

Appendix D Services for people with disabilities

Key points

- Disabled people make up a significant proportion of the New Zealand population. People living with disability often experience poor social and economic outcomes. This case study examines the use of client-directed budgets in the area of services for disabled people.
- A diverse group of people is covered by the term “disabled people”. Disabled people require different services and supports. Client-directed budgets will not be suitable for all of these people.
- In the late 1990s many disabled people were becoming frustrated with what they saw as an ad hoc approach to disability policy and services. This resulted in the development of the New Zealand Disability Strategy (2001). The strategy included an action to treat individual needs in a flexible way.
- In 2003 the Ministry of Health (MoH) established New Zealand’s first (formal) individualised funding (IF) pilot. Prior to this point, some disabled people had been accessing “individualised” services through various ad hoc arrangements.
- In 2008 the Social Services Select Committee undertook an inquiry into the quality of care and service provision for people with disability. The Committee’s recommendations included providing funding in a way that allowed disabled people more choice about their day-to-day living arrangements and better access to IF.
- In 2010 the MoH submitted a proposed alternative model to the Ministerial Committee on Disability Issues for consideration (the so-called “New Model for Supporting People with Disability”). In 2011, the Minister of Health launched the New Model Demonstration Project in the Western Bay of Plenty. Later that year, the Minister for Disability Issues initiated a first principles review of government support for people with disabilities. The output of this process was the “Enabling Good Lives” (EGL) report.
- In 2012, the Ministerial Committee on Disability Issues agreed to the EGL approach, and a vision and long-term principles for changing the disability support system. A trial of the EGL approach commenced in Christchurch the following year. Preparation for a trial of EGL in Waikato commenced in 2013.
- There are a number of lessons from the New Zealand experience with client-directed budgets in the area of disability services. This case study broadly groups the lessons under three headings:
 - general lessons about the value of choice and the process of developing client-directed mechanisms;
 - lessons about the design features of client-directed mechanisms; and
 - lessons about the implementation of client-directed mechanisms.

Services for people with disability are one of four case studies that the Commission has selected in response to the inquiry terms of reference. The case studies draw out lessons that can be applied more widely across the social services landscape rather than draw conclusions about the effectiveness of particular services.

D.1 Purpose of this case study

Since the health reforms of the 1990s, the Government has contracted out the provisions of many social services via bulk-funding and fee-for-service arrangements. Under this model, politicians and government officials select the services that people receive and then contract providers to deliver the selected services.

For some social services, there is movement away from centrally specified delivery arrangements, towards payment arrangements that allow people to manage their own care and service provision. The terms client-directed budget (CDB), individualised funding (IF) or personalised funding are often used to describe this approach. This case study adopts the term *client-directed budget*. A CDB is a form of *client-directed service model* (see Chapters 6 and 11).

Unlike traditional contracting-out models, a client-directed service model allocates funds (or vouchers) directly to the clients. Clients then select the services and providers that best meet their needs. Providers only receive funding if the client chooses them.

This case study examines the use of CDBs in the area of disability services. The study is not an evaluation of the design or implementation of any specific programme. Nor is it a review of funding for these programmes. Rather the case study aims to draw out lessons that the Government can apply across the social services landscape.

The Commission understands that not all services to disabled people are available through CDBs and that not all disabled people access services in this way. Even so, the experiences of disabled people using client-directed models, and of agencies and providers, can provide valuable insights into issues such as:

- the circumstances under which CDBs can be effective;
- the practical issues associated with the design, introduction and operation of CDBs;
- stakeholder experiences with CDBs in New Zealand (and in other countries);
- practical steps that agencies can take to move towards client-directed approaches (where such approaches are appropriate); and
- the impact of CDBs on the quality and efficiency of service provision.

Box D.1 A note on terminology

This case study uses the term “disabled people”. The Commission is aware that there are several alternative terms (such as “people experiencing disability” or “people with disabilities”) and that the term “disabled people” may not sit well with everyone.

The use of the term “disabled people” in this case study is in no way intended to imply a medical model of service delivery (discussed below). Rather, the term is adopted in the interests of consistency with the New Zealand Disability Strategy (2001) and with the New Zealand Convention Coalition Monitoring Group.¹

D.2 Context of case study

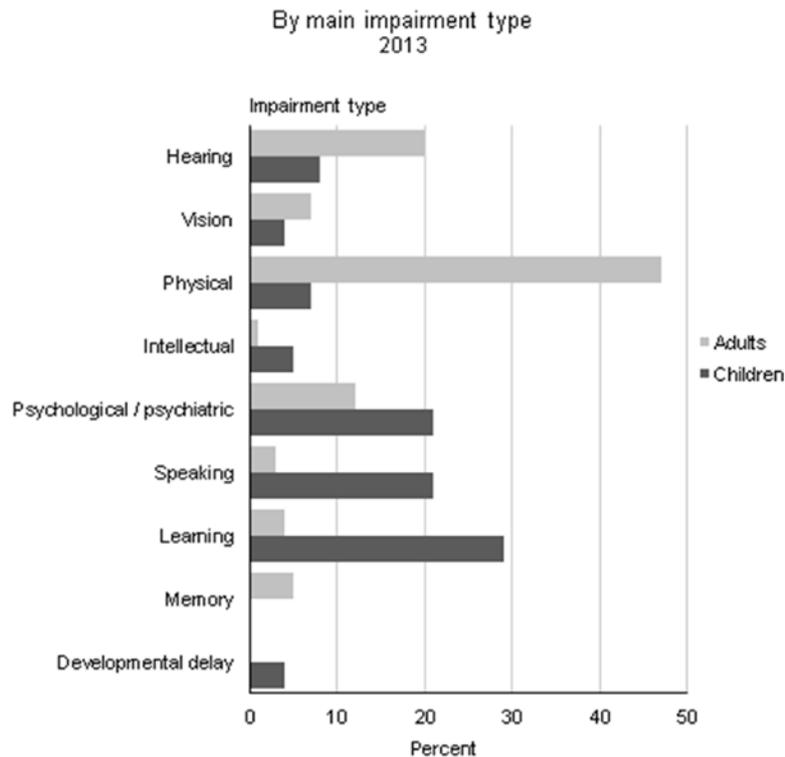
Disabled people make up a significant proportion of the New Zealand population. In 2013, the New Zealand Disability Survey found that 24% of people living in New Zealand have some form of disability.² Approximately half (53%) of disabled people live with more than one impairment. For children, learning,

¹ The New Zealand Convention Coalition Monitoring Group is a coalition of disabled-peoples’ organisations contracted by the Government to report on the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

² For the purposes of the survey, disability was defined “as long-term limitation (resulting from impairment) in a person’s ability to carry out daily activities. The limitations identified were self-reported or reported on behalf of the disabled person by their parent or primary caregiver. The survey collected data from adults (aged 15 years or over) and children (under 15 years) living in private households or group homes and from adults living in residential care facilities.” (Statistics New Zealand, 2013, p. 2)

psychological/psychiatric, and speaking difficulties are the most common impairment type, while for adults physical limitations were the most common type of impairment – see Figure D.1.

