

## 12 MĀORI EXPERIENCE OF DISABILITY AND DISABILITY SUPPORT SERVICES

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The New Zealand Disability Strategy (Minister for Disability Issues 2001) distinguishes between disability and impairments. Individuals do not have disabilities. Rather, they may have physical, sensory, neurological, psychiatric, intellectual, or other impairments. According to the Strategy, “Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have” (Minister for Disability Issues 2001, p. 3).

Both Māori and non-Māori are impacted on by disability and much work is required to provide support for both groups. However, there are wide disparities between the Māori and non-Māori experience of impairments and disability, the impact on Māori being more severe. The consequences of disability extend beyond the individual to whānau (extended family), who have limited resources and capacity to provide necessary care and support. In this context, high quality disability support services for Māori are critical in minimising inequitable impacts on Māori individuals, whānau, and communities.

This chapter briefly outlines Māori understandings of disability and disability support, Māori impairment data issues, and the Māori impairment profile. Issues concerning disability support services for Māori are discussed, with reference to Te Roopu Taurima o Manukau Trust – a disability support service provider for adults with intellectual impairment. While prevention of impairments causing disability is acknowledged by the authors as a critical area that must be addressed, it is beyond the scope of this chapter.

### **Māori understandings of disability and disability support**

Until recently, concepts of disability have tended to emphasise physical, sensory, psychiatric/psychological, learning or intellectual impairments, and reduced functioning. This is consistent with an underlying concept of health that focuses on physical and mental dimensions of wellbeing and the value of independence. In contrast, Māori concepts of health are holistic in nature, locating individuals within the whānau context and, therefore, emphasising interdependence, recognising determinants of health (including cultural and spiritual determinants), incorporating a focus on continuity between the past and the present, and viewing good health as a balance between interacting variables (Ratima 2001).

Inherent to Māori concepts of health is concern for ensuring access to cultural resources, and the notion that a secure Māori cultural identity is central to good health (Durie 1998). Disabled Māori have expressed the value they place on their identity as

Māori (National Health Committee 2004), and Māori concepts of health are concerned with being healthy as Māori and therefore maintaining a secure Māori identity.

More recent concepts of disability, as expressed in *The New Zealand Disability Strategy*, are centred on the interaction between the individual with the impairment and the environment. Māori concepts of disability and disability support are likewise broad and will emphasise the creation of environments conducive to attainment of balance, spiritual and emotional wellbeing, maximum functioning, strengthening positive interdependence (whānau will be central), and maintaining and reinforcing a secure cultural identity.

## Data issues

Data quality issues continue to undermine disability support service planning, purchasing, development and delivery for Māori. There are definitional and data collection problems which include inconsistencies in definitions of ethnicity, variable collection methods, and a limited range of data being collected. Further, while conventional measures of impairment and functioning will continue to be useful there are other indicators that may be equally important in understanding Māori impairment and disability, such as outcome measures that capture positive functioning and culturally specific measures. Work has been carried out in areas such as mental health on the development of indicators that are meaningful for Māori (Durie et al 2002; Kingi and Durie 1998, 2000).

A framework for Māori disability information (Potaka et al 1994) recommended that Māori-specific data collection should include not only ethnic data but also cultural data such as hapū and iwi affiliation, access to Māori networks, whānau support, and other information related to those factors that strengthen Māori identity and may reflect positive functioning within Māori cultural contexts. Information about Māori understandings of disability and support service preferences could also be collected. This broader cultural data would inform the development of disability support services tailored to the specific needs of Māori.

## Impairment among Māori

Despite data limitations, it is possible to get some indication of the extent of impairment among Māori. The New Zealand 2001 Household Disability Survey and the Disability Survey of Residential Facilities provide the most comprehensive Māori impairment profile (Ministry of Health 2004).

