Who is responsible for the provision of support services for people with disabilities?

by Andrew Moore and Margaret Tennant

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Who is Responsible for the Provision of Support Services for People with Disabilities?

A discussion paper commissioned by the
National Health Committee

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The views expressed in this document are those of the authors. Comments received during the consultation process will be included in advice to the Minister of Health.

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FOR PEOPLE WITH DISABILITIES?

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Foreword

This paper, commissioned by the National Health Committee, is a philosophical and historical overview of issues which arise when making distinctions between public and private roles and responsibilities in the disability support sector in New Zealand. The discussion is in two parts: Part One provides a historical overview in which the roles and responsibilities of the public, private and voluntary disability support sectors are explored historically in three parts: (1) Nineteenth Century Approaches, (2) Twentieth Century Services and (3) the period of change in the 1970s and 1980s. Part Two has a philosophical focus.

The document comments on the tensions and potential instability which may be a consequence of public funders taking more explicit responsibility in recent years for maintaining stated standards of care and types of disability support services.

The financial and other risks for disability support services in the post health reform environment from the points of view of Crown Health Enterprises (CHEs), Regional Health Authorities[1] (RHAs) and services which are not CHE based, are considered.

The paper examines arguments and draws some conclusions relating to:

(1) the National Health Committee's four key questions[2] which are designed to be asked as part of the process of developing the Committee's policy advice on the funding and provision of each service:

- Is it beneficial?
- Is it value for money?
- Is it fair?
- Is it consistent with community values?

(2) arguments for substantial public involvement in disability support

(3) the appropriate extent of public responsibility

(4) the role of public purchasers of disability support.

The National Health Committee has commissioned this document as background for discussion of funding issues, policy and resource allocation in relation to disability support services.

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[1] The Regional Health Authorities have, since this document was written, become divisions of the Transitional Health Authority. The term RHA is retained throughout this document for its historical relevance.

[2] For discussion and endorsement of the "Four Questions", see *Best of Health 2*, Core Services Committee, 1993, pp.17–32.

Submissions are invited by 30 October. Submissions should be sent to:

The National Health Committee
PO Box 5013
Wellington.

The authors

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Acknowledgements

Summary

This paper is a discussion document commissioned by the National Health Committee. It is divided into two sections: a historical overview and a philosophical discussion of issues which arise when making distinctions between public and private roles and responsibilities in the disability support sector in New Zealand.

The document comments on, and raises questions about, the nature of the boundaries and interfaces between and among public, private and voluntary disability support service provision.

Historical perceptions of disability are described with the broad underpinning of different ways of thinking about disability: the concept of what disability has meant over time, the overwhelming historical importance of the public sector in providing for disabled persons and the influence of the particular historical periods in which disability has been positioned.

The historical overview moves through the nineteenth century where ill health and disability tended not to be distinguished from each other and medical treatments and hospitals were seen as places of cure for all, including those with disabilities. It examines the environment in which lunatic asylums were established and proceeds to look at twentieth century issues including preventing the procreation of the unfit and the need for early education and training of people with disabilities. The historical overview of the twentieth century also focuses on compensation issues. It explores some of the organisations which arose to provide services for people with disabilities, including CCS and IHC.

Māori perceptions and issues relating specifically to Māori are discussed in both sections of the paper.

The philosophical discussion centres on the boundaries between public, private and voluntary service provision and deals with how responsibility ought to be allocated across these boundaries. It bases much of its argument on the National Health Committee's key questions which ask if services show evidence of benefit, value for money, fairness and consistency with communities' values. It explores the issue of ACC entitlements compared with other entitlements and discusses the appropriate extent of public responsibility for disability support, particularly in light of CHE budget deficits and the funder's role in meeting the full cost of services.

Questions are raised for further discussion, the key ones being (1) the level of accountability which can be fairly demanded of service providers whose service is only subsidised (i.e. partly funded) through public funding; (2) the approach (e.g. prioritisation, identification of gaps and margins) which should be taken by the public funder to the funding of disability support services; (3) the appropriate balance of public and household or family responsibilities for the support of a person with a disability; and (4) the fairness of differences of entitlement between people with disabilities caused by accident and people whose disabilities have other causes.

Introduction

This paper is about the boundaries or interfaces between public, private, and voluntary responsibilities and accountabilities in the disability support sector in New Zealand. It addresses three questions in particular:

What are the boundaries between public, private, and voluntary in the disability support sector?

How ought responsibilities to be allocated within and across these boundaries?

How have these boundary issues in disability support been understood and dealt with historically?

These are big questions, on which there are many different perspectives. One key perspective is that of advocacy but to look at disability issues from only one perspective is to overlook the complexity of the issues. For example, looking at the issues of responsibility for disability support using a framework that makes sense from a disability advocacy perspective might be of little help when viewing the issues from an accounting perspective, and vice versa. Likewise, a boundary drawn to help a service provider might not suit all the aims of a public policy advisor.

Boundary issues from a historical perspective are discussed in Part One. Current boundary and responsibility issues are discussed in Part Two. The paper aims to offer a philosophically and historically informed framework for public policy formation and advice in the area of disability support. It is hoped that the paper will also interest a wide range of groups and individuals with a stake in public policy concerning disability.

Some Basics

Obviously enough, the disability support sector aims to support people with disabilities. To get further than this, it is helpful to consider what disabilities are and what support involves. The United Nations has recently published a useful set of *Standard Rules* on these issues as a guide to governments. Here is what they say about disabilities, including impairments, and about handicaps:

17. The term "disability" summarises a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

18. The term "handicap" means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the person with a disability and the environment. The purpose of this term is to emphasize the focus on the shortcomings in the environment and in many organized activities in

society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms.[3]

The World Health Organisation (WHO) also offers a helpful account, defining impairment, disability and handicap as follows:

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.[4]

These WHO formulations are currently under revision, and they have been criticised for an overly medical and individualistic focus and for paying insufficient attention to the role of social conditions and expectations. Together with the United Nations *Standard Rules*, they do nevertheless contain important insights worth emphasising here, as do the views expressed by the National Health Committee:

Absolute consensus as to the definition of disability has yet to be reached. Traditional definitions based on the medical model have tended to focus on upon illness and the treatment of illness. More recently, at the instigation of people with disabilities themselves, definitions have been broadened to acknowledge the diverse nature of disability and the importance of the wider environment.

"People with disabilities" :

- includes people with a wide range of physical, sensory, psychiatric, learning and developmental disabilities who are disadvantaged by social, economic, political and environmental factors which restrict and/or exclude people from full participation in the community

- refers not only to the people with disabilities but also to their families/ whānau, caregivers and to their cultural identity and communities, and the interdependent relationships between and among all of these. Embracing and considering roles and needs of these groups and wider social context is also essential in facilitating full participation of people with disabilities.[5]

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[3] *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, (New York: United Nations, 1994), p. 9.

[4] See *International Classification of Impairments, Disabilities, and Handicaps* (Geneva: World Health Organisation, 1980).

[5] National Advisory Committee on Core Health and Disability Support Services: *Core Services for 1995/96*, Wellington, 1994, p. 125 and *He Anga Whakamana: A framework for the delivery of disability support services for Māori : A Report to the National advisory Committee on Core Health and Disability Support Services* by MM Ratima, MH Durie, GR Allan, PS Morrison, A Gillies and JA Waldon, Wellington, 1995, p.3

Note the central importance of the values and experiences of people with disabilities in all of the above accounts. Kinds of disability differ greatly from one another. Perhaps more importantly, the experience of disability is very diverse, not only between kinds of disability, but within kinds, and within the experience of individual persons with disabilities as their situation changes over time. The extent of disadvantage faced by a person with a disability cannot be determined unless that person's values, experiences, and preferred activities and ways of participating in the life of the community are well understood. Indeed, whether a person has a disability at all depends in most cases partly on whether that person self-identifies in that way.[6] Among those who do self-identify as having a disability, some will regard themselves as needing support at a given time, and others will not. Where support is needed, its kind, amount, and character will also vary among people with disability, and for particular people over time. It will do so partly on the basis of the self-identified needs and preferences of people with disabilities. This situation might itself be understood in a diversity of ways by those involved. Some may be comfortable to see themselves as individual consumers claiming their rights to goods or services for disability support provided, purchased and funded by various organisations. Others might be repelled by this way of understanding their situation.

There is diversity also in views of what the aim of disability support should be. Some examples are reflected in the United Nations document quoted above which proposes the goal that a person with a disability "take part in the life of the community on an equal level with others". The WHO document discussed above emphasises the importance of individually valued activity. The National Health Committee account emphasises full participation. The "new deal" for support for people with disabilities emphasises the goal of independence.[7] These are just a few of the views of what disability support should be.[8]

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[6] Exceptions arise for people whose disability is such that they are not able to self-identify as persons with or without disabilities.

[7] J. Shipley and S. Upton, *Support for People With Disabilities — A New Deal* (Wellington: Department of Social Welfare and Ministry of Health, 1992).

[8] Note the possibility that these diverse goals can be made compatible; for example, by applying each of them to different aspects of life.

Part One: Historical Overview

Three general observations underlie this part of the paper. First, the concept of disability and what, at any point in time, has been regarded as a 'disabling' condition has changed historically. Today expectations of wellbeing are extremely high. Ideas of 'normality' centre upon media-generated images of perpetual youthfulness, fitness, and constantly high levels of energy. Anything else is likely to be depicted as a lesser state of existence. In the past many people suffered from chronic and debilitating disorders which now might be quite easily treated. Conditions which might today be defined as disabling were likely to be seen as simply one of the crosses that people had to bear in a harsh existence; a matter, perhaps, for Christian fortitude. When exhaustion, suffering, pain and low life expectancy were so much part of ordinary life, disability was less distinguishable than it has since become. So too were the boundaries between disability and simple (but recurring) 'ill health'. The balance between white collar and manual work, levels of education, mobility and affluence across the population as a whole, and developments in medical science: all these have influenced the definitions of 'disability', and 'normality', or 'disability' and 'health'.[9]

A second general observation relates to the overwhelming historical importance of the public sector in providing for disabled persons, either through income maintenance, or by way of habilitation and rehabilitation services for particular groups. Statutory and non-statutory agencies had an often complex relationship, determined partly by historical accident. Right from the early years of Pākehā settlement, governments subsidised voluntary effort. In return, voluntary organisations have often acted as conduits between government and welfare recipients of various kinds, carrying out officially-sanctioned tasks that involved an element of personal support and community mobilisation. De facto agreements between the state and voluntary organisations often encouraged a situation where one provider (such as the Royal New Zealand Foundation for the Blind or the IHC) gained a monopoly on services, to the detriment of consumer choice. This may be contrasted with the greater variety of services within other, larger countries.

Third, in this paper developments are seen as having fallen into three broad historical periods. In the colonial period disability was perceived in a monolithic light, the problem of disabled persons one of potential dependency and need for income maintenance. Towards the end of the nineteenth century a limited number of disabling conditions were singled out for habilitation and rehabilitation. This trend continued over the twentieth century. However, the last twenty five years can be seen as forming a distinctive period in their own right. The marked expansion of specialised disability groups since 1970, the increase in public sector financial transfers to non-statutory

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[9] For a broader survey of some of these issues, including attitudes towards disability, see Margaret Tennant, 'Disability in New Zealand: An Historical Survey', in New Zealand Journal of Disability Studies, No.2 1996, pp.3–33.

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agencies over the 1970s and 1980s, emerging demands for efficiency and accountability, and the recognition given to an increasingly assertive consumer voice distinguish the recent past from earlier decades. In these three broad periods of New Zealand history, ideas concerning disability influenced and were influenced by public policy development. This process is ongoing, and constantly subject to debate and reinterpretation.

1. Nineteenth Century Approaches to Disability

To social policy makers of the nineteenth century there was relatively little distinction between ill health and disability. Both threatened the image of New Zealand as an ideal society, characterised by pioneering vigour. Both might lead to non-productivity and dependency, and this was the key concern. An early public sector response was to discourage the migration of persons with disabilities, through restrictive immigration legislation.[10] A person who was ill might be unable to support himself \ herself and dependants for a shorter time than a person seriously incapacitated, but it was all a matter of degree. In a society where manual labour was important, sickness and disability could seriously disadvantage a breadwinner. On the other hand, the elderly infirm and the less seriously incapacitated were often shielded by informal workplace practices, by mateship and team contract work. It was only later in the century that employers gained greater control of the pace of work and that workers' efficiency began to be measured on a more individual basis.

A question included in the census from the 1870s shows the concern about dependency, for it asked those 'unable to follow their usual occupation' by reason of sickness, infirmity or accident to identify themselves. The range of disability identified within the census encompassed those who were, in the stark language of the day, 'deaf and dumb, blind, lunatics, idiots, epileptics, paralysed, and crippled and deformed'.[11] The first three of these groups were to be singled out for distinctive provision during the late nineteenth century; a number of the others featured more in early twentieth century initiatives. However, throughout the colonial period most of the ill and disabled who were unable to support themselves or to draw upon adequate family support were relegated to the amorphous mass of 'the poor'.

