Submission on the Health and Disability System Review

Literature Review

08 May 2019
Dr Carey-Ann Morrison

Introduction

The New Zealand Health and Disability system is under review. The current system does not deliver equitable health and wellbeing outcomes to all New Zealanders. Disabled people, their families and whānau are particularly disadvantaged.

A focus on systems alone will not improve the health and wellbeing outcomes of disabled people, families and whānau. The underlying drivers of poor health and wellbeing need direct attention.

Disabled people experience disadvantage across a range of areas:
- Relationships and social inclusion
- Education
- Employment and income
- Healthcare
- Transport
- Housing

A focus on these issues will help disabled people experience less poverty, better living standards and equitable inclusion in education, employment, relationships and community. Each of these issues is explored in more detail below.

About us

Imagine Better is a collective of disability activists, advocates and allies working to be a nationally influential thought leader, trainer, research and advocacy organisation supporting the growth and effectiveness of the disability rights, visibility and justice movements. Imagine Better is also a partner in the Family & Whānau Leadership Alliance.

Relationships and social inclusion

There is a large international literature on the importance of positive and meaningful relationships for disabled people. This research continues to show that a significant number of disabled people experience limited social relationships and, by comparison to non-disabled people, have fewer friends.

The negative impact for people with disability of not having friends is well-documented. Amado (1993) shows that for adults with disability, a lack of friendships and loneliness can lead to poor physical and mental health and wellbeing. In the New Zealand context, Milner and Kelly (2009) similarly show people with learning disabilities felt they had few friends and were excluded from the networks of relationships that make up the community. These findings are supported by Statistic New Zealand (2014) who found that disabled adults were more likely than non-disabled adults (38 percent compared with 29 percent of non-disabled) to say they had felt lonely in the previous four weeks. In addition to having a negative impact on quality of life, research has shown that loneliness and isolation also increases the vulnerability to abuse for disabled people (Strully and Strully 1992).

Disabled children similarly have fewer friends than their non-disabled peers and experience feelings of loneliness (MacArthur and Morton 1999). Brown et al., (2003) show that disabled youth report feeling powerless and alienated more often than non-disabled peers, while Hogan et al., (2000) found that disabled students described feeling a sense of belonging, safety and acceptance only half as often as their non-disabled peers. Indeed, disabled children with disability are among the most stigmatised children in the world (UNICEF 2005). It is well-documented that experiencing stigma reduces a person's life chances in terms of employment, income, longevity and social connection (Green et al., 2005; Cooney et al., 2006).

Disabled people also face discrimination and barriers in their intimate relationships and sexual lives. Disabled people are commonly associated with discourses of asexuality, sexual deviance, and /or victimisation. These narrow ideas about disability and sexuality act as a barrier to disabled people receiving appropriate sexual and reproductive education and health services (Anderson and Kitchen 2000) and they limit disabled people's right to sexuality, sexual expression and intimate fulfilment.

Like non-disabled people, however, disabled people experience feelings of desire and love, seek sexual fulfillment, and many hope to sustain long-term sexual relationships and start/care for families. Like non-disabled people they can also be the victims of sexual abuse (Fegan et al., 1993; Watson-Armstrong et al., 1994; Nosek 1995).

Physical and social barriers prevent disabled people from accessing spaces – university, work, pubs – where most people meet potential partners, limiting their ability to form intimate relationships. For people with learning disability, a significant barrier to the rights for sexuality are the attitudes of people who live with, and support, them (Abbot 2003). Unhelpful assumptions about disability and sexuality in general may start early and underpin approaches to planning sex education in schools for disabled children (Blyth and Carson 2007). Support staff may also lack the skills or knowledge to support people (Evans et al. 2009).

Discourses around disability and sexual rights is, by comparison to other areas of disability rights claims less well developed (Shakespeare 2000). Relationships, sexuality, and intimacy have received less attention than issues to do with employment, education and transport, but are by no means less important. It is crucial to include discussions around intimate relationships and sexuality in debates about disabled people's health and wellbeing.

Education

Disabled children, youth and adult learners do not have equal opportunities to learn and develop in their local, regular educational centres (Kearney 2016). Disabled children are treated differently to non-disabled children in relation to enrolment, curriculum and participation in school life. Families report being discouraged from sending their children to local schools, especially if they do not qualify for government support (Wills & Rosenbaum 2013). Exclusion, isolation and bullying remain significant issues for disabled children and youth. Education-related complaints continue to make up a large proportion of disability complaints to the Human Rights Commission (Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities 2014).

