the rubbish, pay their bills and do their own shopping, housekeeping and cleaning (Central Regional Health Authority, 1995:17-19). They were provided housing, and were offered some choice as to where, and with whom, they lived. They could, with support, hold down a job and earn an income. For people with a learning disability, this was an 'ordinary' life (Dalley, 1989:201).

Services in the community for people with learning disabilities began in the 1950s as voluntary provisions established alongside, but separate from, State provisions to the non-disabled. By the 1970s, pressure was growing from service providers for the integration of people with learning disabilities into State-funded services in the community. The impact of philosophies of normalisation and the activities of pressure-groups forced the State to re-appraise its commitment to policies of institutional care, and from this point large numbers of people with learning disabilities were moved out of psychopaedic hospitals into a community environment. Community care policies were a realisation of the beliefs which a small group of parents had striven to persuade the State to accept, on behalf of children with learning disabilities, some forty years earlier.

The argument that social policy which moved people with learning disabilities towards independence required a greater involvement of their

families, is supported by the experience of families themselves during this period. As people with learning disabilities left the confines of institutions and took their rightful place in the community, families of younger children and parents of older dependants became actively involved in supporting them towards independence and a lifestyle of their choice.

## CHAPTER EIGHT

**SELF-ADVOCACY: People with Learning Disabilities****Speaking for Themselves**

Policies of normalisation introduced in the 1970s brought change into the lives of people with learning disabilities. Their move from institutions into the community provided them with opportunities to make choices about many aspects of their lives where decisions had previously been made for them. Institutional care had made learning disabled people dependent, and devalued them as people and members of society. The self-advocacy<sup>11</sup> movement in IHC began as 'People First', supporting learning disabled people living in the community having some input into the services they received. Self-advocacy groups, as service consumers, now have an input into policy formation for disabled people through representation at the policy-making level.

Self-advocacy is, in the broadest sense, "a profoundly political movement" (Young, 1993:70). The self-advocacy movement owes its origins to the activism of parents in the 1950s to move services for learning disabled people into the community, as part of a wider movement amongst minority groups for social change in the 1960s and 1970s. The IHCPA, in

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<sup>11</sup> Self-advocacy is about people with a learning disability understanding their rights and using them responsibly to take control of their own lives. It involves the notion of individual empowerment rather than the support of another person as the means towards this change.

adopting the philosophy and principles of normalisation to develop the small range of services they had already established, adopted a philosophy which also emphasised a valued role and status for learning disabled people in the community.

The belief that the learning disabled were valued, challenged society's perceptions of these people. Medical and educational models of services confined learning disabled people to dependent and powerless roles, as 'sick' or as 'children' (Young,1993:68). As such, they were not expected to be responsible for their actions, and neither did society see it had any obligation to develop their abilities or potential.

In adopting a philosophy of normalisation, IHC became a major advocate of people with learning disabilities. In a move which recognised the adult status of those to whom it provided services, the IHCPA in 1975 dropped the word 'Children' from the organisation's official title. As the New Zealand Society for the Intellectually Handicapped, the name change recognised the right of learning disabled adults to "dignity and acceptance" (Howie & Cuming,1986:31). The organisation's Philosophy and Policy statement affirmed their right as adults, to a lifestyle of independence in the community. Philosophies of normalisation made an important contribution to the lives of people with learning disabilities, establishing an environment in which they would develop their rights as consumers.

Other advocacy organisations have developed to support those with learning disabilities. The Trusteeship Scheme, which was established by

the Society in 1967, in 1992 became the Personal Advocacy Trust. As a stand-alone body funded by its members, it continues to look after the interests of people with learning disabilities where sometimes there are no parents to do so. The Citizen Advocacy movement began in New Zealand in the early 1990s, recruiting volunteers from the community to befriend people with learning disabilities and advocate for their rights and interests. IHC continues to be an advocacy body for all those with learning disabilities, and is moving to separate its advocacy role from its other function as a service provider.

Philosophies of normalisation which moved people with learning disabilities into the community, were based on the premise they should have a say in their lives and be given the opportunity to learn useful, self-enhancing skills. The concept of self-advocacy became the means of achieving this. Daily life in the community meant learning disabled people had to make decisions, to speak up for themselves and to value their own abilities, and so reverse their experience of being devalued people (Williams & Shoultz, 1982:90,92).

The self-advocacy movement amongst learning disabled people in the community arose from small beginnings in 1980. With the support of staff, residents in an IHC home in Auckland formed a committee to obtain the views of other people with learning disabilities, about their accommodation. The Committee's purpose was to develop discussion and decision-making skills, committee skills, and become a forum where their views could

become an influence on policy and service provision (Mitchell & Mitchell,1985:80).

When the IHCPA was first formed, learning disabled people had no right of membership and no decision-making powers (Howie & Cuming,1986:45). Today, as part of IHC, they are able to become members of their local branch, and self-advocates are elected on to branch committees. They are also joining interview panels to select new staff. In 1994, two self-advocates were elected as members of New Zealand Council (the policy making body of the organisation), and a national co-ordinator of 'People First' appointed by its membership. The self-advocacy movement is represented in most branches of IHC and since 1983, representatives have attended their own biennial, concurrent conference. Within IHC, people with learning disabilities have become more actively involved in the direction and development of service provision (IHReview,Vol.24,No.4:3).

However, while self-advocacy was supported in principle within IHC, Howie & Cuming (1986) identified some reluctance on the part of the organisation to implement the decisions made by the 'People First' movement. It took some ten years for instance, for the recommendation that there be client representatives to monitor the issues presented to the New Zealand Committee, to be implemented (1986:63). And although self-advocacy now occupies an important position within IHC, these self-advocates, as yet, are not part of the wider disability rights movement. Efforts to establish a self-advocacy movement for people with learning

disabilities which is independent of IHC, have so far been thwarted by IHC itself. IHC, as the dominant provider in this field, has been able to capture the 'People First' movement, which currently represents only those people with a learning disability who are provided services through IHC. While this situation could be perceived to represent a consensus of consumer interests, in fact it serves to reinforce the role of IHC as a major service provider. There appears to be ongoing debate amongst the wider disability rights movement about consumer representation for all people with learning disabilities.

