

What helps disabled people and their families/whānau to take control of their support and live the lives they want?

Paper prepared for the National Enabling Good Lives Leadership Group

Summary

The paper examines a range of approaches from New Zealand and overseas that help disabled people, and often their families, live the way they want to live and take control over the support they need to do so.

The paper identifies broad themes that are common between different approaches from around the world:

- **Many disabled people and families benefit from developing a vision for a good life.**
- **A plan is often needed to achieve a person's vision**, but effective planning cannot be easily systematised, as it often challenges social and systemic barriers.
- **Disabled people and their families will often need new skills and knowledge to execute their plans.**
- **Relationships within families, with friends, peers and the wider community are essential**, and networks of support may need to be consciously built.
- **Disabled people and families need a strong voice and to speak up for themselves and others** to achieve greater choice and control at a system level.

The paper concludes that building the capacity of disabled people and families to create the conditions of their own lives is an essential role for government and the services it funds. However, such an approach cannot be one-size-fits-all. There needs to be a menu of options available to fit the circumstances of every disabled person and every family.

The purpose of the paper is to identify broad themes that are common to approaches from New Zealand and overseas

The paper identifies common themes from approaches to supporting disabled people and families in New Zealand and overseas. It is not intended to be an exhaustive account, as many good initiatives are poorly documented. Some of the approaches the paper describes have accompanied significant funding and system changes, while others have emerged as innovations before any major shift in system settings.

The need to invest in disabled people and their families has emerged from international trends that emphasise their rights and their strengths

The United Nations Convention on the Rights of Persons with Disabilities (the Convention) requires States to provide the necessary rights, protections and supports to ensure disabled people can participate as full and equal citizens of their society. This rights-based paradigm has been supplemented by strengths-based approaches to support and an international trend to expand disabled people's choice and control over disability supports. These approaches are variously described as personalisation, person-centred planning, cash and counselling, and self-directed support (Carr, 2012).

In New Zealand, Enabling Good Lives, an approach developed by an independent working group representing the disability sector, is guiding a similar movement toward greater choice and control. Two of the areas for long-term change under Enabling Good Lives are to build the knowledge and skills of disabled people and to invest in families/whānau.

This type of capacity building has not traditionally been a focus for direct government investment in New Zealand. The need for this investment rests on the obligation to address barriers to participation. Without it, other changes to funding and systems may not achieve better quality of life for disabled people.

Disabled adults should have the choice to be the primary locus of control over their lives, but families often play a vital role in supporting them

While it recognises the important role of families in contributing towards disabled people enjoying full and equal enjoyment of their rights, the Convention is founded on the principle of individual autonomy and independence, including the freedom of disabled people to make their own choices.

However, the ideal of individual independence is not universal across cultures (Mitchell, 1997). Human rights approaches are emerging that include the need to recognise identity and culture (Ensor, 2005). In the New Zealand context, whānau has a particularly important role as the basic unit of Māori society. Combining rights and cultural interests recognises the central role that families play in individual well-being, which can be threatened if the individual is considered independently of the context of the family.

In any case, researchers have found that the family's attitudes and expectations have a critical influence over a disabled person's level of independence and the extent to which they are involved in decisions about their lives (Mirfin-Veitch, 2003). An investment in expanding families' views of what is possible contributes to disabled people enjoying a broader range of opportunities.

Many disabled people and families benefit from developing a vision for a good life

For many disabled people, society has not had basic expectations of a good life and has in many cases passed its lack of vision on to the people and their families:

One of the most damaging aspects of the social system for families of people with disabilities in the United States is that, all too often, it has destroyed parents' capacities to dream about their children – often from the beginning the child's life (Bergman & Singer, 1996, p. 443).

People who have internalised society's low expectations often need encouragement and support to have even the most ordinary dreams. Some people will require support to identify what they want – to be given options and helped to communicate their wishes (Bergman & Singer, 1996).

In New Zealand a number of organisations and partnerships have attempted to address this need. For example, a group of organisations partnered to develop a series of workshops for families and a matching workbook. The first step was for disabled people and families sit down together and develop a vision for a good life for them (Sullivan, 2010).

A plan is often needed to achieve a person's vision, but effective planning cannot be easily systematised, as it often challenges social and systemic barriers

Many disabled people can build a good life with the informal plans most people have. However, for others, building a good life will require conscious effort from a number of people, particularly where there are societal barriers to overcome to make their vision a reality. A formal plan of action can help to coordinate those efforts and identify creative solutions to difficulties and blocks.