Evidence shows that forty three percent of disabled young people are not in education, employment or training. This is four times more than non-disabled young people (Statistics New Zealand 2014). Many disabled students are under-achieving in their education, with disabled people only half as likely to attend further or higher education as non-disabled people and are twice as likely to leave school with no formal qualifications. For those disabled students who do move on to tertiary education, they face substantial barriers and challenges, including inaccessible physical learning environments, limited specialist learning support, as well as academic staff with little training in working with disabled students (Osborne 2018). The educational profile of disabled people is reflected in their over-representation in lower-skilled occupations.

Article 7 of the Convention on the Rights of Persons with Disabilities requires the government to assist disabled children to have their voice heard on matters affecting them. However, perspectives of disabled children and youth are often not considered in relation to the development of policies and processes that affect their lives (Cavet and Sloper 2004). Too often debates about education are dominated by 'experts', families and advocates. This invisibility means the rights and interests of disabled children and their caregivers are often overlooked.

Employment and income

Disabled people, their families and whānau are poorer than non-disabled New Zealanders. This economic disadvantage is compounded by the personal financial cost of disability (Mitra et al., 2017). Findings from the 2013 New Zealand Disability Survey reveal sixty four percent of disabled adults had an annual gross income of $30,000 or lower, compared with 45 percent of non-disabled adults. Across age, ethnicity and gender, disabled people have a significantly higher unemployment rate. Disabled women aged 15 to 44 are the most disadvantaged, with the highest unemployment rate at 15% (Statistics New Zealand, 2014). People with a learning disability are least likely to be in paid employment, with 59 percent of people who report having a learning disability, not in work (Statistics New Zealand 2014).

Disabled children are more likely to live in low income families (Murray 2018). Data from the 2013 Disability Survey shows:

- 34 % of disabled children live in families that earn under $50,000 a year, compared to only 24 % of non-disabled children
- Approximately 17% of carers of disabled children are unemployed.

A key factor that increases the risk of disabled children experiencing poverty in New Zealand is the disproportionate number of disabled children living in one-parent households. Thirty percent of disabled children live in one parent households, compared to 17% of non-disabled children (Statistics New Zealand), and the vast majority of disabled children who live in households earning less than $30,000 a year are in one-parent households, at 86 percent (Statistics New Zealand in Murray 2018).

Healthcare

International research consistently shows that disabled people have poorer health than the rest of the population and do not receive appropriate health care. Globally, disabled people are:

- twice as more likely to find healthcare provider skills and facilities inadequate
- three times more likely to be denied health care
- four times more likely to be treated badly in the healthcare system (WHO, 2011).

Findings from the New Zealand Health and Independence Report (2017) shows that fifty percent of disabled people rated their health as fair/poor compared with only 10 percent of non-disabled people. The health status of people with learning disabilities, in particular, is worse than other New Zealanders across all of the health status indicators (Milner et al., 2013). People with a learning disability can expect to live for 16–24 fewer years than others (Health and Independence Report 2017). The mental health of disabled young people has been found to be worse than that of other young people (Honey, et al., 2011) and women with learning disabilities are have heightened risk of mental ill health as a result of their social isolation, stigmatization and exposure to sexual and physical violence (Conder et al., 2015). While little information is available, it is widely thought that disabled people have significant unmet needs in relation to sexual and reproductive health (WHO 2011).

Disabled people have the same general health care needs as everyone else. They need access to mainstream health care services. Article 25 of the UNCRPD reinforces the right of disabled people to receive, without discrimination, the highest standard of health care. Yet, a combination of inadequate and poorly implemented health and disability policy, with deeply entrenched physical, communication, and attitudinal barriers limit disabled people, their families and whanau's access to adequate and appropriate health care (Mirfin-Veitch and Paris 2013). Population-based health

promotion strategies rarely include disabled people in their campaigns, and seldom focus on specific targeted interventions to meet any additional needs (Kuper et al., 2018). Research evidence suggests people with a learning disability are at a particular disadvantage, with few health promotions aimed at improving their health literacy and health behaviours (Milner et al., 2013.)

