TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

ccs
disability action
Including all people

Submission to the
Productivity Commission
on
more effective social services

2 December 2014

Contents

Introduction

Economist and political philosopher Amartya Sen believes that when looking at complex problems there is often a range of convincing solutions. Sen believes policy should focus on practical ways to improve the world as it is, rather than trying to create perfectly just, and unobtainable, societies (Sen, 2010, pp. 45-60).

There is unlikely to be one perfect way to deliver social services. There may well be ways that are better than others, however, and there is always plenty of room for improvement. Disabled people often rely on social services and their lives can be heavily impacted by inflexible and inefficient services. Social services need to manage risk in a way that allows people choice and autonomy.
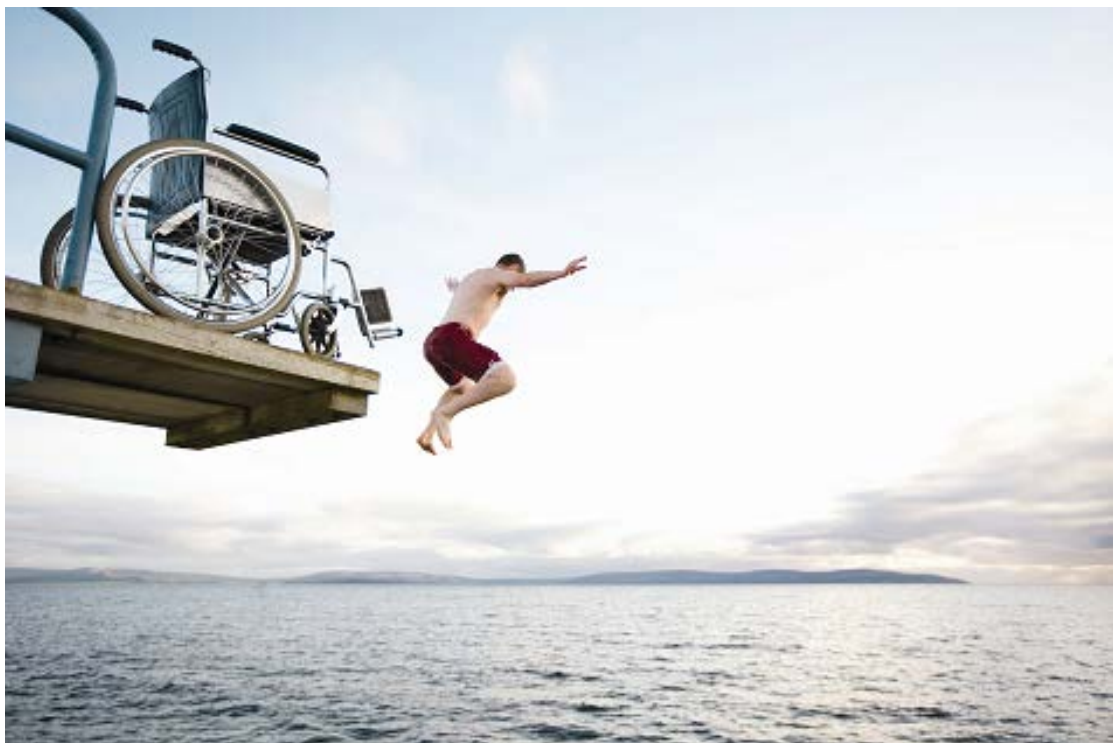
Our vision

Every person with a disability is included in the life of their community and whānau.

About us

CCS Disability Action is a not-for-profit organisation that has been advocating for disabled people to be included in the community since 1935. We provide disability support to over 5,000 people with disabilities and their families and whanau each year. We receive a mixture of government funding and private donations.

We run the Mobility Parking scheme which supports over 115,000 people to more easily access their local towns and facilities.

Our fully owned subsidiary, Lifetime Design Ltd, advocates for and provides universal design guidelines to improve the accessibility of New Zealand housing, which will benefit all people throughout their life. Lifetime Design Ltd is run as a social enterprise.

Our governance has strong disabled leadership.

Our advocacy is evidence-informed, honest and responsible.

What unites and drives our organisation are common values. We believe that the community should value and include disabled people.

Changes in disability services

Disability services have undergone radical shifts in direction in recent decades. The old state paternalism of large scale institutions has moved to a focus on individual choice and community living. This change has mirrored different approaches to disability and impairment.

