Enabling Good Lives

Flexible Funding for Disability Support

Introduction

Impairment and disability tend to get treated as the same thing even though the UNCRPD and New Zealand/ Aotearoa have defined them as different. To briefly recap: “impairment” relates to physical/anatomical characteristics of an individual that perform below the expected norm and which may create a limitation in functioning. “Disability” relates to how people with impairments are treated within a society that does not adapt to naturally include diversity of capability.

Disability then is a consequence of discrimination, not a consequence of impairment. As the UNCRPD puts it: “people who have long-term physical, mental, intellectual or sensory impairments that, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.”

Or as the NZ Disability Strategy (2001) put it: “Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments.

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.”

Disability Support?

One of the most obvious ways these two different but linked terms are treated as the same is within so called disability support funding. Disability support funding is largely designed to cater for limitations in functioning at the individual level. This comes about through a “Needs Assessment,” aka a map of what the person can’t do. Funding is then assigned to support the person with these “deficits.”

Occasionally funding will look to ameliorate obvious structural barriers such as providing ramps, interpreters and easy read formats. However, it rarely factors in the broader impacts of living within a disabling society. Things such as: the accumulated effect of poorly matched schooling, social isolation, an exclusionary labour market, poorly aligned health services and the subsequent poverty and lack of social capital that ensues.

In fact, when things like social isolation, needing to attend cultural events and the like are suggested at most needs assessments, they are rejected on the grounds that they are “nice to haves” rather than “needs.”

For this reason, “disability support funding,” as it is currently available, should really be called “impairment amelioration funding.” At least that way it would be consistent with its current application.

Enabling Good Lives

Enabling Good Lives (EGL) is an approach based on a set of principles. As such, it is an attempt to design and operate support for people based on those principles and not on the state designed service specifications and limited service options as has been the offerings from the Ministry of Health and then Whaikaha over the past 25 years. This is the result of a majority of non-disabled people making biased decisions about how disabled people should live. It has become a self-fulfilling prophecy.

The hope that EGL offers people is that they can actively design their own good life and match that to the support they may need. In this EGL way, disabled people and their families/whānau, get to have the say over both what their life should look like and how they are supported.

The only practical way to achieve this is to allow people the flexibility to purchase the support they need from whomever or wherever they can find to match that support best for them. If that flexibility is not available, or is limited in particular ways, then we end up back in the situation where the state is acting in a “we know best” way.

So far, within the EGL demonstration sites, this ability for disabled people and whānau to design and then commission their own support has been the ‘game changer’ in people’s lives. So, instead of focusing on the deficit based needs assessment people have described their good life. From there, they have been able to target the available funding to precisely match their good life by having control of it.

EGL vs IF

It is often, mistakenly, thought that IF is a flexible funding process that is similar, if not identical to the EGL aspiration.

What IF allows people to do is have a great deal of control over who they spend their support funds with. For example, it allows people to employ their own staff or directly contract with a disability service provider for their support.

What IF does not do is allow people to truly design their own support. The funding for IF is channelled through the standard service specifications that determine the range of support they can purchase via the Purchasing Guidelines. That means, for example, a disabled person may use funding allocated for household management to employ a person to vacuum their house. They cannot use that same funding to have the same person mow their lawns as that isn’t specified in the service specification.   The overgrown lawn might be a priority issue for the person because it might be unusable as a secondary escape route.

In addition to this, all the funding the disabled person uses is exhaustively monitored to ensure that its application is exactly as the State requires it to be. The recent debacle from Whaikaha and the previous Minister of Disability Issues demonstrates how negatively this process works for people.

The at-arms-length decision making also means that the systems has no insight of the real world impacts on people.

So, even though IF is a significant step towards greater autonomy for many people, it is still contained within the overall framework of “the state knows best.”

Flexible Funding to Enable Disabled People to design and be in charge of their Good Life.

If we hold true to the notion that disability is a social construct, that is it is something done to people with impairments through ignorance, indifference and, occasionally still, the fear of difference, then disability support funding should be focused on addressing these impacts as well as any impairment based impacts.

For that reason, we think that once an individual receives their support funding package, they should be able to use it in the same way, and with as much autonomy, as any other New Zealander who receives social assistance can. That means, it should be treated as their money to spend as they please and, if they spend it unwisely enough to mean they miss out on essential support, then, and only then, the state can intervene to provide better budgeting support.

The current resource allocation system ie. NASC has a perverse incentive for people to overstate their disabilities because they know that the budget they would otherwise have been allocated would only allow them to subsist and shelter in place.

Disabled people do not behave like non-disabled people.   Research by Dovetail (Field A, King J, McGechie M. 2015)[1], shows that when disabled people control their funding they use less of their allocation.

(Currently, this view is held as unworkable because of taxation rules. we acknowledge that is the case but we should look to change those rules that further disabled people rather than just accept them. For example, if the money is to be treated as income it will need to be taxed. So tax it! Add in the taxable amount to Whaikaha’s budget and then take it back as tax again. It is a closed circle so costs no more money.)

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[1] Cost Analysis of Individualised Funding