



Enabling Good Lives

Individualised Funding (IF) and EGL

(A discussion paper - 2023)

"This is a 20-year-old model that has not matured enough to really embrace the EGL approach. Where you might find people assuming that it's aligned with EGL is because of good marketing."
(Jade Farrar - 2023)

Introduction

IF (Individualised Funding) has existed in one form or another in the Aotearoa/ New Zealand disability support framework for 25-30 years. It began through NASCs giving some disabled people their money to manage themselves as they had been "difficult" to match with providers. From there it slowly got formalized to where it is today.

IF used to assume the individual had the competency to manage the allocation themselves. Then officials decided there needed to be intermediaries, that is Host Agencies, to carry the risks in case NASCs had assessed people wrongly as being competent to spend their allocation in a way that supported them best. It seemed their assumption was that only the pioneer users of IF had sufficient competency and that later cohorts needed a higher level of management.

In recent times the Purchasing Guidelines represented an attempt to let people buy things to support them rather than assume staff were the only valid support option. This stumbled when officials decided to define what disabled people might buy based on their own understanding of the world. With that change Fundholder Agencies, AKA Hosts, lost their nerve and introduced verification processes that essentially torpedoed the initiative.

There are now three significant questions that can be asked of Individualised Funding as it currently exists. They are:

1. Is it fit for its current purpose?
2. Is it aligned to EGL and therefore fit for the future?
3. Is it operated in the best fashion for now or for the future?

This paper is only looking at the second two of these questions. In doing so though, we wish to comment that the question as to whether or not IF works well now is often conflated into assumptions about the future, is not the same thing. Even if IF suits the current environment, this does not speak to its EGL/ future alignment.

What we do know from a lot of anecdotal comments is that there is a high level of dissatisfaction with IF from many disabled people and whānau. We acknowledge that some people do appear satisfied with IF but this is generally in comparison to even more limiting service streams.

Why is it that some people claim IF is not aligned to EGL?

The key issue here is that IF, like almost all disability support funding, is not actually disability support funding; it is impairment support funding and is based on the medical model of disability.

EGL is premised on the social model of disability and is about people being able to participate in a non-disabling society, or at the very least, ameliorating the disabling effects of society in their lives so they can enjoy their lives.

If this sounds like semantics, it is important to refer to the UN Convention on the Right of Persons with Disabilities and the New Zealand Disability Strategy.

To quote from the latter:

Disability is something that happens when people with impairments face barriers in society; it is society that disables us, not our impairments, this is the thing all disabled people have in common. It is something that happens when the world we live in has been designed by people who assume that everyone is the same. That is why a non-disabling society is core to the vision of this Strategy.

Every human being is a unique individual. Even if we have the same impairment as someone else, we will experience different opportunities and barriers because of where we live and how we are treated by those around us. The time and context in our lives when we may acquire our impairment(s) also informs what barriers or opportunities we may experience.

This is the social model of disability and it is how we understood disability in the first Strategy in 2001. It still holds true today. It is also the same understanding of disability that is embodied in the Convention.

Under the social model as articulated by various disabled researchers including Michael Oliver ("The Politics of Disablement" 1990), the term "disabled people" was revalorised as a way of stating that disability was done to people not something they had.

How does IF describe disability support?

On the Whaikaha website it lists a number of things that Individualised Funding can be used for by a disabled person:

[You can] Get help with household management and the personal care of your disabled person by engaging a support worker (called "employees" these can include family

members, contracted people or organisations) and pay costs relating to the engaging of support workers.

You can spend your IF on any disability support or service that:

- helps you to live your life or makes your life better, and
- Specific to your disability, you would not need this item or support if you were not disabled and
- the use of funding if it is reasonable and cost-effective, and
- not funded through other funding options such as a Disability Allowance.

What you can't use it for are:

It's worth noting your funding cannot be used for illegal activities, gambling or alcohol or things that are not disability supports, such as health services provided by a hospital or income support.

IF also doesn't cover costs related to medical supplies, equipment, home renovations, leisure, recreation and personal or family costs.

You will note from the Whaikaha description of Individualised Funding that the way support is described, it is about a person's impairment; described as "Specific to your disability." If one reads this phrase as "impairment" then the list of remedies that IF allows a person make sense. They are all related to things that a person cannot do. Things like: providing a "disability support or service" such as household cleaning, personal cares, items or supports [that you may need but would need] if you were not disabled [AKA impaired].