The move towards self-advocacy may also be the means of ensuring that IHC develops policies and services which are culturally appropriate for all service users and their families. IHC has acknowledged the need to implement the provisions of the Treaty of Waitangi as part of its Philosophy and Policy (IHC Policy Memorandum, 1995:6). The organisation provides services to significant numbers of persons of non-European origin (Bevan-Brown, 1994:205; Morrison et.al., 1976:26-28).

The commitment to a 'family' perspective that underpins IHC's service delivery would accommodate the development of services which have a bicultural focus. Services in some branches, particularly in areas where there is a significant Maori population, have already involved whanau and iwi in the planning and delivery of services, both at a community and family level.

The overall lack of culturally appropriate services for Maori and other

non- European cultural groups reflects the need for many parents to secure practical assistance in the management of the disability itself, as a first priority. Having achieved this, families are then more able to focus on the context in which the service is delivered.

Self-advocacy as a process of empowerment, seeks to address issues relating to equity and social justice for disabled people (Rees,1991:66). Disabled people themselves have identified issues such as choices as to how, and by whom services are provided, increased accountability of service providers, and their involvement in the design and monitoring of services as issues of importance. The recent policy changes in the funding and delivery of disability support services, recognise these concerns.

While the achievements of self-advocacy may also be more modest, it is the process of gaining confidence to speak and act for themselves which is important. Self-advocacy for people with learning disabilities, is the means achieving significant change in their lives.

## CHAPTER NINE

**SERVICE DEVELOPMENT: State Oversight and Private  
Providers**

The Fourth Labour Government's move to shift funding to the disability sector on to an individual basis and adopt the concept of brokerage to develop a range of service providers, introduced new directions in the care of those with disabilities. These policy changes reflected the influence of libertarian thinking, which from 1984 formed the basis of government economic and social policy. From 1990, the National government furthered the course of these changes with significant shifts in the nature and scope of the Welfare State. This process of reform was expected to provide services which would support disabled people towards greater personal independence. While some evaluation of current policies can be attempted, the ultimate success of these strategies should be judged by disabled people themselves.

**The Influence of Libertarian Theory**

The Government rationalised the changes in the disability sector to service providers in terms of the philosophy of normalisation. They that believed people with disabilities wanted, and should be given, as much control over their own lives as possible (IHReview, Vol.25, No.2:4; IHReview, Vol.28, No.4:2). By funding individual consumers rather than service providers, disabled people would have the opportunity of making choices from those services that were available. For its part, the Government would ensure a full range of

community-based alternatives was in place so choices were available in the initial instance, to those moving out of hospitals (IHReview, Vol.28, No.4:2,3).

But the restructuring of the disability sector was the result of wider fiscal and ideological pressures, of social policy conceived in a free market environment. As such, it reflected the particular objectives of libertarian ideologies which had dominated the policy-making process from 1984.

### Libertarian Theory

The ideology of the 'libertarian right' drew together neo-classical economics and a belief in the equilibrium of the market, and classic liberalism which values the supremacy of individualism and limited government interference. Exponents of libertarian ideology championed individual freedom, minimal State intervention and the supply and demand of the market (relying on monetarist policies) as the solution to the economic problems of the 1970s. Libertarianism set out to change the agenda of both economic and social policy, and in particular, trim the function of the Welfare State (King, 1987:8; Gamble, 1986:30,35).

Libertarians held the freedom of the individual to be the greatest good, something they believed could not be determined by the State (Harris, 1987:20; Walker, 1990:31). Individual wants and preferences (inputs), would determine the production and distribution of services (outputs), constituting the supply and demand mechanism of the market. This process assumed individuals' interactions with the market to be rational and acquisitive, and unaffected by ignorance or uncertainty (Armstrong, 1990:126;

Shannon,1991:7). The State's legitimate sphere of intervention would be the 'public' arena, rather than the 'private' world of the family. In its purist form, there was no recognition of a collective responsibility for the welfare of particular groups in society (Walker,1990: 31). The State's responsibility was merely to protect the rights of individuals in their interactions with the free operation of the market (Harris,1987:16; Shannon,1991:48). Accordingly, people with disabilities as individuals who knew best how to maximise their own best interests, were to have the freedom to make the decisions which would best enable them to pursue this (Harris,1987:18).

#### Social Policy in a 'Free Market' Environment

Libertarian ideology assumes a minimal role for the State in the maintenance of human welfare. Consequently, in the 1980s the State restructured its responsibilities to separate the funder, provider and policy aspects of its functions. Competition between private providers and State agencies was expected to result in increased efficiencies and effectiveness. But services to people with disabilities were to be provided by the private sector, rather than by the State. The Department of Social Welfare was to be responsible for funding these private providers and co-ordinating services to all people with disabilities (IHReview,Vol.28,No.3:1).

This devolution of power and resources was seen as enabling the diverse needs and interests of local communities, and cultural groups, to be better met than through central State provision. Policy makers believed a decentralised bureaucracy meant the possibility of more effective decision-

making at a local level, by those most closely involved (Armstrong, 1990:129). The Government set out, therefore, to encourage the development of a range of community services to meet the many and different client needs (IHReview, Vol.28, No.3:2). Where funding came from the public purse, central government sheeted home accountability to individual service providers. Within the field of learning disability, an independent monitoring and evaluation system would monitor all services funded by the State (IHReview, Vol.28, No.4:2,3).

