SOCIAL POLICY

THE POWER OF FREEDOM

How personal budgets for social services are transforming lives

Matt Burgess
Foreword by Rt Hon Sir Bill English

THE NEW ZEALAND INITIATIVE

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About the New Zealand Initiative

The New Zealand Initiative is an independent public policy think tank supported by chief executives of New Zealand businesses. We believe in evidence-based policy and are committed to developing policies that work for all New Zealanders.

Our mission is to help build a better, stronger New Zealand. We are taking the initiative to promote a prosperous, free and fair society with a competitive, open and dynamic economy. We are developing and contributing bold ideas that will have a profound, positive and long-term impact.

ABOUT THE AUTHOR

Matt Burgess is a Senior Economist at The New Zealand Initiative. He specialises in climate change, energy and RMA issues. This is his first report on health. Matt was Senior Economic Advisor to Minister of Finance Bill English between 2012 and 2016. He was previously Chief Executive of iPredict, a prediction market based at Victoria University, and a Senior Associate at economics consultancy Charles River Associates. Matt has worked on public policy, competition, governance, network industries including electricity, gas and telecommunications and infrastructure.

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Sir Bill English is a shareholder of Manawanui Support Limited.

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Foreword

The best way to understand the impact of individualised funding is to understand the people it impacts. People like John, a 23-year-old with muscular dystrophy who wanted to work after leaving school. But the daily times offered by mainstream care services made this impossible. When John opted for individualised funding, he became the employer and could decide for himself when his carers came. This meant that John could arrange for care earlier in the morning and later in the evening than the mainstream services offer, allowing him to prepare for work. Now, John works 30 hours a week. John and his family are among many who couldn't make critical choices in the mainstream social service system but were offered a new way forward with individualised funding.

I have been part of discussions over many years about collaboration, cross-government projects, and breaking down silos. Each time, enormous effort yields little progress, and significant change looks unlikely. Health, education, and welfare agencies conceived in the 1930s were designed to deliver universal commodity services to ensure that everyone had access to a reasonable level of health, education and welfare. While universalism can work reasonably well for the lower-need 85% of the population who use half of government services, the remaining 15% have more complex needs. Frequently they find themselves like John – stuck in a generalised bureaucratic category, receiving a standardised service that doesn't meet their needs. They survive in the system as passive recipients of well-intended services.

Too often, politics dictates that keeping the universal state systems intact is more important than the integrity and aspirations of the individual. The universal system was not designed to be flexible and individualised. Large-scale agencies will never cater to the myriad preferences that lead to better lives for every person with a disability and their families. They will never be organised around the person, or their needs. Until recently, the cost and complexity of enabling and monitoring so many different preferences for using public money was prohibitive. Now, digital tools mean the individual choices of thousands of people can be implemented and monitored in a timely way at reasonable cost.

Individualised funding enables self-direction for people with complex needs, including those who need someone to act on their behalf – people who were previously seen as not able to make decisions. With individualised funding, they have the opportunity to choose support and solutions unique to them, their family, and their aspirations. Self-direction restores a sense of integrity and agency to the lives of people with low resources and high needs: they can use public resources to choose, demand, expect and complain just like everyone else. Most importantly, they can make decisions to change not only their current environment but also their future.

This report lifts the lid on a successful policy experiment. It turns out that self-directed people with disabilities make good decisions – there is a high level of compliance in spending public money, and the majority run under budget. They can be trusted. More importantly, self-direction significantly lifts their sense of self-worth and wellbeing. With further uptake of individualised funding, more people could benefit, including those with learning needs supported through the Ministry of Education, and those with mental health needs and older people currently supported through District Health Boards.

The current policy question asks if people with disabilities should be allowed self-direction. This report will help answer a different question – why should anyone be denied self-direction?

Rt Hon Sir Bill English

Executive summary

More than one million working-age New Zealanders experience some form of disability.[1] This year alone, the government will provide over $1.8 billion worth of disability support services to 43,000 people.

There are two funding models for disability support. Under the traditional model, the Ministry of Health (MoH) purchases support services from agencies by contract. Agencies deliver support either in community facilities or in the homes of the service recipients.

An alternative model of disability support is Individualised Funding (IF), which allocates each recipient a personal budget to buy their own support. Budgets are set based on an assessment of the recipient's disability support needs. Each recipient has full control over their own budget. Since March 2020, they can buy any combination of support services they choose, within rules called purchasing criteria. Of the 43,000 people who receive disability support, around 8,000 have some form of person budgets.

Under the traditional funding model, support is delivered by people employed by an agency contracted to MoH. Under IF, the employer is the person who receives the services.

Personal budgets put the services recipient in control. They decide who delivers what services and when. The result is a dramatic improvement in the quality and continuity of care. IF recipients can travel with their support worker and enjoy other experiences that may be difficult or impossible to achieve with traditional support.

With freedom comes responsibility. Most IF recipients employ their staff, which means taking on all the usual obligations of being an employer. Recipients take on employment responsibilities such as paying wages and taxes, advertising for and recruiting staff, signing employment agreements, managing terminations, and even personal grievances. Recipients must also manage their budgets, spend within the rules, and take care not to exhaust their funds early. They set aside funds to deal with unforeseen events, and arrange cover for when a caregiver falls sick or takes leave.

To navigate this complexity, every IF recipient receives support from a 'host' organisation. Hosts are the recipient's point of contact with the IF system. Hosts support IF recipients by:

- monitoring 'virtual' budgets;
- providing each recipient with their own coach;
- providing online self-service platforms to assist with budget management and tracking, advertising jobs, and scheduling support services each day; and
- arranging legal advice for recipients as they deal with employment law, payroll, taxes, and disputes.

There are nine IF hosts in New Zealand, each contracted to MoH. The largest, Manawanui, is based in Auckland and is the only exclusively IF host. The other IF hosts provide both IF and traditional support services.

The IF system also allows recipients to be represented by a caregiver or agent who can make decisions on behalf of a recipient. Often the caregiver is a parent of the disabled person (or IF recipient).

Spending from IF is subject to purchasing principles. These principles require that funds

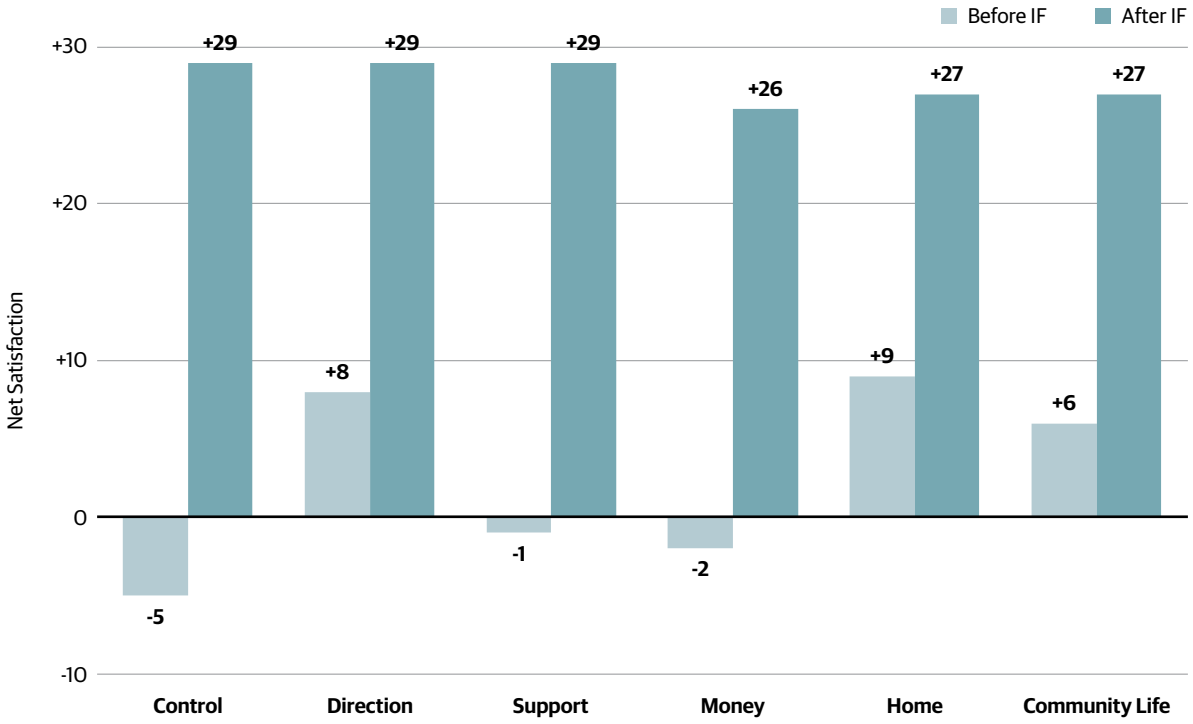
go towards the recipient's disability needs. Hosts help the recipient to decide whether purchases meet the purchasing criteria. The funder – which may be a District Health Board or the Ministry of Social Development but in most cases is the Ministry of Health – is ultimately responsible for determining whether spending is within the guidelines. When a recipient disagrees with the host's assessment, the matter may be escalated to the host's management, then to the funder.

Not everyone with a disability is willing or able to take on IF's responsibilities. Recipients may choose whether to receive traditional support or IF, and can shift between the two models at any time. The system respects individual preferences. In rare cases, an IF recipient who does not adhere to spending guidelines may be moved from IF to traditional support.

Research in New Zealand and studies of similar schemes overseas show individualised funding works. For example, Figure 1 shows the striking change in reported satisfaction of disability support recipients before and after they transitioned to an individualised funding scheme in the UK. These results are consistent with the findings from other research on IF.

This report reveals the profound effect that IF has had on the lives of recipients. IF can dramatically improve the quality of disability support and ultimately the quality of life for recipients and their families. Control of your own budget is control over who comes into your home; who helps to bath and dress you; who helps you with toileting. More than traditional services, IF means recipients get support from people they know and trust. IF is also the flexibility to change your mind about the kind of support you need, or to make plans at the last minute. IF means not asking permission to do the most basic things. It is hard to overstate the significance of the independence and dignity which control gives to recipients and their families.

Figure 1: Net satisfaction before and after transition to IF ('In Control' scheme in the United Kingdom)



Source: Poll et. al. 2006[2]

We want to raise awareness of IF with this report. It is not clear if all disability support recipients know about IF and understand they have the option to take control of a personal budget.

As the mother of one IF recipient said, comparing her experiences with traditional services versus IF is "the difference between night and day."

This report proceeds as follows:

- In the next chapter, we describe how IF began in New Zealand;
- Chapter 2 shows how IF works in practice;
- Chapter 3 compares outcomes between traditional services and IF and explains why they are so different;
- Chapter 4 summarises research findings on the performance of IF from New Zealand and overseas; and
- Chapter 5 concludes.
- There is further information in the Appendix.

CHAPTER 1

Origins of IF in New Zealand and overseas

IF began informally in the early 1990s, demanded by people having difficulty getting the support they needed under the traditional services model (see Philip Patston's story below). The earliest version of IF deposited funds directly into recipients' bank accounts with few if any organised checks and balances on spending. The first IF recipients were spread around the country and may have numbered fewer than ten.

The introduction of IF coincided with fundamental reforms of the health system, including in the early 1990s. The reforms were based on a principle of separating funding, purchasing and services delivery. In 1993, the government established four Regional Health Authorities (RHAs) and began purchasing disability services from provider organisations. At about this time, Needs Assessment and Service Co-ordination organisations, or NASCs, who will become central players in the IF story, began assessing disabled individuals and allocating funds accordingly.[3] Eligibility criteria for disability support gradually widened throughout the 1990s, allowing more people to receive support.