There has been a growing focus on equal opportunities and rights for disabled people as well as encouraging and embracing leadership by people with disabilities. The Convention on the Rights of Persons with Disabilities, the New Zealand Disability Strategy and the disability action plans are evidence of this new direction (Convention on the Rights of Persons with Disabilities) (New Zealand Government , 2001) (Office for Disability Issues, 2014).

The New Zealand Disability Strategy uses a Social Model of Disability. This model emphasises that disability is primarily the result of environmental and social barriers people with impairments face because society is built in a way that does not take into account their needs (New Zealand Government , 2001, p. 1).

There has also been a range of service reforms, under the New Model for Disability Supports and Enabling Good Lives. There has been progress and initiatives like Choice in Community Living are giving people more options and control over their lives (Ministry of Health, 2013).There are still on-going issues, however, with the services available and how they are delivered (Social Services Committee Forty-eighth Parliament, 2008) (Grammer, Russell, & Van Eden, 2013).

Barriers to more effective services

While progress is being made, there are barriers to more effective disability services that deliver the outcomes that disabled people want.

Government teams responsible for disability policy and service delivery are split between large departments and are funded by different budget votes. These teams often have low overall priority within their department (Social Services Committee Forty-eighth Parliament, 2008, p. 13). Managing reforms alongside day to day work has been difficult for the Ministry of Health. The extra workload has created a risk adverse culture (Grammer, Russell, & Van Eden, 2013).

There are also no key performance indicators, or targets, for Ministry of Health or Ministry of Social Development disability services, despite the Ministry spending over one billion dollars a year on services (Grammer, Russell, & Van Eden, 2013, p. 9). There has been a lack of robust evaluation and critical analysis of reforms.

There has been little attempt to objectively compare the effectiveness or efficiency of piloted services to existing services, which provide a similar role. System wide reform needs to be based on reliable data, including data that measures actual impacts by comparing pilots with existing services (Haynes, Service, Goldacre, & Torgerson, 2012, pp. 8-9).

Government and provider control

Disabled people have often been subjected to significant degrees of government control, either directly or through contracted providers. The most serious example of government control was the former psychiatric hospitals. Significant numbers of disabled people lived in these institutions,

These institutions represented a significant departure from what society considered to be an ordinary, or desirable, life. Institutions, by their very nature, were dehumanising and excessively limited people's autonomy. People in these institutions were limited in their engagement with the wider community (Webb, 2004) (People First New Zealand, 2010).

Issues around provider and government control remain, especially as a significant number of people remain in government funded residential care. There is often little choice of provider and disabled people can be afraid to speak out about concerns because of possible consequences (Grammer, Russell, & Van Eden, 2013, p. 10).

Even if someone needs support, the government and providers, should always aim to maximise a person's choices and ability to take risks. Over time, the aim should be to develop a person's capability to be autonomous and make choices to the fullest extent possible.

The impact of inflexible and inefficient services

The Issues Paper notes that the government can often be risk adverse and have strict accountability requirements (New Zealand Productivity Commission, 2014, pp. 3, 14). This can have significant effects on the flexibility of services.

Some disabled people rely heavily on the availability and flexibility of support services in order to live independent lives and participate in society. This means that the government and providers have a large impact on, and therefore control over, their lives

Inflexible and inefficient disability services can severely limit choices and possibilities for disabled people. They can reduce, or eliminate, their opportunities to participate in employment and social life. Disabled people report that one of the biggest barriers they face is a lack of time. Sometimes this is because they have to fit their lives around the availability of services (Wilkinson-Meyersa, et al., 2014, p. 1547).

Person directed budgets

Person directed budgets give people more choice, control and responsibility over their supports. Both Individualised Funding and Enhanced Individualised Funding are forms of person directed budgets (Ministry of Health). Both have proven effective at letting people take more control of their life. There is a strong case for expanding the range of services that can be incorporated in person directed budgets.

Person directed budgets are not silver bullets, however, and are not for everyone. Research from the United Kingdom suggests that person directed budgets still rely on adequate funding levels to be effective and may not be able to deliver better outcomes for less money as has been previously asserted (Slasberg, Beresford, & Schofield, 2012, p. 1033).