Libertarian theory advances "consumer sovereignty", the idea that the welfare of individuals and society is enhanced when individuals, as consumers, are able to make choices (Walker, 1990:35). According to Walker, consumer demand determines the services provided, rather than these being decided upon and provided directly by the State. Disabled people, funded individually by the Government, would purchase the particular services they required. Libertarianism argues that social well-being is provided more effectively through the marketplace than as an entitlement associated with the rights of citizenship, and a collective responsibility of the State (Harris, 1987:20).

The Fourth Labour government wished to see people with learning disabilities and their families with a greater choice in service provision than was currently available. The Minister of Social Welfare expressed the belief that individuals, regardless of ability or disability, enjoyed an increased sense of well-being and belonging in society when able to exercise control over their

own lives (Dr. Michael Cullen, cited in *IHReview*, Vol.28, No.4:2,3). His Government believed families and personal networks would best assist people with learning disabilities to make choices that would maximise their options. The impending Human Rights legislation was intended to establish disabled people's rights and status in the face of these emerging changes (*IHReview*, Vol.28, No.3:3).

Fundamental to libertarian economic theory of the 1980s, and thus contemporary policy development, are concepts of effectiveness and efficiency. Market allocation is regarded by libertarians as generating the most efficient use of resources. Provision by the State is seen as costly and unnecessary (Harris, 1987:20). In the disability field, private sector providers such as IHC had already proved the cost-effectiveness of community provision (*IHReview*, Vol.24, No.2/3:16). This gave the Government a mandate to begin closing State psychiatric and psychopaedic hospitals and move those remaining into the community (*IHReview*, Vol.28, No.3:2).

Notions of equality for consumers (integral to the concept of citizenship) are redefined in this environment. Libertarian theory understands the equal distribution of resources (equity) to be delivered through the individual's interactions with the free market. Where inequalities exist, they are addressed by a minimal redistribution of resources, preferably by the private sector but also through taxation or benefit systems (Harris, 1987:90-91). In this environment, social justice is redefined in terms of economic efficiency. Self-reliance, efficiency, and greater personal choice were the principles

underlying the philosophy of market provision (Boston & Dalziel,1992:7; Harris,1987:20).

### **A 'New Deal' for People With Disabilities**

The immediate implementation of these free market social policies was delayed by the newly-elected 1990 National Government in the face of a looming fiscal crisis (Boston & Dalziel,1992:24; IHReview,Vol.29,No.2:14). During 1991, the new Government reviewed the decisions made on the health/welfare interface with the purpose of further streamlining the funding and delivery of services to the disability sector. The intent as presented was to introduce a "fairer", "more flexible" and "better managed" system of resourcing disability support services (Ministry of Health, Ministry of Social Welfare,1992b:1).

But it was also the Government's intention to 'roll back' the Welfare State as a solution to these growing fiscal pressures (Armstrong,1990:127). While the Labour Government had made significant shifts away from a social citizenship model of welfare<sup>12</sup> to a more targetted approach, the National Government moved quickly towards a residualist approach to welfare provision. The State would provide no more than a 'modest safety net' for those unable to meet their own basic needs (Boston & Dalziel,1992:1,6,7). People with physical, sensory, "intellectual", psychiatric or age-related disabilities would remain eligible for State support, but assistance might be

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<sup>12</sup> A social citizenship model of welfare, or rights-based model, establishes entitlement to social services and income transfers on an individual's status as a citizen rather than on the basis of income, wealth, previous earnings or contributions (Boston & Dalziel,1992:4).

targeted to those most in need (Ministry of Health, Ministry of Social Welfare, 1992b:1).

### The 'New Deal'

The 'new deal' implemented by the National Government endorsed the direction of social policy proposed by the outgoing Labour government. Accordingly, the Government moved to separate its funding role from that of its role as a service provider. The Department of Health, area health boards and the Department of Social Welfare were to be replaced by a single government agency, the Regional Health Authority (RHA). These several authorities would be responsible for purchasing (funding) support services for all people with disabilities, from one integrated budget. This flexibility in funding would enable the purchase of services which would better meet the needs of consumers (Ministry of Health, Ministry of Social Welfare, 1992a:15-26).

New legislation was required to implement these policy changes. The Health Reforms Act (1993), and the Health and Disability Services Act (1993), created the new organisational structures by which the transfer of responsibility and funding for disability support services from government agencies, could be expedited. The Social Welfare Reform Bill (1995) transferred the responsibility and funding for programmes established under the Disabled Persons' Community Welfare Act (1975) from the Department of Social Welfare to the RHAs. The Department's role was now strictly one of paying income support to those with disabilities. The Health and Disability

Commissioner Act (1994) provided for the appointment of a Health and Disability Commissioner who would define, protect and promote consumer rights, investigate infringements of these rights, and establish advocacy services for users of public and private health and disability services. The intention of the Act was to protect consumers' rights in the new market environment.

Hand-in-hand with the separation of purchasing and funding roles was the introduction of a system that would improve consumers' access to the support services they required. Within this new structure, information would be disseminated, the needs of disabled individuals assessed, and the most appropriate services purchased or developed to meet the needs of the consumer (Ministry of Health, Ministry of Social Welfare, 1992a:27-30). Certain specified attributes would be required of agencies providing services to people with disabilities, to ensure this process of change achieved the Government's objectives (ibid:1992a:9; 1992b:10). One of these was a focus on the "well-being" of consumers. In the return of the disability sector to the management of health authorities, the Minister of Health gave an assurance to disabled people that there would not be a return to what the Minister described as a 'medical model' of care (Minister of Health, 1995:2).