There is evidence that the health and wellbeing of families with disabled family members is negatively affected by disabling and discriminatory environments, attitudes and systems. New-Zealand based studies that have found high degrees of stress among carers of disabled adults and children (Milner, Mirfin-Veitch and Milner-Jones, 2016; Jorgensen et al., 2010). Family members take on a variety of care roles. Often their contribution is discounted and their needs not accounted for by health and disability supports and services. Accessing flexible respite care services is difficult for many families. Not having access to supports and services to assist with their caring role limits family members participation in and contribution to social and economic life.

Health care policies need to ensure that disabled people are treated equitably, regardless of gender, age, cultural background, type of impairment or when and how the impairment was acquired. Disabled people, their families and whanau, need to be included in the formulation of primary health care policies to ensure mainstream services are accessible to and inclusive of disabled people's diverse healthcare needs. There also needs to be further research on the challenges disabled people, families and whanau experience so that it can inform the development of these policies.

Transport

Access to transportation is essential for obtaining employment, education, healthcare, and social participation. Disabled people experience inequitable access to both private and public transportation. Barriers to transportation affects disabled people's ability to fully experience the social, economic, and political environments of their community (Christensen 2014)

Disabled people have less access to private vehicles than non-disabled people. Lower incomes as well as high car-related expenses makes personal car ownership unattainable for many disabled New Zealanders (Office of Disability Issues and Statistics New Zealand 2009). Added to this, some disabled people require expensive vehicle modifications. While there is some government provision of vehicles and vehicle modifications, inequities exist between those disabled people whose impairments originated from accidents and those that are non-accident related (Woodbury 2012).

Disabled people who do not have access to a private vehicle, and who do not qualify/cannot afford to use the Total Mobility taxi service, are particularly reliant on accessible public transport (CCS Disability Action 2018). Research shows that disabled people experienced difficulties using all major modes of public transport (Office for Disability Issues and Statistics New Zealand 2009; Human Rights Commission 2005). Although there is public transport in many parts of New Zealand, it is extremely limited outside the main centres and even in main centres public transport can be inadequate to many people's transport needs (Rose et al., 2009). Access to public transport in rural areas is even more difficult, with 54% of disabled adults reporting that they could not easily get to a public transport depot (Ministry of Health 2004).

Housing

Housing impacts upon people's health and wellbeing (Howard-Chapman et al., 2007). For disabled people, families and whānau, where they live – house and neighbourhood – influences their independence, their ability to be socially and economically active, and their quality of life. Some disabled people and their families have little or no choice about where or with whom they live. They may also be living in housing that is inappropriate and unsafe (Imrie 2004).

Disabled people's housing needs are currently not being met. They do not have the same access to warm, safe and affordable housing as non-disabled New Zealanders. Previous research has found strong evidence of a significant undersupply of accessible private homes and social housing (Saville-Smith et al., 2007). Only two percent of New Zealand's current housing stock is accessible (CCS Disability 2017). The 2013 Disability Survey found that:

- 107,440 people with a physical impairment had an unmet need for a house modification
- 26,880 people with a vision impairment had an unmet need for a housing modification.

Research shows that many disabled New Zealand are living in the most deprived areas, in social and rental housing that is damp and difficult to keep warm. Forty-three percent of Māori disabled and 49% of Pacific Island disabled live in the most deprived areas. Private rental housing and home ownership are unaffordable options for many disabled people (Bridge et al., 2002). This lack of choice in housing mean that many disabled people continue to live in institutions such as hospitals, nursing homes and group homes in unsuitable or inappropriate forms of housing or are homeless (Beer et al., 2006; Bostock et al., 2000; 2001; Quibell 2004).

It is important to consider the relationship between disability and housing, within a context of high rates of poverty, high personal costs of impairment, an aging (and therefore increasingly disabled) population, and the absence of government policy and planning around housing and tenancy regulation.

References

Abbott, D. 2013: Human rights and gay men with intellectual disabilities. *J Intellect Disabil Res*, 57: 1079-1087

Amado R. 1993: Loneliness: effects and implications. In A Novak Amado (ed). *Friendships and community connections between people with and without developmental disabilities*. Baltimore: Paul Brooks Publishing Company.

Anderson, P. and Kitchin, R. 2000: Disability, space and sexuality: access to family planning services, *Social Science & Medicine* 51, 1163-1173.

Beer, A., Faulkner, D., & Gabriel, M. (2006) *21st century housing careers and Australia's housing future: Literature review*. National research venture 2, research paper 1. Melbourne: Australian Housing and Urban Research Institute.

