

Reframing Respite through a Wellbeing and Resilience Lens.

NEGL Position Statement

The meaning of respite as stated in a dictionary is “a short period of rest or relief from something difficult or unpleasant”. This implies that disabled children and people are difficult, unpleasant and as such disability is often perceived as something undesirable and burdensome. This deficit framing can be hurtful and harmful for many disabled people and their ¹ families.

It is in fact the barriers and negative attitudes in society along with poor, inadequate systems including disability supports which cause difficulty and challenges for disabled people and their families. This does not seem to be acknowledged at all through the current use of the term ‘respite’ in the contexts of disability supports and services. The current respite purchasing guidelines are based on a medical definition of disability, rather than on a social model of disability. In fact, the current system is built on the notion that there will be cyclical crises with no intention to stop them.

The EGL National Leadership Group promotes the **concept of family wellbeing** (whānau ora) rather than ‘respite’. With this approach the focus becomes creating positive outcomes for everyone. It is essential that disabled children and people are made to feel part of the family and continue to have a strong sense of belonging within the family unit rather than feel like a burden. Therefore, it is essential that individuals and their families determine how they use associated funding based on their unique situations, wellbeing needs and aspirations.

Family wellbeing is crucial for the survival, long term sustainability and resilience of many disabled people and their families. The current language is not indicative of this intent, and young families who are new to care giving are not always well educated or informed about the importance of wellbeing and resilience for sustainable caregiving in the long term.

It is important to note the multiple complexities of all caregivers as they often have varied roles and responsibilities. For example, parents and carers of disabled children may also be caring for other children with their own individual needs, disabled or medically fragile siblings/partners, elderly parents/grandparents, extended family members, etc.

When considering wellbeing for disabled people, it is essential to acknowledge that they may be executing varied roles as carers themselves, such as supporting other family members (eg. elderly parents, siblings, own children, spouse etc.) with or without disabilities or high health needs.

Carer fatigue is a significant risk that must be addressed through creation of wellbeing and resilience in multiple ways such as connections, holidays, self-care, etc. How it can be addressed, depends on the ages and multiple responsibilities of caregivers and the wider networks they are connected to, as well as the regional infrastructure, geographical and environmental contexts relevant in each situation such as rural, urban, access to transportation, services in the local community spaces, etc. Hence, **no one other than the carer can determine how their wellbeing budget should be used.**

¹ In this document, the word ‘families’ has been used to indicate ‘parents, other family members, whānau and carers’ and we acknowledge that each of these groups may have varying wellbeing needs and perspectives.

The current allocation and use of respite funding does not allow for real choice, control or flexibility. Neither is the current process easy to use or mana-enhancing. In an EGL context, built on self-determination, choice and control, family wellbeing would not be limited or defined by a service provider, host or external agency, but rather by the individual disabled person or their family.

In essence, the current focus on “respite” is a deficit-based approach which does not align well with an EGL approach, the creation of well-being and building resilience for disabled people and their families.

NEGL believe it is important to reframe respite and **ensure that the dominant focus is wellbeing and not ‘something difficult or unpleasant’**. NEGL supports ‘respite’ being reframed using a social justice and equity lens, with full flexibility, choice and control for the disabled person and their families. NEGL supports using language that is positive, mana enhancing and focuses on wellbeing and resilience building.

Following are some recommendations from NEGL which have been put together with input from the wider disability community.

1. Reframe ‘respite supports’ as ‘Wellbeing Budgets’.
2. To ensure needs of both disabled people and their family are met, ensure Wellbeing Budgets are allocated for the ‘Disabled child/person’ as well as their ‘Parents/family/carers’.
3. Move away from one carer to ‘multiple carers or family’ as it is often the family/whanau who support the disabled child/person, and therefore focus needs to be on wellbeing of all relevant family members, not just one parent/carers or the disabled individual.
4. Remove the need for system to decide what will provide wellbeing for a disabled person and/or their family members,
5. Turn all current Carer Support and IF respite hours under \$10,000 into personal budgets, with minimal accountability requirements, so they are easy to use.
6. Whether or not wellbeing budgets for the disabled child/person and that for their carers are pooled as one or separately demarcated, is a discussion that needs to be had with the community.