Figure D.1 Percentage of disabled adults and children by impairment type



Source: Statistics New Zealand (2014a)

People living with disability often experience poor social and economic outcomes. The New Zealand Disability Survey found that, compared to non-disabled people, disabled people (Statistics New Zealand, 2014b):

- had lower levels of employment;
- were less likely to hold formal educational qualifications;
- were more likely to experience discrimination;
- were more likely to feel lonely;
- were less likely to participate in popular leisure activities such as visiting friends, going to cafés and going on holiday;
- were less likely to be satisfied with their lives.

The Ministry of Health (MoH), the Ministry of Social Development (MDS), the Ministry of Education (MoE), the Accident Compensation Corporation (ACC) and District Health Boards (DHBs) all fund disability-related support services. These organisations provide a range of services including:

- personal support;
- the provision of equipment (such as wheelchairs and hoists, and housing and building modifications);
- career support;
- specialist education services; and
- financial assistance (such as the disability allowance).

Disability policy in New Zealand

Current disability policy can trace its origins to the human rights movement of the 1960s and 1970s. These movements propagated the philosophy of social equality and the rejection of discrimination – whether on the basis of race, religion or gender.

This period saw the emergence of the disability rights movement in New Zealand and, with it, a new understanding of disability known as the *social model of disability* (Convention Coalition, 2010). The social model of disability makes an important conceptual distinction between *impairment* and *disability*. The New Zealand Disability Strategy highlights this distinction.

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments.

Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. Our society is built in a way that assumes that we can all move quickly from one side of the road to the other; that we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions...

Disability relates to the interaction between... the person with the impairment and the environment. It has a lot to do with discrimination, and has a lot in common with other attitudes and behaviours such as racism and sexism that are not acceptable in our society. (MoH, 2001, p. 9)

In contrast to the social model of disability, the *medical model of disability* holds that disability is an individual problem in which impairment restricts the ability of the individual to undertake activities within a “normal range”.³ The medical model therefore focuses on interventions, cures and programmes designed to “fix” or accommodate disabled people. Conversely, the social model of disability focuses on changing societal attitudes and creating an environment that enables people with impairments to live full and happy lives (Workbridge, sub. 102).

The medical model of disability was the dominant paradigm in disability policy for the first half of the 20th century, resulting in the institutionalisation of many disabled people in “medical” facilities.

During the 1980s, increasing acceptance of the social model of disability, and the growing strength of the disability rights movement, saw a change in government policy away from institutionalisation and towards support for community-based services. This marked a significant point in the history of disability policy in New Zealand.

At about the same time, the Government began entering into contractual arrangements with non-government suppliers of disability services. These arrangements largely replaced the previous system of government grants (Office for Disability Issues, 2002).

In the late 1990s, many disabled people were becoming frustrated with what they saw as an ad hoc approach to disability policy and slow progress towards a more inclusive society.

In April 2000, the then Minister for Disability Issues, Ruth Dyson, commenced work on the New Zealand Disability Strategy by appointing a 15-person reference group. One of the first tasks of the group was to help prepare a discussion document aimed at stimulating public input into the development of the strategy. In September of the same year, MoH released a discussion paper titled *Making a World of Difference: Whakanui Oranga*.⁴ The paper identified a range of issues that the strategy would need to address – one of which was the flexibility of government systems and services.

Although the Government provides a range of services, the experience of accessing these services can be very disabling because sometimes they are not flexible enough to meet individual needs. To get a benefit, a piece of equipment, or maybe some help at home you might have to tell your story to three or four different people — just to get what you need at that particular time. Next year those three or four people may have moved on, with a new lot of assessors in their place. These kind of arrangements and turnover of staff are disabling because the person, their families and whānau spend a lot of time fighting

³ The medical model is sometimes referred to as the Functional-Limitation Model.

⁴ The Government transferred responsibility for overseeing implementation from MoH to the Office of Disability Issues in July 2002.

the system, in order to get access to the same opportunities other New Zealanders have. (MoH, 2001a, p. 13)

The MoH received approximately 630 submissions in response to the discussion document. Analysis of the submissions identified accessing services to be the “number two” barrier to participating in society, the number one barrier being social attitudes (MoH, 2001b). One re-occurring theme in the submissions was the desire for disabled people to have more flexibility and control over the services they receive. Another theme was the need for greater coordination between government agencies responsible for funding services.

Many people suggested that accessing services need not always involve a purchaser and provider approach. Innovative models of direct payments, brokerage, supported living, supported employment etc, that reduce the significant control that purchasers and providers can have over the lives of those experiencing disability, should be actively encouraged as ways for the future.

Along with such flexibility in funding approaches, respondents called for more funding, and increased co-ordination in the funding of services. Suggestions for how to improve co-ordination ranged from reducing the number of service providers, to centralising the funding for all disability support services in one place. (MoH, 2001b, p. 13)

Work on the strategy continued until its release in September 2001. The strategy lists 15 objectives and 113 actions aimed at improving the lives of people with disabilities (Box D.2).

The objectives include creating “long-term support systems centred on the individual”. The actions identified to achieve this objective include ensuring “that overarching processes, eligibility criteria and allocation of resources are nationally consistent, but that individual needs are treated flexibly” (p. 25).

Box D.2 **Objectives of the New Zealand Disability Strategy 2001**

The 15 Objectives are to:

1. Encourage And Educate For A Non-Disabling Society.
2. Ensure Rights For Disabled People.
3. Provide The Best Education For Disabled People.
4. Provide Opportunities In Employment And Economic Development For Disabled People.
5. Foster Leadership By Disabled People.
6. Foster An Aware And Responsive Public Service.
7. Create Long-Term Support Systems Centred On The Individual.
8. Support Quality Living In The Community For Disabled People.
9. Support Lifestyle Choices, Recreation And Culture For Disabled People.
10. Collect And Use Relevant Information About Disabled People And Disability Issues.
11. Promote Participation Of Disabled Māori.
12. Promote Participation Of Disabled Pacific Peoples.
13. Enable Disabled Children And Youth To Lead Full And Active Lives.
14. Promote Participation Of Disabled Women In Order To Improve Their Quality Of Life.
15. Value Families, Whānau And People Providing Ongoing Support.