Person-centred or person-directed planning are common terms for several different approaches to formal planning. They are grounded in a philosophy of inclusion – a good life for a person in the community. They are characterised by:

- gathering insights and intelligence – listening, asking different questions, focusing on the person's gifts and strengths
- making a judgement about how their current situation fits with their dream
- making a commitment to change
- planning what to do (Ritchie, 2002).

Proponents of person-centred/directed planning emphasise that it is not enough to make tweaks to the existing system to adopt a set of tools and techniques – agencies and systems must change (O'Brien & O'Brien, 2002; O'Brien, 2013). They point out that systems are about big numbers and are driven by standardisation and efficiency, so are not natural friends of radically individualised approaches (Mount, 2002; Locality & Vanguard, 2014).

There is some controversy about whether planning should be done before the person has an indication of the funding available for their support. Some people argue that looking to funding first can restrict the person's plan for their life to fit the types of supports that can be purchased (Paradigm Initiative, 2013). Others maintain that people should know about all their available resources, including funding, to allow them to think innovatively (Duffy, 2013). This principle underpins the *In Control* resource allocation system in England (Miller et. al. 2013). However, it has recently been critiqued because in many cases, the

indicative budget bears little relationship to the final allocation (Slasberg, Beresford & Schofield, 2013).

Service providers have often supported disabled people in the planning process. In some cases, such as the Ministry of Health's Choice in Community Living trial, providers have continued in this role, but the funding has been designed to give them greater flexibility to respond to what the person wants to achieve. In other trials, independent allies have been funded (sometimes termed independent brokers or facilitators) to walk alongside the disabled person and their family, particularly in the planning process. The following roles have been designed to be independent of funding allocation and of disability support services:

- The Ministry of Health's Local Area Coordinators
- Navigators in the Christchurch Enabling Good Lives demonstration
- Connectors/Tūhono in the Waikato Enabling Good Lives demonstration.

However, one critique raised the following issues with introducing this type of role into the system:

- the cost of funding the new role is likely to come at the expense of personal budgets for disabled people
- there is an incentive to create dependency among disabled people and families
- having someone whose role is to navigate a complex system means that the system is likely to remain complex rather than be simplified
- there is little clarity around the role definition and expertise required.

Instead, the authors proposed making greater use of community and peer to peer support, existing services and professionals instead. They also suggested that funders invest in training disabled people and families to plan and navigate the system themselves (Duffy & Fulton 2009).

Disabled people and their families will often need to develop new skills and gain new knowledge to execute their plans

The skills, knowledge and information disabled people and families need to make their vision of a good life a reality will be specific to them. Some skills and information may be specialised, but they are also likely to require general skills. For example, taking control of disability support funding will require some disabled people and families to learn new skills such as financial management, communication skills and managing conflict for dealing with staff and providers.

In New Zealand, the Standards and Monitoring Service (SAMS) has pulled together the list of key skills based on several forums of disabled people and families who considered the changes to services and supports and the corresponding skills people and families will need in future.

Supports and services used to be	The new way will see	What this means for disabled people and Families: Key skills to develop
Separate from mainstream services in the community	Increased use of mainstream community supports	<ul style="list-style-type: none"> ○ Know the possibilities in the local community (community mapping) ○ Able to create personal safeguards
Focussed on building good disability organisations	A focus on making it easier for individuals, families and other community services	<p>Know what you want in your life (imagining a good life)</p> <p>Have thoughts about how you can achieve what you want (personal planning)</p> <p>Ideas about how supports can best assist you (examples/stories)</p> <p>Strong disabled persons and family networks</p>
Focussed on providing set 'programmes', services and activities	Supports based on individual preferences and aspiration	Be clear about what you like, what you need and what you want (assertiveness skills)
Standardised	Flexibility	Have good negotiation skills
Accessed through assessment	Things built around an aspirational personal plan	Have a clear "plan"
A limited number of organisations to choose from	Increased choice regarding how funding is used and who/what you want as supports	Know the options (personal and family examples and descriptions of innovative services)
Families sometimes seen as barriers	Disabled people and families seen as key/important allies	'Partnership' skills

Source: Standards and Monitoring Service, unpublished

With the introduction of the National Disability Insurance Scheme in Australia, states funded specific capacity building activities to prepare disabled people and families for the changes. For example, the New South Wales Government's Family and Community Services funded workshops for disabled people and families that covered the range of new skills required from goal setting to problem-solving and self-advocacy to managing individual budgets.¹

In working to expand personal budgets to families with disabled children, the *In Control* programme in England recommends that local authorities fund formal and informal networks of families, children and young people to share skills and support to develop plans, use personal budgets and provide a network of support to reduce isolation (In Control & SQW, 2013).

