

Negotiating New Disability Practice Contexts: Opportunities and Challenges for Social Workers

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Introduction

There are major paradigm shifts under way that are reframing how disability is understood. Disabled activists internationally have led conversations about disability that promote a human rights approach to disability (Shakespeare 2014). In 2006, the United Nations finalized the Convention on the Rights of Persons with Disabilities (United Nations 2006) and the Optional Protocol (negotiations included disabled people from UN member states). The Convention confirms that disabled people have the right to self-determination in all aspects of their lives: to not be discriminated against, to live in the community with their family, to access universal services including health and education, to have employment and economic security, and to access additional supports to enable them to fully participate as citizens in society. The challenges from disabled activists over the last three decades and the development of the UN Convention have required a significant rethink in how disability support and services are understood internationally (New Zealand Disability Support Network 2015, 2016; United Nations 2006).

The New Zealand Disability Strategy 2016–2026 outlines how government will implement the Convention, addressing areas that require legislative as well as policy changes and new initiatives. Specifically, Outcome 7: Choice and Control requires that ‘Disabled people are consulted on and actively involved in the development and implementation of legislation and policies concerning supports and services that are both specific to them and for the mainstream’ (Ministry of Social Development 2016, p.37). There is currently

focus on transforming the Aotearoa New Zealand disability service system based on an approach called 'Enabling Good Lives.'

'Enabling Good Lives' embraces notions of choice and control along with the advent of personalized budgets and is already having emancipatory and empowering impacts on how disabled people and families see the world of support services and funding (Anderson, Ferguson and Janes 2014; Anderson, Janes and Pope 2015; Elder-Woodward 2016; Were 2016, 2017). As a result, markedly different roles and new relationships are being demanded from practitioners and, increasingly, practitioner roles are being filled by disabled people as part of an emerging services by and for disabled people/families paradigm.

However, these changes can also be a double-edged sword as the language of individualization, self-direction, and personalized budgets is readily adopted (some would say appropriated) in an economic and social policy context which is dominated by neoliberal narratives. These narratives regard disabled people as social investment liabilities alongside the ever-present prospect of government austerity (Brookes *et al.* 2015; Runswick-Cole and Goodley 2015). Unintended consequences can emerge as disabled people and families find themselves as a new cohort of consumers in a complex and ever-changing provider market place (Jackson 2005), with a degree of purchasing power constantly under threat from the possibility of government austerity measures. These measures make the possibility of the *good life* just as elusive as it has always been (Power 2014). For disabled people and family members in newly acquired practitioner roles there is the prospect of some challenging dynamics to navigate in a newly emerging service system that they were instrumental in advocating for, but which may struggle to realize its original intentions. An example involves practitioners being required to operate within all too familiar financial constraints that impact on their ability to meet the needs and aspirations individuals have identified in their plans.

For current practitioners who do not have lived experience (as disabled people or family members) there are some emerging uncertainties about future roles and how the social work profession needs to respond to the shift in power relations brought about by service system transformation. There is a consequent need to reassess the training and preparation of social work practitioners internationally who intend to work in these newly emerging service settings and to ask some searching questions about who should be driving the content and future development of qualifications and training (Jeon *et al.* 2015; Williams, Porter and Marriott 2014).

The 'Enabling Good Lives' programme is presented as a case study of emerging disability theory and practice. To explore how new social

work roles, relationships and power dynamics might be negotiated by practitioners, including those with and without lived experience of disability, it is useful to describe key roles in the current service system and then to explore emerging theories that inform the 'Enabling Good Lives' principles and consequent system transformation. This provides a context for a discussion of new and emerging roles and how social workers (with and without lived experience of disability) might contribute in the transformed service system that is envisaged for Aotearoa New Zealand. Other challenges that are likely to occur from this system transformation will be explored, and some reflection questions are posed at the end of the chapter for the reader to ponder their position and ability to respond to significant system changes.

Current roles in the service system

While the focus of the discussion here is on the Aotearoa New Zealand disability service system, similar service developments are being experienced internationally. For example, in Australia the National Disability Insurance Scheme was launched in July 2013 (Australian Government 2013), following years of discussion about the need for a major reform of disability services.

As in many other jurisdictions, there are a number of roles in the current disability service system in Aotearoa New Zealand where social workers have traditionally been employed. Key tasks in these roles include providing information, advocacy, referral/intake, assessment, planning and service coordination, and family support. Disability-specific service providers frequently employ people with social work backgrounds as field officers or service coordinators who provide support to access information and services. Needs Assessment and Service Coordination (NASC) agencies are specific providers funded by government to act as the gateway for access to funded services in a specified locality (Ministry of Health 2015). The focus here is assessment for eligibility for funded services and coordination support to access services once eligibility is determined. Needs assessors and service coordinators often come from social work backgrounds.