Source: New Zealand Disability Strategy, 2001.

D.3 Emergence of client-directed services in New Zealand

In 2003, the responsibility for funding disability support shifted from MSD to MoH. At the time, some 250 disabled people were accessing a component of their entitlements through ad hoc “individualised” arrangements (Social Services Committee, 2008). These arrangements allowed for an element of individual discretion around the use of entitlement funds.

Yet, while these ad hoc arrangements provided disabled people with an element of choice and flexibility, the approach “had limited national guidance and direction, with few processes in place to ensure consistency of service delivery and reduce the risk of funding abuse” (Synergia, 2011, p. 14). Consequently, the practice was stopped by MoH in favour of a more systematic and principled approach (Social Services Committee, 2008).

In 2003, the MoH established New Zealand’s first (formal) IF pilot. The pilot was designed to “...create national consistency and mitigate the risk of different and inconsistent models evolving across the country” (MoH, 2008, p. 7).

In 2005, MoH tendered for a single agency to run the IF scheme nationally. Manawanui InCharge (MIC), an agency formed from a coalition of organisations specifically to deliver IF functions, was successful in securing the contract (MoH, 2008)⁵. MIC provided what was later to become known as “IF host” services (see Box D.3).

Box D.3 Ministry of Health’s individualised funding programme – how it works

Individualised Funding is available for Home and Community Support Services (HCSS). These are services that assist people to live at home and include:

- help with household management, such as preparing meals, washing cloths and cleaning the house; and
- help with personal care, such as eating, dressing and getting out of bed.

People wanting to use IF have their needs assessed via the Needs Assessment and Service Coordination service (NASC). These services are provided by organisations (generally referred to as NASCs) and contracted by MoH to:⁶

- facilitate the needs-assessment process aimed at determining a person’s eligibility for ministry-funded support services;
- service coordination, which includes:
 - giving information about service options that are available to the person;
 - planning and coordinating the supports in a support plan;
 - allocating some Disability Support Services;
- manage budgets – NASCs must manage the ministry-funded Disability Support Services in a fair and cost-effective way.

It is policy that all people eligible for HCSS should have access to IF. NASCs refer people wanting to use IF to their preferred “IF host” – organisations contracted by MoH to help clients use IF. The hosts assist the person to develop an Individual Service Plan (ISP). The client chooses the type of assistance

⁵ Manawanui InCharge was a coalition of Life Unlimited, Disability Resources Centre (DRC), Ripple Trust and Standard Plus.

⁶ All providers contracted with the MoH are members of the *Needs Assessment and Service Coordination Association* – a NFP organisation for people that manage NASCs.

that that the host will provide. Hosts are paid a percentage of the package that a person receives. The more services the host provides, the higher the percentage.⁷

After the plan is established, the disabled person receives the specified service (usually via a separate organisation that is on contract to MoH). People using IF are required to keep records of the services they use and report to hosts on a fortnightly basis on use.

Unlike traditional support services, IF support is allocated on a yearly rather than weekly basis. This gives clients greater flexibility as they are able to “bank” unused hours to use at some time in the future.

Source: Adapted from details off the MoH website (n.d.).

In 2005 and 2006 concerns about services for people with disabilities were raised by the media and discussed in Parliament when two major services providers were accused of mistreating disabled people in their care, and one was found to have received funding that it was not entitled to. This resulted in the launch of a Social Services Select Committee inquiry in May 2006 (Social Services Select Committee, 2008).

Disability policy received additional public attention in March 2007 when New Zealand signed the United Nations Convention on the Rights of Persons with Disabilities.⁸ Article 3 lists the general principles of the Convention, the first of these being:

Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons. (United Nations, 2006)

In August 2007, the Government completed a review of long-term disability supports. The review was aimed at advising the Government on “how to improve its systems for providing disability support services so they improve outcomes for disabled people and their whānau, are consistent with the Disability Strategy, are simpler to access, seamless and more equitable” [Cab Min (04) 22/5 refer]. The review recommended, among other things, enhancing choice and service flexibility for people with a disability (Office of the Minister for Disability Issues, 2008).

Later in 2008, an evaluation was conducted of the IF pilot that had begun in 2003. The evaluation was initiated as part of a government decision to make IF available nationally. The evaluation report noted “...participants are very positive about the scheme and unanimously support ongoing development of and increasing access to it.” (MoH, 2008). Participants emphasised the “sense of empowerment” and “self-determination and flexibility” as important benefits of the approach (p. 4). The evaluation recommended that IF be made available across the country “as soon as possible” and that robust processes be developed to ensure the quality of care provided under IF. The evaluation also recommended that MoH consider joint planning opportunities with other government departments.

Also in 2008, the Social Services Select Committee reported on its inquiry into the quality of care and service provision for people with a disability. The Committee’s recommendations included:

- establishing a new entry point for people seeking disability information, along the lines of the local area coordination system established in Western Australia;
- changing the role of existing NASCs to avoid duplication with the proposed Local Area Coordinators (LACs), and to ensure they focus on meeting the needs of individuals, rather than those of service providers;
- directing the relevant ministries to provide funding in a way that allows people with disabilities more choice about their day-to-day living arrangements and better access to supported independent living and IF; and

⁷ There are currently three levels of service. The percentage of the package a host receives is determined by which level of service a person selects.

⁸ The convention was ratified on 26 September 2008.

- introducing systems for sharing information between the main government agencies responsible for disability support (Social Services Select Committee, 2008).

In February 2009, the Government released its response to the Select Committee inquiry report. The response noted:

The Government supports an approach that empowers disabled people to manage their own personal support services and gives them greater choice and control over their lives, including through providing better access to supported independent living. (Office for Disability Issues, 2009)

Later in 2009, the Government established the Ministerial Committee on Disability Issues to “provide a coherent overall direction for disability issues across government ... by providing leadership and improving decision-making and accountability” (Office for Disability Issues, 2009, p. 1). At its meeting in September 2009, the committee instructed officials to explore the development of a “new model” for funding support for disabled people.