According to the Household Disability Survey, 106,500 Māori living in households have an impairment (this equates to 21% of Māori). Māori experience higher rates of age-standardised impairment (24,000 per 100,000 or 24%) than non-Māori (16,700 per 100,000 or 16.7%). Māori age-standardised rates of both single and multiple impairment were higher than those of non-Māori (9,900 per 100,000 compared to 7,500 per 100,000, and 14,100 per 100,000 compared to 9,200 per 100,000 respectively). The most common cause of impairment for both Māori and non-Māori was disease/illness.

# Māori Experience of Disability and Disability Support Services

With the exception of learning impairment, Māori adults are over-represented in each major impairment category. The most common types of impairment experienced by Māori adults are mobility, hearing, and agility impairments. Māori also experience more severe impairment than non-Māori. Māori age-standardised rates of severe impairment (requiring daily assistance) were more than twice that of non-Māori (4,100 per 100,000 compared to 1,900 per 100,000). Further, approximately 13% of Māori males and 14% of Māori females living in households had an impairment leading to dependency, compared to 9% of non-Māori males and non-Māori females (Ministry of Health 2004).

Māori impairment prevalence increased with age, from 13% for those aged 15–24 years, to 22% for the 25–44 year age group, to 34% for those aged 45–64, and 61% for kaumātua aged 65 years and over. Ethnic disparities exist for each age group. For Māori children impairment requiring special education services was common. Of particular concern in this age group was the wide disparity between the rates of hearing (4,100 per 100,000 compared to 1,600 per 100,000) and speaking (3,100 per 100,000 compared to 1,700 per 100,000) impairment between Māori and non-Māori children, given that these impairments are strongly linked to learning, education, and employment opportunities (Ministry of Health 2002).

There are distinct issues of concern for older Māori. Māori experience an earlier onset of age-related disease and impairment. For example, Māori women aged 45 years and over have a significantly higher rate of impairment caused by disease/illness than non-Māori, similar to the profile expected for the non-Māori 65 and over age group (Ministry of Health 2004). As well, Māori have a shorter life expectancy than non-Māori and therefore fewer Māori survive to old age (Ajwani et al 2003). The implication is that disability support service funding criteria based on age (e.g., eligibility restricted to those aged 65 years and over) discriminate against Māori and advantage non-Māori due to their longer life expectancy. Criteria that make good sense when funding services for non-Māori are not necessarily transferable to Māori if equity is a central goal. Further, older Māori report poor access to disability support services, and cost as a barrier to access to medical services (Durie et al 1996).

Inequalities in the socioeconomic status of Māori and non-Māori are implicated as a major contributor to ethnic impairment disparities and, as well, disabled Māori experience more severe socioeconomic living conditions than non-Māori. In 2001, disabled Māori living in households were approximately two and a half times more likely (43% compared to 17%) to live in the areas of greatest deprivation (NZDep2001 deciles 9–10) than disabled non-Māori (Ministry of Health 2004). Therefore, disabled Māori live in households that are among the most marginalised and have fewer financial resources. The implication here is that where the burden of providing necessary care and support to disabled Māori falls on whānau, the capacity of whānau to fulfil this role is compromised.

There are indications that, based on need, Māori receive lower levels of income support and health and disability services (Robson 2003). Māori children in beneficiary households are less likely to receive the Disability Allowance (a means tested

allowance for those with an impairment or chronic illness of at least six months duration) than non-Māori children in beneficiary households (3.2% compared to 7.4%). Further, the average dollar value received by Māori children is less than that of non-Māori (\$11.05 per week compared to \$15.46 per week) (Hackwell and Howell 2002). There are also indications that there are disparities in access to the Disability Allowance for Māori adults (Hackwell and Howell 2002). Further, Māori have expressed concern that policy that provides lower rates of remuneration for caregivers who are whānau is inequitable given a Māori preference for whānau care (Macdonald et al 2002).