The current service system in Aotearoa New Zealand is characterized by procedures for assessing eligibility for a pre-determined menu of services based on a set of historical assumptions about what disabled people and families need and when. Providers are contracted (and bulk funded) to provide these services based on rigid service specifications. The opportunity for disabled people and families to think and plan outside

existing services is limited due to other options not being available in their region, or where providers cannot provide supports that go beyond the parameters of the service specifications in their contracts (Ministry of Health 2017). Social workers are frequently employed in this system in gatekeeping roles where key tasks are focused on assessment and determination of eligibility for funded services and then coordinating access to these.

The system is slow to respond to innovation and the best that some people experience is being on a waiting list for a service that, ultimately, may only be a limited version of what they really need or want. The system is entirely orientated to conceptualizing what people need only in terms of highly specified and pre-determined services, thus home supports are bundled as hours for home management, personal care and/or supported independent living and are largely delivered in the person's home. Disabled people and families also experience multiple assessment and planning processes, once to get access to the service system as a whole and then again with each service provider they subsequently encounter. The primary contractual relationship (and therefore locus of control) in the system is that between the government and the service provider, not between the disabled person/family and the service provider.

In this system, those in social work roles are overwhelmingly people without lived experience of disability and are more often than not regarded by disabled people and families as access guardians acting either on behalf of individual providers or on behalf of the state in terms of access to the system. If they are seen as advocates and allies it is usually framed in the context of support for gaining eligibility and access to existing services, not in imagining or creating a personalized or bespoke vision of what a *good life* might entail. For example, a person may request an allocation for support so they can participate as a volunteer at the community library only to be told that the only way they could be supported is to attend the library as part of a group activity. Nevertheless, there are some roles where advocacy and being an ally are to the fore, particularly with non-government organizations that do not provide government-contracted services. Such organizations are few in number and, as not-for-profit organizations, they rely on donations and operate on a fee-for-service basis, enabling them to be independent.

Emerging theories: enabling good lives and system transformation

The notion of personalized or individualized support directed by disabled people and/or families has been a narrative within and around disability services in jurisdictions such as the UK and Canada, as well as in Aotearoa New Zealand, for almost a generation (Kendrick 2009; Ministry of Health 2011). A theory of person-directed support has its origins in a drive to de-institutionalize community services based on the now widespread recognition that disabled people so often tend to be *in* and not *of* the community. They are passive recipients of pre-determined service options and not active, contributing and participating citizens pursuing their own personal vision of what a *good life* might be (DeCarlo 2016). Central to these initiatives has been the choice and control that is assumed to flow from having access to a personal budget, either directly or indirectly, through an agent of some kind.

Internationally, various models and approaches have been promulgated to translate these concepts into practice, often with variable levels of success (Kendall and Cameron 2013; Junne and Huber 2014; Mitchell, Brooks and Glendinning 2015; Moran *et al.* 2011; Salsberg *et al.* 2014). Much of this work has often occurred in isolated pockets due to the emergence of local leadership, and any success has usually been in spite of rather than because of the administrative and funding systems that support disability services. Where a *whole-system* approach has been developed, it has usually been limited to specific localities or restricted to specific funding components or cohort populations of the service system. These initiatives have often functioned as demonstrations and pilots that are tacked on to the existing system. Many have foundered or not moved to more widespread implementation due to bureaucratic inertia and the administrative challenges associated with scaling things up and the perceived financial risks associated with doing so (PricewaterhouseCoopers 2012). These perceived financial risks come in the form of either increased costs to the service system as a whole or the political risks associated with the possibility that disabled people and families will mispend or squander tax payers' money.

Nevertheless, despite these challenges, since 2003 the Aotearoa New Zealand context has seen a base of experience develop around the use of personal budgets through the Ministry of Health (for people disabled through non-injury related causes). This has been through the trialling and implementation of individualized funding, with coaching and other support offered through host agencies (Ministry of Health 2011).

However, the scope and availability of these options has meant that the overall uptake to date has been little more than 10 percent of the potentially eligible population. Like other jurisdictions, national scale implementation has been limited to specific population cohorts or funding components of the system.