Other research from the United Kingdom suggests that sometimes people find it difficult to self-manage budgets. In times of emotion distress, people can find it particularly difficult to make choices (Baxter & Glendinning, 2013, pp. 447-449). There will continue to be a need for non-government organisations that people can turn to for advice and support.

There is also a potential issue between moves to person directed budgets and the dependency of outcomes for a person on wider social change. Approaches focused on individuals may be ineffective at creating wider change. (Sherlaw, Lucas, Jourdain, & Monaghan, 2014, p. 449). This is also a potential issue with individual outcomes in performance for pay contracts.

Person directed budgets are a positive direction for social services. They need to be seen alongside other initiatives, however.

A different model of commissioning services

Because of the large impact of services on disabled people's lives, it is widely recognised that disabled people should have a large say in how services are developed and delivered. While the government is increasingly working with disabled person organisations, and disabled people, at a strategic level, it is not, generally, consulting them at the funding and commissioning level. Disabled people have no real say over which providers win contracts and are funded by the government.

Western Australia uses a Disability Commission model for funding services as well as disability policy. The Disability Commission is a crown entity governed by a board. The board has nine members appointed by the Minister. There are criteria in the governing legislation that ensure that disabled people, carers and rural areas are represented on the board. (Western Australia, 2014).

There may be merit in investigating crown entities, with a representative governing board, as a way to develop disability policy and commission disability services. This could be done at a local level, similar to district health boards. A representative governing board may ensure better community involvement and commitment to disability services. It may also relieve some of the workload pressure from government departments, which have in the case of the Ministry of Health contributed to performance issues (Grammer, Russell, & Van Eden, 2013, pp. 4-5).

A disability commission model would also fit with the vision of the 2008 Social Services Select Committee inquiry into disability support services (Social Services Committee Forty-eighth Parliament, 2008, p. 23).

It would be important, however, to adapt the model to a New Zealand context and test its implications. No international model or policy should be introduced to New Zealand without significant change to reflect our unique context, including a Te Ao Māori Perspective.

Disabled people with high and complex needs

Disabled people with high and complex needs are acutely affected by social services. They often have little or no choice about living arrangements and can be cut off from the community. Partly, this is due to inflexible support services that rely on set schedules. This leaves little chance for spontaneous activities or meeting strangers. Isolation is a major issue for many people with high and complex needs. The social, economic and quality of life consequences of this isolation can be severe (Milner & Mirfin-Veitch, 2012, pp. ix-xi, 22-26, 54-62).

People with high and complex needs often rely on families members for direct support. The Ministry of Health estimated in 2012 that 29,000 eligible people with high and complex needs did not currently access government funded disability services and were assumed to be cared for by family members. This is compared to around 30,350 disabled people who do receive government support (Ministry of Health, 2012, pp. 4, 39). People often do not access government funded supports because they are seen to be low quality with very limited, and undesirable, choices available. (Milner & Mirfin-Veitch, 2012, p. vi).

According to these Ministry estimates, around 49 per cent of people with high and complex needs and their family/whānau do not access government support, despite being eligible and having significant needs. The effect of this low uptake on productivity has never been properly examined. It is likely that it creates significant opportunity costs for family members and the wider economy.

The future

As the Issues Paper notes, our population is aging. This will increase the number of disabled people (Ministry of Social Development, 2014, p. 38). The over 65 age group is projected to make up over 20% of New Zealand's population from late 2031, compared with 13% in 2011 (Statistics New Zealand, 2012). In the 2013 Disability Survey people over 65 had a disability rate of 59%, compared to 21% of people aged 15 to 64 (Statistics New Zealand, 2014, p. 3).
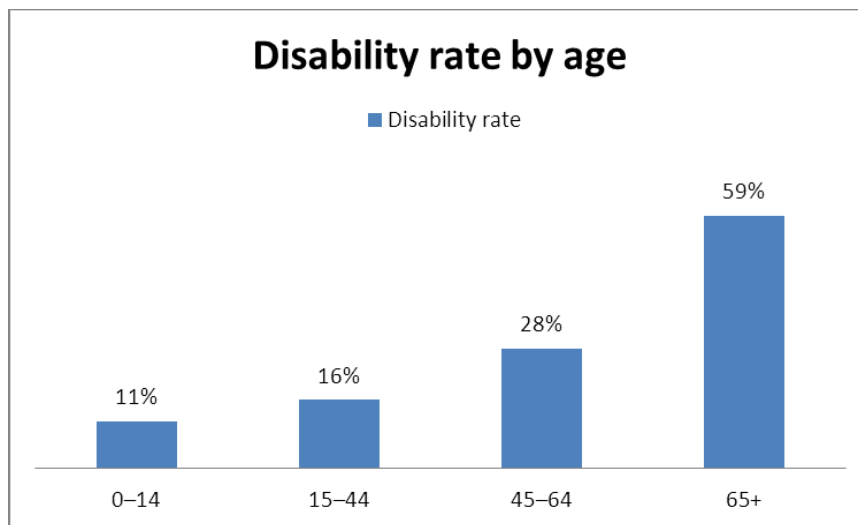
2013 Disability Survey