¹ See http://www.adhc.nsw.gov.au/about_us/strategies/life_my_way/getting_prepared

Relationships within families, with friends, peers and the wider community are essential, and networks of support may need to be consciously built

Relationships are central to human well-being, and this is no different for a person with a disability. However, research has found that families with a disabled member often have fewer or smaller social networks and this makes them more dependent on paid services for support (Mirfin-Veitch, 2003; Orsmund, Shattuck, Cooper, Sterzing & Anderson, 2013; Pitonyak, 2002). Isolation is especially dangerous for vulnerable people. The more positive relationships a person has, the lower their odds of experiencing abuse (Pitonyak, 2013). Many disabled people and families need support to build relationships and valued roles within the community.

The Māori term *whanaungatanga* is ideal for describing the connections needed for a good life because it covers a wide range of relationships and also implies a sense of belonging. The word is defined as:

relationship, kinship, sense of family connection - a relationship through shared experiences and working together which provides people with a sense of belonging. It develops as a result of kinship rights and obligations, which also serve to strengthen each member of the kin group. It also extends to others to whom one develops a close familial, friendship or reciprocal relationship.²

This section describes a range of relationships that fit under *whanaungatanga* – family/*whānau* relationships, friendship, a network of support, peer support, someone to love and a welcoming community.

Family/whānau relationships

Researchers have often reflected society's negative views on disability by focusing on the difficulties families face. The many strong, united families who cope well and look positively on having a disabled family member are overlooked (Summers, Behr and Turnbull, 1988).

For example, the assumption that couples with disabled children are more likely to divorce than others has been challenged (Sobsey, 2004). A recent study found that couples with a child with a developmental disability were no more likely to divorce than parents of children without disabilities (Namkung, Song, Greenberg, Mailick & Floyd, 2015).

Some disabled people have been completely alienated from their families, and sometimes their only relationships are with people who are paid to support them. In New Zealand, disabled children are over-represented in child protection services. Around 20 percent of children in state care have a disability compared with around 11 percent for all New Zealand children (Child Youth and Family, 2010).

Researchers emphasise that the family's role is especially important when a person is going through a transition in life. When their son or daughter has an

² <http://www.maoridictionary.co.nz>

intellectual or learning disability, transition into adulthood can be a highly stressful time for parents. They face additional challenges in supporting their adult children in this new phase of life, when other parents' roles in their children's lives is diminishing (Mirfin-Veitch, 2003).

New Zealand organisations offer family-directed support approaches, for example:

- CCS Disability Action's Supported Lifestyles programme has been independently evaluated and found to be an individualised, flexible and responsive service (Esplin, 2013). It is tailored to an individual family and their circumstances. Respondents found that the service helped to strengthen their family relationships and family decision-making (Esplin, 2013).
- An evaluation of Imagine Better's work with New Zealand families found that it helped them become more resilient and resourceful. This work includes service design, pre-assessment support, assistance with forming and maintaining circles of support, will planning, PATH planning and workshop series, including for siblings (Kendrick, Fulcher, Garland, Manning & Manning, 2012).
- Parent to Parent New Zealand trains volunteers as Support Parents to be there for others in a similar situation as soon as they know their child has a disability. Parent to Parent also recognises the role of siblings and offers camps for siblings. It also explicitly involves siblings with parents in planning for the future for their disabled family member.

However, researchers emphasise that family relationships are not enough on their own. When families are the only source of support for a disabled person, the relationship can become strained (O'Brien & O'Brien, 1991).

Friendships

The importance of friendship to human wellbeing is widely recognised. Disabled people face challenges to making friends simply from it being harder for them to get around, from lack of money, service restrictions and family attitudes, which can prevent them from taking part in activities around which friendships form – sharing common interests that bind them to others (O'Brien & O'Brien, 1991).

Equal friendships between disabled and non-disabled people exist even when the disabled person does not communicate verbally (O'Brien and O'Brien, 1991). On the other hand, it is important not to gloss over the difficulties that friendships can face, especially where communication is difficult (Mirfin-Veitch, 2003).