Box 1: "I don't want a good life, I want a f***ing great life!"

Philip Patston was born after 48 hours' labour on Christmas Day 1967. The attending doctor wasn't on duty that day and Philip didn't breathe for twenty minutes. His brain was starved of oxygen which left Philip with cerebral palsy.

Now 54, Philip employs staff for 30 hours each week. His personal assistants (PAs) support him out of bed, cook meals, help with eating, and maintain the house. Philip has two PAs, with a backup and another friend available if needed. Philip says it can be a problem giving each staff enough hours to make the work viable for them.

Philip was one of the first people to receive an early form of individualised funding in the early 1990s. At the time, Philip was jet set. His consulting business required frequent overseas trips. Philip would travel to other countries and get support from staff living in the destination country. As Philip got older, he began to have his PAs travel with him on trips.

Traditional services struggled to meet Philip's needs. He was having trouble getting support at 3am, which he needed to make his early-morning flights. Agencies simply could not find people willing to work at those times.

In frustration, Philip told his NASC it was not meeting his needs. Officials said they were not sure what to do. "Give me the money and I'll deal with it," Philip said. And they did. Money went directly into Philip's account a week later. After years of trouble getting the help he needed, Philip found he had no problem hiring people to provide him the support he needed on his schedule.

This was the start of Individualised Funding in New Zealand. An informal solution to a pressing problem for Philip and others struggling with unmet needs around the country, and it worked.

Philip was also there at the start of Manawanui, the first IF host established in 2004 in response to the Ministry of Health's tender for its IF pilot that year. Philip worked for one of the four charities that formed the first IF host, Manawanui. Philip was the first Chair of Manawanui.

Box 1 (continued)

For Philip, formalising IF has led to rules which have hurt his experience. When officials put money into his account, Philip was free to spend his money on whatever forms of support he needed, with few if any checks on his decisions. This relatively informal approach lasted for about a decade. But with IF going mainstream came rules on spending, constraints on his purchases, and red tape.

Philip asks why if beneficiaries can spend their money on anything should rules put limits on how disabled people spend their money. Philip is also frustrated that demonstration projects around the country (see page 11) have led to different spending rules in different places. If Philip were part of the demonstration project in Hamilton, he could use his personal budget to help buy equipment. But Philip is based in Auckland, where he can only buy services, not equipment, from his budget. Funding for his wheelchair is under the traditional model, which is based on permissions. Philip has been waiting more than eight months to replace his 10-year old wheelchair.

Philip also asks why the government names one of its disability support programs Enabling Good Lives. "The government should aim higher. If it is only good, then it is below standard," he says.

"I don't want a good life, I want a f*** great life!"

Philip was not the only one needing more flexible support. Demand for IF came from the rising number of people like Philip and from parents who wanted support that better met the needs of their disabled child.

IF was formally launched in late 1998 with a pilot in Christchurch. The pilot was organised by local NASCs and the Health Funding Authority (HFA), the latter formed in 1997 from the amalgamation of the four RHAs.

The Christchurch pilot was the result of years of pressure from disabled people who were dissatisfied with a system that was struggling to consistently meet their needs.

Further reforms of the health system in 2001 disbanded the HFA and shifted responsibility for disability support for working-age people to the Ministry of Health, where it remains today.[4] MoH supported the continued expansion of IF. However, according to MoH, the development of IF in the early 2000s was hindered by consistency problems and a lack of safeguards.[5] At the end of 2001, MoH imposed a moratorium on any further expansion of IF.[6]

In 2004, the Ministry of Health issued a tender for a pilot to provide IF services. Four charities submitted bids. None of the charities individually met the tender's requirements. Together, however, the four charities did comply. They joined forces to form a new organisation called Manawanui In Charge. Manawanui, which was jointly owned by the four charities, won the tender.

By the time the pilot ended in 2008, approximately 130 people were receiving IF support.[7] MoH reviewed the IF pilot and found very high[8] approval among participants. The main drawback of IF, said the participants, was the paperwork.

That same year, 2008, Parliament's Social Services Select Committee delivered a landmark report on the quality of disabled care in New Zealand.[9] Among its recommendations, the Select Committee said NASCs should "focus on meeting the needs of individuals, rather than those of service providers" and that people with disabilities "should have better access to supported independent living and individualised funding".

The review led to the decision to create a National IF framework, extending IF to all people on traditional Home and Community Support Services. The Ministry of Health contracted with additional host providers, increasing the number of hosts from one – Manawanui – to 13. Another significant change was turning IF funding from weekly to annual budgets, adding flexibility to spending through the year.[10] MoH developed a new national framework which standardised IF, then transferred individuals from other IF-like schemes, including *ad hoc* arrangements by NASCs and HCSS providers, to IF proper.

Over time, the Ministry of Health further expanded self-direction through demonstration projects. The projects aimed to reach more disabled people with IF. Each project was located in a particular area:

- Enhanced Individualised Funding in the Bay of Plenty – 2010
- Enabling Good Lives in Christchurch – 2012
- Enabling Good Lives in Waikato – 2015
- Mana Whaikaha in Manawatu – 2017

Most of these demonstration projects still run today. The demonstration projects introduced a version of community navigator role based on the "Local Area Coordinator" model in Western Australia[11] as well as the Connector/Tūhono model.[12]

Lasting changes were made to IF in response to the COVID lockdown in 2020. Purchasing guidelines for IF recipients and rules about paying family carers were relaxed to allow recipients to pay family members to provide support. This change broke a longstanding rule against paying some[13] family members of disability support recipients, but was made to protect household bubbles through the lockdown. The government made the change permanent in February 2021.

By August 2021, the number of people receiving disability support under IF had risen to around 8,000.[14]

The growth of IF in New Zealand since the 1990s has roughly paralleled the growth of the personal budgets funding model in other countries. The worldwide increase in the use of various forms of self-directed funding is grounded in human rights. The right to self-determination of disabled people became widely accepted in the second half of the 20th century as attitudes towards people with disabilities shifted.[15] The Ministry of Health describes the shift as moving from a 'medical model' to a 'social model' of disability support.[16] Rather than see disabled people as having an illness or disease that requires treatment, disabled people are recognised as having equal rights alongside all other members of society.[17] This welcome change has given rise to individualised funding.[18]

CHAPTER 2
How IF works

IF is based on personal budgets controlled by the services recipient or a caregiver acting on their behalf (agent). Recipients use their budget to buy the support they choose. Personal budgets are set based on an assessment of the disabled person's needs conducted by Needs Assessment and Service Co-ordination agencies, or NASCs.

Recipients may use their personal budgets to purchase equipment and disability support services. Depending on the arrangements, personal budgets may cover wages, taxes and holiday pay, expenses, and hosts' fees for various services.

Purchases must comply with the following four principles:[19]

1. The purchase meets their goals, helps the recipient live their life, or makes their life better.
2. The purchase is for disability support.
3. It is reasonable and cost-effective.
4. It is not subject to a limit or exclusion, meaning the purchase is not already funded elsewhere and is not a normal cost of living such as rent, power or groceries.

Hosts can help the recipient decide whether a purchase complies with these criteria. The funder, usually the Ministry of Health, is ultimately responsible for determining whether spending is within bounds. If a recipient disagrees with the host's assessment, the matter is escalated to the host's management. The system works on the principle that decisions are made as close to the disabled person as possible.

In practice, the process usually works by the recipient asking their host if a purchase is within the criteria if the recipient is unsure. The host will discuss the purchase with the recipient. If the host believes the spending cannot be defended as a disability support, the host will decline to approve the spending. If, after the discussion, the recipient still disagrees, the spending request will be referred to the funder. Adjudication may occur before or after a purchase is made.

IF turns each recipient of disability support into a small business. Recipients may hire their support workers either as contractors or employees. Most choose to employ. As an employer, IF recipients must manage a budget, advertise for staff, hire and terminate employees and contractors, and settle personal grievances when they arise. As with any small business, IF recipients must compete for their staff by paying the going rate for their services.

IF recipients do not have direct access to the funds in their personal budget. Funds are not held in personal bank accounts, as in the early 1990s and some versions of IF overseas today. Instead, IF is based on a 'managed funds' model. Usually, the funder, and in some situations the host, holds funds on behalf of each IF recipient. Recipients access their funds either by:

- purchasing equipment or services and submitting an expense claim to the host, who claims the costs retrospectively from the funder, or
- instructing the host to make payments, most commonly wage payments, which are claimed back from the funder by the host.

This managed funds approach can add paperwork, which IF recipients do not universally welcome. Despite this administrative overhead, control of funds ultimately sits with recipients – if not in the form of cash.

Box 2: IF is a leap into small business*

John is one of the estimated 11,000 or so New Zealanders suffering from Parkinson's disease, a degenerative condition of the nervous system marked by tremors, muscular rigidity and slow, imprecise movement.

Parkinson's — or "PD" as the infirmity is commonly termed in medical circles — is widely regarded as an ailment of the elderly.

This incurable illness can develop in middle age, however. John was 45 when he was diagnosed as having PD.

In his case, the progression of the disease was sufficiently slow as to allow him to continue in full-time paid employment for a further 15 years.

Unfortunately, he subsequently experienced a sudden and severe deterioration in his condition which made it impossible for him to look after himself without assistance.

He copes with the day-to-day challenges posed by his disability with the help of his partner and two carers whom he employs utilising IF funding provided by the Ministry of Health

John signed up to IF six years ago following his being discharged from hospital. The alternatives to IF were not appealing. The thought of going into a rest home threatened to "destroy my sanity," says John.

Being able to remain in his own home matters immensely.

What also matters just about as much is that his carers are fastidious about punctuality.

They must arrive at work on time every time.

That said, John notes that IF offers the flexibility to change work hours or shifts to accommodate such requests from staff.

It took some time and several false starts for John to find the right staff. His early hires were not successful. His current support staff have been with him for five years. John prefers to employ his support workers under a standard employment contract, rather than as contractors, because the benefits of job security run both ways: a stable employment relationship means better support.

John stresses that running a household under IF is akin to running a small business. "Being a small business is a leap. IF is more complicated than you might think."

While payroll matters are handled by Manawanui, a management services agency, he says it is vital that those in the household responsible for IF matters become acquainted with the basic provisions of employment law, especially those pertaining to holidays, sick leave, bereavement leave and so forth.

For example, a misreading of the poorly written Holidays Act can have implications regarding staying within the funding allocated to someone utilising IF.

Despite these challenges, John cannot point to anything he would change about the IF system. Overall, he says, the system is excellent. In particular, he speaks highly of Manawanui, most notably its performance during 2020's COVID-19 lockdown.

* Now retired, John Armstrong is a former journalist. He was the New Zealand Herald's political editor from 1989 to 2002 and subsequently the paper's political columnist from 2002 to 2015. He has contributed to this report in the hope that sharing his experience might help push the case for a much-needed public debate on the implications of a rapidly ageing population.

Disability support in New Zealand

About 43,000 people receive disability support – less than 4% of the estimated 1.1 million people living with a disability in New Zealand. It is not known how many people are eligible to disability support but are not receiving it.

Table 1 shows IF recipients tend to be younger and have higher support needs on average relative to all recipients of disability support. People with sensory disabilities are over-represented among IF recipients. Autism is under-represented. About half of IF recipients have an intellectual disability as their principal disability.[20] A further quarter of IF recipients have a physical disability, both in line with the proportions of all disability support recipients.