### **The Influence of the Disability Rights Movement**

The self-advocacy movements that arose in the 1980s amongst different groups of disabled people both in New Zealand and overseas, became the vehicle through which disabled people began to articulate their concerns

about various aspects of the services they received. By the early 1990s, the disability rights movement had become a significant influence on the formation of social policy as it related to disabled people. There were, within this movement, a number of groups concerned about disability issues and the Government invited these groups to take part in the reform process. Disabled people had identified a number of issues as being important, such as a choice between services and service providers, an involvement in the design and monitoring of service standards, participation in the planning and management of services and staff training, and securing increased accountability of service providers (Glendinning,1991:16). The success of disability groups in influencing the policy-making process was facilitated by a policy environment that was receptive to their demands.

Disabled people had also expressed criticism of the organisation and delivery of health and welfare services, in particular of employment and income support policies and the control exercised by bureaucrats and professionals in administering these policies. Superficially, their criticisms bore a similarity to libertarian arguments for reduced State control and less dependency on its provisions. Disabled people saw the organisational and administrative obstacles as symptomatic of the oppression they experienced within a society run largely by, and for, able-bodied people (Glendinning,1991:3,4). As the means of overcoming this oppression, people with disabilities wanted autonomy, integration, an end to discrimination, and the right to an equal share of resources. Their demands appeared to be

advanced by the ideological environment of the New Right.

The desire for an equitable share of the resources by people with disabilities was one of the driving forces behind the health reforms (Minister of Health, 1995:2). The reforms were intended to improve the quality of life of disabled people and give them greater independence. The co-operation of disabled people<sup>13</sup> in the policy-making process added legitimacy to the reform process. The new health system, claimed the Minister, was "grounded in the needs of people with disabilities" (Minister of Health, 1995:2). Their individual needs and those of their caregivers, families or whanau would be met with appropriate support, enabling them to make choices which would, the Government claimed, give them greater control of their lives. As a result of the representations of disabled people, the Government announced its intention to widen the focus of these changes. The Minister wished to implement initiatives that would address the "social and environmental barriers" experienced by disabled people in accessing services provided by Government departments (Minister of Health, 1995:2,6).

### **A 'New Deal' or 'New Right' Rhetoric?**

The rationalising of the health sector was intended however, to maximise existing resources to deliver more, and to shift the costs of providing services back to the consumer (Fougere, 1994:109). Managed competition formed the

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<sup>13</sup> Groups such as Disabled Persons Assembly (DPA), the Federation of Voluntary Welfare Organisations, IHC, New Zealand Crippled Children's Society (NZCCS), the Royal New Zealand Foundation for the Blind (RNZFB), the Schizophrenia Fellowship and Workbridge were amongst those who made submissions in May, 1992 on the funding and delivery of Disability Support Services.

strategy to achieve these outcomes. These changes in the health sector were expressed in terms of improved access, innovative and flexible options, increased efficiency and accountability, equity, choice and responsiveness to consumer and community needs (Ministry of Health, Ministry of Social Welfare, 1992a:10; 1992b:9). The reforms, superficially responsive to the concerns of disabled people, were nevertheless based on free market principles and therefore subject to the outcome of market forces.

For people with disabilities, debates and tensions are emerging in the 1990s around a number of issues related to the restructured disability support services. Of major concern to disabled people is the allocation of resources. The introduction of contestable funding was intended to stimulate competition between providers of services and produce a more efficient use of resources. In turn, increased efficiency was expected to facilitate improved management practices and accountability of provider agencies. However, competition of itself does not guarantee such outcomes and people with disabilities are beginning to believe these efficiencies might be achieved at their expense.

Disabled people's access to service provision and funding is dependent upon assessment of the individual. Although people with disabilities contributed to the development of these assessment standards (Ministry of Health, 1994:3), they had fears that the assessment process itself could be used by professionals to control access to resources (Munford, 1994:287). 'Waiting' lists have emerged as the means of rationing disability support

services in a health system which must manage an open-ended demand for services within a capped budget (Dowland,1994:7). The allocation of funding as an individual entitlement is being shifted towards towards a bulk funding regime (IHC Policy Memorandum,1995:6).

While assessment procedures introduced an element of accountability for the policy-makers, to disabled people they represented potential barriers to accessing the resources for independent living (Dowland,1994:7). People with disabilities had wanted to ensure that service providers were accountable to them, the service users. The funder-provider split has the potential for the relationship between these two parties to be more transparent, making both parties more accountable to each other, and to the public (Fougere,1994:114). But the RHA's accountability to the public has remained ill-defined (Dowland, 1994:7; Fougere,1994:114), and their relationship with the Minister "cloaked in secrecy" (Dowland,1994:8).

Compliance with this accountability is proving costly and time-consuming (IHC Policy Memorandum,1995:5,6). In addition, the complex and difficult process of contract negotiation required agencies to make a heavy investment in new information technology, new staff and new skills (Fougere,1994:115). Dowland (1994:7), has suggested that compliance, quality, and efficiency as outcomes are being achieved through traditional State sector methods rather than as a result of natural market mechanisms expounded by libertarianism.

Competition between providers is not always possible. In many regional

areas, there is little choice of providers in some services (Fougere,1994:115). In the field of learning disability, the range of alternative providers remains small (IHC Policy Memorandum,1995:7). IHC thus remains a major service provider in these areas. This limits the choices by which individuals, and families, are able to maximise their own 'good'. Alternatively, individuals are required to have extra resources to achieve such outcomes. Choice exists only for those who can afford it (Munford,1994:284). Where competition does exist, the outcomes are uncertain. Providers can compromise service quality to produce efficiencies or may enhance the quality of particular services at the expense of efficiency (Fougere,1994:115).

For people with learning disabilities, dependent on financial resources to live a normal life in the community, access to these resources is becoming more difficult. While the benefit system continues to provide part of their financial support, the remainder (the residential support subsidy), is subject to rationing through the health system. This was funding transferred in bulk from the welfare sector to form the RHA's integrated budgets. Under a system of welfare established by legislation in 1975, people with learning disabilities would have been entitled to this funding subsidy 'as of right' (Dowland,1994:7). Although funding to the disability sector is currently 'ring-fenced', there is no guarantee that this protection will remain in place. Other entitlements to support, such as Carer Support, are now subject to targeting. Although families receiving this relief care are not subject to income, asset or means testing, those not using their full entitlement will have this reviewed

from the 1 July 1995 (Ministry of Health, 1995:4).