For all that the nineteenth century has been presented as some golden age of individual responsibility, family, church and voluntary endeavour,[12] the reality is that the public sector was by far the most significant provider of welfare services, directly, and indirectly through grants, subsidies and other assistance to voluntary organisations.[13] As Dr Duncan MacGregor, Inspector-General of Hospitals and Charitable Institutions acknowledged in 1898:

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[10] Tennant, 1996, p.7.

[11] Census of New Zealand, 1874, Part VIII.

[12] See David Green, From Welfare State to Civil Society. Towards Welfare that Works in New Zealand, Business Round Table, Wellington, 1996.

[13] For a detailed study of nineteenth century welfare see Margaret Tennant, *Paupers and Providers. Charitable Aid in New Zealand*, Allen and Unwin/Historical Branch, Department of Internal Affairs, Wellington, 1989.

In the early life of the colonies, while the traditional spirit of *laissez-faire* was still powerful, it was gradually found that the social sanction *(richesse oblige)* was too weak to enable commercial charity to make up for the defects of justice. The social sanction, in spite of its power in an old country, had failed .... Some of its most potent elements at Home were incapable of transplantation here, while others were slow growing and took too long to mature.[14]

The smaller scale of communities appears to have fostered neighbourly and community support for those hit by tragedy, but this seldom amounted to adequate long-term support. The more exemplary among the sick and disabled might get help from churches and voluntary benevolent societies, but these bodies selected their clientele by level of moral deservedness, rather than specific condition. Another potential support agency was the friendly society, neither a voluntary welfare organisation nor a private sector, profit making concern. Friendly societies operated on an insurance and mutual aid basis, but only a minority of workers could afford to belong to them. Withdrawal rates were high and a small society could be ruined by the prolonged incapacity of a single member (others were ruined by absconding administrators!).[15] The private sector in the form of an increasingly competitive medical profession also came into contact with disability, treating some cases on a charitable basis and charging others fees for treatment. Nonetheless, the bulk of the destitute, sick and disabled were aided by the hospital and charitable aid system, New Zealand's public sector equivalent of the English Poor Law.

Hospital and charitable aid boards, which provided income maintenance support as well as hospital and benevolent asylum care, were the agencies with which disabled persons most often came into contact. In late twentieth century terms, these boards were both funders and direct providers of services. They were obliged to channel funds from central and local government taxes to a number of quasi-voluntary organisations (legislatively known as 'separate institutions'), though it cannot be said that this placed them in the position of 'purchasers' of services. The notion of 'purchasing' services implies an element of choice and a situation of competition, and these did not exist under the 1885 Hospitals and Charitable Institutions Act which governed the boards' activities — if 'separate institutions' met the requirements of the Act for subsidies, they received them on an on-going basis, with very little accountability required.[16]

The boards were nonetheless very important, as their activities encompassed both social welfare and health. As well as receiving food and rent assistance in their own homes, disabled persons moved between the

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[14] Report on Hospitals and Charitable Institutions of the Colony, *Appendices to the Journals, House of Representatives (AJHR)*, 1898, H–22, p.2.

[15] Heather Shepherd, 'The Nature and Role of Friendly Societies in Later Nineteenth Century New Zealand', Massey University B.A. (Hons) Research Exercise, 1976, pp. 5,20, 44.

[16] See Tennant, 1989, for more detail on the very complex arrangements which operated at all levels under the hospital and charitable aid system.

public hospitals, where they received fairly rudimentary treatment for their disorders, and benevolent institutions, which provided basic care and shelter. Institutions such as the Otago Benevolent in Dunedin and the Costley Home for the Aged Poor in Auckland were maintained largely from government revenues. They contained younger individuals with tuberculosis and paralysis and persons with terminal conditions such as cancer, alongside the infirm elderly, whose disabilities were often associated with rheumatics and excessive alcohol consumption.

As medical treatments advanced and hospitals began to be promoted as places of cure, those who lacked potential for heroic medical intervention were increasingly rejected by them. There were periodic calls in the 1880s and 1890s for public sector 'homes for incurables'. The hospital board benevolent institutions effectively filled this role, but a few church establishments also stepped into the breach. Most notable was St Joseph's Home for Incurables, founded by Mother Mary Joseph Aubert and the Sisters of Compassion in 1899. This, and the Home of Compassion (opened in 1907) catered for chronically and terminally ill adults and children. Among those admitted were many with disabilities such as hydrocephalus, spina bifida, cerebral palsy, blindness and Down syndrome.[17]

Despite the existence of such negative and catch-all categories as 'incurable', three areas of disability were singled out in the nineteenth century for special provision. First, provincial governments began to establish lunatic asylums from the mid-1850s and, after the abolition of the provinces, the Lunatic Asylums Department was established as the first social service department of state. With the exception of one private asylum (Ashburn Hall, established in 1882), provision for those with a psychiatric disability was overwhelmingly a public sector responsibility until very recent times. Poor diagnosis meant that the asylums also housed many disabled persons who would not be defined as mentally ill today.

The education of deaf and of blind children followed, but went down somewhat different paths. In 1874 a Legislative Council resolution proposed the erection of a central asylum for the education of the 'blind, deaf and dumb' residing in New Zealand.[18] The education of deaf children was revisited in 1878, former Canterbury Provincial Superintendent William Rolleston leading the charge for this to be a government responsibility. The inclination of government leaders was for the voluntary sector to take the initiative, on the understanding that government subsidies would be available. However, the proposal benefited from the recent introduction of compulsory state-provided primary education, Rolleston claiming that it was impossible for any one section of the community to establish institutions of this kind:

There was no doubt that the education of those of [the State's] members afflicted with these infirmities was as much the duty of the colony as the

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17   J. Munro, *The Story of Suzanne Aubert*, Auckland University Press with Bridget Williams Books, Auckland, 1997.

18   New Zealand Parliamentary Debates (NZPD), Vol.16, 1 August 1874.

education of healthy members of the community .... The importance of the subject was measured not by the numbers affected, but by the ... duty of the State to its individual members.[19]

After much hedging by the government, a 'School for Deaf-Mutes' was established at Sumner in 1880 under the direction and funding of the Department of Education.[20]

An important principle had been established, but despite this precedent it was charitably-inclined Aucklanders who established a school for the blind some ten years later. Economic recession may have delayed a government facility, though by 1890 £575 of public money was spent annually on the education of blind New Zealand children in Australian institutions.[21] The Jubilee Institute for the Blind was opened after a fund-raising campaign in Auckland netted more than £1500[22] — blindness has always been more conducive to public sympathy than most other disabilities. It would be wrong, however, to characterise the Jubilee Institute as an example of stand-alone voluntary endeavour. Initial money for the teaching of blind children in Auckland was supplied by the local charitable aid board.[23] After its establishment the Jubilee Institute became a 'separate institution' under the 1885 Hospitals and Charitable Institutions Act. This meant that, by the 1900s, it was receiving 24s from government for every pound donated to it, and a grant of £26 per annum for every child sent to the Institute by order of the Minister of Education. Public sector funding was such that in 1906 the Jubilee Institute for the Blind Act ordered four of the nine trustees of the Institute to be appointed by government. The Institute's accounts were to be audited by the Audit Office and, since there had been disputes between earlier boards of trustees and the Education Department, the Institute was directed to admit any blind children between the ages of 7 and 16 sent by the Minister.[24] The Institute is an early — and very clear — example of the permeable boundaries between public and voluntary effort in disability services, and of state agencies endorsing a monopoly provider in one particular area of disability.

The primacy of the public sector in responding to disability, and especially to long-term needs, was established during the nineteenth century. A good deal of lip service was nonetheless paid to the principle of voluntary charity, which was seen as more personal and worthy than that provided by central or local governments, and of benefit to provider as well as recipient. Although in practice the voluntary sector proved unable to sustain long-term enterprises without public sector help, the esteem attached to the ideal of voluntary aid

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19 NZPD, Vol.28, Aug. 15 1878, pp.276–7. See also NZPD, Vol.31, Aug. 7, 1897, p.434; Vol. 32, 30 Sept. 1879, p.23.

20 See Correspondence Relating to the Establishment of a Deaf and Dumb Institution, Appendices to the Journals, House of Representatives (AJHR), 1879 (Session I), H–17.

21 NZPD, Vol.68, 17 July 1890, p.6.

22 Greg Newbold, Quest for Equity. A History of Blindness Advocacy in New Zealand, Dunmore Press, Palmerston North, 1995, p.20.

23 Newbold, p.19.

24 Statutes of New Zealand, 1906. NZPD, Vol. 138, 2 Oct. 1906; 16 Oct 1906, pp.254–5.

was significant. It meant that it was difficult to demand accountability of voluntary organisations. Such bodies felt free to reject cases which they regarded as unattractive, undeserving, or simply 'too hard' — a tendency which has had resonances in more recent times. And the personal factor, such a valued part of volunteer endeavours, was to be viewed by later generations of disabled as carrying the possibility of paternalism and control.

2. Twentieth Century Disability Services

Over the twentieth century separate services and new organisations began to cater for distinctive areas of disability. Some organisations, such as the Tuberculosis and Amputees Associations, were linked with particular conditions; some such as the Returned Servicemen's Re-establishment League recognised a particular category of persons whose disabilities might be various; others, such as the Crippled Children's Society (CCS), initially targeted their activities by age as well as disability. It is not proposed in this section to rehearse the entire range of disability services which emerged, though two leading organisations, CCS and the Rehabilitation League, provide useful case studies of the relationship between the public and voluntary sectors over time. Generally speaking, public sector activity was most obvious in five areas:

Where there was a perceived need for some level of containment or control.

This had already been demonstrated in the early establishment of lunatic asylums, since psychiatrically disturbed people had been regarded as threats to social order. However, this was also an element in pressures for 'mental deficiency colonies' during the early twentieth century. Under the influence of the eugenics movement intellectual disability was frequently presented as evidence of 'degeneracy' and a threat to national efficiency. The need to prevent the procreation of the unfit was a major theme in the recommendations of the 1924–25 Committee of Inquiry into Mental Defectives and Sexual Offenders, for example.[25]

Where there was a need for early education and training and the 'educability' of the disabled group was endorsed.

The education of blind and deaf children has already been mentioned. The 1907 Education Amendment Act required the education of 'defective and epileptic' children, and the Education Department opened the Otekaike and Richmond Schools for 'feeble-minded' children in 1907 and 1916 respectively. Although some voluntary agencies came to run small special schools, the Education Department has always had the main responsibility for funding and organising special education services.

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[25] *AJHR*, 1925, H–31A.

Where compensation for duty and sacrifice in the interests of the state was an issue.

Governments have accepted in both World Wars that there was a rehabilitation contract between the state and returning servicemen. In the case of disabled personnel this contract was honoured more effectively after the Second World War than the First. Procedures and facilities established for disabled servicemen were sometimes extended to civilians, thus cementing in public sector primacy in disability services.

Where on-going income maintenance was needed.

Discretionary hospital board charitable aid continued into the twentieth century, but pensions, with statutory entitlement, became far more important. Pensions for the Blind in 1924 and the 1936 Invalids Benefit were among early significant measures. A survey by the Department of Social Security in 1957 estimated that there were 9,176 disabled civilians on benefits — 4 out of every 1000 New Zealanders.[26] There were also more than 58,000 full or partial war disablement pensions being paid by this time.[27]

Where medical treatment was required.

Theoretically, the public hospital system was for the destitute, but the refinement of medical techniques meant that, by the early twentieth century, private hospitals were unable to keep up with the technology and range of services provided within the public sector. Admission to a public hospital gradually lost any remaining social stigma, though those able to pay for treatment were supposed to do so. Nonetheless, by the 1920s, a large hospital board like the Otago one was able to collect only 35 per cent of fees charged, and in 1939 the introduction of hospital benefits under the Social Security Act ended the distinction between fee-paying patients and others in public hospitals.[28]

The role of the voluntary sector included advocacy, ensuring government attention to particular groups of disabled persons. For example, the prioritising of visual impairment through the introduction of separate pensions for the blind in 1924 was largely due to effective agitation by the Auckland Institute for the Blind under Clutha Mackenzie. Personal support and counselling, the supply of information about disabling conditions to affected persons as well as the broader community, prevention, and the provision of additional aids and appliances were also among the tasks most readily accepted by voluntary organisations. A small minority ran institutions: for example, the Red Cross opened the Montecillo Home in Dunedin for sick and convalescent soldiers in 1918, the Evelyn Firth Home in Auckland, and the Rannerdale Home in Christchurch (1921); from 1937 CCS ran the Wilson

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[26] New Zealand National Civilian Rehabilitation Commission, *Report to the Minister of Health and Social Security on the Rehabilitation of Disabled Civilians in New Zealand*, Department of Social Security, Wellington, 1965, p.4.

[27] Annual Report, Department of Social Security, *AJHR*, 1960, H–9A, p.5.

[28] Tennant, 1989, p.176.

Home (now the Wilson Centre) in Auckland, and the Homes of Compassion continued to provide for disabled persons.

