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'Try, Learn, Adjust'
it's time to bring workers into disability support policy

Abstract

Aotearoa New Zealand is on the verge of significant change aimed at increasing disabled people's access to and control and choice over the support they receive in order to have the flexible, high-quality care that enables them to lead 'good' lives. However, the system changes – Mana Whaikaha – designed to enact the Enabling Good Lives policy has its roots in neo-liberal funding and policy approaches that undervalue support work, and has largely overlooked workers and workforce development. The lack of recognition of the disability support workforce in this policy development threatens the success of the programme to provide quality support to disabled people.

Keywords individual funding, disability support, support workforce, marketisation of care, care and support workforce planning

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When considering disability support, it is important to recognise how disadvantage is created for people with disability: it is the context, our society and health systems, that creates disadvantage (Murray and Loveless, 2021). These disadvantages are significant for disabled people, with disability linked to increased experience of poverty and unemployment. These disadvantages are exacerbated by an assumption in our health and support system that shifts the costs of disability support onto individuals and whānau (ibid.). This assumption, and the way in which disability support tends to shift costs to individuals rather than the state, is part of systemic and ongoing discrimination that limits disabled people's sense of empowerment and their ability to thrive and take part in society (Fleming et al., 2019).

Individualised funding developments in Aotearoa New Zealand have been introduced within the context of an already underfunded disability support system. The Ministry of Health and Ministry of Social Development spend approximately $1.4 billion to fund support services for around 60,000 disabled people and their families (New Zealand

Disability Support Network, 2020). However, while this seems a large amount of money, it does not provide the full amount required for the people currently receiving support, and it is estimated that around 25% of disabled people do not have access to disability support and could be eligible for it (ibid.). Furthermore, funding from government has not kept up with current cost pressures, and there is a significant gap when considering projected demand for disability support (Deloitte, 2018). Rosenberg (2015) points out that governments in the past have manipulated perceptions of policy development by referring to essentially cost-reducing policy as an 'investment approach'. Murray and Loveless (2021) find that a reluctance to increase funding for disability support services is informed by a reluctance to shift from a privately funded and invisible cost model to a public one. When disability support services are underfunded, those who will shoulder the burden of cost (or lack of support) are disabled individuals and their whānau, and support workers.

Hellowell, Appleby and Taylor (2018) point out that a best practice approach to healthcare and support funding would be to begin by costing out what was needed, and then financing it accordingly. In contrast, current models are confined by a budget from inception, without considering how that impacts on individuals and society. This leads to built-in oppression of a poorly resourced system, which creates potential tensions between the support workforce and those living with disability and needing support, each of which groups bears the burden of an underfunded disability support system (Kelly, 2017).

Although the nationwide Mana Whaikaha programme announced in the 2022 Budget is new, individualised funding is not a new phenomenon in Aotearoa New Zealand or internationally. Individualised funding policy ostensibly shifts away from the paternalistic approach to disability support to a model in which disabled people and their whānau have more ability to identify and access the type of support they need through devolved budgets (Fleming et al., 2019). It is available throughout New Zealand for eligible people who have either home and community support services or respite services. It was designed to address the issue of disabled people not having enough choice and control over who provides the support they need, and how and when it is to take place. Options for those using individualised funding include employing support workers and planning what support they need themselves, through to arranging for a care provider to manage all aspects of service delivery (Ministry of Health, 2021c).

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Support workers are key to the provision of individualised funding, which is often expected to be more flexible and more personally responsive than previous models of disability support. However, the workforce has been largely overlooked in policy development. This is not surprising: as Wright (2022) argues, labour policy in liberal market economies views labour as a 'problem' to be controlled and with least cost. This policy approach is particularly problematic in the development of individualised funding through the Mana Whaikaha programme in Aotearoa New Zealand. It is problematic because of the inequities that already exist in the disability support workforce, and the lack of intent to address these inequities in the disability support system through the system transformation currently underway. This article argues that the flexible, high-quality and personally responsive support promised by Mana Whaikaha is under threat because of the lack of regard for the impacts on the workforce, including attention to workforce planning to support this initiative. The article is set out as follows: the impact of individualised funding on the workforce, as evidenced internationally, is reviewed; the historical background to individualised funding in Aotearoa New Zealand is then presented; the article then discusses how the way in which Mana Whaikaha has been developed and implemented may have negative impacts on the workforce, and subsequently the success of the programme itself.