Disabled Māori living in households have indicated higher levels of unmet need for health services (23% compared to 14% for non-Māori) and transport costs (17% compared to 7%). Māori reported less usage of disability-related equipment (23% used equipment compared to 31% of non-Māori), despite more severe Māori disability. Māori also indicated a greater unmet need for special equipment (15% compared to 11% for non-Māori) (Ministry of Health 2004). This is consistent with Māori concerns that there are insufficient assessment, treatment, and rehabilitation services to meet Māori needs (Macdonald et al 2002).

There are both quantitative and qualitative differences between the Māori and non-Māori experience of impairment and disability that reflect wide inequalities. Māori experience higher rates of single and multiple impairment in all age groups and more severe impairment at younger ages and overall. Further, disabled Māori are more deprived socioeconomically and have higher unmet needs for disability support services and special equipment. Despite compelling evidence of wide inequalities, there has not yet been a comprehensive effort to identify distinctive Māori disability support needs nationally and to action a strategy to address those needs in a co-ordinated way.

## **The evolution of disability support services for Māori**

Historically, disability support services have not only been unresponsive to Māori – they have been destructive. Services consistently dismissed Māori cultural preferences. Some of the most striking examples relate to the impact of institutionalisation on Māori with intellectual disabilities and their whānau (National Health Committee 2004). One Māori woman related her experience of being taken, as a child, from her ailing koro (grandfather) upon the death of her kuia (grandmother). She had always lived with them, and in those days children with an intellectual disability did not go to school, so she had spent her days with her kuia whom she described as the centre of her life. The staff in the institution she was placed in spoke no Māori and she spoke no English. Staff promptly renamed her an English name for their convenience. Over the years she was moved from one institution to another and her original notes and files were lost. No-one remembers who she really is. She has lost her identity, and efforts to try and locate family have failed. She has also lost the ability to speak Māori.<sup>1</sup>

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<sup>1</sup> Personal communication to authors.

# Māori Experience of Disability and Disability Support Services

The 1980s signalled a change in policy, and a move to deinstitutionalisation. At a philosophical level the change was embraced as a mechanism to enable disabled people to more fully participate in New Zealand society. The implementation, however, was strongly criticised for inadequate planning and resourcing to facilitate a reasonable and supported transition to the community, particularly for those who had been institutionalised for many years.

Changes in the philosophy and configuration of disability support services generally coincided with the increasing prominence of the concept of Māori development. The Māori development ideology fostered the emergence of a range of Māori-specific health providers across health issues. However, the area of disability support competed alongside the range of other priorities and lacked the strength of advocacy of other areas such as child health and mental health. Relative to other health areas, it seems that Māori development had lesser impact. For example, despite a Government policy focus on Māori provider development in the last four years few Māori disability support services have emerged.

Generally disability support services were characterised by a lack of specific attention to Māori needs and there are indications that disabled Māori may not have had the same access to Māori development initiatives as other Māori. However, increasing emphasis and recognition of the value of Māori development approaches within the health sector provides a positive context for a strengthened focus on Māori disability support.

## **Addressing Māori disability support needs**

The starting point for identifying Māori disability support needs is recognition that, while Māori and non-Māori will have some disability support needs in common relating to the actual impairment, for Māori there are other distinctive needs. The needs-based case for distinctive strategies is clear in light of the wide inequalities between Māori and non-Māori in the disability sector that have not been addressed by homogenous approaches. Key points of difference in addressing Māori needs will relate to the disadvantaged position of Māori within New Zealand society and cultural requirements.

That Māori do not equitably enjoy the benefits of New Zealand society is well documented (Te Puni Kōkiri 2000a, 2000b). The socioeconomic marginalisation of Māori is strongly implicated as one of the causative factors in the disparities between Māori and non-Māori impairment profiles (Ministry of Health 2004). As well, there are indications that wider societal factors, such as discrimination (Robson 2003), and disability support service inadequacies, contribute to inequalities (Cunningham 2000; Ministry of Health 2004). The Ministry of Health's Intervention Framework to Improve Health and Reduce Inequalities (Ministry of Health 2002) provides a sensible structure to guide action to address, at a variety of levels, the range of factors (such as structural factors and disability support service factors) that largely determine the inequitable Māori experience of disability.