In all cases there appears to have been an assumption that the public and voluntary sectors would interact, though the nature and degree of this interaction varied. Most obvious were financial transfers, principally from the public to the voluntary sector. The subsidies on voluntary contributions and support payments for children referred to the Institute for the Blind have already been mentioned. Grants from the art union lottery administered by the Department of Internal Affairs had become another important source of funds by the 1930s, but other Departments also made limited, special purpose transfers to voluntary organisations. By the late 1960s staff salary and capital subsidies to the voluntary sector had begun to escalate.

Non-financial support should not be neglected. Public sector expertise was often useful, and sometimes this came from the involvement of government employees in voluntary organisations, on a formal or an informal basis. In other cases the public sector provided training, or assistance with publicity (via the National Film Unit or National Radio, for example). Two major disability organisations, the Rehabilitation League, succeeded by Workbridge,[29] and CCS provide examples of the kinds of interaction with government which could occur.

The Returned Servicemen's Re-establishment League arose from the aftermath of the First World War. Although there had been general acceptance of state responsibility for servicemen who had sacrificed health and opportunity in the national interest, the implementation of the rehabilitation contract was less than ideal. In particular, there was insufficient knowledge about the latent effects of war injuries and it was largely because of agitation from the RSA and consumers that an Ex-Soldiers Rehabilitation Commission was established to investigate inadequacies in assistance for returned servicemen. Its 1930 report noted that the governments of New Zealand and other countries had assumed too early that sickness and ill-health due to war had manifested itself. It recommended the formation of a soldiers' civil re-establishment league which would include representatives of government, of war and patriotic funds, the RSA, business and organised labour.[30] The United Government passed legislation endorsing this, but the onset of depression made it reluctant to fund the proposal. Instead, the RSA set up the League with money from patriotic and art union funds. The government belatedly made a grant of £2000.[31] The League became most heavily involved in training and employment schemes, appointing employment officers and eventually opening retail outlets from which goods produced by its clients could be sold.

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29   The League has had a number of name changes since its establishment and is currently known as 'Workbridge'. It is mostly referred to in this paper as the 'Rehabilitation League', a name by which it was known from the early 1970s.

30   Report of Ex-Soldiers' Rehabilitation Commission, AJHR, 1930, H–39, pp.5, 10, 29.

31   'History of the League', *Rehabilitation League NZ Annual Report*, 1990; Jane Thomson, 'The Rehabilitation of Servicemen of World War II in New Zealand 1940 to 1954', Ph.D. Thesis, Victoria University, 1983, p.22.

The League, then, was begun as a result of community concerns, though the nature of its work prompted government support. World War II brought it into close collaboration with government when it was appointed the Rehabilitation Board's agent for the training of disabled servicemen. Between 1941 and 1950, the League received the bulk of its income, nearly £455,000 from the Board. Of this, £208,638 was in training and employment subsidies while the rest went towards buildings, plant and in administration.[32] In 1955 the League's facilities were made available for disabled civilians. It was inevitable, perhaps, that it should be perceived as an arm of government by the 1940s, given its involvement with a clientele to whom the Labour government had made a strong political commitment. In later years it was regarded with envy by other organisations dealing with disabled people, for it did not have to rely on community fund-raising, and deficits in its workshop operations were made up by government after 1969.[33]

As historian Jane Thomson has pointed out, the League provides a case study of the incorporation of a community organisation into the state administrative system. The limited accountability which went with this role is striking. During the war years the League's financial affairs were so muddled that the Rehabilitation Department offered its assistance to investigate the problems — an offer which was not taken up. Some branches suffered large losses due to financial mismanagement, and the League was dogged by internal personal conflicts.[34] Even in 1954 the newly established Interdepartmental Committee on Civilian Rehabilitation had reservations about the League. In a meeting with representatives of the British Medical Association it was suggested that its facilities were limited and the trades offered were narrow or fully supplied. The Health Department representative acknowledged that 'the general impression was the Government had not gained the greatest value for the money which it had poured into the D.S.R.L. premises and it would to some extent like to have a greater say in its management ....'[35] The League appears to have escaped closer scrutiny because, in the long run, the public sector resources put into it were minimal in relation to the generous and expensive war pensions scheme endorsed by Labour. Thomson has concluded that the training the League gave was adequate, given that it provided for men who could not be trained and placed through normal channels. And it did play an important role in exerting moral pressure within the community, circulating businesses to suggest the employment of ex-servicemen and making personal approaches to potential employers.[36] The social policy of the Labour government stressed income maintenance and economic participation through full employment. Agencies such as the League which offered more personal social services were seen as filling gaps left by the public sector.

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[32] Annual Report, Rehabilitation Board, *AJHR*, 1950, H–18, p.8.

[33] *Report of the Rehabilitation Review Committee*, Wellington 1984, p.33.

[34] Thomson, pp.292–5.

[35] Minutes of Meeting of Civilian Rehabilitation Committee with Representatives of BMA 2 Dec. 1954, H1 331/8, National Archives, Wellington. ('D.S.R.L.' refers to the League.)

[36] Thomson, p.295.

WHO IS RESPONSIBLE FOR THE PROVISION OF SUPPORT SERVICES
FOR PEOPLE WITH DISABILITIES?

Something of the moral high ground claimed by the voluntary sector is shown in the early history of CCS (founded 1935). In maintaining an identity apart from government CCS was more typical of voluntary organisations than the Rehabilitation League. It is interesting as an organisation whose foundation years coincided with the establishment of Labour's welfare state, and it illustrates the 'pity' ethos that was often manipulated very effectively by voluntary organisations. CCS initially restricted its activities to physically disabled children and young persons and its publicity material showed engaging youngsters with callipers or on crutches: they were a marketable product in terms of fund-raising and support.

Early reports of CCS contain very clear statements about the relationship between a voluntary disability organisation and the public sector. Its 1939 report felt obliged to defend the voluntary ethos against those who saw it as representing 'a condescending benevolence which is wholly distasteful'. Such work, it was sometimes argued, was most properly a national obligation, which ought not to be dependent upon the limited and uncertain impulses of kindly individuals. But, the report continued:

> ...those who seek to exclude the voluntary element [altogether], forget that an organisation set up and financed by enthusiasts in the cause, while it may have its weaknesses, will yet possess an elasticity necessarily denied a body whose financial resources are levied by assessment on the general public, and that this elasticity should be of priceless value....

> In these days of systematised efficiency the voluntary organisation does not represent, as some people seem to suppose, the inexperienced efforts of an assembled group of amateur philanthropists. Rather it is the means by which skilled pioneers are free to prepare the way for the State's subsequent advance, and experienced workers are provided to cover ground which, open as it is to the personal touch, must always remain outside the official province.

The defensive tone suggests that the voluntary sector felt somewhat under siege from the 'explosion' of state social policy occurring under Labour.[37] CCS leaders were nonetheless keenly in favour of close cooperation between voluntary and state sectors. The latter was to remain responsible for the treatment of the crippled child, which should occur within the public hospital system 'in the hands of trained experts with the expense met by the State'. The role of CCS, on the other hand, was innovation, personal contact, the investigation of personal circumstances arising as a result of ongoing care, and the teaching of occupational work which would 'probably always be more easily undertaken by voluntary effort than by the State'.[38] (By 1941, however, the Society saw occupational therapy and vocational training as being most definitely a public sector obligation.[39])

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[37] The term is W.H. Oliver's, in his historical survey for *New Zealand Today. Report of the Royal Commission on Social Policy*, Vol. 1, Wellington, 1988, p.29.

[38] *CCS, Annual Report*, 1938–9, pp.5–7.

[39] *CCS, Annual Report*, 1940–41, pp.7–9.

This was a division of responsibility endorsed by Labour politicians, who gave the Society's representations a sympathetic hearing. Speaking to its annual meeting in 1941, Arnold Nordmeyer, Minister of Health, paid tribute to the work of the Society and noted that, whatever the future of medical practice and health services in New Zealand in the future, there would always be a place for bodies such as CCS. Most especially, he endorsed its advocacy role: 'It was the function of the State to care for the crippled child; it was the special privilege of the Society to look after the interests of the crippled child'.[40]

Government endorsement was shown in lotteries grants, amounting in 1939 to £2000, or nearly half of the national body's annual income, along with a grant from the Nuffield Trust. Most of this was distributed to branches, though at this level income from members' subscriptions, donations, appeals and legacies was to become much more significant over time (amounting to around £101,000 of a total branch income of £119,000 by 1960[41]). There was also a small movement of funds in the other direction: in 1941, for example, the annual report recorded a grant of £1000 to assist the Health Department and hospital boards set up travelling orthopaedic clinics, with the aim of making specialist diagnosis and treatment more accessible throughout the country. Where clinics were held, CCS welfare officers did much of the preliminary work, arranging the transport of children to the clinics, and completing any follow-up work needed. Clinic assessments were made available to local branches of CCS.[42]

CCS seems, therefore, to have enjoyed a complementary — even, perhaps, a cosy — relationship with the public sector in its early decades. A photo of the minister of health graced the frontispiece to more than one annual report in the 1950s, and the Society was complimented by another on the 'reasonableness' of its requests.[43] The lotteries grant to the national office continued into the 1960s and the Departments of Health, Education and Labour met with deputations from CCS on a regular basis. From the early 1950s senior representatives of the first two departments were given associate status on the Society's Executive Council. It was an example of how, as the welfare state developed, a voluntary disability organisation with a charitable ethos could find a comfortable place working alongside public sector personnel.

Accountability, either to clients or to public sector departments assisting with finance, was not a major issue in mid-century disability organisations. They were expected to be incorporated societies and some monitoring was possible through the presentation of annual reports and accounts. Public sector employees sometimes served in official and unofficial capacities on the committees of voluntary bodies. Closer supervision was exercised over church and voluntary sector institutions, for these were subject to Health

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[40] CCS, *Annual Report*, 1941–2, p.6.

[41] CCS, *Annual Report*, 1959–60, pp.14–15.

[42] H.E. Carey (compiler), *The History of the New Zealand Crippled Children Society's First Twenty-five Years 1935–60*, Crippled Children Society, New Plymouth, 1961, pp.40, 50.

[43] CCS, *Annual Report*, 1952–3, p.4; see also *Annual Report*, 1955–6.

Department inspection. Except in the case of the Rehabilitation League, public sector transfers to disability organisations were modest, and the principle of encouraging voluntary activity probably overrode any concerns about accountability.

The charitable ethos of this period assumed gratitude and quiescence on the part of clientele. There, were, however, two examples of consumer group dissatisfaction which today might be couched in terms of demand for accountability. In 1945 the Dominion Association of the Blind was formed in response to longstanding concerns about the paternalism and autocracy apparent within the Institute for the Blind. The Association did not gain the support of all blind persons, but its vigorous advocacy slowly ensured greater attention to client groups within the Institution.[44] A second example was the Intellectually Handicapped Children's Parents' Association, which came into existence in 1949. The Association began as a group protesting against the public sector's emphasis on institutional care for intellectually disabled children. The IHCPA rejected the Health and Education Departments' longstanding assumptions about 'protecting' parents from the burden of care and, while remaining an active lobby group for public sector community-based care, it began in the 1950s to provide some services itself.[45]

Some issues concerning Māori.

Instances of Māori using Pākehā-dominated disability services, voluntary and public, can certainly be found as far back as the nineteenth century, but numbers were small. For example, one study of the Auckland Lunatic Asylum between 1870 and 1910 shows that Māori formed only 3 to 4 per cent of patients in its early years, while a contemporary source suggested in 1887 that only 21 out of 50,000 Māori were admitted to the colony's asylums.[46] Records of the Auckland Institute for the Blind show that in 1902 its director extracted a promise from Sir James Carroll to have £25 per annum paid to the Institute from the Native Department's vote for each Māori admitted to the Institute.[47] There is scarcely any mention of a Māori presence at the Institute in annual reports or the Institute's official history prior to the 1940s, however, and it is likely that those Māori admitted did so at a price to their cultural identity.

CCS did examine assistance to Māori children early in its existence, but its response was in keeping with the prevailing ethos of the day. A 1938 report submitted to its third annual general meeting referred to the 'reluctance of Māori parents to seek advice', and hoped that with time and education, existing 'prejudices' would diminish. The emphasis, therefore, was on Māori

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[44] Newbold, Ch. 2.

[45] A.J. Riseborough, 'The Intellectually Handicapped Children's Society. The First Twenty Years: From Protest Group to Welfare Organisation', M.A. thesis, Victoria University, 1986, pp.4, 43–53.

[46] Bronwyn Labrum, 'Gender and Lunacy: A study of women patients at the Auckland Lunatic Asylum 1870–1910', MA Thesis, Massey University, 1990, pp.192–3.

[47] Ken Catran and Penny Hansen, *Pioneering a Vision. A History of the Royal New Zealand Foundation for the Blind 1890–1990*, Royal New Zealand Foundation for the Blind, Auckland, 1992, p.137.

gaining greater understanding of the Society, not on the Society understanding Māori reluctance to use its services. It was not until 1960, however, that the Society sought Māori representation on National Council and branch committees. In 1960 the Society decided to apply for a £200 grant from the Department of Māori Affairs to appoint a field officer in the Waikato district (another example of a voluntary organisation playing an initiating role with state financial support).[48]

The general impression is that Māori usage of specialised disability services, public and non-public, was minimal prior to World War II, and that there were a number of reasons for this.