But the likelihood exists that inequities will arise for individuals, and particularly disabled individuals, as a result of their interactions with a free market. To minimise this possibility, the Government moved to introduce a raft of legislation to safeguard the 'rights' of those with disabilities in this new economic and social environment.

#### The 1993 Human Rights Act

The legislation was passed to protect the interests of disabled people in areas such as employment, access to places and facilities, the provision of goods and services, housing and education. However, much of this 'protection' may finally be illusory. For instance, the Human Rights legislation, while making discrimination on the grounds of disability illegal, is still subordinate to all other legislation and Government regulations Human Rights Act, 1993:s151.1). It also contains some exceptions in the provision of special facilities and services for disabled people where risk is involved to the provider (Human Rights Act, 1993:s29,s43,s52, s56,s60).

#### The 1989 Education Act in the Current Environment

The 1989 Education Act made a clear statement that persons with disabilities had the same rights as non-disabled people to enrol and be educated at any State school. But consistent with the Government's intention to reduce the role of the Welfare State, the Act was implemented with resources which some educationalists believed left special education alarmingly underfunded (Special Education Lobby, 1995:1).

Libertarian philosophies have influenced other aspects of special education. Policy development and the allocation of funding remained the responsibility of the Ministry of Education. The provision of services in special education was made contestable in an effort to encourage a range of providers of special education, and cost-effective services. Criteria were developed so that resources for children with particular learning needs could be allocated more effectively (Education Gazette,1995:2). Parents retained the right of choice as to where their children were enrolled, but those in segregated classes and schools were resourced with greater ease and certainty than those enrolled in local schools, where resources have been more difficult to secure (IHC Advocacy Centre,1994:3). Two different philosophies and systems of special education appear to be emerging as a result, and as parents opt for a choice which is more easily resourced there is a 'drift' towards special education in segregated situations (IHC Advocacy Centre,1994:2).

Current policy, released some five years after the legislation was passed, has affirmed the rights of learners with special education needs while reducing the resources needed to implement these entitlements.

#### The 1992 Mental Health Act

The substance of the Mental Health Act (1992) in relation to people with a learning disability was influenced by policies of normalisation. It was the first revision of the legislation since 1969 and was ten years in the preparation, four or five of these in legislative form (NZPD,1992,Vol.525:8455). Patients rights were defined and treatment was to occur in the 'least restrictive

environment'. The legislation included review and appeal procedures, and the definition of 'mental disorder' became more exact. It excluded those with learning disabilities.

For the first time in the history of mental health law in New Zealand, people with a learning disability could not be committed to the care of a psychiatric hospital. A person could not be considered 'mentally disordered' by reason of a learning disability only (Mental Health Act, 1992:s4). Once the new Act came into force, there were many people in psychiatric hospitals who could no longer be kept there because they were not considered to have a 'mental disorder'. People with learning disabilities had finally won the legal right to citizenship, and to live a normal life in the community.

While the Government has been anxious to address the "social and environmental barriers" faced by disabled people (Minister of Health, 1995:6), these initiatives fail to challenge the 'disabling' nature of society itself. The reforms, designed to support people with disabilities towards independence, are based on a strategy of economic rationalism and ignore the materialist analysis of disability developed by theorists such as Oliver (1990). Disabled people, dependent on material resources and services to live a normal life in the community, are likely to experience disadvantage as a result of reforms, reforms which were intended to improve their quality of life. Inequality between individuals in fact is a fundamental assumption of New Right ideology, and regarded as the proper outcome of the operation of the free market (Walker, 1990:32).

But there are wider issues arising from the restructuring of the disability sector. The Government had introduced these changes so that individual funding would enable people with disabilities to have choices in the services they received. Underpinned by the philosophy of normalisation, the reforms made provision for a range of community-based options as the means of providing these choices. However, 'choice' for these people, or their parents, did not include the possibility of them remaining in institutional care. Not all parents are convinced of the benefits of community care for dependants who had lived their lives in institutions, and are still there (many of them) because their behaviour made them less suited to community care. Others have remained in institutions because their profound learning disabilities required high levels of support, more easily provided there. Older parents have concerns as to how they will manage to support ageing dependants placed in the community as they themselves become elderly. The debate over deinstitutionalisation is a debate over the allocation of resources, over differing philosophies of care, and in the final analysis about whose interests are actually being served. Philosophies of normalisation may be compromised in their implementation by the rolling back of the Welfare State and the consequent 'efficiencies' required of service providers.

The restructured disability support services have enabled new providers to enter the market. These new providers are establishing services that are directly responsive to the individual needs of consumers. Philosophies of normalisation have raised the expectations of younger parents of children

with disabilities, who are increasingly demanding of providers greater flexibility in service provision. The self-advocacy movement is achieving the same outcome for older people. For an organisation such as IHC, which has been the dominant provider in the field, there is now a challenge to meet the demands of consumer advocacy groups. To provide services that are responsive to the needs and interests of consumers will require of organisations such as IHC, a devolution of its own organisational structure.

**The Implications of Legislation for Families of People with Learning Disabilities**

Libertarianism, concerned primarily with public sphere activities of the market and the State, nevertheless influenced the private world of the family. Economic liberalism merged with the beliefs of the conservative 'moral' right, which emerged in both the United States and Britain in the 1980s, to establish social and economic policies which were intimately bound up with the family. The policy-makers had sought to recreate and reinstate the traditional nuclear family as being central to future economic well-being of society (David, 1986:137,139).