However, researchers caution against regarding friendships between disabled people as less valuable than those they have with non-disabled people (Mirfin-Veitch 2003). Staff in both institutions and community organisations have sometimes trivialised those relationships, denying people the opportunity to support one another (O'Brien & O'Brien, 1991).

Some people have difficulty establishing and maintaining friendships and may require support. Given the importance of friendships, researchers have concluded that services have a role to play in facilitating friendships. Formally supporting friendships has been critiqued, but can be necessary for people with high support needs (Mirfin-Veitch, 2003). Opportunities to meet friends and

allies can be created by using the person's interests, and then gradually withdrawing staff support, also removing the buffer that paid staff often create and allowing real friendships to form (Rhodes, 2010).

A network of support

Support circles, relationship networks, intentional networks and social networks are all terms for consciously created groups of people who come together as a source of support for the vision of a good life for either the disabled person or their family (Snow, 2002).

A circle of support is about making positive change by taking action, and about sharing ideas and a strategy to move a vulnerable person's life forward. It's about safeguarding a vulnerable person from the isolation and loneliness so common among people with a disability. Most importantly, they're about developing enduring relationships with people who love and care about the disabled person and their family (Paradigm Initiative, 2013, p. 22).

Planned Lifetime Advocacy Network (PLAN) in Canada is an independent (not government-funded) organisation that has made personal networks central to its work. It employs community connectors, or social network facilitators to help disabled people build networks and find ways to be part of in their community. In New Zealand, organisations have used various techniques to help disabled people and families to build a network of support (Sullivan, 2010; Paradigm Initiative, 2013). The process starts with identifying people to be part of the network and inviting them to attend a first meeting. The network will have a clear purpose – and a clear focus of support – either the disabled person or the family.

Successful networks generally meet regularly, but often evolve over time as the person's life develops. For example, a young Auckland man has a circle of support that meets every six weeks over a meal to help him with his goals and to help him take charge of his life. When he went flatting, this group took over from an earlier circle that supported him during his school years. The new members were recruited because they were young and had the flatting and social knowledge to help him in this new phase of life (Paradigm Initiative, 2013).

Peer support

The previous example points to another important type of relationship – the mutual understanding that people in a similar situation share. Both families and disabled people benefit from peer support. Providing opportunities for peer support is an important role of disabled persons' organisations.

A peer support network of disabled people was established in 2013 in Palmerston North, based on the KeyRing Living Support Network in the United Kingdom (Milner & Mirfin-Veitch, 2015). The network is supported by the provider Community Connections, which funds the cost of the network facilitator. It differs from circles of support in that it is not focused on a single disabled

person but instead harnesses the support that a group of disabled people can give each other.

Families often report that one of the greatest benefits from participating in seminars, workshops or programmes is the opportunity to connect and share common experiences with other families. In one example, families involved in a family-family link up programme in Melbourne, Australia, reported that it led to a greater sense of empowerment and helped them recognise that they could share resources – including information, experiences and coping strategies (Higgins, Sheerin, Daly, Sharek, Griffiths, de Vries & McBennett, 2013).

In other cases, families have joined together in groups to share efforts to build a good life for their disabled family members:

- Families Action Support Team (FAST) was started by a group of families in Palmerston North with a disabled son or daughter, who worked collectively to fill gaps in services in their community. Families developed a plan and a support network. Microbusinesses have been established with microfinance from the charity Frozen Funds, including operating laundries, wood work, DVD distribution and food preservation to arts and photography.
- Life Choices was started by a group of eight families in Auckland who came together with the common vision that their disabled family member, when ready to leave the family home, would live in a home of his or her own with flexible supports, not in a group situation. Families work together to find ways for their young people to be active and valued community members. The experiences of some of these young people have been published as a guide to flatting (Paradigm Initiative, 2013).
- Life Choices has drawn on the work of Homes West in Brisbane, Australia, a small service (for 12 disabled people) established and run by families, which identifies (with the person's family and friends) the best option for the disabled person to have a home of their own and undertakes planning and coordination of support over the long-term (Hole, 2007).

Someone to love

The freedom to have romantic and sexual relationships is a basic right. However, expectations families and society have for disabled people often exclude sex, love or marriage (Nemeth, 2000). In particular, it can often be difficult for parents of adults with intellectual or learning disability to accept their son or daughter's sexuality and sexual relationships. Common social prejudices about disabled people portray them as innocent, asexual or predatory. Disabled people who are homosexual face additional prejudice (Mirfin-Veitch, 2003).