Firstly, Māori were sometimes actively discouraged from using services. For example, prior to the introduction of hospital benefits under the Social Security Act 1938, hospital boards frequently claimed that Māori did not pay the fees charged them, failed to contribute their share of local rates, and should therefore not be eligible for treatment in public hospitals.[49] Staff were often unsympathetic to Māori patients, though in the late 1930s is was claimed that younger Māori were becoming less reluctant to use the public hospital system.[50]

Another reason for Māori not using specialised disability support services is that the use of disability services usually indicated, and even necessitated, estrangement from whānau and other traditional supports. This was especially true where institutional services were provided (as was often necessary when transport systems were underdeveloped and geographical mobility difficult). Such institutions tended to be based in urban centres and, at a time when the Māori population was predominantly rural, treatment and other forms of assistance involved travel and time spent apart from whānau. Even in the 1950s, a Māori child whose disability was diagnosed by one of CCS's mobile clinics, for example, might have to spend months in an urban centre, away from family\whānau, having repeated operations. Many Māori understandably resisted this. Most services, public and non-public were monocultural in emphasis, and those limited numbers of Māori who used such services probably did so at a cost to their cultural identity and whānau links.

A third reason for Māori to avoid using specialised disability support services was because those services had tended to become increasingly medicalised and technical, focusing on the physical dimensions of rehabilitation, and on dysfunctional parts of the body. This perspective contrasted with Māori views on wellbeing, which, as Durie has noted, involve a more holistic interaction of spiritual (taha wairua), mental (taha hinengaro), physical (taha tinana) and family (taha whānau) dimensions.[51] It is likely

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[48] H.E. Carey, The History of the New Zealand Crippled Children Society's First Twenty-five years 1935–1960 [N.D. New Plymouth].

[49] See, for example, H1 194/8 Māori Hygiene — Conference on Māori Health 1933–36 (B.125), National Archives.

[50] Ibid., Paper on 'Health Services for the Māori' [1936].

[51] Mason Durie, Whaiora. Māori Health Development, OUP, Auckland, 1994, p.70.

that Māori had different perceptions of just what was (and is) a 'disability' from those of Pākehā health professionals.

For all of these reasons, Māori were not regarded as a significant consumer group among those accessing disability services. Accountability to Māori was not a major issue in this period.

The public sector played a role in meeting Māori needs, but in a public health context. Here the rehabilitation of individuals was, of necessity, subordinated to infrastructural problems involving infectious disease and poor nutrition, housing and sanitation. The definition of 'disability' has historically been measured against expectations of health and wellbeing within wider populations, and where these were low, disability was probably less distinguishable than it has since become. The need to reduce the incidence of typhoid, tuberculosis and infant mortality among Māori sometimes took precedence over concerns about disability. Diseases such as TB were often fatal as well as disabling, and the living conditions which produced them were the focus of public health effort. Until large scale urbanisation brought Māori into closer contact with specialised agencies, it is likely that the majority of disabled Māori stayed in their own whānau, where they encountered varying degrees of care and neglect. Although from the nineteenth century until the 1930s selected general practitioners in a small number of rural districts were paid a subsidy by the Native Department to treat indigent Māori, in the twentieth century the district (later 'public health') nurse was probably the health professional with whom disabled Māori came most into contact, but her function was to function in a preventive and educational role, rather than to provide care.[52]

Durie and others have chronicled voluntary health initiatives within Māori communities, many of them initiated by women during the twentieth century.[53] Again, these were not specifically directed towards disability, but such activities certainly had implications for the incidence of disability among Māori, and Māori access to health services. The work of such bodies as the Women's Health League and the Māori Women's Welfare League also illustrates the links between the voluntary sector and the state in a Māori context. The Women's Health League was formed in 1937 and worked closely with the Department of Health and hospital boards, while the Māori Women's Welfare League had connections with the Department of Māori Affairs. Although both have since been criticised for these ties, as Durie notes, they linked health and other issues with tikanga Māori.[54]

Among the government's 1992 goals for disability support services was a requirement that they be sensitive to the needs and preferences of Māori and

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[52] 'Health Services for the Māori', op.cit.

[53] Durie, pp.42–60; Raina Meha, 'Te Ropu of te Ora: Women's Health League 1937–', in Anne Else (ed.), *Women Together. A History of Women's Organisations in New Zealand. Ngā Rōpū Wāhine o te Motu*, Historical Branch, Department of Internal affairs/Daphne Brassell Press, Wellington, 1993, pp. 30–33; Tania Rei, 'Te Rōpū Wāhine Māori Toko I te Ora: Māori Women's Welfare League 1951 –', ibid., pp. 34–38.

[54] Durie, p. 49.

other groups.[55] This reflected a growing appreciation over the 1980s of the need for Māori to have greater input into, and control over services affecting their wellbeing. On the whole, the public sector appears to have responded earlier and more extensively than the more established voluntary organisations. The Department of Health added a distinctively Māori perspective to its policies and practices in 1984.[56] Some hospital boards attempted in the 1980s to provide parallel Māori services, with varying degrees of success and, in some cases, controversy. By 1990 voluntary organisations such as the IHC had Māori support groups, and were also attempting to consult with Māori, expose staff to biculturalism training, and recruit Māori personnel. However, culturally appropriate mainstream services alone were insufficient to meet Māori needs, as the 1995 report *He Anga Whakamana* pointed out. Māori service providers conversant with tikanga Māori and Te Reo Māori and with access to Māori networks were seen as promising better outcomes for a significant proportion of Māori people with disabilities.[57] Some Māori may argue in the 1990s that the distinction between public and non-public provision of services is less relevant than the degree of Māori autonomy and control over resources achieved in either context. The contraction of the State's role across many sectors has not been mourned by those Māori groups and individuals who perceive the historical role of the state towards Māori as one of paternalism and control. These groups would see the current environment as allowing new opportunities and greater independence of action for Māori service providers.

This does, however, lead to the issue of accountability, and how accountability may be interpreted in different cultural contexts. In the recent and more distant past Māori service providers — individuals and groups, within the public sector and outside it — have faced conflicting agendas. Accountability to whānau and iwi have historically come into conflict with accountabilities to Pākehā-dominated bureaucratic structures. Many attempts by Māori to act autonomously have resulted in claims of 'mismanagement' from Pākehā critics.[58] It remains to be seen whether funding providers in the new health and disability services environment are any more successful than their predecessors in resolving such dilemmas.

3. A Period of Change — the 1970s and 1980s.

A 1975 appendix to the Health Department's annual report made it clear that disability services were still regarded as a public sector responsibility, supplemented in a minor way by voluntary and private agencies. The hospital

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[55] Shipley and Upton, op.cit, p.25.

[56] Ibid., 105.

[57] M.M Ratima, M.H. Durie, G.R. Allan, P.S. Morrison, A. Gillies, J.A. Waldron, *He Anga Whakamana. A framework for the delivery of disability services for Māori*, Massey University, Department of Māori Studies/Te Pumanawa Hauora, Palmerston North, 1995. A report to the National Health Committee.

[58] For comments on this, in relation to a case study of the Māori War Effort Organisation, see Claudia Orange, 'An Exercise in Māori Autonomy: the Rise and Demise of the Māori War Effort Organization', *New Zealand Journal of History*, April 1987, pp. 156–172. Criticisms of Sir Apirana Ngata and Māori land development policies in the early 1930s provide another example of this.

boards were presented as the hub of rehabilitation services, and they were increasingly drawing upon multidisciplinary teams to offer rehabilitation assistance at early stages of disability. The Department of Labour provided an employment service for physically and intellectually disabled persons while the Education Department continued to work more in the area of habilitation, providing special schools, classes and clinics for children with disabilities. Two newer bodies were expanding their domains. The Accident Compensation Commission, set up under the 1972 Act, had a statutory obligation to work on accident prevention, to promote medical, social and vocational rehabilitation, and to liaise with other agencies working in these fields. It is important to note, however, that compensatory entitlements under the Accident Rehabilitation and Compensation Insurance Corporation Act generate entitlements for those whose disabilities arise as a consequence of "accident", but not those whose disabilities arise from other causes. This difference raises issues which are further discussed in Part Two of this paper. During this same period, the Department of Social Welfare not only administered disability pensions, but was providing subsidies for voluntary organisations, particularly those running sheltered workshops. The main national disability organisations were listed and it was noted that, while they received some financial help from government, they depended mainly on support from their members and other interested parties and on donations. The voluntary sector was presented as if it were very definitely on the margins of service provision. Significantly, the survey noted an increase in the number of persons in the community with disabilities. Also apparent was a much more complex definition of rehabilitation, which encompassed vocational and social processes, as well as medical.[59]

In fact, although it was not apparent in this survey, major changes were starting to have an impact upon disability services of all kinds. These encompassed:

the emergence of a much more assertive consumer voice than had been apparent in earlier decades;

the rapid expansion and growing complexity of the voluntary sector, which by the 1980s ranged from small neighbourhood groups with minimal assets to large national agencies with substantial assets and a multi-million dollar turnover;

a marked increase in public sector financial transfers to voluntary organisations, much of it stemming from the new emphasis on community care of disabled people and the 1975 Disabled Persons Community Welfare Act in particular;

the growing significance of private sector provision, especially in private hospital, consultant and physiotherapy services. This was boosted by growing dissatisfaction with the public sector. Even the Accident Rehabilitation and Compensation Insurance Corporation came to rely extensively upon these providers, through initiatives such as the accredited employers scheme referred to in Part Two of this paper;

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[59]   Rehabilitation Services in New Zealand, *AJHR*, 1975, E–10, pp.109–19.

a new emphasis on accountability, both to funding providers and to consumers of services;

acceptance of the need for bicultural policies and a Māori perspective within disability organisations, though some organisations embraced biculturalism more readily than others. Emerging acknowledgement also of a need for multicultural perspectives to reflect the country's increasing cultural diversity.

By the 1970s many minority groups throughout the world were claiming the right to control their own affairs and to participate in decisions affecting their own wellbeing: this was increasingly true of persons with disabilities. Improvements in mobility and communications and the extension of media coverage of social issues all helped disadvantaged individuals identify with others in the same situation nationally and internationally. One of the key international groups responsible for the enhancement of the awareness of issues for disability support was made up of the more assertive Vietnam veterans. As difference and diversity also became recognised motifs within New Zealand society, numerous special interest groups emerged to advocate for newly recognised categories of need. The old, all-encompassing labels were challenged. A majority of our voluntary associations have come into existence since 1960, and disability organisations formed a significant growth point among them.

This proliferation also reflected a growing disillusionment about the ability and, increasingly, the will of the public sector to provide adequate welfare services. In the 1970s the welfare state came under attack from both the political left and from the right. The former often complained of the capture of welfare by the middle classes, or spoke in terms of hegemonic state 'social control', while those on the right were concerned about the sustainability of rising welfare expenditure, and about its effect on individual initiative. Voluntary effort was, on the one hand, presented as more likely to be empowering to communities, free of the bureaucratic rigidities which hampered the public sector; on the other hand, it was seen as combating dependency, through local knowledge of clientele and the personal influence of volunteers. Striking from an historical perspective is the number of reports and discussion papers issued from the late 1970s which examine and re-examine the relationship between public and voluntary sectors.[60] Such

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[60] A number of these issued from the New Zealand Planning Council: see, for example, *The Welfare State? Social Policy in the 1980s*, New Zealand Planning Council, Wellington, 1989; Judith Davey and Maire Dwyer, *Meeting Need in the Community. A Discussion Paper on Social Services*, New Zealand Planning Council, Wellington, 1984; Sue Driver and David Robinson, *Voluntary Social Services, A Review of Funding*, New Zealand Planning Council, Wellington, 1986. See also *Roles of Central Government, Local Authority and Voluntary Agency in Social Welfare*, New Zealand Council of Social Service, Wellington, 1976; *Sharing Social Responsibility*, New Zealand Council of Social Service, [Wellington], 1978; *Partnership. The Delivery of Social and Community Services*, Social Advisory Council, Wellington, 1986; Helen Wynn, *Government Funding of Welfare Agencies. A Review of Funding By the Department of Social Welfare*, Department of Social Welfare, Wellington, 1984. Specifically relating to disability and rehabilitation services were R. Bolt and E.G. Heggie, Report of the Rehabilitation Committee, Department of Social Welfare, Wellington, 1982 and *Report of the Rehabilitation League Review Committee*, (Wellington, 1984). Voluntary organisations also issued internal discussion papers.

discussions previously tended to take place, in a defensive tone, within voluntary organisations' annual reports or magazines. By the 1970s government departments and quangos were taking the issue much more seriously and commissioning their own papers.