Trials and demonstration projects

In 2010, the MoH submitted a proposed alternative model to the committee for consideration (“New Model” for Supporting Disabled People). The key characteristics of the model include (MoH, 2010):

- improved access to information and personal assistance through introducing LACs;
- moving towards allocating indicative dollar values of support rather than allocating particular types of service;
- more choice and control for people through making IF available to most people and for most supports, and making contracted supports and services more flexible and focused on outcomes; and
- broadening accountability arrangements from the present focus on providers to cover the responsibilities of MoH and disabled people and their families.

To inform the expansion of IF, in 2011 MoH commissioned a consultant (Synergia Ltd) to undertake an evaluation of the existing IF programme. The evaluation involved both qualitative and quantitative assessments of the programme, which at the time had approximately 935 users. The qualitative component of the evaluation explored the experiences of host providers, NASCs, MoH staff, and disabled people and their carers’. The financial component included an assessment of the costs of services under IF compared to the cost of services for people prior to their transition to IF. Key findings of the evaluation included:

- Inflexible services specifications restricted in provider’s ability to respond to client needs. Service specifications locked providers into hourly rates, types of services and delivery mechanism. As such, IF requires contractual frameworks that are more appropriate for the model.
- There was a perception among providers, disabled people and carers that the management of perceived risks (such as potential fraud) was leading to additional processes and layers of bureaucracy.
- There was inconsistency between the underlying rationale for IF (ie, the freedom for individuals to choose the services that meet their needs) and elements of the existing institutional framework of government services provision. One example is structuring entitlements around “service areas” and “silos of funding”, which the report describes as “...labels given to silos that bear little relationship to actual needs and/or how individuals want to meet these needs” (p. 24).
- There were concerns that MoH had allowed too many host providers and that some were financially unsustainable.
- There were concerns about the payment mechanism for host providers. Concerns included reduced incentives to take on small packages and increased incentives to “upsell” the services they provide.
- There were concerns that many providers did not have systems designed to handle the large number of individual invoices generated by IF and that the administrative cost of managing a large number of small invoices was considerably higher than managing one large contract.

- The uptake of IF appears to have been most prominent among disabled people with larger than average support packages. And that those moving to IF, on average, receive higher support packages than they received previously. The reviews attributed this, in part, to the observation that the initial cohort of people accessing IF were generally well informed, understood the system and were better able to articulate their needs.

In 2011, the MoH also undertook a review of the experiences of people in the Western Bay of Plenty using MoH disability support services. The review aimed at establishing a baseline for future evaluations of the New Model.

The review found that, while some of the barriers to disabled people leading a good life relate to services supplied by MoH, others relate to services provided by other areas of government. As such, when considering the efficacy of services it is important to take a “whole of life” approach to services rather than focusing on specific services provided by one area of government. The report found that many people felt there was a lack of coordination between government agencies. The review also highlighted these points.

- Information about services is important to the likelihood of disabled people leading a good life.
- Most disabled people and their families believe services were inflexible and that they have little control and not much choice. The report provides several examples that illustrate how lack of flexibility, choice and control play out in the realities of the everyday lives of people with disabilities and their families. For example, one participant is quoted as remarking:

There’s very little flexibility. For example, Patsy would like to have someone come in the evenings to give her a shower but they will only come if they have at least 2 hours of work to do. But night time is family time and the family don’t want someone hanging around for two hours in the evening. (Patsy’s mum) (MoH, 2011c. p. 35)

- In some instances, Māori with disabilities received culturally insensitive and inappropriate services. Some Māori interviewed said they would like to see tikanga protocols and practices being more consistently included in service delivery.

On 23 August 2011, the Minister of Health officially launched the New Model Demonstration Project in the Western Bay of Plenty. The project included the introduction of LACs and a new approach to needs assessment called “supported self-assessment”. The government contracted Inclusion Aotearoa to set up the LACs. The demonstration began with LACs working in the Western Bay of Plenty and extended in 2012 to include the Eastern Bay of Plenty. MoH appointed four LACs who by December 2012 had worked with 27 disabled people and their families in an “active ongoing way” (MoH, 2012, p. 3).

Trials of another aspect of the New Model called “Choice in Community Living” (CiCL) began in 2012. The CiCL programme aimed at providing disabled people in Auckland and the Waikato the opportunity to move out of residential facilities or their family home and into their own home. The programme enabled disabled people to choose their service provider, and to have control over how and what services they provided.

A third component of the New Model is Enhanced Individualised Funding (EIF). This programme expands on IF by enabling people choice and control over a wider range of service than is available under the “traditional” IF programme (which only allows choice over home and community support services). EIF empowers disabled people to decide how they use their funding allocation to purchase disability supports, products, services and/or arrangements that meet criteria set by the Ministry of Health. The programme was introduced in the Bay of Plenty in late 2012, with the first disabled people taking it up in March 2013.

In 2011, the Minister for Disability Issues, the Hon Tariana Turia, initiated a “first principles” review of government support for people with disabilities. An independent working group of disability sector stakeholders undertook the review, with MSD and MoH acting as the secretariat for the working group. The output of this process was a report titled “Enabling Good Lives” (EGL).

Although the working group was tasked with looking into day and community participation services, the group “...soon concluded that it was not possible to address one element of disability support without looking at the whole system” (Minister for Disability Issues, 2011, p. 2). Consequently, the EGL report

outlines a model of service delivery that is applicable to a range of services. The model seeks to address two key shortcomings identified by the working group.

- Existing day services and community participation services provided limited interaction with communities. Further, these services offer little opportunity for individualised support as they are provided in a group environment.
- Under the current system, people with disabilities need to deal with three or four sources of support, each focusing on a small aspect of their lives.

The EGL model aims to achieve principles-based transformation of the system. Central to the transformation is the use of *client-directed planning* in which disabled people and their families develop a plan for the individual. The EGL report proposed that facilitators (contracted by the Government) work with the disabled person and their family to identify their goals and aspirations, and to choose a combination of support that best meets those goals and aspirations.