Blyth C. & Carson I. (2007) Sexual uncertainties and disabled young men: silencing difference within the classroom. *Pastoral Care* 25, 34–8.

Bostock, L., Gleeson, B., McPherson, A., & Pang, L. (2000). *Deinstitutionalisation and housing futures: Positioning paper*. Melbourne: University of New South Wales and University of Western Sydney Research Centre, Australian Housing and Research Institute.

Bostock, L., Gleeson, B., McPherson, A., & Pang L. (2001). *Deinstitutionalisation and housing futures: Final* report. Melbourne: University of New South Wales and University of Western Sydney Research Centre, Australian Housing and Research Institute.

Brown, M., Higgins, K., Pierce, T., Hong, E., & Thomas, C. 2003: Secondary students' perceptions of school life with regard to alienation: the effects of disability, gender and race. *Learning Disability Quarterly*, 26(4), 227-238.

Cavet, J and Sloper. P 2004: Participation of Disabled Children in Individual Decisions about Their Lives and in Public Decisions about Service Development. *Children & Society.* 18.4: 278-90. Web.

CCS Disability Action, 2018: Briefing to the Housing Minister, available at https://www.ccsdisabilityaction.org.nz/news-and-views/news/addressing-our-lack-of-accessible-housing/

CCS Disability Action, 2018: Briefing to the Transport Minister, available at https://www.ccsdisabilityaction.org.nz/advocacy/submissions/

Christensen, K. M. 2014: Socially equitable community planning: Including individuals with disabilities in democratic association of place. *Review of Disability Studies*, 5(3), 49–52.

Conder, J, Mirfin-Veitch B., & Gates, S. 2015: Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability, *Journal of Applied Research in Intellectual Disabilities*, 28, 572–583

Cooney, G., Jahoda, A., Gumley, A., and Knott, F. 2006: Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research*, 50(6), 432-44.

Evans D., McGuire B., Healey E. & Carley S. 2009: Sexuality and personal relationships for people with an intellectual disability: staff and family perspectives. Journal of Intellectual Disability Research 53, 913–21.

Fegan, L., Rauch, A., & McCarthy, W. 1993: Sexuality and people with intellectual disability (2nd ed.). Artarmon, NSW, Australia: Maclennan & Petty.

Green, S., Davis, C., Karshmer, E., Marsh, P., Straight B., 2005: Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry,* 75(2) 197-215.

Hogan, A., McLellan, L., and Bauman, A. 2000: Health promotion needs of young people with disabilities-a population study, *Disability and Rehabilitation*, 22(8), 252-257.

Honey, A., Emerson, E., Llewellyn, G., 2011: The mental health of young people with disabilities: impact of social conditions Soc Psychiat Epidemiol (2011) 46:1–10

Howden-Chapman, P., Matheson, A., Crane, J., Viggers, H., Cunningham, M., Blakely, T., Cunningham, C., Woodward, A., Saville Smith, K., O'Dea, D., Kennedy, M., Baker, M., Waipara, N., Chapman, R. and Davie, G. 2007: Effect of insulating existing houses on health inequality: cluster randomised study in the community, BMJ 334(7591), 460; National Health Committee (1988) Social, Economic and Cultural Determinants of *Health: Action to Improve Health*, National Health Committee, Wellington.

Human Rights Commission, 2004: Making Disability Rights Real: Second Report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities, Wellington, New Zealand.

Human Rights Commission. 2005: The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport. New Zealand Human Rights Commission. Retrieved from http://www.hrc.co.nz/report2/index.html

Imrie, R. 2004: Housing quality, disability and domesticity. *Housing Studies* 19(5), 685-690.

Jorgensen, D., M. Parsons, S. Jacobs and H. Arksey 2010: 'The New Zealand informal caregivers and *their* unmet needs', *New Zealand Medical Journal*, 123 (1317), pp.9–16.

Kearney, A. 2016: The right to education: What is happening for disabled students in New Zealand? *Disability Studies Quarterly,* 36,1.

Kuper, H, Smythe, T Duttine, A. 2018: Reflections on Health Promotion and Disability in Low and Middle-Income Countries: Case Study of Parent-Support Programmes for Children with Congenital Zika *Syndrome*, *Int. J. Environ. Res. Public Health* 2018, 15(3), 514.

MacArthur J., and Morton M. 1999. 'I'm still trying to make friends…' *Children's Issues* 3(1), 38-42.