One of the reasons for public sector interest in this relationship was the rapid increase in government funding of voluntary organisations over the 1970s and 1980s. This had reached a major threshold of alarm by the mid-1980s. The increase was due partly to pressure of demand, some of it urgent, as voluntary agencies began to meet new needs in the community, or to provide services for which the public sector was reluctant to assume responsibility. It has been suggested that governments subsidised voluntary activity in the hope of encouraging a 'bottom-up' approach to welfare and ultimately reducing public sector expenditure.[61] For the most part, it seems to have happened in an *ad hoc* way, with large, nationally-organised bodies benefiting most.[62] Overall financial transfers increased enormously until, by 1986, government departments were allocating nearly $75.4 million annually to the voluntary sector for services, $24.5 million of it for the care of disabled persons.[63] Less obvious, but also critical to many organisations was non-financial assistance in the form of advisory and support services, training provision, accommodation and equipment made available at minimal charges, assistance with volunteer expenses and secondment of public sector staff.[64]

One area of growth in transfers to the voluntary sector came in the form of subsidies to sheltered workshops. From 1970 voluntary organisations were encouraged to develop workshops for those unlikely to be able to take up outside work, while the Rehabilitation League catered for those potentially able to compete on the open labour market. Subsidies were initially set at 50 per cent of the cost of approved supervising staff and a 50 per cent subsidy towards the cost of land, buildings and alterations.[65] Within three years the subsidies had risen to 75 per cent and 66.66 per cent respectively. The Disabled Persons Community Welfare Act of 1975 led to heightened expectations of disability services, gradually increasing the range of programmes which were subsidised by government departments. A 1984 study of the Department of Social Welfare's transfers to voluntary welfare agencies showed that subsidies of $627,239 in its first year of operation had risen to $20.4 million by the 1982–3 year and $25.5 million by 1983–4.[66] Particularly concerning was the lack of a funding philosophy with consequent reliance on ad hoc and uncoordinated decision-making. The main kind of accountability was financial, with checking of accounts and annual reports, and evaluation of programmes was not given any great priority.[67]

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[61] Davey and Dwyer, p.1–2, 37.

[62] Social Advisory Council, 1986, p.8.

[63] Driver and Robinson, p.12. This excludes $6 million to the Rehabilitation League, which was by then regarded as a quasi-government agency. (Ref footnote 60.)

[64] Driver and Robinson, pp.19–22. (Ref footnote 60.)

[65] New Zealand Social Security Department, *Assistance Organisations Providing Training and Sheltered Employment for the Disabled. The New Zealand Government Rehabilitation Programme*, Wellington, 1970.

[66] Wyn, p.1. This figure is to all voluntary agencies, not just the disability sector.

[67] Wyn, pp.22–5.

WHO IS RESPONSIBLE FOR THE PROVISION OF SUPPORT SERVICES
FOR PEOPLE WITH DISABILITIES?

The expansion of the Intellectually Handicapped Children's Society (IHC) as a service provider over the last thirty years illustrates these trends. Formed in 1949 as a lobby group of parents, the Association had begun by 1953 to acquire properties for short-stay homes and occupational groups. Amendments to the Mental Health Act in 1954 and 1956 made it easier for the association to run short-stay homes, and in 1954 the Minister of Health began to approve limited capitation subsidies and grants for capital expenditure.[68] Ten years later, in 1964, the IHC received around 10 per cent of its annual operating budget of £55,688 from the Health Department in respect of children under 16 boarded in its hostels. It also received a 50 per cent subsidy on building costs, totalling £150,000.[69] A constant refrain in the Society's annual reports from this time is the inadequacy of government assistance. Intellectually handicapped people, it was claimed, were living much longer and there were higher expectations as to their standard of care. Institutions run by the Department of Health had substantial waiting lists, and the Society was under growing pressure to provide the necessary accommodation and relief.[70] As the Department and, later, the hospital boards proved slow in moving towards community care of the intellectually disabled, the IHC took the lead. By 1986 the Society was spending over $43.3 million annually (more than double its 1981–2 expenditure), $29.3 million on salaries. It received over $20 million annually from government sources[71] and was a key recipient of the $25.5 million transferred as a subsidy by the Department of Social Welfare to voluntary welfare agencies in 1983.

The IHC had made the transition to a large, nationally organised service provider relatively rapidly, but not without on-going debate as to whether this, or advocacy, was its proper role. A 1986 working paper noted tensions caused by the expansion of services over the previous five years. These included pressures for quality and accountability, and pressures on leadership. As in many large organisations the role of volunteers had become problematic. The paper noted problems with the numbers offering for committees and presidential positions, adding that the quality of volunteers was also inadequate for the task required.[72] For their part, many individual members and branches came to feel that they had lost autonomy, and that the organisation was dominated by an over-heavy and costly bureaucratic structure.[73] Management estrangement from at least some of the organisation's volunteer base was compounded by the decision in the late 1980s to abandon large IHC hostels. The IHC was not alone in experiencing tensions between the new managerial thrust and an older charitable ethos. The Royal New Zealand Foundation for the Blind and CCS were others.

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[68] Riseborough, p.113; R.W.S. Botting, 'Historical Notes on I.H.C. to 1972', IHC Library.

[69] *The Intellectually Handicapped Child*, November 1964, p.2.

[70] 'Extracts From the Society's Submissions to the Social Security Commission', *The Intellectually Handicapped Child*, March/May 1971, p.13.

[71] *IHC Annual Report* 1982; *Intellectually Handicapped Review*, March 1986, p.14.

[72] IHC Conference Working Papers, 1986, IHC Library, Wellington.

[73] *Report of the IHC Review Working Party*, 1991 [p.3].

The IHC shows how voluntary organisations were able to play a pioneering role, providing community-based services before the public sector felt ready to do so. However, the scale of its activities meant a shift from the historically dominant pattern of voluntary organisations working on the margins of public endeavour, providing supplementary 'extras': by the 1980s the IHC had become a basic service provider. With this came financial difficulties as government refused to fund the rate of growth experienced by the IHC.[74] Resentment from other disability organisations was another consequence, as newer, smaller bodies found themselves unable to bid into preallocated funding.[75] Accountability became an issue; the more so since the Society's service provider, monitoring and advocacy roles were perceived to be in conflict.[76]

Other large disability organisations faced similar problems around this time. Disability services were being negotiated against a background of profound political change, involving the withdrawal of the state from a wide range of activities. Under the fourth Labour government, change was most apparent in the areas of economic and fiscal policy, with more extensive changes in social policy taking effect under the 1990 National government. In the disability sector this saw the refinement of a market model of service provision during the early 1990s.[77] Theoretically, disabled persons became individual consumers of services within a competitive economy. Instead of a whole range of government departments subsidising voluntary agencies, single purchasers, the Regional Health Authorities, began to purchase services on behalf of persons with disabilities. Significantly, the document which introduced this last change, *Support for Independence for People With Disabilities — A New Deal*, not only stated the government's desire to improve the quality of life for such persons, but it also '[recognised] the financial realities facing the country today'.[78]

4. Conclusions

The history of social policy does not provide ready answers to contemporary questions. It nonetheless indicates the cyclical nature of policy emphases, and shows how readily one generation's orthodoxies can become superseded by another's certainties.[79] In the past there have also been considerable gaps between policy formulation and policy implementation.[80] The success or otherwise of recent policy changes have yet to be assessed, but it must be recognised that they are a product of a particular economic, social and

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[74] IHC Submission to Review Team, *Report of The IHC Review Working Party*, Wellington, 1991.

[75] Driver and Robinson, p.8. (Ref footnote 60.)

[76] *Report of the IHC Review Working Party*, Wellington, 1991.

[77] For an exceptionally clear critique of these developments see J.B. Thomson, 'Indigence to Independence: The Development of Social Policy in New Zealand for People With Learning Disabilities', Master of Social Work Thesis, Massey University, 1995, Chs. 9 and 10.

[78] Shipley and Upton, op.cit, p.25.

[79] Thomson, 1995, p.201–2; Tennant, 1996.

[80] Tennant, 1989.

ideological climate. They may, in the future, be as vulnerable to critical assessment as policies and practices endorsed, equally sincerely, by earlier generations. In relation to the balance of responsibility between public, voluntary and private sector provision for disability, an historical perspective highlights the magnitude of recent shifts in thinking. Although the boundaries between the sectors have always been permeable, especially in a financial sense, it can be argued that they have become even more blurred, and perhaps meaningless in the current environment. Longstanding ways of doing things within both the public and voluntary sectors have had to shift as a result of a common managerial ethos at many levels and by staff movement between the two sectors. Voluntary organisations are likely, even at community level, to be employing paid staff. Parts of the public sector are now required to return a profit, as has long been required within the private sector. Private, voluntary and public sector providers are all likely to be competing for contracts to provide disability services.

Some general conclusions are nonetheless relevant to current discussions:

- Despite suspicion of malingering, disabled persons (and especially those with an obvious physical or sensory disability) have tended to be placed among the 'deserving poor'. They were least likely to be expected to show self-help and initiative. Relatively sympathetic attitudes were fostered by the association of many forms of disability with war service. However, this was often predicated upon a 'pity' ethos which many disabled people find offensive today. Those with a psychiatric disability elicited least sympathy, and in this area, community support and voluntary effort were, historically, little apparent.

- Over time the public sector has always been the main provider of financial support for persons with disabilities, and of disability services, especially where long-term aid was needed. This was true of the nineteenth century as well as the more recent past.

- The public and voluntary sectors were in the past seen as having a complementary, not a competitive relationship. The effect of the state's endorsement of, and assistance to, many voluntary organisations in the past was to place them in a privileged position as monopoly service providers. This was to the detriment of the consumer choice apparent in many other, larger countries. In the current funding environment many of the old complementarities are being profoundly altered, partly in the name of consumer choice, but also in the hope of ensuring more efficient use of resources, resulting in considerable tension, both between purchasers, providers and consumers of disability support services, and, within these broad categories, amongst individuals, organisations, and communities with diverse perspectives and interests.

- If the private, profit-making sector has not featured in this part of the paper, it is because, historically, it does not appear to have been very significant in its own right before the 1970s. The medical profession, both general practitioners and consultants, certainly played an important part in the rehabilitation of disabled persons, but they tended to do so in

conjunction with the public system. The main exception to this would be the care of elderly persons with disabilities through privately-run rest homes, and this was mainly since the 1950s.

- People with disabilities can no longer be regarded in a unitary light — diversity and difference have become significant motifs in modern society. Most services in the past were monocultural in outlook, and those using them probably did so at a cost to their cultural identity. The current structure allows, indeed expects, greater recognition of diversity in service options. This may, however, raise issues of conflicting accountabilities for service providers: to the funder, purchaser, and to a range of client groups.

- As in health more generally, there has been a very marked increase in expectations of disability services over the last thirty years. This may have upset some of the established complementarities and has clashed with the more recent desire to reduce government expenditure. Although political and economic expediency have to some extent meshed in the move towards community care, the effect of greater efficiencies in services may well be negated by still increasing demands and expectations.

Part Two: Philosophical Discussion

What are the boundaries between public, private and voluntary in the disability support sector?

The centrality of the experience and values of people with disabilities to public policy in the disability area has been emphasised earlier in this paper. The great diversity and change over time in these values and experiences have been noted, as has the diversity in the perceived goals and even the basic ways of understanding and expressing notions of disability and support. People with disabilities have direct, immediate and ongoing access to understandings of this diversity and change, since such understandings are inherent in how things are for them. Information about this extraordinary diversity and change is highly relevant to the appropriate design of disability support.

The Individual Entitlement Model

The individual entitlement model attempts to build on and take advantage of this diversity, and to give due regard to the centrality of the experience of people with disabilities.[81] It takes seriously the frequently discussed need for consumer focus in the area of disability support. Using this model, there is independent confirmation that a person has a disability and related needs generate an individual entitlement to publicly funded support. The level of this entitlement is proportional to the level of the individual's disability or handicap or need. The individual may then make use of that entitlement in whatever way she or he sees fit. The public has a central role in acknowledging and funding this entitlement through the design of relevant public policy and institutions. Beyond this, however, the individual entitlement approach holds that there is no general requirement that any public or other service purchaser or provider or other agent act on behalf of the person with the disability. It makes no restrictive distinctions over whether the entitlement may be devoted to private as well as public goods or services or support, and there is no ring-fencing of entitlement to prevent it being spent on health services, or on other things entirely, rather than specifically on disability support services.

The individual entitlement approach to disability already has an established place in New Zealand public policy. For example, the *Accident Rehabilitation Compensation Insurance Act 1993* (hereafter, "ARCI Act") sets out in s. 54 amended with effect from 1 July 1997, an individual weekly entitlement for those assessed as having disability due to accident. This entitlement is to a maximum of $60 per week for those assessed under the AMA guidelines as having a permanent impairment level of 80 per cent, the scale beginning at 10 per cent impairment level. The payment is made on top of the provision of a range of disability support services.

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[81] It is possible, of course, that some proponents of the individual entitlement model are responding to concerns other than these ones.