The working group also proposed, “cross government individualised/portable funding” (p. 6). This would entail identifying the level of funding that each person currently receives and pooling this amount on a case-by-case basis. The disabled person would then be able to select services up to the value of the funding they are entitled to. The working group proposed pooling relevant MoH and MSD resources to enable disabled people to select from a range of available services. They noted their suggestion was:

...broadly consistent with the Ministry of Health’s New Model for Supporting Disabled People, but goes further in several ways. For example, it extends the facilitation approach across government, and encompasses support funded through the Ministries of Health and Social Development, and potentially other government agencies. It is likely to require the development of cross-agency (or joint) facilitation, entry processes, funding allocation, purchasing and accountability arrangements. (Office of the Minister for Disability Issues, 2011, p. 9)

In 2012, the Ministerial Committee on Disability Issues invited the disabled community and sector to develop proposals for demonstrating EGL in Canterbury and the Waikato (Office of Disability Issues, 2013). The subsequent reports were submitted mid-2012 and describe how to transform the existing disability support systems into one that gives disabled people greater choice and control over their lives.

In September 2012, the Ministerial Committee on Disability Issues agreed to the EGL approach, and a vision and long-term principles for changing the disability support system (See Box D.4).

Box D.4 Disability Action Plan vision and principles

Vision

In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports. Disabled people and their families, as appropriate, will be able to say:

- I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
- I have real choices about the kind of support I receive, and where and how I receive it.
- I can make a plan based on my strengths and interests.
- I am in control of planning my support, and I have help to make informed choices if I need and want it.
- I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
- The level of support available to me is portable, following me wherever I move in the country.

- My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
- My family, whānau and friends are recognised and valued for their support.
- I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
- I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed.

The Government will get better value for the funding it provides because:

- the new approach will generally provide better quality of life outcomes for disabled people and their families (based on international evidence);
- less money will be spent on providers' premises and more on support; and
- government agencies will work more closely together, for example using shared ways to determine support needs, integrated funding and contracts.

Principles to guide change (drawn from the Enabling Good Lives report)

- Self-determination: disabled people are in control of their lives.
- Beginning early: invest early in families and whānau to support them to be aspirational for their disabled child, to build community and natural supports and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- Person-centred: disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
- Ordinary life outcomes: disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life.
- Mainstream first: disabled people are supported to access mainstream services before specialist disability services.
- Mana enhancing: the abilities and contribution of disabled people and their families are recognised and respected.
- Easy to use: disabled people have supports that are simple to use and flexible.
- Relationship building: support, build and strengthen relationships between disabled people, their whānau and community.

Source: Ministerial Committee on Disability Issues (2012).

In December 2012, MoH released an evaluation of the first year of the New Model Demonstration Project in the Western Bay of Plenty. The evaluation assessed the use of LACs and the self-assessment tool. It also looked at the implementation of the project.

The evaluation noted the demonstration was progressing at a “slower-than-expected pace”, due in part to the limited resources available for implementation (MoH, 2012, p. 3). Despite this, the experiences with LACs were largely positive, with disabled people and their families identifying valuable changes arising from the demonstration.

The evaluation found confusion around the role of LACs. In particular, some people believed that LACs replicated services already offered by providers and that they were a “waste of resources” (p. 3). To address the confusion, the report stressed the need for a communications strategy to ensure people understood the role of the LACs: “who are they, where do they ‘fit’ in the disability sector and what do they do?” (p. 19).

On the implementation of LACs, the evaluation noted three important insights from the experience in the Western Bay of Plenty (p. 15):

- Establishing community networks and building the LAC profile takes time.

- The importance of face to face interaction in building relationships and rapport in the community.
- The importance of LAC activities being aligned with community-based expectations and practices i.e. 'the way we do things around here'. For example, the protocols for people to 'enter' a small community.

Other observations from the evaluation included those noted below.

- Developing relationships between Ministry staff and people with "on the ground" local knowledge was important for the credibility of the project.
- Introducing new approaches alongside existing ones can confuse stakeholders, particularly when the new system has a number of components that are not fully developed. The report highlighted the "...importance of working at a pace that allows for relationship-based, genuine consultation with key stakeholders..." (p. 5).
- There was uncertainty around the role of the National Reference Group (NRG), with different views about the extent to which the group would influence decisions. For example, the evaluation notes that

..[t]he Ministry's use of the term 'co-development' to describe how they planned to work with the NRG further fuelled their expectations about the extent to which they would be involved.

Members were therefore surprised and disappointed to learn the Ministry had made "a number of significant decisions" about the New Model prior to the NRG being convened. This led to some members wondering if the NRG was a "rubber stamping" exercise". (p. 25)

A subsequent evaluation of LACs in the Western Bay of Plenty (2014) noted:

Much of the value of local area coordination was evident in how disabled people and whānau described their lives. Many respondents had experiences that indicated they were now 'in charge' rather than having to fit in to someone else's 'agenda'. In telling their stories, the LAC's role was visible but not at the forefront, indicating disabled people and whānau had strong ownership of decisions about how they want to live their lives. The changes resulting from these decisions differed according to people's individual needs and circumstances.

Eight dimensions of value are identified in the report. They include people developing their own vision of a good life; recognising their own strengths; getting information about what is available; making use of, and building on networks; strengthening their voice; taking practical action for change; taking up new opportunities in the community; accessing enhanced individualized funding and support services. (Evaluate Research, 2014, p. 7)

However, the review noted that

The potential of local area coordination (particularly in the Western Bay) as a change agent at the individual level and beyond, is being inhibited. The reasons are contextual (and inter-related), rather than about local area coordination per se. Most importantly, local area coordination is operating in parallel with, or as a 'tack on' to the existing system. In the Western Bay, the existing system is both active and well-established. While efforts have been made to coordinate local area coordination and the DSS system, they are not yet coordinated from the perspective of disabled people, or in the day-to-day functions and relationships between LACs and others working in the sector. (p. 7)

The evaluation also noted that LACs are a "bottom-up approach, and as such, can be at odds with traditional top-down service-orientated models.

A further evaluation of the components of the New Model was undertaken in 2015. The evaluation examined the implementation of CiCL and EIF, and the fiscal neutrality of local area coordination (Evaluate Research, 2015).

The evaluation highlighted the sense of freedom that CiCL gives disabled people – particularly those that had previously been in residential care. It also noted that some disabled people came out of residential care with "institutionalised behaviour" – highlighting the importance of preparing people for living more independently.

On EIF, the evaluation noted that the programme is “yet to achieve its full potential for disabled people” (Evaluate Research, 2015, p.12). Two main reasons for this are given.

- The amount of time and effort needed to set up EIF for a person is much more complex than IF. This means “the amount of resources needed to manage EIF is three to four times greater than IF” (p. 12).
- Disabled people and those working with them are often confused about what they are able to spend their funds on. There was a perception among disabled people and providers that a top-down, accountability driven, approach to approving the purchase of supports was “rubbing up against” the founding principles of the New Model.