Milner, P. and Kelly, B. 2009. Community participation: people with disabilities defining their place. *Disability and Society*, 24(1), 47-62.

Milner P., Mirfin-Veitch B. & Conder, J. 2013: On the Margins of Good Health: An analysis of the health status, health knowledge and health literacy of people with a learning disability who completed the Special Olympic HAS Health Promotion Screen. Dunedin: Donald Beasley Institute.

Milner, P., B. Mirfin-Veitch and M. Milner-Jones 2016: 'You care about me when you care about my *son'*: an exploration of the respite experiences of New Zealand carers, Dunedin: Donald Beasley Institute.

Milner, P., Mirfn-Veitch, B., Brown, S., & Schmidt, L. 2017: Getting the Life I Want Online Survey. CCS Disability Action.

Ministry of Health. 2004: *Living with Disability in New Zealand: A descriptive analysis of results from the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities*. New Zealand Ministry of Health.

Ministry of Health. 2018: Health and Independence Report 2017: Ministry of Health, New Zealand, retrieved from https://www.health.govt.nz/publication/health-and-independence-report-2017

Mitra, S., Palmer, M., Kim, H., Mont, D. and Groce, N. 2017: Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal* 10(4), 475-484.

Mirfin-Veitch, B. & Paris, A. 2013: Primary health and disability: A review of the literature. Auckland: Te Pou o Te Whakaaro Nui.

Murray, S. 2018: Breaking the Link Between Disability and Child and Whanau Poverty, *Policy Quarterly,* 14(4), 68-78.

Nosek, M. 1995: Sexual abuse of women with physical dis-abilities. *Physical Medicine and* Rehabilitation, 9(2), 487-502.

Office for Disability Issues and Statistics New Zealand. 2009: *Disability and travel and transport in New Zealand in 2006: Results from the New Zealand Disability Survey.* Wellington: Statistics New Zealand

Osborne, T. 2018: Not lazy, not faking: teaching and learning experiences of university students with disabilities. *Disability & Society*, 1-25.

Quibell, R. 2004: *The living history project: The lived experiences of people with disability and parents of people with a disability in the period 1981–2002*. Scope Vic Ltd.

Rose, E., Witten, K., & McCreanor, T. 2009: Transport Related Social Exclusion in New Zealand: Evidence and Challenges. *Kotuitui: New Zealand Journal of Social Sciences Online*, *4*(3), 191.

Russell, P. 2003: Access and Achievement or Social Exclusion' Are the Government's Policies Working for Disabled Children and Their Families? *Children & Society* 17, 215–225.

Saville-Smith, K., James, B., Fraser, R., Ryan, B., & Travaglia, S. 2007: Housing and Disability Future Proofing New Zealand's Housing Stock for an Inclusive Society. Centre for Housing Research Aotearoa New Zealand.

Shakespeare T. 2000: Disabled sexuality: towards rights and recognition: a keynote conference address. *Sexuality and Disability* 18, 159–66.

Statistics New Zealand 2014: *Social and economic outcomes for disabled people: Findings from the 2013 Disability Survey*. Wellington: Statistics New Zealand.

Strully J. and Strully, C. 1992: The struggle towards inclusion and friendship. In J Nisbet (ed). *Natural supports in school, at work, and in the community for people with severe disabilities*. Ohio: Paul Brookes Publishing Company.

UNICEF, 2005: *Summary Report. Violence against disabled children, UN Secretary General's report on violence against children; Thematic group on violence against children. Findings and recommendations*. Retrieved from: https://www.unicef.org/videoaudio/PDFs/UNICEF_Violence_Against_Disabled_Children_Report_Distributed_Version.pdf

Watson-Armstrong, L. A., O'Rourke, B., & Schatzlein, J. 1994: Sexual abuse and persons with disabilities: a call for awareness. *Journal of Applied Rehabilitation Counseling,* 25(1), 36-42.

Wills, R., & Rosenbaum, S. A. 2013: Parental Advocacy and the Safeguards Necessary for Inclusive *Education*: New *Zealand* Lessons for Pacific-Asian Education. *Pacific-Asian Education*, 27-40

Woodbury, E. 2012: Auto-Mobile: Disabled Drivers in New Zealand, unpublished PhD thesis, University of Otago, New Zealand.

World Health Organisation, 2011: World Report on Disability, Malta, retrieved from https://www.who.int/disabilities/world_report/2011/en/