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The current system provides a mixture of individual entitlement and other approaches to actual, additional expenses of specified types which the person incurs due to their disability. Some entitlements are paid in the form of an allowance, such as the Handicapped Child's Allowance which is paid to parents caring for a child with a severe disability. Other allowances are assigned to the service provider nominally to pay for the costs of vocational services. Thus some people with disabilities do not have access to an individual allowance for other extra expenses they may incur relating to their disability.

Should the individual entitlement approach of New Zealand's accident compensation framework be extended to disability in general, or are there important differences between disability arising from accident and disability arising from other sources? Various aspects of these questions are pursued later in this paper. They cannot be fully explored here, and they remain important questions for policy makers in the disability support area. Three objections to extending the individual entitlement approach will be discussed now.

One objection is that the individual entitlement framework cannot extend convincingly to the least articulate and most vulnerable people with disabilities. This objection is important, since policy makers should be particularly concerned about the situation of these people and the issue of responsibility for funding advocacy services. But note several things. First, it is not obvious why high levels of vulnerability undermine the idea of individual entitlement, rather than simply increase the level or amount of entitlement. Second, high vulnerability might instead justify a key role for families, voluntary organisations, mentors, brokers, or other agents in *protecting* that individual entitlement. In a small proportion of circumstances, there might be a legitimate paternalistic role for others to administer this entitlement on behalf of a person with a disability. The difficulties here should, however, not be underestimated. In a small number of cases, these can involve issues as basic as conflict between people's self-identified disability status and needs, and the identifications of disability and need made by family members, professionals, or others. Third, it might be helpful to look further here at the success or otherwise of accident compensation, because the ARCI Act seems to persist with an individual entitlement approach even in the context of 80 per cent or more disability.

A second objection is that the individual entitlement approach is too individualistic and consumer focused, and too Pākehā, and consequently threatens communities and the sense of community in the disability sector. This again raises complex issues which cannot be fully dealt with here, but several quick comments can be offered. First, there perhaps are genuine individual-community conflicts here, but these can often just as usefully be seen as arising between some individuals and others, or between the claims of already established communities and those of emergent communities. Second, even if an individual entitlement approach were applied more broadly across the disability sector, levels of entitlement might not initially be set as high as people with disability and their supporters might wish. In that case, these people would still have a very powerful community of concern and

interest, even given a setting of individual entitlement. Third, if people are committed to their disability communities, then they might well use their individual support entitlements in ways which reflect that commitment. Fourth, it is not clear how one can consistently emphasise the centrality of the experience and values of particular people with disability, and yet at the same time firmly resist a central role for an individual entitlement approach to disability support.

A third objection to extending the individual entitlement approach is that it tends to conflict with other objectives. It was suggested above that on this approach, the level of entitlement is proportional to the level of the individual's disability or handicap or need. If resources are scarce and precious relative to all the good things they could be used for, then entitlement based on need or extent of disability will sometimes conflict with more beneficial allocations which could otherwise be made with that scarce resource. The reason for this is simply that the greatest need cannot always be met. Lesser needs can *sometimes* be met to a greater extent. The entitlement approach gives priority to the extent of need, not to the extent of potential benefit. It focuses on immediate outputs, rather than longer term outcomes. To say the least, it is not easy to trade off the entitlements of some against potentially greater benefits to others. If resources genuinely are scarce, as it seems they are on any politically and economically feasible total budget for disability support, then this conflict of values will be hard to

We shall now offer some thoughts about how best to understand the boundaries between public, private, voluntary, and other sectors in disability support. We shall work our way into these fairly abstract issues by means of the following Cooking Case:

> Kim, Robin, and others share a busy and reasonably well-off household. They decide to pay someone to cook for them. Kim agrees to find the cash for both cook and materials. Robin claims to know what is needed, and is given the cash to organise that on the household's behalf. Alex agrees to come in and do the cooking, using the household's materials and food.

This tale illustrates three different roles or functions. Kim funds the cooking, Robin purchases these services and goods, and Alex provides or does the cooking. Each function here is served by a different person, and the arrangements among them are more or less contractual. In disability support, as in household cooking, the roles or functions of funder, purchaser, and provider can be identified, and questions asked about who should have responsibility for each function, and to whom they should then be accountable. Sometimes, more than one function is served by one person. For example, Robin could have decided to pay himself to be cook, thus being both purchaser and provider. Oversimplifying considerably, this is what Area Health Boards used to do when they bought health (and some disability support) services mainly from themselves with funds supplied to them by central Government.[82]

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[82] Other examples of this can be found in Department of Social Welfare settings, and historically in a wide variety of direct funding arrangements by parliamentary Vote for charitable disability support organisations. Examples involving the IHC, Foundation for the Blind, and Hospital and Charitable Aid Boards, are discussed in detail in Part One of this paper.

Alternatively, Kim might have decided to be both funder and purchaser of the cooking goods and services. Again, the distinction between these two roles would then have been less obvious. Though the details are not yet settled, it might be that the current move from four Regional Health Authorities (RHAs) to one national funding agency is a move to an organisation which is both funder and purchaser of health and disability support. The Cooking Case suggests that wherever goods or services are exchanged for money, these three functions of funder, purchaser and provider are served.

The household discussed in the Cooking Case might decide or be forced into being self-sufficient, providing its cooking needs as far as it can from its own unfunded household resources. In this case, the funder and purchaser functions would largely disappear. That would leave only the provider function, to be served by the householders themselves as best they could, together with whoever else might help them. Again, there are possible analogies here to certain disability support settings. Disability support which is not funded will either not be provided at all, or it will be an unfunded provision by the person with a disability herself or himself, and/or by any others whose assistance she or he might be able to secure. Increases of public funding can reduce this pressure on private provision or non-provision. Decreases of public funding can increase this pressure. A key issue arises over where to strike the balance between public and other forms of funding for the provision of disability support, and how to give a rationale for any particular balance struck. We return below to these issues.

Consider the following general framework for understanding boundary issues in disability support:

Responsibility in the disability support area is responsibility *of* someone *for* something, with accountability to someone.

As reflection on the Cooking Case suggested above, there are responsibilities for functions such as the funding, the purchase, and the provision of disability support in all its diverse forms, including equipment, home alterations, attendant care, respite care, and so on.

Cases in which disability support services are funded by the public as a whole via parliamentary Vote will be a primary focus below. In these cases, one line of accountability for delivery on these responsibilities runs back to Parliament, and thereby to the public as a whole.[83] There is an important contrast between these responsibilities taken by the public as a whole, and all those responsibilities taken by local or regional authority organisations, by iwi or other Māori organisations, by voluntary organisations on the basis of nationwide public appeals, by households and individuals, and so on. Important as they are, all these other funding responsibilities are taken by *parts* of the public, and not by the community or public as a whole. These various responsibilities are nevertheless related to one another in many important ways, some of which will be discussed further below.

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[83] There might of course be other accountabilities here, including accountabilities to disability communities and individuals.

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FOR PEOPLE WITH DISABILITIES?

What of the responsibility *of* someone for funding, purchase or provision of disability support? There are many "someones" here, including the public as a whole via Parliament, people with disabilities themselves, their family or whānau or household members, publicly-owned organisations or agencies, iwi or other Māori organisations, the Accident Rehabilitation and Compensation Insurance Corporation (ACC), local or regional authority organisations, voluntary organisations, philanthropic organisations, and for-profit business organisations.

One way to group the various individuals and agencies with responsibilities for disability support is in terms of a public — private distinction. CHEs and their successors and RHAs and their successors might be considered to be public entities, and businesses, households, and individuals might be considered to be private entities. One problem with this distinction is that some very important cases are hard to put clearly on one side or the other. Another problem is that some important disability support agencies are not well described as either public or private.

The current situation in accident compensation illustrates the first problem with the public — private distinction. ACC might initially seem to fall clearly under the "public" rather than the "private" heading. Under the *ARCI Amendment Act 1996*, however, there is a scheme in which large employers with a good accident record can be accredited as exempt from paying a significant portion of their ACC premium if they undertake in return to provide rehabilitation and compensation at least as good as that offered by ACC. It is true that claimants on weekly compensation for more than one year revert back to ACC, but many of these people will in the meantime have need of disability support services such as home help, attendant care, and aids and appliances. In short, there is scope within the current ACC framework for private purchasing of health and disability support services, and for these to be delivered through service contracts with private for-profit providers.

Consider now disability support agencies which are not well described as being either public or private. Some local and regional authority organisations deal with disability. They are not agents of the whole public, and it is important to observe a distinction between responsibilities assumed by the whole community and those assumed only by parts of the whole community. On the other hand, these are clearly not private organisations. Secondly, some Māori organisations, including iwi organisations, urban Māori authorities and national organisations, deal with disability issues. Again, these organisations seem to be neither straightforwardly public, nor straightforwardly private. Might they instead be regarded as Treaty Partners? That may depend on which Māori organisations are appropriate successors of the rangatira or chiefs who signed the Treaty of Waitangi and whether disenfranchised Māori and urban Māori authorities are included. That issue is difficult and controversial. Another issue concerns the notion of "responsibility" as applied to Māori. The Māori concept "by Māori, for Māori" implies that Māori decision making about funding and provision of services, including disability support services for Māori, should be made by collectively by Māori at least in partnership with Māori. However these issues may be resolved, it is clear that Māori

organisations and Māori decision making processes have a special standing, and that the public — private distinction may require appropriate adaptation to be culturally relevant.

One alternative to the public — private distinction is that between for-profit and not-for-profit individuals and organisations. Public organisations such as state owned enterprises are for-profit organisations, and some private clubs and philanthropic organisations are not-for-profit, so the public — private distinction does clearly differ from the profit — not-for-profit distinction. There are some well established and in some cases long-standing for-profit organisations in the disability support sector. Those which arise in the ACC setting have already been noted above. Others include various manufacturers, distributors, and retailers of disability aids and equipment, some organisations which make home alterations for disability support purposes, GP practices when they offer services in the disability support area, a number of for-profit rest home organisations, and so on. It is also worth noting that from a management accounting perspective, units or organisations which are profit centres can include those which have a balanced budget or zero profit target, and even those which are given a negative profit target, as well as those with positive profit targets.[84]

If it is agreed that for-profit organisations play an important role in disability support, and that some of them are likely to continue to do so, then it will be hard to make sweeping generalisations about their place or absence of place. There is nevertheless considerable debate and disagreement about the nature and appropriate scope of that role. Concerns have been expressed, for example, about the impact a profit-oriented approach might have on the ethos of disability support, and on the quality of service delivery. In general terms, the issue is perhaps this: Can those with responsibility for public resources for disability support arrange things with for-profit organisations such that their profitability depends vitally on their treating their customers well and delivering excellent services to them? If this is the central question, then it will need to be answered on a case by case basis, in the light of evaluations of the overall value for money offered by any alternative service options which might be available. Also, if this is the central question, requirements such as "treating customers well" and "delivering excellent services" will have to be grounded in ways which are culturally appropriate.

Some issues involved in developing policy advice.

The National Health Committee is required to advise the Minister of Health on the kinds and priorities of publicly funded health and disability support services. RHAs are required to purchase services in accordance with the priorities set out by the Minister. Both of these public responsibilities are performed in a setting in which many others are also purchasing, providing and giving public policy advice about various disability support services.

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[84] See, for example, J. Hoggett and L. Edwards, *Accounting in Australia*, 3rd edition (Brisbane: Wiley and Sons, 1996), pp. 1045–47.

These others include organisations responsible for public disability support funds in other parliamentary Votes such as Education and Welfare, people with disabilities, their whānau, families and households, voluntary organisations, the ACC and its agents, some Māori organisations, some local authority organisations, some business organisations, and so on. Given that responsibilities in this area are not unified in any single process or organisation, it seems that each agency must determine its own priorities, assess the "gaps and margins" left by the priority setting and activities of others, and then act to advance those priorities in the gaps and margins identified. This situation generates a number of co-ordination problems for all parties involved. We shall now briefly discuss several of these problems particularly relevant to the Vote Health setting for disability support.

One co-ordination problem arises over the need for constant monitoring of changes in what other organisations and individuals are doing, and adjustment to the new gaps and margins they create and/or plug. To the extent that the disability support environment is constantly changing, the costs of keeping up with information about this, and the risk of doing so rather imperfectly, will be substantial. It should be emphasised that these problems arise just as much for the National Health Committee, as it attempts to give sound advice to the Minister of Health on the kinds and relative priorities of disability support services, as for the RHAs and their successors. It is a general problem for public policy in the disability support sector.

A further problem arises over value-for-money issues. Value-for-money has been a key emphasis in the public health and disability support sectors since 1991, and arguably for a lot longer than that. With this focus, RHAs have detected and corrected some cases in which best value was not being gained for public money spent. It is likely, however, that a value-for-money focus will also bring to light cases in which best value is being gained, and public money is not being spent. More specifically, many organisations can argue that they provide significant value in various areas of disability support, for which they receive little or no public money. They can respond to persistent value-for-money demands from RHAs and their successors with powerful money-for-value demands of their own. This situation is likely to generate antagonism and misunderstanding unless a generally shared understanding can be developed about the respective roles in disability support of the state and its various agents, on the one hand, and the numerous other individuals and groups, including Māori, making important contributions to disability support, on the other hand. Such a common understanding will not be easily reached. Movement towards it might well require national leadership, perhaps from the National Health Committee itself.