Using Māori concepts of health as a foundation for assessing Māori disability support needs enables the identification of a clear goal for disability support services for Māori – that is, for Māori to have maximum functioning and wellness as Māori. Disabled Māori and their whānau are a diverse group. However, all need to have access to a disability support needs assessment process and support services that address Māori cultural preferences and thereby enable individual choice. This approach would support the ongoing development and strengthening of Māori-specific assessment processes and disability support services, and of culturally safe mainstream disability support services that do not require clients to compromise their values and preferences as Māori. It is important to bear in mind that most disabled Māori and their whānau will access their support through mainstream services. Mainstream services receive the vast majority of disability support service funding and are required to meet the needs of both Māori and non-Māori. Therefore, if disability support services are to equitably meet the needs of Māori, mainstream services in particular will need to be enhanced. Close working relationships between Māori and mainstream providers, strengthened Māori advisory functions, and close monitoring and accountability for responsiveness to Māori would contribute to meeting this aim.

There is a very limited evidence-base to inform the development of disability support services that are responsive to Māori. *He Anga Whakamana, a framework for the delivery of disability support services to Māori* (Ratima et al 1995) was developed in 1995 based largely on interviews with disabled Māori. The framework recommended an approach to the delivery of disability support services for Māori that remains relevant. Key features of the approach are that services need to be based on Māori concepts of health (therefore service goals and measures would be reflective of Māori notions of health), reflect client, caregiver, and whānau participation and preferences, and be linked to wider Māori development initiatives (and therefore have relationships with Māori institutions). It was recommended that enhanced function and client participation in the community should be primary drivers of disability support services for Māori, and that services need to meet high professional and cultural standards. In order to meet these standards, a technically and culturally competent workforce would be necessary. This will be particularly important for carrying out assessments, and disabled Māori have indicated a preference for Māori specific needs assessment criteria and cultural expertise and input as part of a team approach to assessment (Ratima et al 1995).

Improving disability support services' responsiveness to Māori will be important, but must be contextualised within efforts to address broader socioeconomic determinants of Māori health.

### **Māori specific service provision – Te Roopu Taurima o Manukau Trust**

Te Roopu Taurima o Manukau (TRTM) is a kaupapa Māori support service for adults with an intellectual impairment and their whānau. TRTM's vision is "to develop Māori services that will provide and manage services encompassing tikanga Māori (Māori custom and process) and that will determine positive outcomes for Māori people with

# Māori Experience of Disability and Disability Support Services

disabilities and their families demonstrating self-determination for all Māori people” (Christensen 1997, p. 57). The vision identifies Māori values as underpinning service activities (and therefore a Māori concept of health is embraced). It makes explicit the central role of whānau, and through reference to self-determination locates the service within a Māori development framework.

Korowai Aroha Whānau, one of the service teams, is comprised of kaumātua (elders) who have Māori cultural expertise and provide support to all clients, their whānau, and other staff, particularly in relation to the Māori language, Māori process and custom, and other Māori cultural issues. Korowai Aroha has been described as the ‘backbone’ of the service.

Distinctive qualities of the service are the recognition that cultural identity, including participation in whānau and wider Māori communities, is central to enhanced functioning for Māori with intellectual impairment. One of the implications for the service is that work to strengthen cultural identity and reinstating or maintaining contact between clients and their whānau, hapū, and iwi is prioritised. As an example, the Korowai Aroha Team oversees the reconnection process whereby links between clients and their whānau may be reinitiated and/or strengthened. It is a complex process that requires acknowledgement of the difficulties of tracing families and the diverse realities of those whānau, including dysfunctional whānau. Links to Māori institutions, extensive Māori community networks, and the ability to work within Māori contexts are prerequisites to facilitating reconnection.