Researchers have also pointed out that the tendency to value disabled people's friendships with non-disabled people more highly than their friendships with other disabled people can also leave them more isolated from their peers – which limit their opportunities to form romantic and sexual relationships with other disabled people (Mirfin-Veitch, 2003).

Evidence shows that disabled people are at far higher risk of sexual abuse. Researchers emphasise importance of building disabled people's capacity to make safe decisions about sex and learn how to protect themselves from abuse.

People need information about abuse and support to develop skills that could reduce their vulnerability. In general, sexuality education needs to be more widely available to disabled people (Mirfin-Veitch, 2003).

Internationally, there are a number of organisations that aim to support disabled people's sexuality:

- The Australian charitable organisation Touching Base links disabled people with sex workers, and there have been calls for a similar service in New Zealand (Cooke, 2012).
- The U.K.'s Sexual Health and Disability Alliance has a broader social change mission, bringing together health professionals who work with disabled people to empower and support them in their sex and relationship needs.

A welcoming community

In contrast to institutions, which tend to encourage people to be dependent by focusing on their needs, communities tend to help people become self-sufficient by building on their strengths (Diers, 2004). They also invite reciprocity – so that disabled people contribute to the community.

Writers on person-centred planning describe building a community around one person at a time (O'Brien & O'Brien, 1991; Wetherow & Wetherow, 2002). A common approach that has been used is community mapping – surveying the area the person lives in for places, spaces and activities (including employment) that match their strengths and interests.

There are also wider approaches to making communities more welcoming:

- The Think Differently campaign ran in New Zealand between 2010-15 to change communities' attitudes to disabled people. It included a fund to support specific community-based projects to promote disabled people's inclusion in the community. Think Differently also funded media training for groups to learn how to get positive messages about disabled people in the media.
- In 1994, a pilot project began in Seattle about how best to involve people with intellectual or learning disabilities in neighbourhood community organisations. It started with a neighbourhood time bank that matched people and allowed them to gain credits from their respective skills that could be exchanged for others' skills.
- The Seattle pilot project was expanded city-wide. It built community in two ways – by starting with a person and matching them to an organisation in line with their interests and by approaching organisations that wanted help to reach out to include disabled people. In an unplanned development, a local People First chapter recruited a range of people from the neighbourhood to help them create a community park (Diers, 2004).
- In December 2014 the peer support network in Palmerston North (referred to above) participated in a community working bee. Members said they valued giving back to their community. The researchers who evaluated the network pointed out that having an opportunity make a productive contribution to their community brought the members in from the margins of community life, where people with learning disabilities tend to live (Milner & Mirfin-Veitch, 2015).

Disabled people and families need a strong voice and to speak up for themselves and others to achieve greater choice and control at a system level

Disabled people often lack a voice. They are poorly represented or not represented at all in the democratic institutions that give people a voice. For example, only in 2011 was the first deaf MP elected to Parliament in New Zealand.

On an individual level, having a voice and being heard is vital to protect disabled people from abuse. It also gives people the power to make choices in their lives. It can be difficult for people with high and complex needs to have a voice, especially if they cannot communicate verbally (which makes them more vulnerable to abuse) (Van Eden, 2013).

This section breaks having a voice into three components – advocacy, leadership and involvement in policy.

Advocacy

Advocacy can happen at an individual level, where someone is personally affected by discrimination, unfair treatment or abuse, or at the wider social level, where advocacy attempts to make changes for a group of people so that they are no longer at risk of these things. In this respect, it can be defined as trying to change societal behaviour or institutional practices to benefit disabled people (National Council for Persons with Disabilities).

Advocacy is a major role of Disabled Persons' Organisations. Indeed, self-advocacy by disabled people and their organisations is often regarded as the most effective and empowering form of advocacy. Self-advocates with an intellectual or learning disability have said that self-advocacy is the essence of self-determination for them. Some of the benefits include: speaking up for oneself, being listened to and taken seriously, not being treated as a child, rights and responsibilities, taking risks, independence and being part of the real world (Mirfin-Veitch, 2003).

Families often take on an advocacy role for a disabled family member. A confident and articulate family member can play an important role in improving the quality of service their disabled family member receives. Their role is crucial when the nature of a person's impairments make it difficult or impossible for them to speak up for themselves (Van Eden, 2013).