An example of system-wide change is the establishment of the National Disability Insurance Scheme (NDIS) in Australia (Australian Government 2013). A transformation that is national in scale, it attempts to bring together a theory of person-directed support with system architecture that supports and encourages this in practice. This is a response to a system that was emphatically regarded by nearly everyone as broken. Implementation of the scheme is creating widespread turbulence and varying degrees of uncertainty for all participants, including disabled people, families, service providers and the administrators of the scheme. While there are some promising developments, the scheme will clearly take some time to embed so that all key stakeholders can participate with confidence (Green and Mears 2014; National Disability Services 2017).

Disabled people, service providers and policy makers in Aotearoa New Zealand have also developed similar aspirations. While there is not the same sense of a *burning platform* as experienced in Australia, there has been a gathering momentum and consensus that some kind of step change is needed if the disability service system is going to be more responsive and enable a person-directed approach in practice.

In 2008, a Select Committee Inquiry (Social Services Committee 2008) was held as a response to some serious shortcomings in the disability service system. It found that the system was not orientated to serving the interests of disabled people or families. System change was needed if their choice and control over what happened with disability services and supports was to be central.

A Ministerial Working Group was established in 2011 and developed a vision they called 'Enabling Good Lives'; this initiative was underpinned by a set of eight fundamental principles:

1. Self-determination – disabled people are in control of their lives.
2. Beginning early – investing early in families and supporting aspirational thinking about what they want for their child.
3. Person-centred – supports that are directed by, and are tailored to, an individual's needs.
4. Ordinary life outcomes – living an everyday life in everyday places.

5. Mainstream first – support to access mainstream services before specialist disability services.
6. Mana-enhancing – a Maori (indigenous) concept referring to respecting and recognizing a person's abilities and contribution.
7. Easy to use – supports that are simple to use and flexible.
8. Relationship building – supports build and strengthen relationships between disabled people, family and community.

(Cabinet Social Policy Committee 2017)

In 2012, the government signalled the prospect of fundamental change to the disability service system in the section of the New Zealand Disability Action Plan headed 'Shared result: Transform the disability support system' which is informed by the 'Enabling Good Lives Principles'.¹ An 'Enabling Good Lives' National Leadership Group was established to provide guidance and oversight. This group was made up primarily of disabled people and family members; it still exists today. These developments collectively established the links between 'Enabling Good Lives' (as a theory of change) and 'System Transformation', the leadership role of disabled people and families, and the support of government for change.

Since 2012 a number of pilots, demonstrations, and trials have sought to test various elements of what a transformed system might look like. As the result of this activity and several evaluations, along with a consideration of international experiences, some basic building blocks of a transformed system were arrived at which were in turn used as the basis for some initial high-level design work. This work has provided the central components of a transformed system (Anderson *et al.* 2014, 2015; Cabinet Social Policy Committee 2017; Were 2016, 2017). Further detailed design work continues to be undertaken. The new system was implemented in the MidCentral region of New Zealand's North Island² on 1 October 2018, and will be followed by staged implementation across the rest of the country from 2020.

Throughout the design phase, the role of disabled people and family members has been to the fore. A co-design and co-governance approach was adopted whereby a specific proportion of roles was reserved for disabled people and family members on all working groups looking at

1 See www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/long-term-change-september-2012, accessed on 17/09/2018.

2 See www.midcentraldhb.govt.nz/AboutMDHB/Pages/Geographic-Area-and-Population.aspx, accessed on 17/09/2018.

both design and implementation (Cabinet Social Policy Committee 2017). This has not been without its challenges in terms of sourcing enough people with the time, experience and knowledge to contribute. However, it is also providing an enormous opportunity for a large group of people with lived experience to explore the world of disability policy and service development for the first time. Having disabled people and families as active and integral participants in both co-design and co-governance has established a bedrock not only for the design of a transformed system, but also for its implementation and ongoing operation.

Some essential components of a transformed service system informed by the 'Enabling Good Lives' principles are now emerging:

- *Independent facilitation-based support and planning* that actively supports self-direction so that disabled people have greater choice and control over their lives and support. A process that supports and encourages disabled people and families to imagine and navigate different futures that are not constrained by the current service system. People are considered in their wider context, not just in terms of formal support services.
- *Personal budgets* that are drawn from cross-government pooled funding that enables flexibility and self-directed purchase of supports and services.
- *A range of management options* that enables a person to determine how much or how little self-management they undertake in relation to their personal budget, and creates opportunities to easily change management options over time.
- *Accountability arrangements* that are proportionate to the size of a personal budget.
- *Investing in disabled people and families* so that they can participate in a transformed system with confidence and know how to maximize their choice and control.
- *A community facilitation and community building approach* that actively assists and supports disabled people to be valued and contributing citizens with an everyday life in everyday places. An approach that does not merely assimilate but changes the nature of the *mainstream* community so that it responds readily to diversity.
- *Access to independent advocacy* for those people who do not have families and personal networks or who rely on others to support

their communication and decision making. Independent advocacy is focused entirely on the best interests of the person.