Some whānau are shocked to learn of a disconnected whānau member with an intellectual impairment. TRTM report that it is not unusual that surviving members of the whānau lack any memory of an older sibling or whānau member who was taken from the family at a young age. In some cases, the hurt suffered from the removal of their family member has meant that families never spoke about them again. For other whānau there has been an awareness that someone from the whānau had been taken away (Tui Tenari, Chief Executive Officer of Te Roopu Taurima o Manukau Trust, Personal communication, 2002). Like the client, whānau too require support to best ensure a positive reconnection process and outcome.

The range of culturally specific service components provided by TRTM is broad. They include group activities such as gathering of traditional foods (e.g., pūhā, pipi, cockles) and other resources (e.g., flax for weaving), Māori arts and crafts, kapa haka (Māori performing arts), and Māori language learning. Clients are supported to participate in whānau and Māori community events such as tangihanga (bereavement ceremonies), hura kōhatu (a ceremony to unveil a headstone, often 12 months after a burial), and hui (Māori gatherings). Individual clients and whānau also have access to traditional healing services and more general cultural support (National Health Committee 2004).

There are real costs in providing these services that are additional to ‘standard’ disability support services. TRTM estimated that 45% of the costs of the cultural services that they provide are not funded. Effective disability support services for Māori will rely upon adequate types and levels of resources – that is, access to cultural resources such as the expertise of kaumātua and funding levels that realistically reflect

the additional costs of delivering culturally responsive disability support services for Māori.

## Conclusion

For years Māori have been calling for standardised ethnicity data collection. However, this remains an area requiring further work in the disability sector. Accurate ethnicity data is necessary for planning Māori disability services, and therefore improvements in ethnic data collection are urgently required.

With the data that is available it is obvious that the Māori experience of disability is characterised by both quantitative and qualitative inequalities relative to non-Māori. If equity is to be a central goal, action will be required at both the structural level to reduce socioeconomic inequalities that cause and replicate disparities, and in the disability sector to ensure quality Māori-specific and mainstream disability support services that meet high professional and cultural standards. These services will acknowledge that disabled Māori have needs related to impairment and to being Māori, and should aim to facilitate maximum functioning and wellness as Māori. Among other things, this will require greater attention to culturally appropriate needs-assessment and service co-ordination, areas that have long been neglected for Māori. Levels of service funding should reflect the additional resources required to meet cultural needs. More generally, an intensive effort is required to ensure all disabled Māori receive their entitlements to disability support services and related income support.

While increasing the numbers and capacity of Māori-specific providers will be very important, at least of equal significance will be the strengthening of mainstream providers to meet their responsibilities to provide services that are accessible and deliver equitable benefits to Māori. This will require partnerships between Māori and mainstream services, increased Māori participation in a decision-making capacity, and continual strengthening of the Māori disability workforce.

Attention will also need to be given to the varied needs of different age groups, and the implications of the Māori impairment profile and changing population patterns. The disproportionate impact of hearing and speaking disabilities on young Māori leads to educational and employment disadvantage that limits the potential contribution of Māori to society. For older Māori, with increasing numbers reaching old age and disproportionately experiencing disability, it will become even more important that disability support services are geared to meet their needs. For example, residential facilities that are accessible and positive environments for older Māori and their whānau will be required.

There is huge potential to make positive change in the Māori disability sector. Immediate steps can be taken to enable the collection of accurate ethnicity data, to provide a clear picture of the state of Māori impairment and disability that is required to conduct strategic planning around the needs of Māori. Strengthening the Māori disability workforce, funding of research focussed on disabled Māori and their whānau, including the development of appropriate needs assessment and service

# Māori Experience of Disability and Disability Support Services

co-ordination tools, and factoring into funding formulas the additional costs of culturally responsive disability support services, are all necessary precursors to a responsive disability sector. There is much to be learnt from the ways in which Māori development approaches have been implemented in other health areas and in other sectors.

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