If one reads this with the concept of disability as a structured discrimination as it is essentially described in the NZDS and NUCRPD, then it makes no sense at all. Here are some examples.

"Disability support or service:" All of the Whaikaha contracted disability supports and services are based on a person's needs (AKA deficits) and as such, look to overcome those deficits. From a medical model of disability which only considers impairments, this makes complete sense. If one considers "disability" as a societal construct, it looks very different. A disability support then could arguably be anything that reduces the impact of a disabling society on a disabled person.

One of the most disabling institutions within society is the current employment market. In fact this is the original locus for impairment discrimination dating back to the industrial revolution. So, given that disabled people are largely excluded from employment because of the way we construct it, that means they are prevented from earning an income that will allow them access to society on the same footing as others. Therefore, a "disability support" could well be a reasonable income, yet income support is specifically excluded.

(NB: We are not arguing that Whaikaha should provide everything and we are aware that income support is another Ministry's role. What we are arguing is that Whaikaha's description of "disability support" is purely focused on impairment support to the extent that it constrains people rather than enhances their lives.)

"Specific to your disability": People don't have a disability. People have impairments. Society does not account for the fact that different people operate differently; that is disability. Disability is to impairment what sexism is to females.

"Support with Personal Cares": this may be a legitimate impairment related need in the form of staff as per the HCSS service specification. However, from a disability perspective it could also mean having accessible toileting and bathroom environments. For many people this is the only disability support they require but "home renovations" to achieve this are specifically excluded from IF. EGL, the NZDS and the UNCRPD are all about altering environments not fixing people or their perceived shortcomings.

The NZDS lists the following domains as their major foci for disabled people to live well in Aotearoa/ New Zealand.

1. Education
2. Employment and economic security
3. Health and wellbeing
4. Rights protection and justice
5. Accessibility
6. Attitudes
7. Choice and Control
8. Leadership

If we compare this list with the implicit and explicit exclusions Whaikaha lists for IF we find that almost all of these outcomes are not allowed by IF. This is because IF is impairment support and not disability support.

Is IF operated in the best fashion for now or for the future?

We would say a resounding "no" to this question. The reason being that IF is still largely an allocation that is tied to service specifications that define how it should be spent. Although the Purchasing Guidelines allow more flexibility than previously, the NASCs still need to use the same tools and allocation framework as they always have.

This means there is no "Good Life" conversation; it is still about assessed needs or deficits. These rules (service specifications, Purchasing Guidelines, etc) came about through officials deciding what should count as disability support and what should not. This is akin to men deciding how women should organise themselves!

The other poor fit with an EGL aligned future is the compulsory role of Host agencies. Requiring these appears to be based on one of two possible premises. Either disabled people are not

competent to manage their own support resource or they cannot be trusted to manage their own support. Either way, the current arrangements prefer that strangers do this on their behalf.

A fundamental principle of EGL is that disabled people and, where appropriate, whānau have control of their own support resource. This means they have the ultimate “say so” over how it is spent to support them. This does not mean they have to manage the resource themselves but, if they choose to have it managed for them, they should decide who undertakes that function. Having Host Agencies is one option but it cannot be the only option. It is this compulsion that is so antithetical to an Enabling Good Lives approach.

So, what would real disability support look like?

To find out what might assist a person to live a good life, one would start with a conversation about what a good life looks like for that person. From there, one would consider how their home and community could be made more accessible to them as they are.

After this has been done, an allocation of government funding could be provided to the person to use to make these things happen. The person would “own” this resource but could decide what level of management they wanted to have over its use. They would have absolute control over what it was used for so that the way it was used fitted their specific circumstances.

The resource could be used on items, developing natural supports, staff supports, koha and any other way that meant the person had a good life and could grow and develop as a participating citizen. Personal budgets are the competency mechanism that will create different buying habits for disabled people to live lives that are unimaginable today.

As you may have noticed, what is described is exactly what was described in the high level design of a transformed system that supports people to have a good life according to EGL principles. Until IF aligns with this vision, it is not aligned to EGL, nor is it fit for the future in a transformed support sector that is based on EGL principles and practices.