The evaluation concluded that...

An urgent issue is the need to realign EIF with the principles of the New Model, that is, adjusting the imbalance between accountability and risk reduction on the one hand, and trust of the disabled person, NASC and EIF Host on the other. This trust involves acknowledgement that disabled people know best what support they require to achieve the outcomes they seek, and the NASC and EIF Host know best how to support them to do this. If this fine-tuning is not done and there continues to be downward pressure on accountability and risk reduction from the Ministry, EIF is likely to fail to achieve its intended purpose of increasing choice and control of supports for disabled people. (p.14)

On the fiscal neutrality of LACs, the evaluation noted that expenditure data does not provide a robust basis for judging fiscal neutrality. The report noted:

[T]here are sound reasons, related to the intended functions of local area coordination, to anticipate fiscal savings that will not be shown in the data e.g. negating or delaying the need for expensive supports such as residential care. Available information indicates that offsets from deferral/avoidance of high cost disability services, together with other unused [Contract Management System] allocations that might have been taken up in the absence of LAC, could potentially offset increases in DSS funding.

Further savings seem likely if local area coordination is fully implemented in the context of overall system redesign, for example, by reducing duplication and inefficiencies associated with multiple access points. (p.75)

In July 2013, Cabinet agreed to a three-year demonstration in Christchurch of EGL - focusing on school leavers with high, and very high, needs (Minister for Disability Issues, 2013). In August 2013, the Government announced the members of the EGL Advisory Group and appointed a director of the demonstration. The Government announced that an important feature of the initiative would be the involvement of disabled people, families and providers in “co-designing” the demonstration. Box D.5 outlines the objectives of the Enabling Good Lives Approach.

Box D.5 **Objectives of the Enabling Good Lives Approach**

Individuals and Families

- Individuals and their families have increased control over their lives.
- Individuals and their families are able to imagine what a good life looks like for them and experience supports and services as something that makes this easier to achieve.
- Individuals and families have one “plan”. In this, plan individuals and families describe what they need and want to build a good life for themselves. This plan is based on strengths, preferences and aspirations (dreams). All supports, services and funders use the same plan as the key point of reference.
- There is one pool of funding i.e. all government agencies will put the money into one “bucket”.
- Any funding is worked out on a person by person and/or family by family basis. Individuals and families have control of this funding.
- Individuals and families will have initial contact with an Independent Facilitator (Navigator). They will be available to work with individuals and families in considering what a good life

looks like for them and how they might achieve it. Note: Navigators do not decide on the level of funding.

- Individuals and families decide on the level of involvement they want with an Independent Facilitator (Navigator).
- Individuals and families have increased choice. These choices range from managing all of their resources themselves to choosing to buy support from service providers. Some individuals and families may choose a mix of options. Others may want the “say so” regarding their resources but have an organisation manage some or all of the tasks associated with making things happen.
- Individuals and families will be able to connect with networks of disabled people and/or families to give them ideas about the choices they can make and the wide range of options that are possible.
- Individuals and families will have input into designing and governing systems, supports and services.
- Individuals and families will have key roles in the monitoring and evaluation of any systems, supports and services.

Service Providers will:

- operate with a clear set of principles and expected outcomes.
- negotiate how they work on a person by person and/or family by family basis. Note: This will initially be informed by the disabled person’s plan.
- experience one monitoring and evaluation process that is developmental.
- operate according to a facilitation based approach i.e. make it easier for individuals and families to achieve their goals by tailoring supports rather than the provision of a set range of service types.
- work to ensure community (generic) options are exhausted before specialist services are considered.
- operate with significantly reduced bureaucratic restrictions.
- experience the “system” as being supportive of innovation.

Government Departments will:

- have shared principles and outcomes that guide their decisions and actions.
- have a shared monitoring and evaluation process.
- ensure that all endeavours they fund directly or indirectly (e.g. workforce development) operate in accordance with the same principles and intent as Enabling Good Lives.
- be trusting and trustworthy partners.

Source: www.enablinggoodlives.co.nz

In December 2014, MoH, MoE and MSD released an in-depth evaluation of phase one of the Christchurch EGL demonstration (MSD, MoE & MoH, 2014). The evaluation highlighted the strong commitment of stakeholders to the EGL principles. It also noted large improvements in wellbeing that some participants had experienced as result of greater choice and control over services. The evaluation attributes the improvements partly to a change in mindset that occurred as disabled people and their families recognised they could explore previously unavailable possibilities.

The evaluation noted a number of challenges associated with the design and implementation of the demonstration, and provided suggestions on how the Government could improve these aspects of the project. For example, to improve the design process the evaluation suggests (p. 6):

Having greater clarity about what co-design means in the context of the Demonstration. There were different understandings of what co-design meant in practice ... The concept of co-design implies shared decision-making responsibilities but this was not the case in the Demonstration...

Allowing sufficient time to develop the components of the Demonstration. Not doing this has meant that some of the changes so far have focused on modifying the existing system (e.g. developing workarounds) rather than transforming it. For example, the rush to implement the Demonstration meant there was a reliance on less than ideal temporary solutions for disabled people to receive and manage their allocation of pooled funding.

Having the right people involved in the design process. The design and implementation would have benefited from the earlier involvement of operational people from the Ministries.

Developing a shared understanding of the design. There was not a shared understanding of what the Demonstration design entailed. Some saw the design as something fluid that evolved over time whereas others saw it as something that was fixed and only changed after the three years of evaluation.

The evaluation also noted that implementation was “rushed and placed considerable pressure on ministry staff. The workload to implement the Demonstration was higher than expected, in a short timeframe and on top of existing workloads” (p. 7). As a result, key components of the demonstration were not in place when it began in November 2013. For example:

- The mechanism for pooling funding for individuals was not fully developed.
- The navigators were still being hired and the role of the navigator was still evolving.
- Work remained to be done on how providers would be paid and how they would be assisted to operate in line with the principles.
- Accountability mechanisms had not been developed and it was unclear how disabled people would be safeguarded.
- It was unclear what community development meant in the context of EGL as this work had not been done.
- The mechanisms for bringing about change in government systems were unclear (p. 7).

A number of important barriers to disabled people achieving greater choice and control were also noted in the evaluation.