How should responsibilities be allocated within and across public, private and voluntary service provision boundaries?

The National Health Committee has developed a framework of questions for advising the Minister of Health on the kinds and relative priorities of

publicly funded health and disability support services. The questions are these:

Is it beneficial?

Is it value for money?

Is it fair?

Is it consistent with communities' values?[85]

This same framework is also well suited to addressing the appropriate balance of public and other responsibilities for the purchase and provision of disability support services. In what follows, we do these things:

(1) Comment in the disability context on each of the four questions;

(2) Argue a case for substantial public involvement in disability support;

(3) Discuss the appropriate extent of this public responsibility.

(1) Disability and the Four Questions.

Benefit. The question "Is it beneficial?" can be applied to a particular proposed balance of public and other responsibilities for disability support, just as it can be applied to a particular proposed health or disability support service. These issues concern not just the fact of benefit as opposed to harm, but also the amount of benefit. Evidence of benefit is in principle available about the balance of responsibilities, just as it is on issues of service provision. Evidence of benefit itself comes in various strengths. The ideal is strong evidence of large benefit.[86] The notions of benefit and harm themselves need to be well suited to the context of disability. The values and experiences of people with disabilities should be central to this. Generalisations in this area are hazardous, but given the long-term nature of many disabilities, long-term notions of quality of life seem likely to be particularly important in the disability support setting. Two of the crudest proxies for measures of long-term benefit are life expectancy and lifetime income.[87] A problem even for these proxies, and certainly for more subtle ones, is that it is difficult and expensive to collect information about how people are faring and might fare in the future in these terms.

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[85] Refer Footnote 2 for background on the origin of these questions.

[86] Where benefit is modest, strong evidence can to some extent offset this. Where evidence is modest, large benefit can to some extent offset this. For an excellent example of strong evidence of large benefit, see Richard Sainsbury et. al., *Guidelines for the Support and Management of People with Dementia*, National Health Committee, 1997. Among many other things, this excellent document presents strong evidence in the context of dementia that the support of carers brings substantial benefits.

[87] A sophisticated version of the income proxy is sketched by George Barker, "An Economic Analysis of Income Inequality, Health Outcomes and the Role of Social Policy", in Peter Crampton and Philippa Howden-Chapman (eds.) *Socioeconomic Inequalities and Health* (Wellington: Institute of Policy Studies, 1996).

Value for money. The question "Is it value for money?" can usefully be understood as an all-things-considered question, roughly as follows: "Given the considerations of benefit, fairness, and consistency with communities' values, is this proposal overall value for money?" This question explicitly brings issues of cost into play. It can be asked of many different kinds of proposals, including those involving services, or the appropriate balance of public and other responsibilities for disability support. It also invites examination of whether any alternative uses for that scarce and precious resource might be better value for money. Advocates in the disability support area, as in education, welfare, health, conservation, and so on, might feel uncomfortable with this sense that their proposals are competing for scarce public resources with other proposals to which other advocates are equally committed. For public policy advisors, however, who know that resources are scarce relative to all the good things could potentially be done, such comparisons seem unavoidable. Advocates of disability support nevertheless have some reason, at least in theory, to welcome this environment. Disability support funding and health funding have historically been allocated to a large extent from different parliamentary Votes. Of the two, health has historically had higher public profile and esteem, more secure public funding, and more professionalised advocacy and provider groups. In light of this, we might reasonably expect the historically generated anomalies between the two to favour health. In value for money comparisons, advocates for disability support might consequently fare rather well, in theory at least, as they seek to close these historical gaps.

Fairness. Fairness is a matter of decreasing inequality, of securing a minimum baseline for people, or of giving priority to those who are worst-off. The United Nation's *Standard Rules* offers an example of an equality goal; equal participation in the community. Concern about the poverty line and the people at or below it is a good example of a minimum baseline approach, as is the safety net approach to social policy.[88] Policies which give priority to the worst off do so even if those people cannot be brought above the minimum baseline, and even if they are already above it. This is not the place to attempt a rationale for one or more (a combination?) of these different approaches. Instead, we shall just make several brief observations of particular relevance to policy debates concerning disability.

First, many fairness arguments are essentially comparative. For example, the equality, baseline, and priority approaches all draw conclusions about fairness from specific comparisons between people. Consistency arguments are also comparative in this sense. They insist that it is unfair to treat people differently if their situations are relevantly similar, and unfair to treat them in the same way if their situations are relevantly different.

Second, there is an important difference between fairness arguments which appeal to people's current status, and those which appeal to people's lifetime

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[88] For an interesting example of the poverty line approach adapted to an Aotearoa/New Zealand setting, see Robert Stephens and Charles Waldegrave, "Measuring Poverty in New Zealand", in Peter Crampton and Philippa Howden-Chapman (eds.) *Socioeconomic Inequalities and Health* (Wellington: Institute of Policy Studies, 1996).

status.[89] For example, some people argue that fairness requires people to be treated equally if they have equal current need. Others argue, against this, that people have a past and a future as well as a present, and that fairness should be assessed in terms of people's lifetime need (or income, quality of life, community participation, or whatever). This debate over current status vs. lifetime status is particularly relevant to issues of disability support, for at least two reasons. One reason arises from the fact that most people with disabilities have their disability for much of their lives. Priority setting in health and disability support which ignores these facts about people's history will tend to give priority to those with the strongest current claim, but not necessarily the strongest lifetime claim. Because disability is often long-term, this form of allocation will tend to disadvantage people with disabilities, relative to people with *health* needs. Another reason that the current status vs. lifetime status issue is important to disability support arises from the fact that our population is ageing, and the fact that there are age-related disabilities. Even at present, 63 per cent of public spending from Vote Health on disability support is for services to people with recognised age-related disability.[90] From the point of view of current disability status, this weighting of priorities in the disability support area might well be about right. If priorities are based on lifetime disability status, however, then this priority weighting will be more difficult to justify.[91] Any shift from current status approaches to lifetime approaches would also face legal questions in terms of the age ground of discrimination under the *Human Rights Act 1993*. It is not entirely clear whether public priorities set on the basis of lifetime rather than current status would be determined to have "good reason" or "genuine justification", in terms of that Act.[92]

Consistency with communities' values. This is difficult. There are many and diverse communities. Many communities distinguish themselves precisely in terms of inconsistencies and other differences between their values and those of others. Perhaps the best we can look for here is allocations of public responsibilities consistent with each affected community's standards of what is tolerable, given their values. Of central importance in the disability support area will be the diverse disability communities themselves. Differing values

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[89] For an example of a dispute over lifetime versus current status considerations as applied to the relevance of income mobility to issues of poverty, see the paper by Barker referred to in Footnote 12, above, and the commentary on it by Susan St John in the same volume, especially at pp. 127–8. Neither author expresses the issue between them in quite this way.

[90] *Health Matters: An update from the Minister of Health*, March 1994. The figures concern the 1993–94 financial year.

[91] The provocatively named "Fair Innings Argument" is one argument that takes lifetime status rather than current status to be of central importance for public policy. For discussion of the argument, see Michael Lockwood, "Quality of life and resource allocation", and John Harris, "More and better justice", in S. Mendus and M. Bell (eds.) *Philosophy and Medical Welfare*. See also John Harris, *The Value of Life*, pp. 91ff; and Alan Williams, "Intergenerational equity: an exploration of the fair innings argument" [manuscript].

[92] For excellent discussion of these sorts of issues, see Ron Patterson and Paul Rishworth, *Priority Criteria and the Human Rights Act: An Interpretation*, National Health Committee, Consultation Document, Parts A and B.

within disabilities communities and across different communities involved with disability must be central. If these communities are particularly suspicious of the involvement of for-profit companies in disability support, to take but one example, then this will be an important factor in overall value for money judgements.

(2) A case for substantial public involvement in disability support.

The following are three linked arguments from fairness for the public as a whole to have a substantial role in disability support.

One consideration of fairness is the consistency argument that public policy should treat like cases in a like manner. In more down-to-earth terms, the idea is that it should treat people whose situation is relevantly similar in a relevantly similar way. With this simple principle in hand, we can compare the entitlements of those whose disability is a result of accident with those whose disability has some other source. As noted on page 34 of this document, s. 54 of the *ARCI Act 1993*, as amended, provides for an entitlement of up to $60 per week for those assessed as having 80 per cent disability. Those with a lower percentage disability attract a correspondingly lesser entitlement. These entitlements might not seem to be large. However that may be, they are well recognised as entitlements, rather than (say) as optional assistance or discretionary payments. Furthermore, even the well recognised *entitlements to* support for "non-accident" disability are often more modest than these ACC entitlements. It is not obvious that there are relevant differences capable of justifying these differences of entitlement. It cannot be that accidents are beyond people's control and responsibility, and that other causes of disability are individually controllable. In virtually all cases in which people suffer accidents, considerations of fault are excluded from consideration, for purposes of assessing ACC entitlement. There is powerful reason for like levels of disability to generate like public entitlement, regardless of whether or not the cause is an "accident" in terms of the ACC legislation. The conclusion of this argument is not that the ACC system should be massively expanded. It is simply that those whose disability situation is relevantly similar to that of people who do have ACC entitlements should have like entitlements, providing of course that the size of, and assessment criteria for, ACC entitlements are worth replicating. It is not an argument for any particular level of entitlement. Nor does it have any specific implications for the budget total to be allocated to this entitlement.

A further fairness argument appeals to the underlying principles of New Zealand's accident compensation framework. The influential report of the Woodhouse Commission lay behind the introduction of New Zealand's accident compensation framework in the 1970s. It proposed an insurance scheme to provide compensation for all personal injuries resulting from accident, regardless of fault or where the accident occurred. A core part of its underlying philosophy was the principle that a modern society which benefits from the productive work of its citizens should accept responsibility for those

prevented from working by physical incapacity.[93] It is now widely recognised that valuable productive work is done in the household and the community, as well as in the paid workforce.[94] It is also clear that in the environment of contemporary societies, capacities of communication, intellect, and so on, are at least as important as are physical capacities. In short, the philosophical basis of the Woodhouse Report is inherently generalisable to non-accident causes of disability. It might be objected that the philosophical basis set out in the Woodhouse Report has been overturned in subsequent reforms of New Zealand's ACC framework. But it is not clear that this is correct. It seems instead that concerns to do with fraud, cost-escalation, and so on, have been added to that underlying philosophy, or have assumed greater urgency within it. It might further be objected that the expanded entitlements argued for here are inconsistent with the funding base of the current accident compensation system, or are otherwise unaffordable within that framework. It is true that the argument here is for a substantial broadening of public involvement in disability support. Again, however, there is no commitment here to any particular budget total, or to any particular delivery framework, whether ACC or otherwise. Once again, the argument is primarily for consistency of support rather than for any particular level of support.

Another fairness argument for a substantial public role in disability support starts with the idea that we all share some responsibility to offset the effects of misfortune, in the sense of disadvantages over which the person concerned could not reasonably be expected to have had any control. As John Rawls puts it, "justice ... mitigates the effects of natural accident and social fortune."[95] For example, the fact that individual health status in a significant range of cases is a matter of good or ill fortune beyond our control does the work in many arguments for public funding of health services. Similarly for accident, and for the public role of ACC. A corresponding inference about public responsibility can also be made for disability and handicap, except that for disability, unlike accident, there is no opportunity for employers to benefit as they can do under ACC's rating scheme, for having implemented injury prevention strategies and having a low incidence of injury. Medical models of disability emphasise the role of people's "pathologies" and "impairments" in producing their handicaps. Social models emphasise the role of society's customs and institutions, and the role of factors such as prejudice and discrimination. Despite their differences and disagreements, these models and the various more subtle models which have been developed, are united in implying that handicap typically arises as a matter of "fortune". It arises

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[93]   Report of the Royal Commission of Inquiry, *Compensation for Personal Injury in New Zealand* (1976). See especially pp. 26, 40.

[94]   In the New Zealand setting, important work has been done on these issues. See, for example, M. Waring, *If Women Counted: A new feminist economics*, (San Francisco: Harper & Row, 1988), and *Counting for Nothing: what men value & what women are worth*, Australian edition, (Sydney: Allen and Unwin, 1990).

[95]   John Rawls, *A Theory of Justice* (Harvard University Press: 1971), p. 585. See also p. 102. Other influential discussions include W. Kymlicka, *Contemporary Political Philosophy* (Oxford: Oxford University Press, 1990), ch. 3, and especially p. 56; and R. Dworkin, "What is equality: Part 2", *Philosophy and Public Affairs* 1981, 283–345.

through no fault or responsibility of the person concerned. Ironically, personal responsibility is perhaps most common where *accident* is the cause of disability and handicap, and yet it is here that entitlement to disability support in New Zealand is most secure and extensive. To sum up: Disability and handicap generally arises beyond the control of the person concerned. There is consequently a strong fairness case for public responsibility to support people in (at the very least) mitigating the misfortunes of handicap.