- *Co-governance arrangements and protocols that involve disabled people and families* at regional and national levels in the design, operation and evaluation of the service system.

Collectively, these components offer both a theoretical and practical framework for understanding the rationale for change and how it might be implemented. In addition, they signal that new skills and approaches are required by practitioners working in the disability sector, and that entirely new roles will need to be developed.

New roles: contribution, partnership and negotiation

Given the components of a transformed service system, assumptions can be made about the opportunities social work practitioners might assume and regard as simple variations on current roles. For example, facilitation and navigation roles, independent advocacy roles, professional development roles and participation in evaluation activities. Such assumptions would be mistaken for two reasons:

1. The notion of co-governance means that increasing numbers of disabled people and family members themselves will be looking to assume practitioner and leadership roles in these very same areas – as well as in the delivery of support services – and thus demanding access to resources that can enable them to do so.
2. The concept of self-direction means that not all current (and mostly non-disabled) practitioners will easily adapt to an environment where the power and decision making are shifting from those who deliver services to those who use (and purchase) services. There is a significant difference between providing support *to* or *for* disabled people and walking alongside someone where the decision making about what, who, how and when rests with the person. New relationship dynamics and ways of thinking and working are required.

This is not to suggest that all social workers will struggle with what is essentially a paradigm shift in the dynamics of power that frame disability support and services. There is no doubt that given the origins of social work and its commitment to social justice and the challenging of marginalization and inequality, many social workers will already have

an embedded understanding of these changing relations of power. These social workers are largely seen by disabled people and family members as allies in their struggle for access to appropriate support and services. However, there will be a number of social workers who are challenged by the territory of change and how to traverse a new landscape of roles and relationships.

Non-disabled social work practitioners will be required to negotiate their way through a system that increasingly features services *by and for* disabled people. Lived experience as either a disabled person or family member will more frequently become a prerequisite for roles that have traditionally been regarded as the domain of (mostly) non-disabled social workers, as facilitators, planners, coordinators, evaluators and trainers as well as leadership roles in management and governance. There are readily observable parallels to these developments in the wider Aotearoa New Zealand context. We have seen the widespread emergence over the past two decades of Kaupapa Maori services – these are education, social and health services *by Maori, for Maori* (Pipi *et al.* 2004). Whānau Ora is a Kaupapa Maori approach that is based on the premise that whānau (extended family) should be directly resourced so that they can make the critical decisions about supports and services. A navigator provides a support role to explore possibilities and put together a plan (and a budget) that reflects the whānau's decision making and priorities (New Zealand Productivity Commission 2015). There are some very clear similarities between this approach and the concept of independent facilitation and access to personal budgets envisaged for the disability system transformation project.

The emergence of a practitioner workforce made up of disabled people and family members with lived experience does not mean that current (and largely non-disabled) social workers in the disability field are going to be entirely displaced. What it will mean is that the recruitment of social workers will increasingly be in the hands of either disabled people and family members themselves (through their personal budgets as users, and therefore a growing cohort of employers) or because disabled people and family members will be in leadership and governance roles with employing organizations. There will be times when there will be an explicit preference for someone with lived experience. An example is the independent facilitation role which is envisaged as the new front end or entry point to the disability service system. A recurring theme expressed by many (but not all) disabled people and family members is the need for this first point of contact to be a peer, someone with whom they can identify as having a similar lived experience.

The contribution of social workers without lived experience will need to focus increasingly on a *negotiation* to partner and collaborate with this emerging group of practitioners who do have lived experience. Central to this will be the need to create empowering environments where disabled people and family members are welcomed, can explore and take the opportunity to prepare, train and be supported into roles traditionally reserved for non-disabled practitioners. Creating empowering environments means organizing, designing and structuring learning and working environments that remove access barriers to the participation of disabled people and family members (Schalock and Verdugo 2013).

In preparing practitioners for disability practice contexts, social work training programmes need to consider how they ensure that courses and qualifications are accessible to disabled people and family members. Their participation in these programmes is critical to establishing a sustainable core of qualified social work practitioners with lived experience. Prioritizing the appointment of academics who are disabled or who have lived experience as family members to key roles in relevant course development and delivery is another critical dimension to ensuring that collaboration and partnership are embedded into leadership roles in these programmes. Having people with lived experience in these roles sends powerful messages around relevance and accessibility to aspiring practitioners and academics who are disabled. Equal opportunity and affirmative action approaches could be developed to address current inequities, both for students and staff, in social work education programmes.