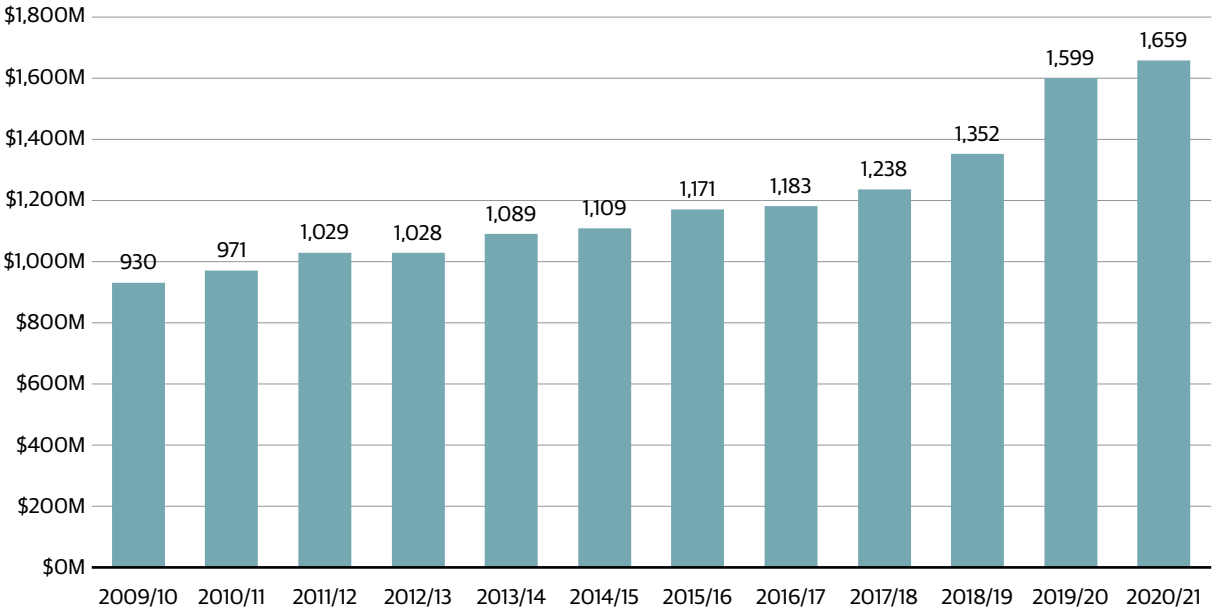
In 2021, the government will spend more than $1.8 billion per year to provide disability support to 43,000 people. Funding for disability support has increased substantially in the past decade, with an increase of 42% since 2016 (Figure 2 and Figure 3). However, over the same period, overall Crown spending increased by 50% (Figure 4).

Table 1: Age and type of principal disability: Individualised Funding vs all support, 2018

	All	Individualised Funding
Median age	**26 years**	**19 years**
Type of disability		
Intellectual	19,227 (50%)	2,414 (45%)
Sensory	1,096 (3%)	1,447 (27%)
Physical	8,662 (23%)	1,238 (23%)
Neurological	303 (1%)	175 (3%)
Autism spectrum disorder	8,858 (23%)	52 (1%)
Other	196 (1%)	12 (0%)
Total	38,342	5,338

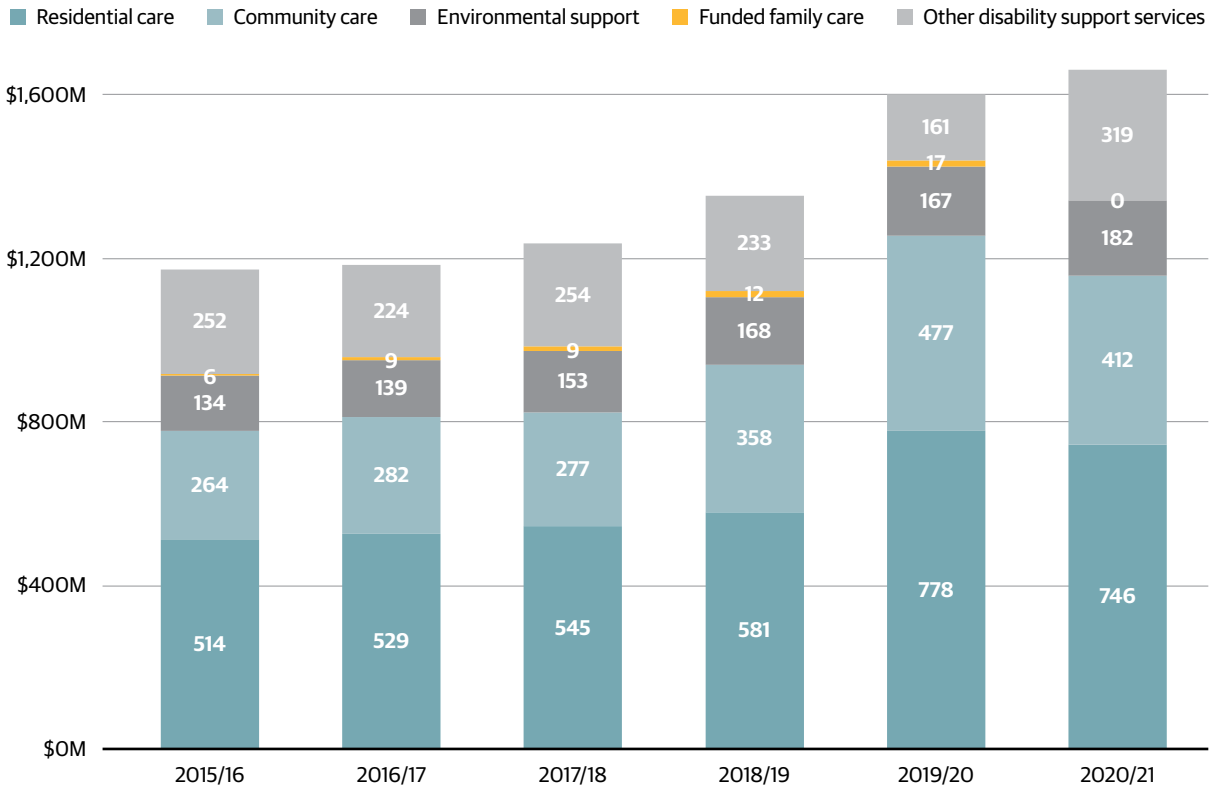
Source: Ministry of Health (2018c).

Figure 2: National Disability Support Services funding 2010-2020



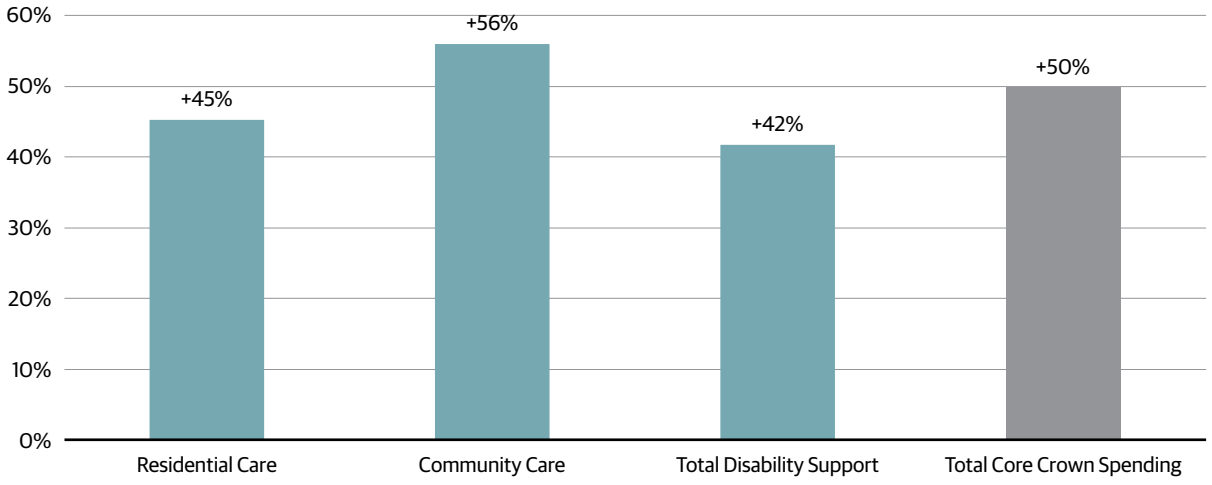
Source: Vote Health, New Zealand Treasury.

Figure 3: National Disability Support Services funding components



Source: Vote Health, New Zealand Treasury.

Figure 4: Changes in National Disability Support Services funding 2015/16–2020/21



Source: Vote Health, New Zealand Treasury.

Primary IF roles

IF has three main institutional players:

Needs Assessment and Service Co-ordination providers, or "NASC": NASCs assess each person to determine their support needs and allocate support. NASCs conduct assessments for both traditional and IF support. They are non-government organisations contracted to MoH. There are 14 NASC providers in the country (see Appendix).[21] Once a NASC has assessed a person's needs and determined their support allocation, a decision is made between traditional service or IF and the person is referred to a host.

Hosts: Support recipients in all aspects of IF. Hosts are the main point of contact with the IF system for recipients. Hosts are contracted to MoH, and earn revenue through their MoH contract and by selling support services to recipients. Today, there are a total of nine IF hosts (see Table 2).

Ministry of Health: Responsible for policy and funding of disability support services for working-age people (less than age 65), covering both traditional and IF models.

Table 2: IF host providers

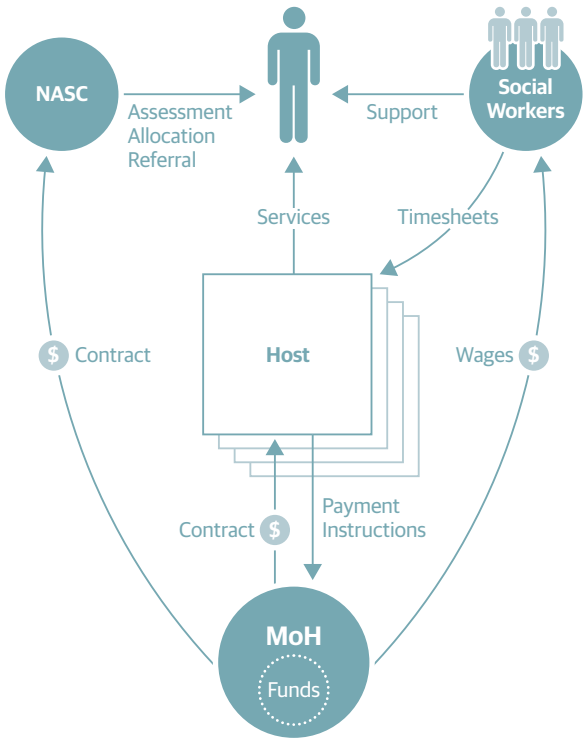
IF Provider	Region
Access Community Health	Nationwide excluding Auckland
Florence Nightingale Agency	Marlborough, Christchurch, Invercargill, Dunedin
Geneva	Nationwide
Healthcare NZ Limited	Nationwide
Home Support North	Northland
Lifewise	Auckland
Manawanui Support Ltd.	Nationwide
Presbyterian Support Northern (Enliven)	Auckland, Bay of Plenty
Vision West	Auckland West, Waikato, Bay of Plenty

Hosts provide the following services:

- provide each recipient with a personal coach;
- pass funding from MoH to people to pay for supports;
- approve or decline purchasing decisions based on the four purchasing principles;
- monitor recipients' spending, providing accountability; and
- provide advice to help each recipient navigate the complexities of employment and tax law, among other things.

