



CCS
disability action
Including all people

TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA

Submission on the Living Standards Dashboard

31 July 2018

Recommendations

1. Remove activity limitations as an indicator of wellbeing.
2. The Living Standards Dashboard should use a modern theory of disability that acknowledges that the human capital stock of disabled people are often dependent on social, financial and physical capital stocks in wider society.
3. Disabled people should be a sub-population for wellbeing and capital indicators to be disaggregated by.

About us

CCS Disability Action is a community organisation that has since 1935, supported disabled people and advocated for their inclusion in the community. As of May 31 2017, we were providing support to around 4,000 children, young people and adults through our 17 branches, which operate from Northland to Invercargill. Our support focuses on breaking down barriers to participation. We receive a mixture of government and private funding.

Activity limitations should not be used as an indicator of wellbeing

The concept of activity limitations is used incorrectly and inappropriately as a suggested indicator of wellbeing under the category of health. Activity limitations are a single component of a complex multifactor framework called the International Classification of Functioning, Disability and Health (ICF), they are not a standalone concept.

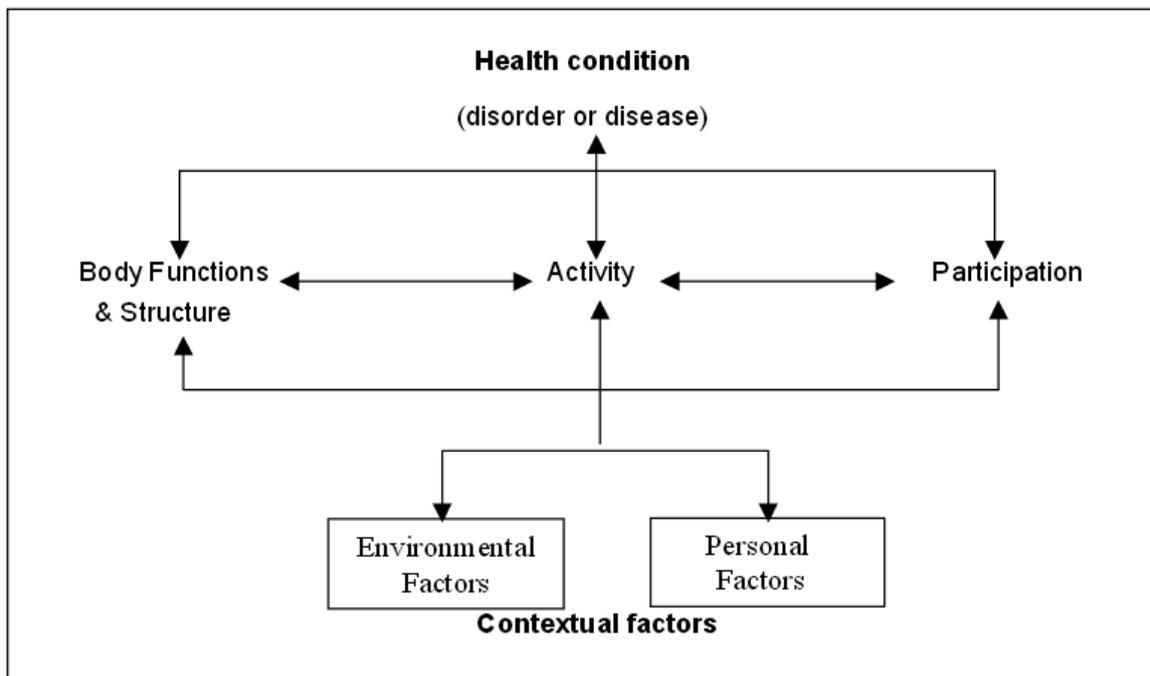


Figure 1 the ICF as a conceptual framework, note that activity is only one part of the overall framework and is influenced by a wide range of factors (and influences those factors in turn)

Source: (World Health Organization, 2002, p. 9)

The reason the Washington Group on Disability Statistics chose to measure activity limitations in their Short Set of Disability Questions is because they believed it was more amenable to measurement than other parts of the framework. The purpose of measuring people who have activity limitations is to identify people at greater risk of participation restrictions and hence disability. The sole purpose of measuring activity limitations is to examine the equality of opportunities (or outcomes) between two population groups. In particular, to quote the Washington Group to:

“...compare levels of participation in employment, education, or family life for those with disability versus those without disability to see if persons with disability have achieved social inclusion (Washington Group on Disability Statistics , 2016).”