For women, libertarian social policy was to re-define their role within the family, especially as mothers. Whereas feminism had pushed personal issues for women (such as sexual and social relationships) on to the political agenda, New Right ideology would ensure the responsibility for such matters returned them from this 'public' sphere to the 'private' world of the family (David, 1986:136). This model of the family was intended to recreate the traditional

nuclear family (ibid:139) and within this private world of the family, relations of power and differences in production and consumption between individual family members, could remain a private family matter.

Motherhood, according to this model, is an all-consuming, full-time, and unpaid activity sustaining both spouse and dependant family members through domestic care (David,1986:139). Fatherhood, on the other hand, is synonymous with procreation and more distant economic responsibilities. Much libertarian economic and social policy assumes the existence of such a set of relationships in the marketplace, thus facilitating the transfer of certain social responsibilities back to the family (ibid:139). David argues that increasingly in Britain and the USA, such policies are being used to prevent mothers participating in the labour force and to impose on them moral obligations of care (ibid:140).

The model of the private, nuclear family has come to underpin many of the principles which inform current social policy. Community care policies are based on the notion that the only valid alternative to family care when the immediate nuclear family is unable to provide this, is a model of care which most closely resembles it. The philosophy of normalisation provides such a model of care, the norms and values of family care, (privacy, independence, small domestic units, with few significant others), matching the structure of this alternative model (Dalley,1992:106,107). Collective responsibility for the welfare of disabled people is realised through models of care that are individualistic in nature (ibid:106).

Normalisation however, has failed to recognise that this model of care has implications for women who, as mothers and caregivers, bear the economic, emotional and social costs of responsibilities transferred from the State to the family (Brown & Smith, 1992:164,165; Munford, 1991:10,11). Brown and Smith suggest that normalisation has recognised the needs of the cared-for at the expense of the caregivers (ibid:164). Pascall suggests that the philosophy of normalisation is an ideology which, like motherhood, romanticises caring and, thus, fulfills "a very similar function in legitimating minimal State activity in the private sphere of the home and family" (1986:85). The philosophy of normalisation has a certain congruence with the ideology of libertarianism.

Libertarian ideologies of the family are likely to exacerbate the effects of community care policies for women. There are tensions in providing care and support for dependant family members in an environment which condemns mutual inter-dependency and favours self-reliance and independence (Dalley, 1992:109). Brown and Smith, writing of the situation in Britain, suggest the State has been able to ignore inequities in policies of community care between carer and cared-for in the public sphere (1992:164). Such issues will be considered now by the State as belonging to the private world of the family.

Families, and agencies providing services to people with learning disabilities in the 1990s, will also have to face the issue of the 'new' eugenics. Advances in genetic knowledge and medical techniques have arisen alongside a renewed interest in the biological basis of human behaviour, and arguments

for 'economic realism' in providing for the less able in society. Defining disability as a burden on the public purse revives Social Darwinist doctrines which fuelled the eugenic movement earlier this century. Such developments require a vigilance of advocacy groups to ensure these notions do not again find fertile ground (Stanworth,1989:90,91). For notions of discipline and deservedness, the fear of inbred degeneracy and pauperisation have influenced the growth of the Welfare State, and the eligibility of its citizens to State support, since the period of early European settlement (Tennant,1989:201). In another climate of *laissez-faire*, such ideas could once again gain ascendancy.

The restructuring of the Welfare State has impacted more noticeably on those who are most dependent on its provisions for support, such as people with disabilities. Some claim the current environment has produced "social welfare policies for the poor and economic policies for the better off" (Bryson, cited in Munford,1994:283). If these policies herald the advent of "post-capitalist society", Sullivan suggests it is unlikely that the improvements sought by people with disabilities in their material and social conditions will eventuate (1991:261). In terms of Oliver's materialist analysis, such circumstances become a context of social oppression for people with disabilities. Their daily experience is thus a measure of the success (or otherwise) of social and economic policies in enhancing their social well-being (Shannon,1991:99) or in terms of the health reforms, improving their quality of life.

Current policy, has responded to the concerns of disabled people at a non-materialist level, thus failing to address the real causes of their material and social oppression. This economic rationalism could result in a 're-institutionalisation' of people with learning disabilities within community settings. Were the Government to move back towards a social citizenship model of welfare, one in which the State ensured all citizens were supported to levels which ensured their well-being and enabled their participation in society, the reforms in the disability sector would have the potential to fulfill the objectives for which they were designed.

In the short term, this seems unlikely. Entitlement to welfare is no longer based on the rights of citizenship but on the degree of individual need. According to libertarian theory, there is no such thing as society "only individuals and families" (Bentham,1970:12 cited in Kingdom,1992:1). Whereas in 1938, the State saw fit to mobilise a substantial portion of its economic resources to secure socially desirable ends for its citizens, in the 1990s the State saw its task as limited to stimulating economic growth and recovery so that citizens could secure these ends for themselves (Shannon,1991:48). Libertarian social policy has sought to "weld together the instincts of individual greed and collective self-righteousness in a coherent model of the world" (David,1986:77) as a powerful attempt to reverse the effects of policies introduced through fifty years of social democracy. Its purposes are to bring about social efficiencies rather than social justice. The shift to libertarian social and economic policies has been implemented by

Government in the interests of an elite group (an elite of business interests) regardless of majority group opinion, or of the fierce debate Fougere suggests is still raging about the desirability of such reforms (1994:108). For people with learning disabilities, there is some uncertainty as to whether libertarian policies will maintain social and economic equity between themselves as disabled people, and the "ablist" mainstream of society.

In the final analysis, the argument that families have become increasingly involved in the lives of people with learning disabilities as social policy has moved them towards independence, can be clearly seen from the changes which have occurred during this period. Libertarian economic and social policies have transferred responsibility for the welfare of people with learning disabilities transferred not from the State to disabled individuals, but from the State to their families, siblings, advocates and their support networks, as those who have always been involved in the decisions of their day to day lives.