Some hosts also offer an online job listing service. Under their contract with MoH, each host must provide a minimum set of services to each recipient. Beyond this minimum, recipients are free to purchase additional services from their host or from anyone.

Figure 5: IF system structure



The process for accessing IF

Access to disability support with IF is in four steps:

1. The recipient's support needs are assessed

The disabled person (or their parent or caregiver) contacts their local NASC agency. NASCs are publicly funded organisations that provide needs assessments for various types of funding, including IF. For IF, the NASC provider has two jobs.

- Set personal budgets. A NASC representative meets the individual and/or their caregiver to assess their needs. Assessments are conducted as one-on-one interviews between the person and a NASC assessor. The NASC determines the allocation by estimating the number of hours of support the recipient needs per week based on their needs. The recipient's personal IF budget is calculated by multiplying the number of hours by a standard hourly rate, which is currently $34.74. To be eligible for IF, the person or their caregiver or their agent will need to be capable of managing a budget.
- Refer the recipient to an IF host. In theory, NASCs should give each recipient a list of available hosts.

2. The host onboards the recipient

The NASC sends the host a referral to the recipient. The host contacts and onboards the recipient. Onboarding includes the host

- setting up a new profile in their system;
- obtaining information and signed consent forms from the recipient;
- assigning a coach; and
- meeting the recipient and walks them through their host's systems, and explaining the recipient's obligations under IF.

The coach will sign a Service Agreement – a contract for service – with the recipient. This agreement sets out the responsibilities of the host and the recipient. The coach explains the purchasing guidelines of the relevant funder and works with the recipient to create a budget for the allocation period.[22]

Hosts' agreements with the Ministry of Health require each recipient have a coach.

3. The recipient writes a plan

The recipient writes an individual service plan with their coach. The plan sets support goals and establishes what the recipient will need to achieve those goals.

The recipient must decide whether to buy insurance, and work out their purchasing approach for support (employment vs contracting, mix of support). Recipients may need assistance to understand how to use their budget effectively, decide what they will purchase and when, and how to stay within their budget.

4. The recipient hires support staff

The recipient is mostly unconstrained in how they obtain their support staff. The recipient can hire almost anyone at any agreed wage on whatever terms the recipient agrees with support workers, within the bounds of employment law and pay equity legislation. However, purchasing rules can limit payments to family members who live with the recipient (see endnote 17).

Recipients can contract or employ their staff. Most recipients choose to employ their staff. Disability support tends to be regular, long-term and predictable, which employment legislation defines as an employee. The host is responsible for supporting recipients to pay their employees or contract with a payroll provider to pay recipients' employees.

Further details on how IF works in practice:

- Personal budgets are usually capped annually. This gives recipients the flexibility

to vary the timing of spending within the year. Recipients commonly under-spend their budgets early each year either to save for exigencies or in case support needs unexpectedly increase.[23] Recipients may also save for a planned event that will require extra support – for example, a trip they will need support staff to attend with them (see Philip's story above).

- If money remains in a person's budget at the end of the year, the budget is not reduced. This removes the incentive to spend up to the limit each year.[24] On average, only 70% to 80% of personal budgets are spent each year.[25] Unspent funds at the end of each year remain with MoH and are not returned to the Crown.
- NASCs review each recipient's needs and support package every one to three years, or whenever the recipient asks. If needs change, recipients are required to notify their NASC and request a review.
- Under their contracts with the Ministry of Health, IF hosts are responsible for managing the risk of individuals exceeding their budget. Hosts monitor for excessive or unusual spending, particularly early in the year. Where excessive spending is identified, a host will contact the recipient to discuss their spending.
    1. The host will contact the recipient to inform them of potential over spending.
    2. If the recipient requires support to get back on track, the recipient's coach will make contact.
    3. If the recipient disregards advice and continues to overspend against their budget, the host will notify the NASC and/or the funder to discuss potential options or solutions.
- If the budget is spent early, the NASC may start the new allocation early, particularly if the overspend is the result of a change in need.
- Payroll works as follows: the support worker completes a time sheet and the recipient approves it; the recipient sends the time sheet to the host; the host pays the support worker and claims the funds back from MoH. Staff may also file expense claims.[26]
- Accountability for the use of IF funds rests with the recipient or their agent. Recipients and agents cannot assign accountability to another person.[27]

Hosts receive payments from the funder for onboarding ($550) plus an annual fee ($980). Fees are set by the Ministry of Health and paid by the funder, not recipients. Hosts can earn additional revenue by selling other services to recipients, including job matching, payroll, and tax support services. Recipients have the option to purchase these services from their host or from elsewhere using their personal budgets.

Funding for IF and traditional support services comes from the same pool of public money. Pooling provides valuable flexibility for individuals to transition between IF and traditional services. Disability support recipients can switch models whenever they choose, and change host providers at any time.

If a person is not satisfied with their assigned personal budget, they can appeal to the NASC, who will arrange a "peer review" of the decision by another NASC.

Checks and balances

As with any scheme that puts public money in the hands of private individuals, IF brings with it the possibility of fraud. Thankfully, fraud is rare in New Zealand and overseas (see the literature review in section 4). Only a handful of cases of IF fraud has ever been identified in this country.

Nevertheless, the IF system is organised to identify and respond to fraud if it occurs. Hosts are often the first to identify a potential misuse of funds.

Hosts have visibility over IF recipients' spending, allowing hosts to identify and investigate unusual spending patterns that could indicate fraud. MoH has an audit and compliance unit responsible for managing instances of fraud. Where hosts find potentially fraudulent activity, they will usually refer the matter to MoH for investigation and potential prosecution.

A plural approach with IF and traditional models working in parallel gives policymakers flexibility for responding to fraud and other forms of misbehaviour. When fraud has occurred, the person responsible will usually lose access to personal budgets and will be required to transfer from IF to traditional support.

Recipients may lose access to IF for other reasons. For example, recipients who are chronically non-compliant with their purchasing may be required to shift to traditional support. A recipient can also be removed from IF after two personal grievances resulting in payouts (see the Appendix for a list of ways recipients can be removed from IF).

Who uses IF?

In the past, IF tended to attract higher-needs individuals. This may have been because the greater complexity of high-needs raises the returns to have decisions made inside the home rather than by a third party under the traditional services model. Greater needs may also justify the investment of time and effort required to learn to manage IF (hiring, budgeting, compliance and so on). More recently, an increasing number of IF recipients have smaller budget allocations.[28]

IF greatly simplifies some tasks such as travel, which requires arranging specialist transport to the airport and throughout the stay at the destination city. In addition, equipment and a support person must also travel, with accommodation and meals to be arranged. We spoke to a person who contrasted the experience of arranging travel for her severely disabled mother under the traditional support model versus IF. She said bringing together all the pieces needed for travel under a 'beg steal or borrow' approach of traditional services can be extremely complicated. A successful trip requires each part of a visit to come together at the right time and place. By contrast, IF makes travel "a breeze." She simply hired the equipment and bought the services she needed using her mother's IF budget, which she manages. IF eliminates much of the red tape around spending.[29]

However, IF is not for everybody. It requires the capacity to make decisions or access to a caregiver who can act as the recipient's agent to make decisions on their behalf under a supported decision-making framework.[30]

Overseas, IF can be used temporarily to make one-off purchases as needs arise:[31]

> Moreover, some people may only use self-directed funding temporarily. Some people may want one-off payments at certain points in their lives or at a given time of year (for example, to purchase short breaks for the carer, education services or equipment), without having to have ongoing budget holding responsibilities. This arrangement is now common in the UK.

Disability support targets vulnerable households

Disability support, under both IF and the traditional model, must work for people who are often in a vulnerable position.

When a child is born with a disability, or a person has a disability due to an event during their lifetime, their whole family can be affected. The primary earner in a household may need to leave their job to care for their disabled child full time. This can dramatically reduce household income. The most recent Disability Survey by

Statistics New Zealand, now almost a decade old, showed only 34% of households with a person residing had an income of more than $70,000, which compared to 50% of all households.[32]

Sadly, the effects of disability on a household can go well beyond income. Disabled people are far more likely to suffer abuse than the general population. According to the Australian Productivity Commission:[33]

> [P]eople with disabilities and their families are sometimes vulnerable — tired, isolated, poor, and in some cases, unable to complain due to their disability. Overall, rates of abuse of people with disabilities are multiples of those for people without disability, indicating their general vulnerability. Data from examination of referrals to the United Kingdom's Protection of Vulnerable Adults list shows that people with a learning disability were more likely to be abused physically or sexually than those with a physical disability.

Abuse may come from caregivers. The abuser can also be a flatmate in shared facilities.

IF provides the following protections against abuse:

- **Hosts provide support:** coaches required under MoH contracting rules.
- **System checks:** purchasing guidelines, MoH audit function, fraud detection and prosecution, employment law, insurance.
- **Option to change systems:** In some sense, the traditional model is a safety valve for IF. Traditional models are available as an alternative when IF is not a good fit for an individual. MoH rules require a person to leave IF when specific rules are breached, e.g. two or more PGs, repeated overspending, or fraud.
- **Informal support:** community and online support; advocates.

Clearly, disability support raises sensitive and difficult issues for policymakers.

Traditional model vs IF

Some recipients of disability support resent the dependency aspect of the traditional model, where officials and support staff make decisions for recipients. Changing support, going away for a day or longer, or purchasing one-off equipment – all require permission under traditional funding.

Dependency can lead to frustration. For some people, that frustration turns into violence. In fact, this report originated from the story of an unnamed man whose frustration with the traditional support services he received led him to lash out at his caregivers. Things reached a point where nobody wanted to work with him. It turned out his frustration stemmed from a desire to control his own life, which he could not do with the traditional support model. After shifting to IF, the man's behaviour improved immediately. He thrived once allowed to make his own decisions, take responsibility, and manage his own life.

Many recipients receive both IF and traditional support.[34] This plural approach offers flexibility. IF and traditional support can act as safety valves for each other. If people find the responsibilities of IF too onerous or are not interested in dealing with the compliance of IF and have no person they can nominate to act on their behalf, the traditional service model may be the better option.[35]

CHAPTER 3

Comparing outcomes under IF and traditional models

IF and traditional services differ by who pays the person providing support:

- Under IF, the recipient of services employs or contracts with the person delivering support.
- Under the traditional model, an agency contracted to MoH pays the person delivering support services.

This section describes the profound consequences of assigning decision rights to the person who receives support services. The evidence in this section was gathered from IF recipients who told us about their experiences under the traditional disability support model and the changes they experienced after moving to IF.

Here is what IF recipients told us:

- IF provided greater scheduling flexibility.
- Increased reliability of services. Under the traditional model, support was often late arriving, did not arrive at all, or was curtailed by scheduling conflicts.
- Allowed rapid adjustment to the types of support, as needed.
- IF supports variation in spending through the year, meaning spending within a fixed budget can be brought forward or postponed through the year as a way to manage uncertainty.
- Ability to trade off spending on support versus one-off purchase of equipment e.g. a replacement wheelchair (though the option to purchase equipment is limited in some areas).

These results are consistent with the findings from both New Zealand and overseas research on individualised funding (see Chapter 4). Improved outcomes under IF appear to be systematic for those people in a position to take on the responsibilities of IF.

Before we consider the benefits of IF in more detail, we share the story of Sarah and Lisa, who received support under the traditional model before moving to IF.