- *Organisations that disabled people interact with can make achieving greater choice and control harder:* Under EGL, disabled people may choose not to use disability support providers. However, where disabled people attend school or need support from a provider, the degree of choice and control they have will depend on the approach of the organisations they have access to. Families gave several examples of organisations (e.g. schools, providers) not always supporting their choices. ...
Navigators, individuals and families also described past experiences of providers not respecting their choices. For instance, one family gave the example of their disabled family member in respite care being “forced to go to bed at 7pm when he wanted to watch a movie”...
- *A belief that greater choice and control was not appropriate for some groups:* Some providers, schools and ministry staff interviewed were of the view that the EGL approach would not be appropriate for everyone, especially those with learning disabilities. These interviewees expressed concern that disabled people would be more vulnerable to abuse...
- *Limited options mean there may not always be real choice:* The respite options available for young disabled people, for example, appeared limited and while they would not have been the choice for some families there was no alternative to use them as they needed the break...As one parent said “Respite, this was a physical rest for us but not a mental rest”.
- *Transport can be problematic and may limit choice:* The disabled people in this evaluation have access to transport. However, families and providers raised concerns about the cost of transport and how this would be funded to support disabled people to have a good life...(p. 26)

Preparation for a second EGL demonstration in the Waikato kicked off in 2013 with the appointment of a leadership group consisting of three local forums representing providers, and disabled people and their families. The Government confirmed funding for the demonstration in the 2014 Budget (\$3.8 million over two

years). In September 2014, the Government appointed two directors to lead the Waikato project. The government used the first year of the demonstration to design and plan the project's rollout.

ELG Waikato began in earnest in July 2015 with 105 people participating in the demonstration in the first year.

While the demonstration is in its early stages, there are signs that the agencies involved have learnt a lot from the teething problems experienced by the Christchurch demonstration. For example:

- more time and resources have gone into planning and designing the demonstration;
- the demonstration is open to a wider group of disabled people and cover more services⁹;
- arrangements for pooling agency funds were worked out well in advance of the project going live; and
- there was greater involvement of disabled persons' organisations in the design and planning of the demonstration.

Co-director of EGL Waikato (Chris Potts) noted the initial learnings from the demonstration.

- Having one place to contact for information, support with making community connections, and which provides funding is something disabled people, families and community agencies are saying they value.
- Engagement from Māori has been high, with strategies to get better outcomes for disabled Māori and their whānau proving successful.
- Some disabled people have said they didn't know where to go for assistance until they heard about the demonstration.
- Some community agencies, including local Government agencies, have said they didn't know where to go to access services for disabled children, adults and families they work with.
- Flexibility with funding within and across Government agencies is a key success factor to achieving demonstration outcomes but barriers around amount of funding and contracting arrangements pose difficulties.
- The demonstration has put significant effort into making all process easy to access and understand, for example, putting all resources in easy read format. Participants see reducing complexity as a positive difference from the current system. (Chris Potts, pers. comm., 14 September, 2015)

D.4 Lessons from the use of client-directed budgets for disability services

There are a number of lessons from the New Zealand experience with CDBs in the area of disability services. This section broadly groups the lessons under three headings.

- general lessons about the value of choice and the process of developing CDBs;
- lessons about the design features of CDBs; and
- lessons about the implementation of CDBs.

General lessons

Choice has value: One rationale for CDBs is the empowerment that individuals obtain from the ability to exercise choice. As illustrated in the case study, empowerment can itself lift client wellbeing – particularly among groups in society that feel marginalised by the existing system of service delivery.

⁹ Enabling Good Lives Waikato will be working with four groups of people: disabled people who would like increased choices in their lives; disabled children aged 0-18 and their families; disabled Māori; and disabled people who, with a small amount of assistance, could be employed.

For disabled people, the quest for greater choice has occurred in parallel with a quest for greater social inclusion and the pursuit of human rights. Such “deeper” values should be recognised and understood when considering the use of CDBs in other areas of social services.

Choice means agencies need to let go of control: Many disabled people receive services from more than one agency. Pooling government funds into one “budget” and allowing flexibility in how funds are spent, increases the likelihood that CDBs will lead to better outcomes for disabled people.

Yet, cross-agency pooling of funds is difficult in a social services system built around robust lines of vertical accountability. Each agency (and minister) has a strong incentive to manage political and fiscal risks. As such, conditions around spending often accompany access to pooled funds. Agencies view these conditions as necessary to manage risks. However, for disabled people, conditions on spending reduce flexibility, and therefore the gains offered by CDBs over “top-down” models of service delivery. Ad hoc arrangements and “workarounds” may address this problem in the short-term, but questions around the scalability of such arrangements remain. The solution requires government to pay greater attention to system architecture (Chapter 5).

Design matters: The social and economic benefits of choice will only be realised under a well-designed CDB. This requires a deep understanding of the alternative design options and the incentive and fiscal implications of choosing one option over another. Experience to date suggests these are some of the key design questions:

- What service will people get choice around and on what terms?
- How will the Government fund the scheme? Will government agencies need to pool funds? What vehicle will agencies use to pool funds?
- What is the mechanism and processes for assessing individual entitlements?
- What roles will different agencies play? How will these roles be coordinated and governed?
- Is the design consistent with existing government institutions and frameworks? Where are the likely “sticking points”? How can agencies overcome these sticking points?
- Are any institutions or functions missing? What will be the form and function of any new institutions? How will agencies fund those new institutions or functions?
- What are the transactions costs that the different players in the system are likely to face? How can transaction costs be minimised?
- What are the implications for service providers?

Good design takes time and resources: Designing a CDB is a complex exercise. It takes time and resources for officials, clients and providers to understand the implications of alternative design options. It also takes time (and resources) for providers to learn how to work under the new system and to develop organisational structures and processes that fit with the new ways of working.

The EGL demonstration in Christchurch illustrates that rushing to implement a programme can result in foreseeable problems being overlooked, necessitating the need for expensive “workarounds” to patch holes in the design of the mechanism.

Operation is as important as policy: Too often agencies consider policy “development” and policy “operation” in isolation from each other – resulting in potential barriers to implementation going unnoticed until late in the design process (or worse, until the programme is operational). A clear understanding of the limitations posed by existing government institutions and procedures is central to designing and implementing CDBs.