In Aotearoa New Zealand, the employment rates of people with lived experience working in disability service settings where social work roles occur is about the same as for the general labour market, even in those agencies where disability employment services are the focus of delivery (Te Pou o te Whakaaro Nui and New Zealand Disability Support Network 2016). Participation in leadership, management and governance roles occurs at an even lower rate. The same can be said of government agencies where the focus of activity is disability-related policy and services. Disability services focused on areas like advocacy, audit and evaluation tend to follow the same trend. Undertaking accessibility audits and the meaningful implementation of diversity programmes with a disability focus are urgent priorities in these contexts. There are a range of well-established approaches that could be drawn on to address current shortfalls, including prioritizing students with lived experience for practicums, internships and leadership development initiatives (for management and governance roles), and promoting equal employment

opportunity policies and affirmative action programmes. Again, seeing people with lived experience in frontline social work roles as well as in leadership and governance roles collectively sends important signals about shifts in power and the likely relevance of services for disabled people and families.

Both government and non-government employers can also reposition power dynamics by ensuring that people with lived experience are trained and supported into advisory, audit and evaluation roles within their agencies so that the voices of those who use services and programmes are central to decision making about their design and quality. These opportunities can often be the beginning of a career in the disability sector (and lead to training and qualifications in areas like social work) or could be employment opportunities as the result of undertaking such training.

A natural extension to having these opportunities is that disabled people and family members develop the skills and knowledge needed to establish and run their own programmes. Those who currently hold the power (funding, contracts, knowledge and skills) have important roles to play in facilitating and supporting the development of services by and for disabled people and family members.

Social workers without lived experience (in frontline and leadership and training roles) also have a critical role to play in developing this capability and capacity, as the transfer of knowledge and skills is a transfer of power. For example, practitioners could work alongside and partner with practitioners who have lived experience, supporting the acquisition of social work knowledge and skills (for example, through peer supervision and co-facilitation of services). Educators in social work training programmes could partner in both the transfer of existing knowledge and the creation of new social work theory and knowledge relevant to practice in disability service settings. Finally, social work leaders and managers could structure learning and work environments to be accessible and accommodating to students and employees with lived experience.

Future challenges

The changes being undertaken in 'system transformation' in Aotearoa New Zealand are significant and have relevance for other countries that are also planning system-wide transformation. As we have observed in the Australian scenario with the introduction of the NDIS, there are a number of future challenges at many levels that practitioners need to be prepared for.

Social workers who do not have the lived experience of disability will be required to negotiate a practice arena where the relations of power are shifting. This will be an ongoing challenge and the extent of this challenge will depend on the practitioner's understanding of the changes that are occurring around them and their ability to adapt to and accept a new status quo. Taking the time to reflect on and understand why these changes are occurring and what imperatives are driving them is essential. Doing so will shed light on new values, practices and approaches. Participating in opportunities that support this reflection and learning will be important. This can come in the form of seeking out supervision arrangements that challenge current values and practices and expose the practitioner to new ways of thinking. It will be important for those in social work roles to take up opportunities afforded through concepts like Communities of Practice (New Zealand Disability Support Network 2015, 2016) where facilitated groups of practitioners can learn about, implement and reflect on new approaches. It will also be important to have access to retraining through short courses and qualifications that anticipate the changing practice landscape.

These possibilities for new learning assume that such opportunities will be available. This kind of supporting infrastructure has long been overlooked as a critical component of system redesign, particularly when it comes to embedding innovation as everyday practice. In Aotearoa New Zealand, there is currently some effort to review disability-focused qualifications so that they anticipate and reflect the principles, practices and theoretical underpinnings of 'Enabling Good Lives'. These reviews are also looking at the knowledge and competencies needed to operate in a person-directed paradigm where the focus is on facilitation and community building. There is a need for social work internationally to keep up with the new thinking and practice in education and training if it is to continue to have, and be seen to have, relevance to those in the disability sector.

Another challenge is the development of the role of independent facilitation as the new front end to a transformed disability service system. This role is receiving a lot of attention not only because of its pivotal importance, but also because of the variety of views about who can be an independent facilitator, what constitutes independence and what kind of training and support is needed for the role. How this role is constructed and deployed in a transformed disability system is particularly relevant because it is one that will have a strong interest from those with social work backgrounds. Aside from one's view on what qualifications and training may or may not be needed, the role is a highly nuanced one

requiring a rare blend of values, interpersonal skills and knowledge – about the service system, about community and about the impact of a disabling society.