Box 3: "Luck and love"

Sarah, 27, lives with mum Lisa in Auckland. Sarah receives disability support through IF for Rett Syndrome, a neurological disorder which almost exclusively affects females. Lisa is Sarah's IF agent.

Lisa has supported Sarah full-time since Sarah was born. When Sarah turned 12 or 13, Lisa found the physical strain started to take its toll. Lisa needed help.

Initially, Sarah received three hours of traditional support services each week. This included a shower after school at 3:30 every Monday, Wednesday and Friday. Support increased to 18 hours when Sarah turned 15 or 16 after Lisa developed chronic health conditions.

Box 3 (continued)

"Most likely from burnout after trying to live a normal life. I was going to university to complete a degree in occupational therapy while being a solo full-time mother of a child that does not sleep normally," says Lisa.

"Add to that the stress of numerous health issues and you get the picture."

Lisa ran into serious limitations with traditional home support services for Sarah. There was no flexibility to reschedule as support workers went from appointment to appointment throughout the day, or because the agencies only allowed them to work very rigid rosters. Lisa's agency could never find anyone to support Sarah during weekends or provide cover when the support worker was sick or away. Different support workers would often turn up to deliver support.

Lisa says she had to rely on "luck and love" to get through.

Despite these problems, Lisa says support worked reasonably well overall in the first few years. But things gradually went downhill. Sarah's care provision became unreliable and the agency provided no replacements.

Lisa heard about IF from a Facebook group and shifted to IF in 2011. With IF, Lisa was able to hire her own people. The result has been positive: greater flexibility and reliability, improved continuity, and the ability to get support on weekends. Staff are happier with better pay rates (even before pay equity legislation) and better working conditions than their previous work. IF allows greater flexibility for both Lisa and Sarah and their support staff.

Lisa says the difficult part of IF is getting carers who can competently carry out complex tasks. "Good staff are few and far between," says Lisa, "and worth their weight in gold. There is not a great workforce for the higher end of care needs out there."

Lisa believes staff for high-end needs could be affected by competition from the Accident Compensation Corporation (ACC).

"For example, ACC serious injury is funded at a higher rate than MoH disability support," Lisa told us. "MoH pays the same hourly rate for low to very high care needs. The care we need is more in line with serious injuries, but because Sarah was born with these needs rather than acquired them through injury, the provision is different. It's very discriminating."[36]

"You rely on your luck and people who love what they do as it's not seen as a "career" to be a support worker. We have a big shortage in NZ with our disability work force for very high complex needs that is not currently being recognised," Lisa says.

Lisa worries about how Sarah will cope if she (Lisa) dies. Lisa would like Sarah to stay in the house and get a flatmate with a similar funding package to live together. But Kainga Ora (formerly Housing New Zealand) will not transfer control of tenancy to Sarah because Sarah cannot communicate. Alternatively, control of the tenancy could transfer to an agency. But Lisa says her agency will not take a tenancy in isolation, and the providers tend to want to have a residential care contract. Lisa worries Sarah will be "at their mercy".

"It's time that the choice and control was truly in these vulnerable people's hands. I want Sarah to be able to purchase her care. If they don't provide a good service, she has the power to purchase elsewhere. Instead of being powerless with the provider being given her funding to 'manage,'" says Lisa.

"We need an independent support system that has no conflict of interest in housing or funding to oversee these aspects of Sarah's life if I'm not around to be her agent. I feel that is what's missing with IF, along with a workforce provision to purchase from," Lisa says.

"At present, it will come down to the luck of what will happen."

Despite these problems, Sarah has carers who have been with her for over four years now. Lisa and Sarah are in a positive place.

Recipients we spoke to in preparing this report told us IF gives them the following benefits:

Flexibility

The most-cited and possibly the most-valued advantage of IF over traditional support among the recipients is flexibility. They found the traditional model rigid, while IF gave greater flexibility. Of their experience under the traditional model, recipients told us:

- They could not get support at the times they wanted, especially on weekends.
- Little or no ability to reschedule on the day.
- Problems getting the type of support that was required, and
- Severe logistical problems with travel.

Two recipients told us they felt they had to fit into their agency's schedule, not the other way around.

Flexibility may be a universal characteristic of IF. Our review of academic research of individualised funding is consistent with the comments from recipients we spoke to. Carmichael and Brown (2002) state:

> "direct payments [i.e. IF] have 'permitted' disabled people to employ personal assistants, a facility that, in turn, has enabled them to participate in many activities outside the home, such as shopping trips, attending education and training courses, and leisure activities: pursuits which many non-disabled people take for granted, but which are often denied to people who have their personal support needs met through less flexible arrangements.

Continuity of care

IF recipients consistently reported that under the traditional model, agencies would regularly send different support people, often people the recipient had not previously met. Agencies send different people due to the complexities of scheduling. Each agency employee supports multiple people, and agencies try to set a schedule that minimises travel time. This is not an unreasonable approach by agencies who must manage their costs. However, it can make the system brittle. Unforeseen events, such as traffic or illness, can disrupt appointments throughout the rest of the day.

Continuity of care – receiving support from the same person or people each time – is significant for at least two reasons. Trust between the person providing support and the recipient is essential. Support can be very personal (showering, toileting, dressing). Knowing the person who is providing support is important given the circumstances.

Second, continuity of care means familiarity with the individual's disability and specific needs. For example, we spoke to Susan, whose autistic son, John (not their real names), wants to exit a vehicle immediately after it has parked. That is a serious problem when there is nearby traffic. John's caregivers, who have supported him continuously for more than three years, know to tell John to stay put when parking. But *ad hoc* carers may not know to tell him.

IF improves continuity of care because only people contracted to or employed by the recipient or caregiver delivers support.

Reliability

Recipients told us they found their support was unreliable under the traditional model and that the shift to IF improved reliability. We heard many stories of support staff arriving late, or not at all, under the traditional model. We also heard how support could often be curtailed by the travel required to get to the support person's next appointment. One recipient told us one hour of support often lasted only 15 minutes.

Reliability has consequences. One recipient told us that when her support person did not turn up, her daughter had to go to school without a shower, sometimes for days at a time. Despite

no-shows being a recurring problem, the recipient's support agency had no contingency in place. Recipients reported more reliable support after shifting to IF, in part because IF recipients can make their own contingency arrangements.

Knowing that support will be delivered at the agreed time is important for the recipient and their family. For the recipient, the ability to hold down a job, or to make and deliver on any commitment, can depend on support that is on time, every time. Unreliable services can have broader effects. It is often up to the family of a disabled person to step in and cover if a caregiver does not arrive, affecting the ability of family members to plan their day.

Dignity

Control of a personal budget means IF recipients decide who comes into their home. For many recipients and their families, who enters their home is their dignity. Traditional services sometimes meant a different support person each visit, often someone the recipient had never met.

As a recipient of IF support in Britain said:[37]

> I get to choose who, where and what. I wasn't comfortable when we had the lady coming in, putting me to bed at 6 and getting me up at 9, I'm 25, I don't want a complete stranger coming in to my house and washing my hair for me. Now, I can choose somebody that I trust and that I'm comfortable around.

Risk management

IF gives recipients ways to manage uncertainty about their condition or unexpected events. Individual budgets are a fixed annual amount, which allows IF recipient to vary spending within the year.[38] This ability to adjust the time of spending is valuable as a way to:

- manage the risk of an unexpected health event or transition (e.g. moving out of home).
- trade off services against the alternative of one-off equipment purchases, and
- reliably fund support and equipment needed for travel.

In practice, IF recipients only spend about 70% of their annual budgets on average, partly reflecting risk management. Underspending budgets each year does not lead to those budgets being cut, which removes the incentive to spend all available funds each year.

Equipment and travel

Traditional support gives recipients ways to buy equipment and travel. However, recipients told us the process can be cumbersome. Under the traditional model, one-off expenses require either

- an application for funding, with decisions in the hands of officials who are often distant and not acquainted with the applicant, or
- requests for services in kind, for example, borrowing a vehicle to travel.

The traditional model may work for simple requests, although nobody we spoke to said that. However, 'beg, borrow or steal' is not well-suited to more complicated problems like travel, which requires simultaneously choreographing many elements.

One recipient told us about her experience arranging travel under traditional support. Her mother has high disability needs. Travel requires access to an electric (motorised) bed, support services, and other equipment at the destination – and access to special vehicles at both the origin and the destination. Every element must be in place for each trip. The recipient said it was a "logistical nightmare" assembling the pieces using traditional support. IF made travel simple. There was nobody to ask – the money was available in her mother's IF budget, and the rights to spend the funds on support for travel were clear. They could simply book and pay for the necessary equipment and support, she said.

The problem is not just whether spending will be permitted but also that decisions are timely. Consider, for example, the plight of a mother of a disabled child receiving traditional disability support. The mother wanted to purchase a home pool for $1,000. Her child was having continence issues, and the mother believed regular time in the water could help her child distinguish between wet and dry. Under traditional support, the mother needed the permission of a purchasing committee to buy the pool. Three months after sending her application, the committee had not reached a decision. Summer was ending, and with it, the opportunity to use the pool. (The committee ultimately declined the request.)

IF succeeds in part because spending within guidelines is mostly *permissionless*. Funding is assigned, and purchasing criteria – the four principles listed on page 12 – are clear. This clarity makes access to support simple, predictable, reliable and flexible. That unlocks access to life experiences that are difficult or impossible under traditional support. Things like overseas or domestic air travel, driving to another town, or even a last-minute decision to go to the local mall or cinema can be difficult or impossible with traditional support. But IF makes all of these things straightforward. Control of a budget with clear decision rights avoids most of the limitations that go with decisions in the hands of third parties. It is hard to overstate the impact for recipients and their families from planning travel or purchases with the confidence that funding will be available and that those plans are not subject to the risk of tardy judgments by others.[39]

IF also works because using limited personal budgets confronts recipients with the *opportunity* costs of their spending. They are forced to consider budget trade-offs to find purchases that will have the greatest positive impact in their life. We come back to opportunity costs later in the report.

The benefit of being an employer

Under IF, recipients use most of their funds to purchase support services. Although recipients have the option to receive services from contractors, recipients usually choose to become employers.

Employing support workers means recipients take on the full responsibilities of being an employer. This includes finding staff, agreeing employment conditions including wages, scheduling, budgeting, and organising payroll, taxes, and holiday pay. As employers, recipients also deal with personal grievances, though these arise infrequently.

For some, the responsibilities of IF are a burden to be weighed against the benefit of independence. However, other IF recipients find becoming an employer is rewarding in its own right. Some welcome the challenge of learning new systems, while others get great satisfaction from creating opportunities for others by employing them. IF is the opportunity to make decisions, to take a chance and bear the consequences – sometimes called independence. All of these are the product of control over a personal budget, which is the essence of IF.

The weight of responsibilities of IF is avoided under the traditional model of disability support, which for many disability support recipients is a welcome feature of the traditional model. All of this reinforces the value of New Zealand's plural system.

Box 4: Susan and John

Susan and her 17 year old son John (not their real names) live in the lower North Island. John is autistic and attends a special unit at a local high school. Before starting on IF, Susan received $700 per year in respite support and a Child Disability Allowance from WINZ. Respite (Carer Support) paid $75 and required the purchase of 24 hours of support.[40]

Susan first heard about IF when John was 12. Her first NASC assessment in 2016 resulted in Susan receiving a $2,000 annual IF budget to support John. Susan then suffered a serious illness, and at about the same time, met an IF advocate through school who offered to help. With the support of her advocate, Susan went back to the NASC and increased her IF support to $30,000 per year.