Statistics New Zealand likewise solely uses the Short Set of Disability Questions, including in the General Social Survey, to produce estimates of socio-economic measures by disability status. Statistics New Zealand explicitly does not use the Short Set of Disability Question to produce estimates of disability prevalence or of demand for services (Statistics New Zealand, 2017, p. 4).

The Short Set of Disability Questions is not designed to identify all people with impairments or all disabled people. Instead it is designed to identify a significant sample of people who probably have a disability in order to collect data on their outcomes compared with the wider population. The Short Set of Disability Questions is a tool for disaggregating other data by disability status. It does not measure disability prevalence (Office for Disability Issues, 2017, p. 3).

The number of people reporting activity limitations does not accurately indicate the prevalence of health conditions or impairments in society. This is because activity limitations occur because people with impairments face an unaccommodating environment. It is impossible to tell from a count of the number of people with activity impairments, especially through the Short Set of Disability Questions, what factors are causing the limitations. Environment factors, such as poor access, a lack of support, or negative attitudes towards disabled people usually play a major role in causing activity limitations (Mont, 2007, pp. 2-3). Activity limitations are not a good measure of health in society, nor are they designed as such.

Further using the number of people experiencing activity limitations as an indicator of wellbeing is inappropriate. It would be completely inappropriate to suggest as an indicator of wellbeing the number of people of a certain gender, ethnic group or sexual orientation, even if that group experiences worse wellbeing on average. Because this would imply reducing the number of people in this group is an acceptable way to increase overall social wellbeing. The same is true for people experiencing activity limitations.

Having activity limitations as a wellbeing indicator is particularly inappropriate because of the dark history of eugenics in which societies have pursued the goal of reducing the number of disabled people through deeply unethical and horrific means (Chaloupka, 2016, pp. 408-410; Oliver, 1990, pp. 46-54). However well intentioned, it devalues the lives of disabled people and is not acceptable in modern disability policy. Current New Zealand government disability policy expressed in the New Zealand Disability Strategy and backed by the Convention on the Rights of Persons with Disabilities is centred on the goal of equality of opportunities and outcomes between disabled people and non-disabled people (Convention on the Rights of Persons with Disabilities; Office for Disability Issues, 2016).

The International Classification of Functioning, Disability and Health and norms

One of the reasons using activity limitations as an indicator is problematic is because it exposes a weaknesses of the ICF. The ICF uses norms and divides bodily functions and structures in a wide variety of different parts. There is a norm for each body function or structure indicated by zero. Numbers from one to four indicate a “problematic” variation from the norm. The number four indicates a total “problematic” variation from the norm (World Health Organization 2013, 26). Impairment is defined thus by the ICF as problematic variations in body functions/structures from the norm (World Health Organization 2002, 10).

Although the use of norms is an important part of statistical measurement, norms become incredibly dangerous for disabled people when they are linked to moral status (Feely 2016, 864). This has particularly been a risk for people with significant

learning disabilities; philosophers have questioned whether they have full moral status as human beings because they are perceived to negatively deviate from the intellectual norm for a human being (Wasserman, et al. 2012).

The use of norms by the ICF is not generally a major problem, while the focus is on collecting data to assess socio-economic outcomes between disabled and non-disabled people. It becomes a problem if the focus is on collecting data on the number of disabled people as an indicator itself of wider social wellbeing. This starts to link moral value and norms (because it implies a society with fewer people varying from the norms for body function/structure would be a better society, which in turn devalues people who do vary from the norm).