## CHAPTER TEN

### CONCLUSION

The purpose of this thesis has been to examine the development of social policy for people in New Zealand with learning disabilities. The intention behind such a focus was to achieve a better understanding of the origins of current social policy, so that in turn, its future implications might be better understood. As a means of making this policy development more explicit, I have argued that families have become increasingly involved in the support of dependants with learning disabilities, as social policy has moved them towards greater personal independence.

In the context of this study, I have set about examining the development of social policy by discussing the concept of learning disability and the way the concept has undergone changes in meaning over time. In each of the subsequent chapters, I have reviewed a period in New Zealand's social history in terms of society's perceptions of people with learning disabilities and the prevailing concepts of learning disability, the dominant ideologies of the period as they related to social policy and service provision, and the particular individuals and groups who have had a significant influence on the policy-making process on behalf of people with a learning disability. I have suggested that these constituted the social influences which have been instrumental in shaping the development of current social policy for people with learning disabilities. As part of each chapter, I have

attempted to relate the theoretical to the practical, to interpret these social influences in terms of the possible impact they might have upon the lives of individuals with a learning disability, and their families.

From a brief analysis of this research, it becomes clear that the successive changes in social policy have, to date, culminated in outcomes which have benefitted people with a learning disability in increasingly positive ways. For instance, policies which segregated people with learning disabilities from the wider community gave way to policies of integration. People with a learning disability have finally been acknowledged as people in their own right rather than in terms of their disability, and have been accorded the same individual rights as other citizens in the community. Each chapter captures something of the progress of social policy towards arriving at these more recent outcomes.

A second important finding from this research is that cycles are repeated over time. For example, over the past hundred and fifty years social policy for people with learning disabilities has turned a full circle. From being the sole responsibility of their families during the period of early European settlement, people with learning disabilities were cared for in asylums and institutions for more than a century until new ideas initiated their return to the community, and families once again became responsible for their overall welfare and their care. A similar cycle can be observed in the re-emergence of policies based on ideologies of *laissez-faire*. The individualism and independence encouraged by social policies in the latter

part of the nineteenth century re-emerged one hundred years later as the basis of New Right economic and social policy. Individualism, efficiency and sturdy self-reliance became the principles underlying policy initiatives, and social policy for people with a learning disability, in the 1980s. Similarly, notions of 'survival of the fittest' underlying Social Darwinist theories of the 1880s could be re-translated in the 1990s as 'survival of those with the economic resources to do so'.

A third important conclusion that is evident from this research is that the philosophy of normalisation became a major influence for change in the lives of people with learning disabilities. Although criticised since for its inadequacies as a theory of disability, in the 1960s normalisation provided a radical challenge to existing ideas that institutional care best served the needs of those with learning disabilities. According to Brown and Smith, normalisation achieved a 'quantum leap' in the quality of lives of people with a learning disability (1992:51).

In the context of this study, the early efforts of the IHCPA must also be regarded as having had a significant impact on the development of social policy for this group of people. The beliefs of a determined group of parents not only challenged established ideas about service provision but captured the concepts of community care that were later to emerge as the philosophy of normalisation.

This research also demonstrates that from a very early point in New Zealand's social history, the State had declared an involvement with those

who in some way were mentally impaired. In fact, this group were the first citizens for whom the State made any long-term provision. The manner in which these people were provided for through subsequent years, was influenced by the same social pressures which impacted on policy and provision in other related areas, such as health and education.

These overall findings have implications for future policy development and service provision. Current social policy for people with learning disabilities has been arrived at through a 'marriage of convenience' between the philosophy of normalisation and libertarian social and economic policy. These policies initiated the restructuring of disability support services, offering people with learning disabilities living in the community greater possibility of independence. To be successful, these reforms must be accompanied by adequate resourcing. Should the level of resourcing be compromised, then current policies have the potential to reverse the positive outcomes accumulated by past policies. Current policies could return people with learning disabilities to the kinds of material and social oppression they have experienced in the past.

There are implications of current policies that have yet to be addressed by service purchasers and providers. People with learning disabilities are now living longer as a result of the benefits of medical science, but they are aging earlier than the rest of the population. Once, the rigours of institutional life would have shortened their years and many would never have reached older age. These older people have particular support needs.

Children with more profound learning disabilities and challenging behaviours who have been mainstreamed in the education system are now old enough to require full adult services. They have high support needs. People with learning disabilities who have lived their lives in institutions and moved now into the community, present particular challenges to service providers. They often have behaviour patterns which are not acceptable to the public at large. For current policies to be successful, services must be purchased at realistic, not economic, levels of funding.

This study has undertaken to research an aspect of social policy over a period spanning one hundred and fifty years of New Zealand's social history. Such broad parameters mean that inevitably, there are limitations to the research. One obvious bias to the research is that it is grounded in a knowledge of the services provided to people with learning disabilities by IHC. The role of government departments such as Health and Education, also concerned with service provision to learning disabled people, are discussed only in the context of this perspective. A second clear bias is evident in the critique provided of current social policy, the reduced role of the State and the move towards a market model of service provision. Another limitation of the research is the lack of primary sources relating to certain periods. The 1840s are such years. An understanding of the impact of a child with a learning disability born into a family during the 1840s has had to be constructed from other social histories of the same

period, and my own knowledge of the impact people with learning disabilities can have on families.

The inclusion of a section which attempts to relate the impact of policy development to the lives of people with learning disabilities is not an attempt at qualitative research. Rather, it is an attempt to create a context for policy development. Were it possible for people with learning disabilities to describe their own experience through these periods, the text would read very differently again. This study is a social history, and the inclusion of such a perspective was intended to strengthen the relevance of social policy development to those whom it concerned. The work has a strong research basis, which is a comprehensive study of an area of policy development that to my knowledge, has not been previously researched.