International experiences of individualised funding

Care and support work has been treated as a physical interaction – providing the basic physical support people need to survive. This is due to increasing policy focus on efficiency and cost reduction arising from the marketisation of care work (Macdonald, 2021). Part of the focus on physical and transactional support has been the removal of the sense of how the person providing support and the person receiving it are, in fact, working reciprocally, thus overlooking the importance of relational care (Dew et al., 2013). Indeed, support could be viewed as a production process, in which both parties are co-producers of the end product (Austen and Jefferson, 2019). Arguably, the care and support system that we have in Aotearoa New Zealand, and other countries, removes the agency of both disabled people and the support worker to work together, and in a reciprocal manner that respects each party, thereby disempowering workers and people with a disability.

The work of disability activists to gain more control and choice for people with a disability is part of reclaiming the relational part of care and support. As Cortis et al. note, individualised funding has been introduced after 'decades of activism aimed at: promoting the self-determination of people with a disability; transforming paternalistic, inequitable and unresponsive service delivery models; and expanding services to people whose needs were poorly met under previous arrangements' (Cortis et al., 2018, p.587). Individualised funding is a 'new' approach to funding disability support in which, to varying extents, person-centred care is key. Under individualised funding, people with a disability are empowered to determine what type of support they need and how it is provided (Fisher et al., 2010). Ideally, individualised funding takes into account the disabled person's circumstances, their strengths and the context of their family and social networks (Dew et al., 2013).

Individualised funding, therefore, responds to the human rights concerns of disabled people, enabling them to be self-determining, empowered and to take part in life (ibid.; Macdonald, 2021). However, individualised funding for people with a disability has also arisen within the policy environment that marketised care, focusing on efficiency and cost reduction. Thus, current versions of individualised funding have emerged out of two parallel arguments that can be taken to focus on individuals: first, the marketisation of care that has been driven by women's entry into the labour market (and therefore lack of 'free' care) and neo-liberal policy drivers since the 1980s; and arguments based on human rights (Macdonald, 2021) which can be misconstrued to be about individuals only, rather than the collective rights of groups of people who have been historically marginalised.

Support provision under individualised funding internationally has remained stuck in neo-liberal concepts of individual choice. This has been done without consideration of the context in which many will not be resourced to manage their own support and care, and in which large for-profit companies are often the dominant care and support providers (Austen and Jefferson, 2019). Indeed, individualised funding as it has been implemented in various countries holds the prospect of further marketisation of care and support, reducing costs for government as it steps further out of the provision of care and support (Macdonald, 2021). Individualised funding, therefore, entails inherent conflict between the radical personalisation and empowerment aims of disability advocates and the ongoing neo-liberal policy approach to care and support (Williams and Dickinson, 2016).

Individualised funding policy changes have been promoted on the basis that they increase choice and flexibility, but this is a rhetoric that does not always play out in actual funding. Most indications are that individualised funding improves the quality of life of many of those disabled people who engage with it. However, individualised funding is also constrained by the pricing models set by funders. In Australia, pricing models were set without inclusion of disabled people or unions and based on the cost of engaging 'entry-level' support workers with little or no training and experience (Cortis et al., 2018; Hall and Brabazon, 2020). Entry-level care does not include relational elements of care and support, nor the skill and knowledge required of support workers to note and respond to a service user's emotional state and needs, and to personalise and adjust the care accordingly. Furthermore, the pricing and resourcing of individualised funding often does not include the time and skill involved in workers' regulatory labour, such as administrative tasks, incident reporting, training and supervision (Van Toorn and Cortis, 2022). There is some evidence that the introduction of individualised funding models is associated with greater demand for support workers that has not been planned for by funders, thus reducing the possibility of the promised flexible support (Macdonald, 2021). Research indicates that, at least in the short term, disabled people may not be getting what they need from services (Cortis and van Toorn, 2020).

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Just as individualised funding models have underpriced the relational elements of care and support work at the micro level, they have also threatened existing community networks and relationships, as evidenced in Australia. Funding models in Australia have encouraged larger providers to move into the market, thereby squeezing out some more local providers (Stampooulis-Lyttle, 2019). As smaller, often not-for-profit providers have been pushed out of the market (Macdonald, 2021), their working relationships and networks with community and other organisations have been lost (Austen and Jefferson, 2019; Stampoulis-Lyttle, 2019). The shift away from smaller, local providers to larger providers, alongside increased demand, has had immediate impacts on the workforce and ability to provide the kind of support promised by individualised funding.