Independent facilitation requires that one is able to walk alongside individuals and families in a way that enables as much self-direction as possible, but also exposes a person and family to new possibilities and a potential future that has not hitherto been considered. This process can create levels of discomfort and new experiences of dissatisfaction about one's current circumstances, confusion and a sense of powerlessness, but also the opportunity for positive change and a different future. Walking alongside people where they may start with new insights (enlightenment), move towards an understanding that things could change (emancipation) and then decide to exercise more choice and control (empowerment) can be truly transformative (Freire 1970). A practitioner undertaking a facilitation role, in relation to this process, should be guided by a coherent theoretical model of social change that clearly informs and guides practice.

Initiating and supporting people through such a process in an empowering way that respects the current values and worldview of the individual and family is paramount. It is also an enormous privilege and responsibility. The absence of the right approach and values framework can easily result in the imposition of the facilitator's values and worldview or that of the organization they work for, leading to disorientation, disempowerment and a perpetuation of power and control by others in the lives of disabled people and families. It is essential, then, that the independence of the role is about being free not only of the vested interests of organizations (funders and providers), but also of the imposition of the values and worldview of the facilitators themselves. There is a fine balance between respecting people's values and lives and gently introducing new ideas, alternative ways of seeing their world and imagining new possibilities; and then ensuring there is support and respect for a journey of personal or family change that can have unexpected and unforeseen consequences. Thus, independent facilitation is not just about independence from the vested interests of organizations, but also about independence from the vested interests of practitioners in these roles, with regard to how or with whom they are employed. This is a challenge that will be equally relevant for practitioners with and without lived experience.

As with any discussion about vested interests, it will be interesting to see how this narrative about the role of independent facilitation plays out in the context of system transformation. Central to resolving the embedded issues will be some kind of validation process or protocol that ensures the integrity of the role in relation to its perceived and actual independence.

It will be important for those in social work roles to participate in this dialogue. A validation process should ensure exposure to the required values frameworks, ethics, principles, skills and knowledge that underpin the role. The construction of this role and the capability of the practitioners involved are central to the success of system transformation. It will be essential to strike a balance between avoiding the creation of yet another imposed professionalized elite in the lives of disabled people and ensuring that there is a capable and diverse workforce in these roles.

A final challenge worth canvassing is the ethical dilemmas that may confront practitioners with lived experience. Having managed to overcome barriers to training and access to employment opportunities in a newly transformed system they will need to navigate some inevitable realities where the newly emerging system is struggling to match its original aspirations, especially if they have been instrumental in supporting or designing that system. While people may have more choice and control at one level, there will still be rules and guidelines around how and on what personal budgets are spent. These constraints may be the result of system design shortfalls, changing policy imperatives, but also of wider economic changes where government austerity measures could be implemented. Poor market stewardship on the part of the state could also lead to an overly complex marketplace of service providers, with the range and quality as variable as ever.

While navigating such dilemmas would not just be the province of practitioners with lived experience, their ability to straddle the boundary between the aspirations of disabled people and families (and their allies) and the constricting imperatives of the state could be especially challenging. In these circumstances, practitioners can opt for roles where the boundaries are more blurred or where the role is constructed as advocacy or activism. Where the practitioner (with and without lived experience) is on the boundary itself, the power of deeply embedded reflective practice, solid supervision and ethical coherency will be paramount. Examples of boundary roles include those involving decision making about personal budgets, policy and regulatory design, the rationing of resources and broader decisions about eligibility.

While 'Enabling Good Lives' and the 'system transformation' it is informing have the potential to be a step change in how disabled people and families access supports and services, it will not in and of itself transform wider society. One of the 'Enabling Good Lives' principles is *mainstream first*, which speaks to the imperative of participation in the mainstream rather than in services, and the need to build and change communities so that barriers to access are removed. Having access to

independent facilitation and a personal budget will not, on its own, transform society in disabled people's interests.

As with other jurisdictions that have engaged in transformational change in partnership with disabled people, there are wider and deeply imbedded structural issues at work in Aotearoa New Zealand society that create the experience of being disabled. These include the lack of affordable and accessible housing; the absence of accessible transport options; an education system that struggles to be inclusive; and deeply rooted income inequality (New Zealand Disability Support Network 2016). Comprehensive legislative and regulatory developments are required to address these issues and make it possible for disabled people to actually exercise their citizenship rights. Organizations and groups focused on initiatives that seek to address these shortcomings are also opportunities where those with social work backgrounds may have much to offer.