Also it is important to note the extent to which labelling negative deviations from the norm can be heavily influenced by political decisions as well as cultural and societal factors. As even one of architects of the ICF, Jerome Bickenbach, notes, we all vary from the norm in some respect so impairment (of some kind) is roughly universal in society. The key decisions in measuring disability, or determining eligibility for services, are therefore what impairments matter and at what level. Jerome concludes that these decisions cannot be made fully conceptually or scientifically, they are, at least in part, political and cultural decisions (Barnes & Mercer, 2010, pp. 38-39; Bickenbach, 2008, pp. 120-121).

Human capital and theories of disability

The embodiment of knowledge, skills, competencies and attributes in disabled people is mediated through the environment to a much greater degree than for non-disabled people. The proposal notes one narrow aspect of this, solely focused on the individual. The proposal notes that disability can reduce the amount of time, effort and attention the person has available (Smith, 2018, p. 32). The theoretical approach taken here to disability appears to be the outdated medical model, or realist approach, that stresses the individual's differences as the dominant cause of disability and largely ignores environmental and societal factors (Barnes & Mercer, 2010, pp. 18-24). A realist approach is profoundly disempowering for disabled

people and prevents any effective disability social policy because it ignores the person's environment (Barnes & Mercer, 2010, pp. 23-24).

All modern disability theory converges on rejecting this and acknowledging that environmental and societal factors play a key role in creating the disadvantage disabled people face. The interactional model of disability used by the Convention on the Rights of Persons with Disabilities and Statistics New Zealand as well as the social model used by both New Zealand disability strategies all focus heavily on the importance of environmental and societal factors (Schneider, 2016; New Zealand Government, 2001; Office for Disability Issues, 2016; Statistics New Zealand, 2015). Materialist, post-structuralist and critical realist theoretical approaches to disability all acknowledge the importance of environmental and societal factors (Shakespeare, 2014, pp. 72-76; Thomas, 2004, p. 572; Hughes & Paterson, 1997, pp. 325-330).

The proposal should adopt a modern theoretical approach to disability and acknowledge that the human capital stock of disabled people is often dependent on social, financial and physical capital stocks in wider society. For example, a lack of accessible buildings, transport, information and infrastructure can prevent someone with access needs from working or studying, regardless of their internal, potential, level of human capital. Likewise, someone with a learning disability or experience of a mental health condition may be unable to exercise or develop their human capital due to negative attitudes towards these conditions in society.

If a disabled person is unable to access education and employment opportunities because of access or attitude barriers, or a lack of support, that is a problem with the social and physical capital stocks in society, not the human capital stock of the disabled person. A net approach to stocks will not capture this dynamic and will effectively render the experiences of disabled people invisible, especially if an outdated approach to disability is used. It is crucial the wellbeing and capital indicators are disaggregated by disability status so we can identify and target the barriers disabled people face in the development and exercise of their human capital.

Recommendations

1. Remove activity limitations as an indicator of wellbeing.
2. The Living Standards Dashboard should use a modern theory of disability that acknowledges that the human capital stock of disabled people are often dependent on social, financial and physical capital stocks in wider society.
3. Disabled people should be a sub-population for wellbeing and capital indicators to be disaggregated by.

Conclusion

Disabled people should be treated the same as any other sub-population group under the Living Standards Dashboard. This means activity limitations should not be used as an indicator. Instead wellbeing and capital indicators should be disaggregated by disability status (activity limitations). The Living Standards Dashboard should align with current government policy and focus on measuring the equality of opportunities and outcomes between disabled people and non-disabled people.

A modern theoretical approach to disability should be used in the Dashboard and for the Living Standards. The Dashboard needs to acknowledge the importance of environment and societal factors in preventing disabled people from exercising or developing their human capital.

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