There is a need for further research in areas relating to current policy outcomes. One important focus would be whether or not people with disabilities as consumers, had found the health reforms to have delivered the 'support for independence' it was claimed they would. Another important area of research would be the impact of current social policy on caregivers, particularly women, as those expected to maintain responsibility for care of dependant family members. More than research, there is a need to respond to the issues surrounding the most recent advances in medical science and genetic knowledge in a way that advocates for those with disabilities. Research however, can monitor the climate of public opinion in which these issues are being debated.

This study has discussed the role of particular social influences in developing social policy for people with a learning disability. But from a wider perspective, the development of social policy for people with learning disabilities can be seen to have simply followed the development of social policy in other areas of welfare, of practices and provision in health and education for example. Thus, as Simmons points out, the future treatment of people with learning disabilities "is inextricably linked with the future of a variety of social policies" (1982:257).

Social policy itself, however, is influenced by a dominant discourse. The social group creating such discourse has the power to move social boundaries around themselves, as they wish. Brown and Smith suggest this group will allow labels to be sanitised (from 'subnormal' to 'learning disabled'), concede improvements in material conditions (moves from institutions into community housing) or confer rights on marginalised groups such as those with learning disabilities (Brown & Smith, 1992:110). But just as 'rights' are conferred, so they can be taken away. They suggest this was the experience of parents of people with learning disabilities who were told in the 1930s to place their children in institutional care, and some fifty years later told their dependants were to move into the community because institutions were to close (ibid:110). Other writers have similar concerns, noting that ideas and methods considered and rejected early on in the development of services can later be 'rediscovered' and accepted without scrutiny, as new ideas (Heaton-Ward, 1977:46). The concern that

arises from the cyclic nature of change is the possibility that present social policy which provides services in the community for people with learning disabilities could turn a full circle, in favour of practices such as institutional provision once again becoming a legitimate form of care.

Changes in social policy are in themselves not the main concern, the critical issue is the outcomes as they affect people with learning disabilities. In 1992, for the first time in the legislative history of New Zealand, people with learning disabilities were excluded from the provisions of the Mental Health Act. The legislation had placed them back amongst the community with a status as citizens that had not been theirs since New Zealand was first settled. Currently, it is politically and economically expedient for people with a learning disability to be cared for in the community. For these hard-won rights not to be eroded, will require the vigilance of advocates and advocacy bodies on behalf of people with learning disabilities to ensure any changes in social policy are not to their disadvantage. New Right ideologies responded to the demands of disabled people at the same time as shifting responsibility for the welfare of people with a learning disability from the State back to the family. It is to be hoped, therefore, that New Right ideologies, as the dominant discourse of the 1990s, do not also become the means of shifting the issue of disability, to misquote Borsay (1986), from being a public issue to a private trouble.

## APPENDIX I

### **Timeline of Events Influencing the Formation of Policy for People with Learning Disabilities.**

LAISSEZ-FAIRE period	-1840	Commencement of white settlement
	-1846	<u>Ordinances</u>
	-1854	First asylum built in Wellington
Influence of SOCIAL DARWINIST THEORIES	-1868	<u>Lunatics Act</u>
	-1882	<u>Lunatics Act</u>
	-1885	<u>Hospitals and Charitable Institutions Act</u>
	-1886	Appointment of Dr. Duncan MacGregor as Inspector of Hospitals and Institutions
	-1889	(Defeated Hospital and Charitable Aid Bill)
Influence of EUGENIC THEORIES	-1907	Founding of the Plunket Society
	-1911	<u>Mental Defectives Act</u>
	-1922	Report of the Committee of the Board of Health
	-	Separate provision for "mental defectives" within Nelson Hospital
	-1924	Committee of Inquiry into Mental Defectives and Sexual Offenders
	-1928	<u>Mental Defectives Amendment Act</u>
	-1929	Templeton Farm and Training School opened

	-1938	Social Security Act
	-1949	Formation of the IHCPA
	-1952	Consultative Committee of Inquiry
	-1953	Report of the Consultative Committee of Inquiry
	-1954	WHO Report
	-	<u>Mental Health Amendment Act</u>
	-1957	<u>Mental Health Amendment Act</u>
	-1959	Burns Report
	-1961	<u>Mental Health Amendment Act</u>
	-1969	<u>Mental Health Amendment Act</u>
	-1972	Amendment to Social Security Legislation
	-1973	Royal Commission of Inquiry into Hospitals and Related Services
	-1974	Department of Health Review of Hospitals and Related Services
	-1974	Commencement of Community Care Programme
	-1975	Disabled Persons Community Welfare Act
	-1975	Amendments to Social Security Legislation
	-1978	Amendments to Social Security Legislation
	-1984	Election of the fourth Labour Government
	-1988	Protection of Personal and Property Rights Act
	-1989	Education Act
	-	Introduction of consumer-based funding for people with disabilities
	-1991	Election of the National Government and further dismantling of the welfare state
	-1992	<u>Mental Health Act</u>
	-1993	Human Rights Act
	-	Health and Disability Services Act
	-1995	Implementation of the final stages of reforms to the health sector

Influence of  
PHILOSOPHIES OF NORMALISATION

Influence of  
LIBERTARIAN IDEOLOGIES

**APPENDIX II****Abbreviations**

AJHR	Appendices to the Journals of the House of Representatives
BMA	British Medical Association
DPA	Disabled People's Assembly
IHC	The New Zealand Society for the Intellectually Handicapped
IHCPA	Intellectually Handicapped Children's Parents' Association
IHCS	Intellectually Handicapped Children's Society
NZCCS	New Zealand Crippled Children's Society
NZEI	New Zealand Educational Institute
NZPD	New Zealand Parliamentary Debates
OECD	Organisation for Economic Co-operation and Development
RNZFB	Royal New Zealand Foundation for the Blind
UPIAS	Union of Physically Impaired Against Segregation
WHO	World Health Organisation

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