Conclusion

This chapter has described a practice context in Aotearoa New Zealand that is in the midst of major transformation where both practitioners and disabled people are having to increasingly negotiate new roles and relationships based ultimately on a shift in power. This experience parallels developments in other jurisdictions that are aimed at transforming power relations in disability support. The debates and dilemmas for social work practitioners (with and without lived experience of disability) have been explored in the context of a rapidly evolving landscape of service provision where disabled people themselves are forging new roles and relationships with the service system. Some guidance has been offered on how practitioners can navigate this new landscape.

Reflection questions

- Can you identify roles in the disability service system where social workers can have an important role to play? To what extent are these roles on the boundary where the aspirations of disabled people and families meet the state's imperative for rules and regulations about funding and eligibility?
- Reflect on your own values and approaches in relation to the concept of being *person directed*. What changes do you think you might need to consider in relation to how you engage and work

with disabled people and their families? Are there new frameworks and models that you need to explore?

- What roles in a transformed disability service system would be most compatible with your values, skills and goals?
- Reflecting on a social work education programme you are or have been enrolled in, how accessible is it for disabled people and family members aspiring to be social workers? Are there currently any students with lived experience of disability? What changes can you think of that would make the programme more accessible?

References

- Anderson, D., Ferguson, B. and Janes, R. (2014) *Enabling Good Lives Christchurch Demonstration: Phase 1 Evaluation Report*. Wellington, New Zealand: Office for Disability Issues.
- Anderson, D., Janes, R. and Pope, P. (2015) *Enabling Good Lives Christchurch Demonstration: Phase 2 Evaluation Report*. Office for Disability Issues. Accessed on 28/02/2018 at www.odi.govt.nz/nz-disability-strategy/other-initiatives/enabling-good-lives.
- Australian Government (2013) *National Disability Insurance Scheme Act 2013*. No. 20. Australia: Australian Government.
- Brookes, N., Callaghan, L., Netten, A. and Fox, D. (2015) 'Personalisation and innovation in a cold financial climate.' *British Journal of Social Work* 45, 86–103.
- Cabinet Social Policy Committee (2017) *Disability Support System Transformation: Overall Approach*. Accessed on 28/02/2018 at www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/Disability-Support-System-Transformation-Overall-Approach.pdf.
- DeCarlo, M.P. (2016) *Implementation of Self-Directed Supports for Individuals with Intellectual and Developmental Disabilities: A Political Economy Analysis*. Richmond, VA: Virginia Commonwealth University School of Social Work.
- Elder-Woodward, J. (2016) 'Disabled people's independent living movement in Scotland: A time for reflection.' *Ethics and Social Welfare* 10, 3, 252–266.
- Freire, P. (1970) *Pedagogy of the Oppressed*. New York, NY: Herder and Herder.
- Green, J. and Mears, J. (2014) 'The implementation of the NDIS: Who wins, who loses?' *Cosmopolitan Civil Societies Journal* 6, 2, 3915.
- Jackson, R. (2005) *Who Cares? The Impact of Ideology, Regulation and Marketisation on the Quality of Life of People with an Intellectual Disability*. Sheffield: Centre for Welfare Reform. Accessed on 27/02/2018 at www.centreforwelfarereform.org.
- Jeon, H., Mahoney, K., Loughlin, D.M. and Simon-Rusinowitz, L. (2015) 'Multi-state survey of support brokers in cash and counselling programs: Perceived roles and training needs.' *Journal of Disability Policy Studies* 26, 1, 24–32.
- Junne, J. and Huber, C. (2014) 'The risk of users' choice: Exploring the case of direct payments.' *German Social Care, Health, Risk & Society* 116, 7–8, 631–648.
- Kendall, S. and Cameron, A. (2013) 'Personalisation of adult social care: Self-directed support and the choice and control agenda.' *British Journal of Learning Disabilities* 42, 264–271.
- Kendrick, M.J. (2009) 'Some lessons concerning agency transformation towards personalized services.' *International Journal of Leadership in Public Services* 5, 1, 47–54.