(3) The appropriate extent of public responsibility for disability support.

Given that there are powerful fairness arguments for a substantial public responsibility for disability support, where ought the boundaries to be set between these public responsibilities and the responsibilities of others? This question probably has to be broken down into much smaller ones before it can helpfully be answered. We shall focus on the relation between public responsibilities and household responsibilities.

Many households, families, and whānau provide disability support to one or more of their members. They often face heavy financial costs, including opportunity costs, when they do so. Many people within these households also devote substantial portions of their lives to the support or care of their members with disability. Like all other unpaid household work, this does not appear in analyses of the public funding of disability support. As we saw in the Cooking Case above, funder and purchaser functions simply disappear if householders do the job entirely themselves. One possible reason why some households do much of the disability support job themselves is that they cannot afford to fund extra assistance. Since public funders of disability support should be particularly concerned about this group of people and their situation, their invisibility in the funding picture needs to be addressed.

We can anticipate assistance here from the *Census 1996* data, and especially from analysis of the answers to its questions about disability and the extent of household care for dependent members. More usefully still, Statistics New Zealand is currently conducting a national disability survey which uses the *Census 1996* questions on disability as starting points for its data sample. When full results of this survey are available in middle to late 1997, the picture for household provision of disability support should be much clearer than at present. These data should indicate the extent to which non-financial household support, hidden in the funding picture, affects the current balance of responsibilities for disability support between the public as a whole, and households and families of people with disabilities. Analysis of the data also offers the prospect of providing insights into just how extensive the demands of household disability support are. Similar studies in the future would enable policy makers to track changes in, and possible inter-dependencies between, these patterns and the patterns of publicly funded support services and entitlements.

It is a commonplace that RHAs are purchasers of disability support services. In some contexts, however, there is only one feasible service provider.

RHAs and their successors could be regarded as simply funders rather than purchasers in these settings. On the other hand, wherever there is the potential for alternative providers to enter, and wherever there are contracts for the purchase of specific services, there remains some good sense in talk of a "purchaser".

Perhaps of more importance to the disability support sector than this funder vs. purchaser debate is the fact that a lot of disability support arrangements take the form of subsidies, transfer or benefit payments, or unrequited grants, rather than contracts for the purchase of disability support goods or services. For example, some programmes progressively transferred to RHAs from other agencies in the first half of the 1990's were subsidy or grant or transfer arrangements, rather than purchase arrangements. In these cases public funds were transferred for disability support but no service contract was entered. RHAs have in nearly all cases "grandparented" these programmes with much the same form and funding levels as they had in their agencies of origin. With the transition to just one funding/purchasing authority, it seems likely that this pattern will to some extent be repeated. These disability support arrangements are often not intended to be funded at full cost, and because they also do not involve contracts for specific disability support services, public accountability for disability support actually delivered in these cases is relatively weak. In health services, on the other hand, there typically are specific contracts and public accountabilities for services, where the cost is at least intended to be fully funded by the purchaser. This suggests that we have imbedded in New Zealand's current health and disability support system a fundamental priority for health services over disability support. If this is true, and more argument is needed to check whether it is, then it is a very important fact, which should be made clear and explicit. Its appropriateness would then be much more fully open to debate.

RHAs are regional monopsonies; that is, dominant purchasers of disability support and health services in their regions.[96] The successor of RHAs seems likely to be a national monopsony also. Because of their powerful buying position, monopsonies are price setters, with a general tendency to drive down prices. In the disability support context, this raises various questions. For example, do RHAs meet the full cost of those disability support services they do actually purchase? Will their successors do so? These are hard questions, in part because full costs are hard to determine except in a fully functioning market. Even those who think the disability support sector is some sort of market would agree that it is not a perfect market. The question is nevertheless very important. If RHAs and their successors do not pay the full cost of the disability support services they contract for, then there seem to be two main possibilities. One is that others meet the cost shortfall on an ongoing basis; the other is that the services cease to be provided. In both cases, important costs and responsibilities shift onto others, and especially onto providers of disability support and people with disabilities themselves. There are important

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96   Monopsony buyers are parallel to monopoly sellers. For general discussion of monopsonies, see, for example, H.R. Varian, *An Intermediate Micro-economics*, (New York and London: Norton, 1990).

risks here of disability support providers exiting services altogether, new providers failing to develop,[97] and increasing burdens of underservicing, gaps in provision, and increasing demand for voluntary and unpaid provision to offset this. These risks arise particularly in areas of disability support without a history of high profile advocacy from voluntary organisations or professionals, and where support is inherently difficult to provide.

One response is that the problems noted in the previous paragraph obtain for health just as much as for disability support. For example, it can be argued that persistent CHE budget deficits and high CHE debt reflect the fact that RHAs have not been meeting the full cost of these health services either. Even if that is true, however, there remain very important differences between health and disability support. CHEs are publicly owned organisations. Their deficits and debts have high public visibility, and they are public responsibilities. To date, these responsibilities have been honoured by means of parliamentary Vote. Most disability support organisations, on the other hand, are not owned by the public as a whole. Their deficits and debts consequently do not have a high public profile, and the public as a whole does not have financial responsibility for them. Their burdens fall more narrowly, to a large extent on disability communities themselves. Furthermore, CHEs which wish to exit services for which they are perhaps not fully funded have clear lines of public accountability before they can do so. In disability support, by way of contrast, exit from services and the emergence of gaps in provision can happen with much less publicity and much less public accountability. If the reason for exit is that full costs of services are not being met, then the promise that alternative providers will enter to fill the gaps might well be simply empty. Once again, the consequences of this would fall heavily on disability communities themselves.

Finally, if RHAs and their successors are in some cases not full cost purchasers of services, then accountability issues arise. In particular, it is unclear whether in such contexts they can reasonably demand full accountability for service delivery to contracted volume, specification and quality. If organisations or individuals must meet a substantial part of their cost-of-services from their own resources, then it seems unfair and unreasonable to make them fully accountable to the RHAs or their successors for these self-funded parts of their activities.

There are important general questions about public, household, and other responsibilities for disability support. We have tried to address some of the main ones above. There are also a number of specific issues which arise at these boundaries, wherever they are drawn. Sometimes these issues arise simply as instances of the more general ones. In closing this part of our paper, we shall briefly discuss two of these more specific issues.

In some cases, public funds are used to pay outsiders to enter households for purposes of disability support. It is often thought, however, that there is something wrong with paying householders themselves to provide that same

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[97] From a Māori point of view, the risk of new Māori providers failing to develop is greater if there is a continued focus on individual entitlement to disability support.

support. One worry is that some might profit from the disabilities of other family members. Another worry is that such payments might inappropriately commodify or commercialise family relationships. But these concerns are themselves puzzling. Is it better that non-family profit instead? Is there not also a sense in which child-parent relationships are commodified or commercialised whenever child support payments are made? There are nevertheless difficult issues about incentives here. Would payments to household members for disability support services make it harder for them to increase their independence, and to reduce their need for disability support, if the consequence would be a drop in their family or household income? Similar issues arise about many entitlements, benefits, and transfer payments. In an ideal world they would be worked through case by case. Under a capped budget, the size and extent of entitlements, benefits and transfer payments must be worked through in a way which sorts cases in an acceptable way.

Finally, there is one further point to be made about the relation between public funding responsibilities and household or other non-public forms of disability support. This will lead naturally back to the issues we discussed above, concerning public responsibilities for the purchase of disability support. Health services purchased from provider organisations typically have an overhead or capital component built into their cost-of-services. Where disability support services are purchased from household, family, or whānau, that same component should be built in. This point is particularly important in contexts of de-institutionalisation. Where moves are made to more community oriented services, care needs to be taken to ensure that overhead costs and associated responsibilities are not simply shifted silently onto these communities.

Issues and questions which arise from this document

1. Should the National Health Committee further examine the suggestion, made on pages 13 and 16 of this document, that public responsibilities for health services in New Zealand seem to enjoy a fundamental priority over disability support services?

2. Should the National Health Committee pursue further work on issues of consistency and fairness more generally at the boundaries between ACC and non-ACC responsibility for disability support services?

3. Should the National Health Committee examine further the impact and merits of current status and whole lifetime approaches to priority setting in disability support?

4. Should the National Health Committee give further consideration to the merits and appropriate scope of the individual entitlement model for disability support?

5. Should the National Health Committee give consideration to sponsoring a further national process to move toward a common understanding among the relevant interest groups, including Māori, about where the appropriate boundaries are in terms of public responsibility for disability support?

6. How can the roles and responsibilities of Māori be recognised and expanded in the area of disability support?

7. How should the values and experiences of people with disability be included in assessing service benefit?

8. Should specific strategies be developed to minimise historical anomalies between the funding of health vs disability support services? Which anomalies are of most concern?

9. Should consideration be given to fair and acceptable ways of assessing payment for previously unpaid caregivers who support members of their own families?

10. What approach should a public funder take to the funding of disability support services? Priorities? Identification of gaps and margins? A mixture?

11. Should some or all disability support services be wholly funded through Vote:Health? If only some, which ones?

12. Should people with disabilities have to rely on charity for the full or partial funding of some of the disability support services on which they rely?
    Alternatively
    Are there some advantages for people with disabilities if their organisations are NOT reliant on public funding?

13. What level of public accountability can fairly be demanded of service providers whose service is only subsidised (i.e. partly funded) through public funding?

NATIONAL HEALTH COMMITTEE

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WHO SHOULD FUND SUPPORT SERVICES FOR PEOPLE WITH DISABILITIES?

The National Health Committee has today issued a discussion paper designed to inform and stimulate public debate about the roles and responsibilities involved in providing support services for people with disabilities. Questions discussed in the document include: What is the responsibility of government to fund support services and what is the responsibility of private organisations and voluntary services? Should it be only a public responsibility to support people with disabilities? If one service provider has a variety of sources of funding, which funder is entitled to ask the hard questions about the kinds of services provided? What about the difference between ACC funding and other public funding for support of different people with similar disabling circumstances? What are the implications of people with disabilities choosing their own support and making all their own decisions about how to spend the money allocated to them?

"It's a debate we need to be having," says National Health Committee member Anne Bray, "because - at 25% of Vote: Health - the amount of funding for disability support services is quite considerable, yet the way that level of funding has developed has been historical in that it is not necessarily based on transparent comparative decisions people have come to - it has just grown up over the years."

With over half of DSS funding being spent on elderly people now, it is inevitable there will be increased pressure on funding in future years, given that we know that the proportion of elderly people in the population is increasing, says Anne Bray. She points out that 19.2% of people living in households identified themselves as having a disability in last year's census. Add to that people living in rest homes and institutional care and the figure would pass 20%.

"So we're talking about a lot of people. But disability has always been seen as an invisible issue, something that only affects a few people, but it's not, it's actually a major issue. Everyone is touched by disability at some stage in their lives - and even if not themselves, then someone in their family," says Anne Bray.

In addition to the amount of public funding that goes to DSS, a lot comes from organisations in the community that fundraise to provide at least some, if not all, of their support. The paper puts forward different views about where the responsibility for funding should lie. For instance, some people with disabilities find it demeaning and depressing to have to get support from an organisation that has to fundraise - it has an image of charity - and they find some of the ways that fundraising is carried out

embarrassing. Some people with disabilities say they have a right to publicly funded support rather than relying on charity.

The paper discusses inequities in the access different people have to support depending on whether services are funded from ACC or Health. The level of service from ACC for people whose disability is the result of an accident is often a lot higher than the level of service from Health for people whose disability is the result of disease or illness.

"There is an issue of fairness there," says Andrew Moore, lecturer in philosophy at Otago University who co-authored the paper with Margaret Tennant, associate professor of history at Massey University.

How and whether the unfairness is addressed is a major question for government, says Anne Bray, "But it is an inequity that we need to at least acknowledge - bring out into the open and look at."

There are other inequities, including how services have been provided for Maori with disabilities. One of the key questions listed at the end of the document asks "How can the roles and responsibilities of Maori be recognised and expanded in the area of disability support?"

Some support services for some people come by way of Income Support entitlements that people get as of right. But with the transfer in the last five years of much of the money that used to be distributed through Social Welfare to Vote: Health, most of the services that used to be available on the basis of entitlement are now available from a capped budget. They are distributed on a priority basis not a rights basis.

"A capped budget poses problems around how we make decisions about different people's priority" says Anne Bray. "Another tricky funding issue at the moment is whether you are described as having a chronic illness or a disability. A critical pressure area within the capped DSS funding is around the availability of continuing care, so that if you are labelled as someone with a disability, you usually have some access to funding for continuing care, but if you are labelled as a person with a chronic illness, there may be problems in who provides that care. So there are interface issues as well and they are quite illogical some of the time," says Anne Bray.

She says many people are aware of these issues but what the paper says is: "Look, services and funding change like Topsy and we need to stop and look at some of the basic issues so that decisions about funding are transparent and so that people with disabilities and their families have more certainty about how the system works and what is likely to be provided from public funding. So it's really bringing DSS into the debate the National Health Committee has been promoting elsewhere in health: for decisions to be made transparently showing that there are fair reasons for them."

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