Susan uses the money to hire caregivers to take John out to the mall and the zoo or take trips to towns outside Wellington. Susan also uses the budget to purchase non-funded equipment. For example, she purchased a bicycle rack for her car so that John can ride his bike in an area well away from traffic.

Susan has used the same two caregivers since 2017. She values the flexibility of IF. Rescheduling times for John's care is simply a matter of sending a text or making a phone call. Recent changes to the rules mean she can use her budget to pay a family member for giving care. This is especially useful because John needs support for one hour in the morning and another two hours between the end of the school day and bedtime. Allowing payments to a family member is good because it is difficult to find people from outside the home willing to provide support for only 15 minutes at a time.

Since 2016, John has been assessed three times by his NASC, Capital Support. Yet the NASC has never met John, only Susan. In the third review, the NASC officer did not even meet with Susan. The NASC sent her previous assessment in a Word document and asked Susan to update it.

If Susan could give advice to herself five years ago, it would be talk to other people and listen. "There is no handbook" which explains how the system works and all the ways it can help, she says. Susan has found her IF host does not tend to offer proactive advice. "Be one step ahead," says Susan.

Explaining the performance of the traditional model

> "It's a good day when my support worker turns up" – reported statement of traditional support recipient

Traditional support services can work well. However, recipients we spoke to gave us a reasonably consistent picture of the limitations of traditional services. Support tends to be inflexible, unreliable, and offers poor continuity, among other problems. What explains these limitations?

We see four reasons for poor outcomes under the traditional model:

1. Information losses when third parties decide spending
2. Constraints of the purchasing and the appropriations system
3. Resource constraints lead agencies to offload some risk to clients
4. Incentive problems

We consider each of these in turn.

Information losses when third parties decide spending

When it comes to disability, every person is different. Disabilities can be more or less severe; a disability can change over time; many disabled people have multiple disabilities; living with a disability is a learning process, meaning needs can change over time.

Placing decisions in the hands of a third party, whether an individual, agency, or committee, carries a penalty in the form of forgone information. The third party must choose between competing claims against their limited budget, which is difficult if the goal is to maximise overall well-being. With the best will in the world, the committee whose job it was to consider a mother's application to buy a pool for a disabled child cannot know whether that is the best use of available funds under the purchasing guidelines compared to the other applications before them. Inevitably, other factors come into play – the quality of the application, the applicant's ability to present her case well, the committee's workload, whether committee members know the applicant, and so on.[41]

Mother and daughter know better than anybody else the value of a pool, given their situation. But it is hard to credibly signal that knowledge when every application to the committee talks (no doubt honestly) about the great benefits that will follow from approval of *their* request.

IF solves the information problem first by putting decision-making into the hands of people with the most information, the disabled person or the caregiver and confronting the recipient with the opportunity cost of spending, the valuable by-product of a limited personal budget. Finite funds force the recipient to consider trade-offs. That is not a characteristic of collectively-controlled budgets under the traditional model. Collective budgets do not confront applicants with opportunity costs, which gives each recipient the incentive, whether acted upon or not, to ask for as much as possible. Economists call this the free riding problem. The limited personal budgets of IF avoid free riding.

Constraints of the purchasing and the appropriations system

The traditional model subjects the purchase of disability support services to the vagaries of the government appropriations system. Appropriations require officials in Wellington to decide in advance what services they will purchase in future years, which in turn requires officials to anticipate the future needs of disabled people. This forward-looking approach is necessary for MoH to contract for services from service providers. After all, MoH must state what it is buying. Inevitably, frictions will emerge as ministries and officials make imperfect guesses, and the wording in appropriations or contracts is misinterpreted.

For the recipients of disability support, the end result of these unintended consequences is unmet needs. Recipients report that one of the problems they have experienced under the traditional model is that they could only get some types of support they needed but not others. This is likely the product of the agency's contract with the Ministry of Health which did not specify, and therefore did not fund, certain types of support.

These problems are the by-product of information losses and the lags and inflexibility inherent in a system of centralised decision making. Boundary problems, or "siloing," is a real problem, particularly when trying to meet complex needs. When Parliament funds services, the appropriation must say what it is buying. The wording Parliament uses in its appropriation constrains what MoH can purchase. The Ministry cannot write a contract with a broader scope than the appropriation which pays the bill.

Changes to the Public Finance Act by Parliament over the last decade has introduced greater flexibility to the appropriations system,

giving MoH more ways to have traditional services meet the wide-ranging demands of disability support recipients:

- Parliament could authorise the Ministry to purchase "disability support services" from support agencies rather than "home management" or "showering" services. This would allow agencies to do what recipients need and still be paid.
- Rather than write fixed support schedules, NASCs and contracted providers could delegate to recipients the authority to tell their support person what services they will need that week. This would do away with the current rule, which says recipients must ask their NASC and the contracted provider for changes.

Of course, these changes to the traditional model would make traditional support more like IF.

IF avoids the mismatch between the supply and demand for support by giving purchasing decisions to recipients with broad and well-defined limits on purchases. Thus, IF relieves officials and agencies of the problem of anticipating disability support needs, allowing distributed decision-making in real-time by people who have better information about their own needs. This helps avoid many of the unintended consequences which can arise from third-party decision making in a complex area.

Resource constraints lead agencies to offload some risk to clients

While information and purchasing constraints explain some of the problems with traditional in-home support, they say little about its lack of flexibility, reliability and continuity.

The immediate cause of these problems is clear: logistics. Agencies deliver services using full-time workers and must make best use of their time to manage costs. On a given day, support workers must travel from client to client with schedules ordered to minimise time spent traveling. Unfortunately, this approach leaves little slack in the system, causing support to be brittle and inflexible.

Agencies do not appear to build contingency into their schedules. Recipients told us, for example, that when their support person's car broke down, they did not get support that day. For a recipient, that could mean not getting out of bed that day.

The use of full-time workers by agencies also explains another phenomenon of traditional support, the persistent difficulty that agencies seem to have providing support outside office hours and at weekends. Agencies generally buy their labour in blocks of hours at a time. That may make it prohibitively expensive to deliver support at unusual hours. If a work day is a continuous 8-hour block, meaning the work day ends 8 hours after the start of the first job, for example, then it will be difficult for an agency to provide support at 3am since this will likely lead to stretches of costly downtime.

Why have agencies adopted such inflexible work practices? The IF model tends to deliver support from workers who deal with recipient at a time – one support worker, one recipient. By contrast, traditional services tend to share each support worker across many recipients to manage costs. This shared approach constrains agencies' ability to meet needs at unusual hours. The result is less flexible traditional services.

Incentive problems of the traditional funding model

The New Zealand Productivity Commission (2015:271) captured the contrasting incentives between IF and traditional funding:

> Within a given [personal] budget, clients have a strong motivation to make decisions that [meet their needs in an efficient, effective and timely manner]. However, while providers and government officials often have the best interests

> of the client at heart, they can face multiple incentives. At least some of these incentives can conflict with the objective of meeting client needs. For example, a government agency may face pressure to minimise the political risk arising from the provision of a service. The agency may respond by seeking to minimise political risk through specifying the core choices in their contracts with providers.
>
> Providers, faced with tightly specified contracts, may have to provide a service in a manner that meets the conditions of the contract but not the needs of the client. The client, in turn, may be discouraged from using the service and their needs may go unmet.

Respecting the rights of the individual

The traditional model of disability support includes care provided in shared residential facilities. A person in residential care lives in a common space with other disabled people. IF recipients live in private homes, often the family home.

We understand a disabled person sometimes can be placed in a communal facility without their agreement. The individual may have no say in the matter because:

- The person is deemed not to have the capacity and therefore their family decides for them.
- The family has convinced the disabled person that they will like it, or
- The disabled person has been placed in a facility under legislative or court authority.[42]

Communal living brings the risk of bullying and assault by other residents or staff. Disabled people are protected by the right to exit from or choose another facility – if one is available. There are also risks associated with divulging abuse when it has occurred. Victims of abuse may be intellectually disabled, or nonverbal. Getting help is usually up to the person or their family. Police may be brought in after abuse has been disclosed.

An individual who reports bullying but who is not supported to leave the communal facility runs the risk of retribution.

Worker wellbeing under IF and the traditional model

Disability support workers also face the risk of physical or mental abuse under both IF and traditional funding models. It is not clear how serious the problem is in New Zealand. However, overseas research suggests abuse is a more pressing concern in traditional services. The Australian Productivity Commission cited evidence on abuse from the UK:[43]

> A more detailed empirical examination of rates and types of abuse experienced by people with disabilities under self-directed and traditional funding arrangements in the United Kingdom found that the rates of any form of financial abuse was 5 per cent under self-directed funding and 9 per cent under traditional care models. The comparable rates of psychological, physical and sexual abuse for the two different forms were 6 and 13 per cent, 1 and 3 per cent, and 0 and 2 per cent (with the first number of each set being for self-directed funding).
>
> Other evidence more generally points to the considerable problems of abuse in specialised institutions compared with informal settings, notwithstanding the quality controls that governments put in place in the former. For example, in the United Kingdom, a relatively significant number of complaints of abuse (for the elderly disabled) relate to nursing homes and hospitals, and there are similar concerns about abuse in specialised residences for those with an intellectual disability.

The Commission also reported evidence from the United States:[44]

> [T]here is little consistent evidence of low wages, but reasonably reliable evidence that wellbeing of employees is typically better, or at least no worse… In the United States, there was likewise little evidence of any systematic exploitation, neglect or fraud associated with self-directed funding, even though the target populations tended to have lower than average incomes. There were very few instances of reported fraud or abuse (of consumers or workers) in the large US Cash and Counseling trials of self-directed funding. Counsellors periodically contacted consumers and their representatives in person and by telephone, and both counsellors and bookkeepers reviewed consumer spending.

CHAPTER 4
Does IF work?

Research in New Zealand and overseas has tested the effects of IF on recipients' outcomes and cost-effectiveness compared to traditional services. In this chapter, we survey the findings from this research.

Caution is required when considering research on the performance of IF. Three factors complicate quantitative analysis of IF. First, IF participation is usually by self-selection, which can bias estimates of the attributable effects of IF. Moreover, people who choose to participate in IF tend to have more complex needs. Second, participation in IF is often associated with transition points in individuals' lives, such as starting school or leaving home. Transition points tend to be periods of higher support needs. As far as possible, studies should disentangle the effects of the transition from the effects of IF *per se*. Third, some of the benefits of IF are qualitative. Factors like the timeliness or reliability of support services are clearly important to the recipient's wellbeing but are hard to measure. Studies of IF often use surveys of participants' satisfaction to quantify these qualitative factors.

Caution is also necessary due to the limited number of studies on IF both in NZ and overseas.

Not all of the studies of IF are of good quality. A meta-study by Fleming et. al. (2019) reviewed seven quantitative studies of IF, rating three studies as "good," three studies as "fair" and one as "poor". Dickinson (2017:7) also expresses concerns about the quality of some studies. She cites an IF study which "simply measure[d] the experience of having an individual budget in comparison with no service at all, and therefore is likely to make the findings look more positive than they in fact are." Our survey of the literature in this chapter excludes findings based on such questionable counterfactuals.

This review focuses on studies which either

- Attempt to statistically isolate the effects of IF on outcomes relative to traditional services, or
- Compare outcomes before and after a shift between traditional services and IF in either direction.

Our review includes studies of IF under some other name, including "self-determination." We treat the use of personal budgets controlled by recipients as a flag for IF in overseas schemes.