- Ministry of Health (2011) *Evaluation of Individualised Funding Following the Expansion to New Host Providers*. Accessed on 28/02/2018 at www.health.govt.nz/system/files/documents/publications/evaluation-individualised-funding-oct11.pdf.
- Ministry of Health (2015) *Disability Support Services: Needs Assessment and Service Coordination (NASC) Organisations*. Fact Sheet. Accessed on 28/02/2018 at www.health.govt.nz/system/files/documents/topic_sheets/needs-assessment-service-coordination-organisations-mar15.pdf.
- Ministry of Health (2017) *Disability Information and Advisory Services and Needs Assessment and Service Coordination Review – A Proposed Design and Framework*. Accessed on 08/02/2018 at www.health.govt.nz/system/files/documents/publications/dias-nasc-review-proposed-design-framework-jan17.pdf.
- Ministry of Social Development (2016) *New Zealand Disability Strategy 2016–2026*. Accessed on 28/02/2018 at www.odt.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf.
- Mitchell, W., Brooks, J. and Glendinning, C. (2015) 'Carers' roles in personal budgets: Tensions and dilemmas in front line practice.' *British Journal of Social Work* 45, 1433–1450.
- Moran, N., Glendinning, C., Stevens, M., Manthorpe, J. et al. (2011) 'Joining up government by integrating funding streams? The experiences of the individualized budget pilot projects for older and disabled people in England.' *International Journal of Public Administration* 34, 4, 232–243.
- National Disability Services (2017) *State of the Disability Sector Report*. Australia: National Disability Services: NDS. Accessed on 28/02/2018 at www.nds.org.au/news/state-of-the-disability-sector-report-2017-reflects-sector-under-pressure.
- New Zealand Disability Support Network (2015) *Investing for Innovation and Quality: A Sector Briefing from NZDSN, the New Zealand Disability Support Network*. Wellington, New Zealand: NZDSN.
- New Zealand Disability Support Network (2016) *Transformation, Inclusion and Citizenship: A Sector Briefing from NZDSN, the New Zealand Disability Support Network*. Wellington, New Zealand: NZDSN.
- New Zealand Productivity Commission (2015) *Appendix C Case Study: Whānau Ora*. Accessed on 28/02/2018 at www.productivity.govt.nz/sites/default/files/social-services-final-report-appendix-c.pdf.
- Pipi, K., Cram, F., Hawke, R., Hawke, S. et al. (2004) 'A research ethic for studying Māori and iwi provider success.' *Social Policy Journal of New Zealand Te Puna Whakaaro* 23, 141–153.
- Power, A. (2014) 'Personalization and austerity in the crosshairs: Government perspectives on the remaking of adult social care.' *Journal of Social Policy* 43, 829–846.
- PricewaterhouseCoopers (2012) *Planning for a Sustainable Disability Sector*. Accessed on 03/05/2018 at www.dss.gov.au/sites/default/files/documents/05_2014/fahcsia_sector_capacity_report_november_2012.pdf_-_adobe_acrobat_pro.pdf.
- Runswick-Cole, K. and Goodley, D. (2015) 'Disability, austerity and cruel optimism in big society: Resistance and the disability commons.' *Canadian Journal of Disability Studies* 4, 2, 162–186.
- Salsberg, C., Watson, N., Beresford, P. and Schofield, P. (2014) 'Personalization of health care in England: Have the wrong lessons been drawn from the personal health budget pilot?' *Journal of Health Services Research and Policy* 19, 3, 183–188.
- Schalock, R. and Verdugo, M.A. (2013) 'Intellectual and developmental disabilities: The transformation of disabilities organizations.' *Intellectual and Developmental Disabilities* 51, 4, 273–286.
- Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited*. London and New York, NY: Routledge.

- Social Services Committee (2008) *Inquiry into the Quality of Care and Service Provision for People with Disabilities*. Accessed on 28/02/2018 at www.parliament.nz/resource/en-nz/48DBSCH_SCR4194_1/cb220d2e3ba25dc33dec0b28b29b30578d110dd5.
- Te Pou o te Whakaaro Nui and New Zealand Disability Support Network (2016) *The New Zealand Disability Support Workforce: 2015 Survey of NZDSN Member Organisations*. Auckland, New Zealand: Te Pou o te Whakaaro Nui.
- United Nations (2006) *Convention on the Rights of Persons with Disabilities and Optional Protocol*. Accessed on 28/02/2018 at www.un.org/disabilities/documents/convention/convoptprot-e.pdf.
- Were, L. (2016) *Summary Evaluation Report Phase One Enabling Good Lives Waikato Demonstration*. Office for Disability Issues. Accessed on 08/02/2018 at www.odi.govt.nz/nz-disability-strategy/other-initiatives/enabling-good-lives.
- Were, L. (2017) *Enabling Good Lives Waikato Phase Two Evaluation Summary Report*. Office for Disability Issues. Accessed on 28/02/2018 at www.odi.govt.nz/nz-disability-strategy/other-initiatives/enabling-good-lives.
- Williams, V., Porter, S. and Marriott, A. (2014) 'Your life, your choice: Support planning led by disabled people's organisations.' *British Journal of Social Work* 44, 1197–1215.

Note

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