The effects of the aging population will impact more on provincial and rural New Zealand (Bascand, 2012, pp. 15-16).
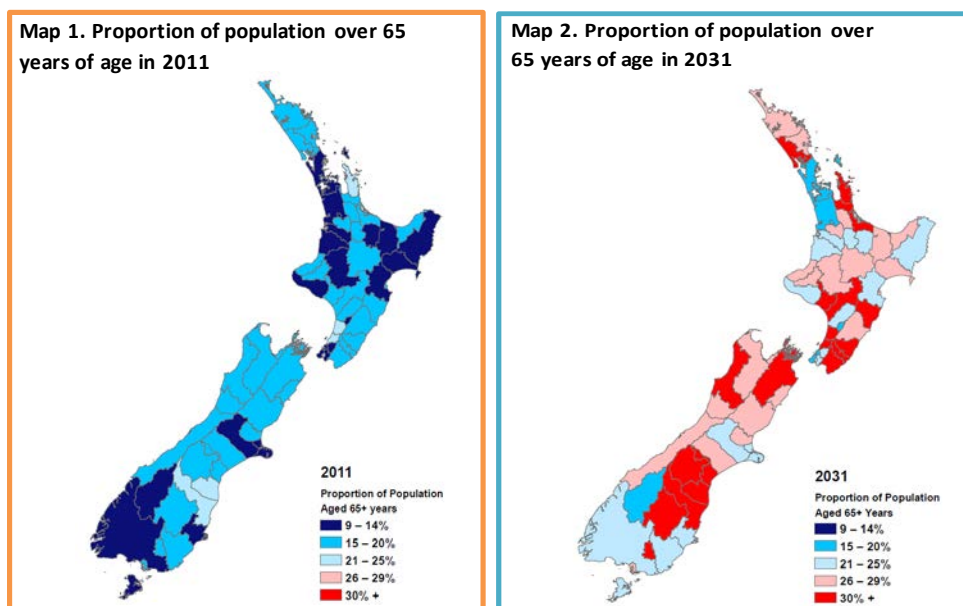
The increasing number of disabled people will affect demand for both disability specific and wider social services. There will need to be a greater focus on ensuring the built environment and public attitudes are welcoming to disabled people. The issues people with disabilities face are not primarily individual issues, but are environmental and social issues (Sherlaw, Lucas, Jourdain, & Monaghan, 2014, p. 449).

Preventing people from needing expensive specialist services, such as residential care, will be vital to ensuring the sustainability of disability and aged care services. In the long-run segregated specialist services are likely to be inefficient compared to preventative and investment approaches. The government will need to invest in disabled people and communities to ensure disabled people are included in society. This will, hopefully, reduce demand for segregated services

The government will need to develop a better understanding of the links between different factors and outcomes for disabled people to enable fair and efficient investment in services. This will require better linking of data and a commitment from government, disabled people, communities and non-government organisations to share responsibility for outcomes.

For example, a lack of accessible housing can cause people to go into residential facilities, especially as people's needs change over time (Saville-Smith & Saville, 2012, pp. 22-24). This creates high costs for the government. There may be ways for the government to invest in more accessible housing and reduce the number of people going into residential facilities.

Conclusion

Thank you for taking the time to read our submission. Social services play a major role in the lives of many disabled people. For disabled people to get a fair go, with the same opportunities as non-disabled people, they need flexible and responsive social services. With an aging population and a rise in number of people with disabilities, the demand for flexible services that allow people to live good lives will only grow.

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