Lessons for design

For CDBs to be effective, people must be aware, informed and capable of making decisions: People need good information to make good decisions. In designing CDBs, it is important to understand what information different players in the system need to make effective decisions, and to design the system in such a way as to make this information available. This means asking questions such as:

- Are people aware that they have a choice?
- What information will people need to make informed choices?
- How will people receive information in a way they can relate to and understand?
- What are the barriers to people making informed choices? What measures would overcome these barriers?
- What support is required to help people make decisions (eg, “supported decision making”). If people cannot make choices for themselves, what checks and balances need to be in place to ensure the person acting on their behalf (the substitute decision maker) is informed and acting in the person’s best interest?
- How can the cost of obtaining information be minimised?
- Does the system create incentives for all those involved to provide accurate information?

In New Zealand, LACs and Navigators have been important providers of information and decision support. To be most effective, the role of LACs and Navigators should be clearly articulated, and understood by clients, agencies and providers. The effectiveness of LACs is heavily influenced by the skills and competencies of the individual LAC working with disabled people. This suggests that choosing the right people and ensuring they have adequate training should be an important consideration for providers of LAC services.

Restricting spending should be minimised: As a general rule, the more freedom that people have over how to spend their entitlements, the more likely it is that services will meet their needs. That is, the wider the range of choices, the greater the potential for efficiency gains from choice. Chapter 11 discusses the efficiency gains from choice.

Dividing services into “service areas” (with some areas allowing choice and others not) undermines the potential efficiency gains from client-directed approaches. Demand side allocative efficiency will be greatest when people are free to choose the level and form of different services. For this to occur, government agencies need to provide service entitlements in a manner that allows people to substitute one service for another. Expressing some entitlements in hours of assistance and others as a dollar value is likely to add to the costs of managing and implementing the system.

Officials designing CDBs need a good understanding of the existing institutional setting: Governments commonly introduce new approaches into existing institutional settings. These institutions determine the fundamental conditions that the approach will operate in, and have significant impact on the outcomes achieved.

Formal institutions impacting the design of CDBs include legislative and procedural requirements (such as Treasury Instructions and Cabinet Directives). These formal institutions often set boundaries around the use of public money and the reporting procedures that agencies must follow when public money is used. Agencies designing CDBs must understand the impact of such institutions so that either:

- CDBs can be designed within the boundaries of existing institutions; or
- reforms to existing institutions can be identified and implemented.

The Christchurch EGL highlighted the need to understand the existing institutional setting. An example was the challenges that arose around the payment of Goods and Services Tax (GST).

Some participants who directly purchased services from a GST registered provider in effect ended up with a reduction in their personal allocation because they could not claim GST back from the Ministry of Health. By contrast, participants who chose a government agency to purchase the same type of service on their behalf had the GST component paid directly by Government to the GST registered provider. (Office of the Minister for Disability Issues, 2014, p. 4)

Officials also need to understand the relevance of informal institutions - such as society's values, customs, norms and culture. Choice models such as a CDB can often challenge the underlying assumptions of sections of society (including the culture of government agencies). This can lead to resistance from groups that feel threatened by the change in approach (see below).

There must be clearly defined and articulated governance arrangements: Use of stakeholder advisory groups has been an important feature of the EGL and IF design process. These groups have made a significant contribution to the programmes. However, at times a perceived lack of influence over decisions has frustrated members. The use of poorly defined terms such as "co-development" and "co-design" has fuelled this frustration, as such terms imply the advisory groups will have decision-making rights.

The Commission has previously identified five factors central to the success of collaborative processes (New Zealand Productivity Commission, 2014):

- a shared understanding of the boundaries of influence of the group;
- commitment to implementing the outcomes of the collaborative process;
- understanding the information needs of all parties and reducing information imbalances;
- selecting participants that represent the wider interests of the [relevant] community; and
- ensuring a clear and transparent process is in place.

Experiences in the area of disability services suggest that these five factors are also relevant in this context. Further, stakeholders may perceive representation as "tokenistic" if these factors are not in place.

Providers need flexibility to respond to variations in service needs: To realise the potential gains from CDBs, providers need the flexibility to increase, reduce or change the services they offer in response to the needs and preferences of clients. Services specifications that lock providers into explicit methods of services delivery reduce the range of choices available to clients, and therefore the possibility of allocative efficiency gains.

Of course, every service delivery model needs a way to prevent the misuse of public money. CDBs do not preclude the need for boundaries between "acceptable" and "unacceptable spending". Yet such boundaries can run counter to the intent of client-directed approaches (ie, personalising services to meet the needs and aspirations of the individual). Indeed, there may be no "hard boundary" that can be applied across all clients. Rather, the boundaries may need to be set on a case-by-case basis. This creates a significant challenge for officials designing CDBs as they must designing a system that is responsive to needs on the one hand, yet accountable and equitable on the other.

Lessons for implementation

Officials need to manage change carefully: Changes to how the Government funds and supplies social services can (naturally) create great anxiety for clients and their families as people struggle to understand what the changes mean for them. Failure to acknowledge and manage these feelings can result in public resistance to new initiatives (even before the Government has finalised the details of the initiative). This, in turn, can require managers to devote scarce time and resources towards negating public criticism (ie, "fighting spot fires").

Experience with disability services illustrates the importance of "bringing the community along" with any proposed changes. This reduces the likelihood that the changes will be met with opposition arising from limited information (or misunderstanding) about how the system will work. It also increases the likelihood of stakeholders having constructive input into the design process.

Empowering clients to make decisions can sit uncomfortably with the culture of some organisations, whether government agencies or non-government providers. Deep (and often unconscious) assumptions about the role of clients in the social services system can make organisations resistant to change. The successful implementation of a CDB model requires leaders to consider cultural changes as well as operational and procedural changes.

D.5 Summary – valuable insights from New Zealand’s experience with CDBs

This case study examines the use of CDBs in the area of disability services. The study is not an evaluation of the design or implementation of any specific programme. Rather, it has sought to draw out lessons that can be applied more broadly across the social services system.

For disabled people, the development of CDBs has occurred in parallel with their quest for greater choice, empowerment and social inclusion. Experience to date has highlighted that these models, if well designed, can improve the match between service delivery and the needs and aspirations of clients.

The EGL demonstration projects provide valuable insights into the implementation of CDBs. The lessons include:

- the importance of having sufficient time and resources to design and implement the programme;
- the need to carefully consider how existing institutions will impact the implementation of the programme and the incentives of different entities and people in the system;
- the importance of “bringing the community along” with the proposed changes to how services are delivered;
- the need to ensure that governance arrangements are clearly specified and articulated – particularly where stakeholders expect a “co-design” process to be followed; and
- the importance of change management, including the need for cultural change within government agencies and non-government providers.

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