Support workers in an individualised funding environment need a range of skills that are not covered by 'basic work' costing models. Skills such as service user-focused skills, decision making and risk management, as well as the above-mentioned regulatory labour, become more important under individualised funding (Moskos and Isherwood, 2019; Cortis et al., 2018). Support workers also have an important role in 'safeguarding' and reporting on behalf of their service users, which is not recognised in pricing and funding models (Cortis and van Toorn, 2022). Disabled people are more likely than abled people to experience family or intimate partner violence, and are less likely to know how or be able to access information and support should they experience family violence (Ministry of Justice, 2022). This means that support workers, especially under individualised funding, can have an important role to play that requires skill, judgement and knowledge in order to know how to respond to and support disabled service users where there is family violence. This requires training and ongoing organisational support, which is not recognised in low-cost pricing models.

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There is emerging evidence that in Australia, while some providers do provide additional training, it is sporadic (Moskos and Isherwood, 2019). Furthermore, evidence suggests that due to demand for support workers, and perhaps also to minimise costs, inexperienced and untrained workers are recruited to fill shortages (Macdonald, 2021). These recent findings in Australia echo earlier work that found that individualised funding with flexible support worked best in areas that had high migrant numbers – in other words, a greater pool of workers whose choices are constrained enough to encourage them into low-paid work that has uncertain or anti-social hours (Ungerson, 2004).

As mentioned above, funding models for individualised funding in Australia, and in the United Kingdom, have been introduced at a low-cost level, not taking into account the full costs of providing a highly skilled, trained and flexible workforce. This has an impact on quality of care in the short term, but also the longer term, especially as individualised funding models are often implemented without national oversight for workforce development and planning (Macdonald, 2021; Moskos and Isherwood, 2019). Importantly, pricing has not factored gender discrimination into costing of wages (Cortis et al., 2018). In practical terms for workers, aside from greater health and safety risk, there is a greater financial cost as they may need to spend personal money on work-related costs – such as phones and internet plans, purchasing things they wouldn't otherwise purchase when accompanying service users (such as food, parking, activities), and buying things for service users – that is not always reimbursed. Unsurprisingly, 2020 research indicated that nearly half of disability support workers surveyed in Australia disagreed with the statement that 'the NDIS has been positive for me as a worker' (Cortin and van Toorn, 2020).

Individualised funding as a result of collective action for the rights of disabled people is a huge step forward for disability support. However, when taken up by policymakers in our neo-liberal policy environment of marketised care, 'individualised' is used to sell a sense of choice of high-quality support that may not be backed up by adequate funding, resourcing and workforce. This is underpinned by funding models that underestimate the cost of care, and of flexible, high-quality support. Indeed, it could be argued that rather than address the needs of disabled people, in this environment models of individualised funding become another vehicle to reduce the costs and responsibility of state-funded care and support (Macdonald, 2021). International research already shows that individualised funding is more often than not implemented on a low-cost basis, and fails to take into account how a trained, well-supported workforce is integral to high-quality, flexible support. Through a shift to 'individual' responsibility, funders' role in workforce planning and development is often abdicated with the introduction of individualised funding, and a shift away from national oversight of the implementation of its policy. This has had both short-term and long-term consequences for how much individualised funding can actually empower disabled people.

Aotearoa New Zealand's path to individualised funding

New Zealand has been on a long path towards supporting people with a disability to live in the community, beginning in the early 1970s with the deinstitutionalisation of disability support. Key to these developments was the 1972 introduction of the accident compensation (ACC) scheme, with individually targeted assistance to those people with a disability caused by an accident. A second important milestone was the passing of the Disabled Persons Community Welfare Act in 1975. This Act provided the statutory right to support for disabled people, who were not ACC claimants, to enable them to access services and help them stay in the community through respite care, home help, the provision of aids and appliances and vocational training. Little has changed, it seems, in how funding is devolved by way of service contracts through a government ministry or agency to regional health boards and to private providers of disability support services, setting in place a lack of central oversight, and some distancing of government from responsibility for the service.

Attempts at individualised funding have been underway since 1998, when individualised funding for some people with disabilities who have high health needs was introduced. However, this was stopped by the Ministry of Health following an inquiry because of concerns about inconsistent management and use of the funds (Social Services Select Committee, 2008). The same inquiry revealed that under this iteration of individualised funding, disabled people reported feeling that they had little control over the services they received, and the funding was relatively inflexible. The inquiry also reported that the Ministry of Health was considering expanding individualised funding and improving access to it. It noted that individualised funding requires greater involvement of disabled people and their families in decision making, and that it does not resolve all issues with disability support, particularly the availability of 'good' support workers.