New Zealand evidence

We found two studies of IF in New Zealand. In 2011, Synergia (2011:8-9) found higher costs associated with IF:

> The financial analysis undertaken indicates that allocations for people who move from non-IF to IF are increasing by 14.9%. It also shows that allocation for those who remain on IF are increasing by 25.5% from [year] 1 on IF to year 2 on IF. Utilisation appears to be stable across years at approximately 13.9% less than allocations or 86.1% of allocated budget. These trends are of concern… That said when asked about these trends interviewees were not surprised. They outlined that the roll out of IF was causing people to seek reassessments and to present strong cases to NASCs. This behaviour often results in clients having a comprehensive review and updated needs assessment.

However, a later study by Dovetail (2015:16,19), which was commissioned by Manawanui In Charge, considered IF's costs and cost-effectiveness and reached a different conclusion. Dovetail found:

> [A]verage costs for IF users appear to reduce to a significantly lower level than non-IF costs in both total DSS costs and HCSS over the three year period in the $60,000 and over group – regarded as having the most complex users… residential care costs in both cost bands are substantially lower among complex IF users than complex non-IF users. Furthermore, these costs grow at a much lower rate among IF users in the $30,000-$60,000 band, and decline in the $60,000 and over band. This suggests that IF users are less likely to transition to residential care than non-IF users and supports previous data indicating IF as a means of containing costs.

Dovetail (2015:20) finds support costs increase when individuals shift from traditional to IF support:

> This study shows that the transition from pre-IF to IF marks a shift in costs; our analyses indicate average annual costs per user increased from $14,030 to $27,969 (based on HCSS costs for IF users in the school leavers to 65 years age group). This would plausibly reflect transition at a point of significant change in a person's care needs, and where IF is part of a new suite of services that a person is receiving, rather than the cost of IF itself.

However, Dovetail (2015:20) suggests transition, not IF *per se*, may be responsible for higher costs:

> It is not possible in this data to identify non-IF users at a similar transition point to explore comparative transition costs. This is consistent with the issue noted earlier that since 2009, stability of personal circumstances was removed as a criteria for IF selection by NASCs; instead NASCs have assessed if the shift would be cost neutral (i.e. would be likely to cost the same as non-IF). The implication of this is that by applying a principle of cost neutrality, then an increase in costs would be expected to occur regardless of whether IF was adopted or more traditional approaches… it is difficult to accurately compare these users with non-IF users in the same category, given the changing needs that often mark the point of transition.

Despite the present of confounding factors, Dovetail (2015:23) concludes IF is effective in containing costs because "[t]he growth in the numbers of people using IF is higher than the growth of IF spend, indicating that either costs are being controlled to some degree, and/or that increasing numbers of people with less complex needs and lower costs are receiving IF."

Dovetail based its analysis on a Ministry of Health database called Socrates. Unfortunately, the data from Socrates does not allow comparison of the services IF and traditional services recipients receive (Dovetail 2015:21).

In 2015, the New Zealand Productivity Commission reviewed social services including disability support. The Commission considered versions of IF under the rubrics of client choice and empowerment. The Commission found:[45]

- Most recipients report higher satisfaction after moving from traditional support IF or equivalent services;
- The effect of IF on health outcomes is ambiguous;
- Little evidence that IF is at greater risk of fraud or misuse than other service models;
- The cost of client-directed service models relative to other models is difficult to determine. However, the most recent New Zealand study suggests that, over time, costs for users of Individualised Funding (IF) fall below those of comparable non-IF users; and
- There is some evidence that pay and conditions of workers under IF are superior to workers delivering traditional support.

The Commission recommended expanding the use of IF in disability support and trials of IF for home-based support of older people, respite services, family services, and drug and alcohol rehabilitation services.

Box 5: Sharon and Dorothy

In October 2016, Sharon's mum Dorothy suffered a serious stroke leaving her with very high and complex needs for disability support services. Dorothy now lives at home with Sharon and her family with support provided through IF.

Initially, Dorothy received support under the traditional funding model. However, under traditional services, Sharon found it difficult to arrange support, such as arranging access to a suitable vehicle for travel and the use of an electric bed.

For Sharon, traditional services funding was financially ruinous. In part, this was due to an arcane funding rule for respite (Carer Support) services. The rule requires support services to be purchased in blocks of 8-24 hours at a time. However, funding pays only a fraction of the cost of this block of time: $75. The difference must be made up by the person receiving support or their family. Support for 24 hours may cost $600.

The system makes information hard to find. For example, Sharon sought financial assistance for the services she was providing to her mum. The DHB declined her request. However, Sharon discovered her DHB had a Family Funded Care (FFC) policy in a document released under the Official Information Act.

Sharon arranged Dorothy's shift to IF in two stages. Respite funding shifted first. This allowed funds to be used when needed for respite carers and equipment purchases. Later, Sharon transferred personal care from HCSS to IF. All up, Dorothy receives 40 hours of personal care each week plus respite.

Sharon calls IF "life changing," the difference between "night and day". IF gave Sharon flexibility to arrange her day. The flexibility of IF, without an eight-hour minimum, made support more affordable. IF also makes it possible for Sharon to book and pay for services when they are needed. For example, Dorothy visited Auckland with Sharon and her family for a wedding in late 2019. Sharon said the visit was "easy to organise" using IF.

IF "absolutely" saves the government money, says Sharon. Despite Dorothy's very high support needs, annual costs are less than $100,000. The DHB told Sharon that Dorothy would need to be placed in a care facility, the most likely alternative to IF. The costs of a state-funded communal care facility, with support on top, would almost certainly exceed the cost of support through IF at home.

Dorothy is over 65 years old, which means dealing with the DHB rather than disability support through MoH. The disparity between DHB and MoH is "huge," says Sharon. However, she says she is pleased to see the system is transforming to enable over 65's to access IF.

Despite the difficulties Sharon experienced with the traditional support model, Sharon says the traditional model can work for people with lower needs and believes each individual should have the right to choose their funding model.

International evidence

Fleming et. al. 2019

The study by Fleming et. al. (2019) is a meta-analysis of IF research worldwide between 1992 and 2016. Fleming et. al. found 73 studies on IF (66 qualitative, seven quantitative), including one study from New Zealand, with data covering 14,000 people.

Fleming et. al. find:

- positive effects from individualised funding concerning quality of life, client satisfaction and safety, and fewer adverse effects.
- Only limited evidence that IF improves physical functioning and cost-effectiveness and reduces the unmet need.
- IF recipients report greater flexibility, improved self-image and self-belief; better value for money; community integration; freedom to choose who supports you; social opportunities; and needs-led support.

Table 3 summarises findings from the quantitative studies covered by Fleming et. al.

Green rows indicate a statistically significant finding which is favourable to IF compared with traditional services.

Red rows indicate an unfavourable finding for IF compared with traditional services.

Rows which are neither red nor green indicate no significant result.

Table 3: Meta study findings (Fleming et. al. 2019)

Outcome	Study	Location	IF	Control	Diff	Stat Significance	Stat Significance	N
Quality of life outcomes	Brown et. al. 2007	Site 1	43.4	22.9	20.5	p<0.001	Very high	1822 across the 3 sites
		Site 2	63.5	50.2	13.3	p<0.01	High	1822 across the 3 sites
		Site 3	37.5	21	16.5	p<0.001	Very high	1822 across the 3 sites
Quality of life outcomes	Woolham & Benton 2013		10.12	13.28	-3.16	p<0.001	Very high	402
Client satisfaction	Beatty et. al. 1998		61.4	52.1	9.3	p<0.01	High	92
Satisfaction with technical quality	Benjamin, Matthias & Franke 2000		20.9	20.07	0.83	p<0.001	Very high	1095
Satisfaction with service impact	Benjamin, Matthias & Franke 2000		8.09	7.63	0.46	p<0.001	Very high	1095
General satisfaction	Benjamin, Matthias & Franke 2000		9.06	8.66	0.4	p<0.001	Very high	1095
Satisfaction with interpersonal manner	Benjamin, Matthias & Franke 2000		7.45	6.43	1.02	p<0.001	Very high	1095
Satisfaction with caregiver help	Brown et. al. 2007	Site 1	90.4	64	26.4	p<0.001	Very high	1822 across the 3 sites
		Site 2	85.4	70.9	14.5	p<0.01	High	1822 across the 3 sites
		Site 3	84.4	66	18.4	p<0.001	Very high	1822 across the 3 sites
Satisfaction with overall care arrangements	Brown et. al. 2007	Site 1	71	41.9	29.1	p<0.001	Very high	1822 across the 3 sites
		Site 2	68.2	48	20.2	p<0.01	High	1822 across the 3 sites
		Site 3	51.9	35	16.9	p<0.001	Very high	1822 across the 3 sites

Table 3 (continued)

Outcome	Study	Location	IF	Control	Diff	Stat Significance	Stat Significance	N
Client satisfaction	Caldwell, Heller & Taylor 2007		3.89	2.82	1.07	p<0.001	Very high	87
Cost effectiveness	Brown et. al. 2007, Dale & Brown 2005	Arkansas	5435	2430	3005	p<0.001	Very high	Not reported
		Florida	22017	18321	3696	p<0.001	Very high	Not reported
		New Jersey	11166	9220	1946	p<0.001	Very high	Not reported
Unmet need	Benjamin et. al. 2000		5.07	5.38	-0.31	p<0.001	Very high	1095
Incremental activities of daily living	Benjamin et. al. 2000		4.37	4.28	0.09	p<0.22	Not significant	1095
Physical or psychological risk	Benjamin et. al. 2000		29.25	29.05	0.2	p<0.13	Not significant	1095
Adverse effects	Caldwell, Heller & Taylor 2007		3.11	7	-3.89	p<0.001	Very high	87
Unmet needs with daily living activities	Brown et. al. 2007	Site 1	25.8	41	-15.2	p<0.01	High	1822
		Site 2	26.7	33.8	-7.1	p<0.05	Medium	1822
		Site 3	46.1	54.5	-8.4	p<0.05	Medium	1822
Reported falls	Brown et. al. 2007	Site 3	18.7	28	-9.3	p<0.01	High	1938
Reported contractures developing/ worsening	Brown et. al. 2007	Site 2	9	14	-5	p<0.05	Medium	1938
Reported bed sores developing/ worsening	Brown et. al. 2007	Site 1	5.9	12.6	-6.7	p<0.05	Medium	1938
Reported urinary tract infection	Brown et. al. 2007	Site 2	7.7	11.7	-4	p<0.05	Medium	1938
Safety/sense of security	Benjamin et. al. 2000		9.18	8.96	0.22	p<0.05	Medium	1095
Quality of life	Glendinning et. al. 2008		0.45	0.49	-0.04	p<0.28	Not significant	943
Client satisfaction	Glendinning et. al. 2008		0.78	0.7	0.08	p<0.01	High	909
Psychological ill-health	Glendinning et. al. 2008		0.36	0.33	0.03	p<0.36	Not significant	644
Self-perceived health	Glendinning et. al. 2008		0.33	0.34	-0.01	p<0.87	Not significant	953
Community participation	Caldwell, Heller & Taylor 2007		2.39	2.26	0.13	p<0.439	Not significant	87

Other international studies

In 2011, the Australian Productivity Commission delivered a report on disability care and support. The report, in two volumes, included a survey of research on IF available at that time. Here is a summary of findings from the Productivity Commission's literature review.