Organisations play an important role in both advocating for disabled people and supporting disabled people and families to be advocates. For example, in New Zealand, IHC provides both advocacy and self-advocacy support, such as an advocacy toolkit. There are also more general third party advocacy services for people who use disability supports, such as New Zealand's nationwide health and disability advocacy service.

Leadership

The New Zealand Disability Strategy includes an objective to foster leadership by disabled people. This includes modelling the inclusion of disabled people as leaders in government departments. The Office for Disability Issues runs a nominations service for disabled people who are interested in serving on government boards and committees and have the skills to do so.

The following programmes in New Zealand focus on building leadership skills in disabled people and/or family members:

- SAMS has adapted a US family leadership workshop series for New Zealand. The series covers both the personal e.g. planning, but also includes a more outward focus, by giving disabled people and families the skills and confidence to take up leadership roles in the disability sector e.g. advocacy skills, communication skills and dealing with the media (Kendrick, 2009).
- *Be.Leadership* is a one-year leadership programme that Be.Accessible runs. It is held over 21 days for 20 participants and covers a range of aspects of leadership to create a strong, resilient and sustainable community of disability leaders.
- Since 2013 the Ministry of Youth Development has funded IHC to offer a programme for young people who are transitioning from school or have recently left school. The aim is to help them to develop the skills to be able to speak up for themselves, to make decisions and take a leadership role in developing support that works best for them.
- New Zealand is a member of the International Initiative for Disability Leadership, which was established to foster good leadership, by sharing good practice and facilitating international leadership exchanges. It encompasses leadership by disabled people, families, service providers and policy makers.

Involvement in policy

Personalising support for disabled people is often accompanied by engaging them and their families in new, collaborative ways of working on the associated policies. Engaging in this way is variously known as co-production, co-creation and co-design (Carr, 2012).

In New Zealand, Enabling Good Lives demonstrations in Christchurch and Waikato have been co-designed with local disabled people, families and disability service providers. The Office for Disability Issues has co-developed two successive Disability Action Plans with Disabled Persons' Organisations. These approaches are consistent with article 4.3 of the Convention, which states that disabled people, through their representative organisations, should be involved in developing and implementing policies and legislation that relate to them.

Because most people with intellectual or learning disability are supported at home, some researchers have argued that families are the main stakeholders in disability policy (Fujiura, 1998, cited in Mirfin-Veitch 2003). This is particularly the case for people who can't speak for themselves. However, families can sometimes be given the role of the "consumer" of disability services, to the extent that the disabled adult is overlooked (Mirfin-Veitch, 2003). In Enabling Good Lives, attempts have been made to manage the issue of representation by

including disabled people, families and disability service providers on advisory bodies, but having greater numbers of representatives of disabled people than of the other two groups. The first evaluation of the Christchurch demonstration highlighted the value of having a diverse group with different perspectives in a leadership role (Anderson, Ferguson & Janes, 2014, p. 69).

Conclusion

The approaches described in this paper ultimately aim to ensure that all disabled people can participate in their communities as full citizens, with the benefits and responsibilities that entails.

This paper started with a question about what needs to be done to help disabled people and families take control of their support. The theme that comes through is that government itself, and the services and supports it funds, can best act as facilitators, by creating the conditions that make it possible for disabled people (and their families/whānau) to take control of their own lives as participating and contributing citizens in their communities.

However, one size does not fit all. Any system needs to provide menu of options to suit the broadest possible range of individual circumstances. Some disabled people and families will have complex needs and may benefit from more tailored, intensive support to navigate systems. Others will have more straight-forward requirements and just need information to do everything themselves (NZ Productivity Commission, 2015; Duffy & Fulton, 2009). Others will lie somewhere in between. No matter what level of support is required to do so, building people's capacity to create the conditions of their own lives is an essential role for government and the services it funds.

Note on the sources

This paper draws on research and descriptions of practices and innovations in New Zealand and overseas. Evaluations have tended to focus on the funding and system changes that enable greater choice and control, rather than the support for disabled people and families to make the most of these changes.

As there has been little systematic research or evaluation, many of the sources for this review are from expert practitioners describing approaches and the philosophy behind them, with specific examples of how they have affected individuals. There have been few studies to explore what works across larger groups. The findings in the paper have not therefore been widely tested, but generally reflect an international consensus among leading practitioners.

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