Further work by the Ministry of Health resulted in the implementation of several trial projects: the 2011 New Model for Supporting People with Disabilities demonstration project in the western Bay of Plenty, followed by Choices in Community Living projects in Auckland and Waikato. This process resulted in the Enabling Good Lives report (Ministry of Social Development and Ministry of Health, 2011) and model of individualised funding, which was trialled in Christchurch in 2013 and in Waikato the following year. In February 2017, Cabinet directed the ministries of Health and Social Development 'to work alongside the disability community to design a process for a nationwide transformation of the disability support system that would be based on the EGL vision and principles, and underpinned by a social investment approach' (Office of the Minister for Disability Issues and Office of the Associate Minister of Health, 2017a). It is worth noting that these initiatives were under a National-led government, whose approach to social investment was not one of fully funding services, but instead included a narrow 'cost' versus investment approach (Rosenburg, 2015).

The roll-out of the new system commenced in Manawatū in October 2018, under a Labour-led government. In November 2021 the government announced the setting up of a Ministry for Disabled People and the national roll-out of the Enabling Good Lives programme as Mana Whaikaha. This has been cemented through funding allocated in the 2022 Budget for the roll-out of Enabling Good Lives, and through extra funding for disability support services and the establishment of the ministry (Sepuloni, 2022).

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The aim of Mana Whaikaha is to create greater choice and control for people, and 'universally available' support. It purports to use a 'try, learn, adjust' approach to implementation, implying that it is flexible if implementation does not work as anticipated. Although Mana Whaikaha is presented as a single 'system', it comprises several government and other agencies. Prior to its national implementation, Mana Whaikaha comprised two teams located in different government agencies: the kaitūhono/connectors team, employed directly by the Ministry of Health, and the tari/system team, who are employed by Enable New Zealand (contracted by the Ministry of Health). Connectors work with the disabled person to develop their goals and plans and identify the government agencies and support that will enable them. Mana Whaikaha itself does not provide support; rather, it offers a single point of contact, information and funding (combining funding from the ministries of Health, Social Development and Education) for disabled people. Therefore, multiple for-profit and not-for-profit organisations are identified that can be contacted to provide disability support. Additionally, disabled people can choose to use a 'broker' organisation to manage their support provision.

One core element that has been neglected in the development of these programmes is the workforce. Evaluations of the earlier Enabling Good Lives projects (Office for Disability Issues, 2014) identified employment challenges, but did not seek any involvement or feedback from support workers or their unions. Rather than being seen as core to providing flexible, high-quality support, support workers have been on the periphery of considerations in the system transformation. Indeed, clear involvement of support workers and their unions in the development of individualised funding was not started until the instigation of the workforce working group in 2018, which included the Council of Trade Unions, E tū and the Public Service Association. This working group was then suspended in 2020 until late 2021, the two years prior to national implementation of Mana Whaikaha. The lack of consultation, as a minimum, with support workers is particularly startling given that the need to protect workers' rights was noted early in the development of Enabling Good Lives (Office of the Minister for Disability Issues and Office of the Associate Minister of Health, 2017b) and that the Health and Disability System Review (Health and Disability System Review, 2020) also noted that poor working conditions, low wages and low qualification levels were key issues for the care and support workforce.

The impact of individualised funding on the care and support workforce in Aotearoa New Zealand

Disability support workers have struggled to gain decent work conditions. Their unions have represented them in legal actions, including: the 2011 sleepover case, which saw support workers doing sleepover shifts being paid at the minimum wage for every hour worked rather than a $30 allowance, and sleepovers recognised as work; the in-between travel settlement which guaranteed home and community support workers at least the minimum wage for their travel time between service users' homes (extended in Budget 2021 to be their regular wage for this time) (Ministry of Health, 2021a); and the pay equity settlement, which saw raises for the predominantly female workforce of between 15% and 50% (Ministry of Health, 2021b). Additionally, collective agreements include provisions superior to the minima that are legislated for, and unions provide advocacy and dedicated support for workers who are invisible in other respects.

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However, implementation of some of these legal initiatives has not been consistent, nor to the letter of the law (Douglas and Ravenswood, 2019; Ravenswood and Douglas, 2021). Indeed, as this was being written, support workers had to fight again (as yet unsuccessfully) to have their wages won through the 2017 pay equity settlement maintain relativity with the minimum wage, let alone gender equity, and avoid another entire pay equity process under the amended Equal Pay Act (Ravenswood, 2022). These struggles are for workers employed under the current system of disability support, not under individualised funding, where support workers risk working as 'contractors' and therefore without the protections afforded employees under the Employment Relations Act 2000, and potentially unable to access gender-equal wages resulting from settlements for employees.

Providing flexible, empowering care not only creates better life opportunities for disabled people; it is also rewarding for support workers, who often feel that funding and organisational constraints prevent them from delivering high-quality care (Macdonald, 2021; Ravenswood, Douglas and Ewertowska, 2021). Unions, such as the PSA, support the Enabling Good Lives principles (Public Service Association, 2018) and have recommended that a well-trained and properly paid workforce is critical for this programme to provide the high-quality support it promises. E tū recommended that the funding model both increase the flexibility for people with disabilities and health conditions towards a more person-directed approach, and retain a workforce that provides these services that has not been either casualised or required to be contract workers (E tū, 2020).

In addition to the above, some other examples also suggest that individualised funding will worsen the situation of support workers. First, there is evidence that family carers are often forced to work for below the minimum wage and need to top up the funding from their own resources (Murray and Loveless, 2021). Second, anecdotal evidence suggests that disability support providers offering individualised funding are experiencing labour and skills shortages and that there has been little ability to cover planned or unplanned absences, with the consequence that service users do not receive the support they need, and indeed have funded. Finally, there is little, if any, consideration or inclusion of the disability support workforce in the development of the funding model for Mana Whaikaha.

Conclusion

As outlined above, evidence from Australia and the UK shows that social justice goals will not be met if pricing models are underpinned by an approach that focuses on cost efficiency, and a gendered view of care as low-skill, low-cost (Cortis et al., 2018). Relational elements of disability support are key to individualised funding, and this is often overlooked in costing out funding models (Dew et al., 2013). Indeed, consideration of the workforce, gender equity, training and workforce planning have often been left out of the development of individualised funding models (Cortis et al., 2018; Macdonald, 2021; Moskos and Isherwood, 2019). This has resulted in labour and skills shortages, some of which has been noted already in the Enabling Good Lives trial projects in Aotearoa New Zealand, and consequently in a lack of available support for disabled people.

Mana Whaikaha is set up with a 'try, learn, adjust' approach. It is crucial at this juncture that early lessons around funding caps and central coordination of support workers are addressed. The new system change for healthcare and the creation of the Ministry for Disabled Persons is the perfect opportunity to ensure that funding for Mana Whaikaha is based on what is needed to provide high-quality, individualised support, including good working conditions, workforce planning and development. It provides the opportunity to also begin to shift these services to a more centralised operation, perhaps moving away from multiple for-profit funders that operate on contract to various government agencies and ministries. However, a shift to centralised services should take into account the need for local delivery, and the relationships and knowledge that are built up by small, locally based not-for-profit providers. This is an important issue which must be addressed in policy development, but is outside of the workforce focus of this article. These changes would address the lessons learned internationally, and here, that individualised funding can increase the number of for-profit operators in the market, which is associated with a loss of community knowledge and networks (Austen and Jefferson, 2019; Stampoulis-Lyttle, 2019), worsening work conditions and increasing casualisation of the workforce (Macdonald, 2021), with subsequent impacts on quality of support when untrained, inexperienced and underpaid support workers are the main source of disability support.

When individualised funding is sold as flexible, empowering and new, but underpinned by an approach that is really aimed at cost efficiency (Macdonald, 2021; Williams and Dickinson, 2016), it shifts considerable risk onto individuals: people with disability and their family, and support workers, all of whom subsidise underfunded state care with their own skills, knowledge and time. Furthermore, workforce issues such as coordinated, quality training, general oversight and coordination, which are barely achieved currently, are further overlooked under these kinds of models. Now is the time to adjust the approach through: ensuring that support workers' voices are included in the development and implementation of Mana Whaikaha; reassessing the pricing and funding models to recognise the value and costs of a skilled workforce to provide high-quality, flexible and personalised support; and creating national systems for workforce planning and development, as well as for monitoring employment conditions of this workforce. Constrained funding sold as greater choice and flexibility risks pitting disabled peoples' rights against workers' rights without addressing the elephant in the room, that the funding is not sufficient to create the environment needed for disabled people and support workers to enjoy quality of life, economic and social opportunity and social justice.

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