Table 4: Summary of the impacts of self-directed funding

Consumer and family benefits	Person with a disability	Family members
Met individual needs	Improved	..
Satisfaction with care	Improved	Improved
Sense of control over life/empowerment	Improved	..
Community interaction (circles of friends)	Improved	..
Greater use of mainstream services	Improved	..
Quality of care/confidence in care	Improved	Improved
Costs of supports	Down or no change	
Personal dignity	Improved	..
More independent living	Improved	
Abuse and neglect	Down	..
Satisfaction with life	Improved	Improved
Culturally and linguistically appropriate care	Improved	..
Providing care during non-business hours	Improved	..
Continuity of care	Improved	..
Employment and productivity gains	Improved	
Use of preventative care	Improved	
Use of hospital, other health services & residential care	Down	
Economic wellbeing	Improved	Improved
Health status	Improved or no change	Improved
More aids & appliances and home/vehicle modifications	Improved	

These results are derived from the studies cited in appendix E. While they include studies from Canada, the Netherlands and Australia, they mostly relate to the Medicaid waiver self-directed funding programs in the United States and to direct payments in the United Kingdom.

Source: Australian Productivity Commission (2011:360).

The Productivity Commission also referred to the results of an evaluation of a trial of self-directed funding (i.e. IF) by the Victorian Government, which found (quoting verbatim):[46]

- 97 per cent were quite happy or very happy with the control over their support since starting direct payments, compared with 47 per cent before direct payments.
- 90 per cent were quite happy or very happy with the quality of their supports since starting direct payments, as compared with 52 per cent before direct payments.
- 91 per cent were quite happy or very happy with the involvement in the lives of family and friends since starting direct payments, compared with 70 per cent before direct payments, and
- 84 per cent were quite happy or very happy with the involvement in their local community since starting direct payments, as compared with 62 per cent prior to direct payments.

Based on their review of the literature, the Australian Productivity Commission (2011:359) concluded:

- "[P]eople with disabilities derive significant benefits from greater control over their budgets and lives, with their needs better met, greater life satisfaction, more interaction with people and the community, higher quality and continuity of care, with positive or no changes in their health status. As one participant remarked

in this inquiry, self-directed funding 'was a huge relief; the quality of support workers and support services increased.'
- Family members providing support have greater confidence in care, satisfaction with life, less financial strain, and improved health status.
- Employed support workers generally get better outcomes, though this is not uniform.
- Self-directed funding is likely to partly alleviate the (current and impending) shortages of workers in specialised disability services by shifting the emphasis to mainstream services and allowing friends, people in the local neighbourhood (and potentially relatives) to be paid for services.
- There is little evidence of major difficulties for service providers from self-directed funding over the long run, but some evidence of transitional costs associated with new systems, and
- Ongoing costs appear to be generally lower (and at worst no higher) than traditional agency-based disability systems, though there are significant upfront implementation costs. An individual example was given by one participant in this inquiry, in which the available package was $14 000 per year, but actual usage under self-directed funding was never more than $10 000.

A more recent study by Dickinson (2017) included a survey of the literature. Dickinson found:

- Improved satisfaction from IF depends on whether appropriate management systems are in place, and
- Studies conducted in England found that while traditional disability support packages were not more expensive for those with personal budgets, their care management costs were higher, and care managers spent longer on assessments of people with individual budgets.

Puheenvuoro (2019) also reviews research, finding:

> Most robust research has been carried out in England and the USA. The use of PB [personal budgets] has been shown to increase satisfaction and the sense of control and feeling of empowerment, especially among the young and people with disabilities. For older people, PB has also been found to increase stress and it might become a burden. Some of the PB users require support from social or health care professionals or a third party to use the PB and benefit from it, and such support influences the costs of the PB. Furthermore, it has been noted that the opportunity to choose – even though people highly value it – does not always improve the service's desired outcomes.

In 2006, a UK programme called "In Control," an IF scheme based on a brokerage model, conducted before-and-after surveys of people with disabilities who had transitioned from traditional care to IF. Though small – the study evaluated 93 people in six areas of England – the results are striking (see Figure 1 on page 7). Participants reported substantial improvements in their satisfaction across the board.[47]

Glendinning and Challis (2008) conducted a Randomised Control Trial (RCT) with 130 people divided into treatment and control groups to test the performance of IF. They found:

> When pooling data across the sample as a whole, we found that the IB [Individualised Budget] group were significantly more likely to report feeling in control of their daily lives, the support they accessed and how it was delivered. We did not find significant differences between the IB and comparison groups in the other outcome domains, although the tendencies in the data generally suggested that the IB group was enjoying slightly better outcomes… Interestingly, almost half of those who accepted the offer of an IB who were interviewed for the qualitative study described how their aspirations had changed as a result, in terms of living a fuller life, being 'less of burden' on their families, and having greater control and independence.

Fleming et. al. 2016 reviewed the literature specifically for mental health effects of IF, reporting the findings of 15 studies. Fleming et. al. concluded:

> …personal budgets can have positive outcomes for people with mental health problems in terms of choice and control, impact on QoL, service use and cost-effectiveness. However, methodological shortcomings, such as variation in study design, sample size, and outcomes assessed, were reported to limit the extent to which the study findings could be accurately interpreted or generalised.

While research suggests IF delivers higher satisfaction and improved outcomes for recipients, findings are more ambiguous about the cost-effectiveness of IF and whether IF delivers cost savings for governments. Fleming et. al. (2019) summarises the available research:

> The small pool of evidence would suggest that individualized funding can be cost effective, ranging from 7% to 16% in the US. Conversely, one UK study suggested that individualized funding may not result in cost savings, but does represent value for money. Stainton, Boyce and Phillips (2009) support these more conservative findings showing relative cost neutrality for individualized funding when compared to independent service providers; however, individualized funding was more cost effective than traditional in-house service provision. Furthermore the authors reported higher levels of user satisfaction for those availing of individualized funding, thereby highlighting the link between client satisfaction, quality of life and cost benefits.

Glendinning and Challis (2008) found IF had little effect on costs:

> We found very little difference between the cost of support received by the comparison group and the cost for IB holders. Over the full sample, IBs funded a mean of about £280 of support per week compared with an estimated mean weekly cost of about £300 for support packages for people receiving standard mainstream services. This difference was not statistically significant, but it is likely from this evidence that IBs would be at least cost-neutral.

Puheenvuoro (2019) similarly finds evidence that costs and cost-effectiveness of IF is "weak":

> John Woolham and Chris Benton (2013) observed that the costs of PB users in England were higher than those using conventional ways, even though the users feel that they benefit from the PB. In the Netherlands PB was found to increase the use of services and encourage people to purchase more expensive services, both of which increased the costs of the PB. Costs may also be higher because the use of private services increases the indirect costs and reduces the economies of scale for public service providers. According to an evaluation study conducted in England, the use of a personal health budgets did not influence the costs or increase people's health-related quality of life. It did increase their social care-related quality of life, however, and was cost-effective when the outcomes were measured based on people's social care-related quality of life. Budgets were cost-effective for people who needed continuing health care and people with mental health problems. According to a previous personal social care budgets evaluation study, the PB did not influence costs but improved quality of life, particularly in the case of young disabled people and people with mental health problems.

Summary of research findings

Overall, research offers clear evidence for improved outcomes and higher reported satisfaction from IF relative to traditional disability support services. However, findings are ambiguous as to whether IF delivers cost savings. Overall, the evidence is strong support for the performance of IF.

Conclusion

Government policies should be judged by the outcomes they deliver for people who need public support. This report has described a fundamentally different funding model for public services which gives control and responsibility to recipients of support services. Traditional models of publicly-funded disability support treat recipients as dependents, with services delivered by people employed by a third party. The company, under contract with MoH, not the services recipient, has the final say on who delivers services on what terms. If the disabled person needs different services or wants to buy unfunded equipment or other things to support them, they must ask permission.

IF uses personal budgets to put the recipients of disability support in control. IF turns services recipients into paying customers. The result is a transformation in the quality of services and quality of life for recipients and their families. Spending must be within well-defined limits, giving individuals flexibility to tailor support to their needs with the confidence their needs will be met. Relative to traditional funding models, research suggests IF offers large wellbeing gains through greater flexibility and responsiveness to needs, and higher quality of service. It is less clear whether IF also delivers fiscal benefits.

IF's benefits over the traditional services model are due to:

- Dignity from control over who comes into your home.
- Independence.
- Better services flexibility.
- Increased services reliability.
- Clear decision rights which make spending permissionless.
- Encourages recipients to make best use of available funds, and
- Greater continuity – the same person delivers services each time.

Giving control of public funds to private individuals carries clear risks for officials accountable for public spending. The Ministry of Health deserves credit for working to solve the problem of having accountability for the specific uses of public funds assigned to a private citizen. IF is a significant innovation in public finance: assignment of decision rights over public funds to private individuals while maintaining accountability for public spending.

The personal budgets model has ready application to Aged Care, which with only a few exceptions District Health Boards (DHBs) have so far declined to do. Aged Care continues to operate almost exclusively under the traditional funding model.

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Appendix

Glossary

EGL	Enabling Good Lives
EIF	Enhanced Individualised Funding
HCSS	Home and Community Support Service
IB	Individualised Budget
IF	Individualised Funding
NASC	Needs Assessment and Service Coordination
PB	Personal Budget

Terms

Budget Period	The NASC will give a Person a start date and a review date for the Person's Personal Budget. This time frame is known as the Budget Period.
Coaching	Service and support a Host provides to the Person that assists them to manage their Support allocations.
Direct Fundholding	Where the provider hosts funding for a Person. Exists within CiCL and FDS. Similar to Individualised Funding.
Disability Supports (Supports)	Supports provided due to the additional cost of living with a disability. Disability supports should also contribute to outcomes in a Person's plan and must be within the Ministry of Health's Guidelines and Policies.
Enabling Good Lives Purchasing Guidelines	The Purchasing Guidelines for the Enabling Good Lives Demonstrations in Christchurch and Waikato. These Guidelines set out what can be purchased through Disability Support funding.
Funding Manager	An organisation or individual who determines the level of disability support to be provided to a Person (often a NASC).
Host Provider (Host)	A provider who is contracted to the Ministry of Health to provide Host services to a Person as a way to purchase and manage their Disability Supports, including but not limited to Coaching.
Hosted Scheme	One of the funding mechanisms listed in paragraph 1.0 of this Operational Policy, being IF, EIF or EGL.
Ministry	The Ministry of Health (funder), with Disability Support Services (DSS) representing the Ministry for the purposes of this Policy.
NASC (Needs Assessment and Service Coordination Organisation)	NASCs are services funded by the Ministry. Their roles are to determine eligibility, assess the Person's level of disability support needs, inform People / families / advocates of what the support package contains, discuss options and co-ordinate support services to meet those needs. NASCs co-ordinate such services, but do not themselves provide the services.
New Model Demonstration	Demonstration in Bay of Plenty, Auckland and Waikato areas that is focused on giving Disabled People and their families/whānau more choice, control and flexibility over support and funding in their everyday lives.
New Model Purchasing Guidelines	The Purchasing Guidelines for the New Model for Supporting Disabled People issued by the Ministry in 2013 (or any superseding guidelines). These Guidelines set out what can be purchased through Disability Support Services funding.
Nominated Agent (Agent)	An individual who is able to make decisions on behalf of the Person that relate to the management of the Person's Supports.

Payroll (payroll support)	Where the Host (or another organisation) looks after paying Support Workers and a number of the employee or contractor related tax obligations on behalf of the Person.
Person/People	A Person who is eligible for disability support services funded by the Ministry of Health (or the Ministry of Education/Social Development where the Person is participating in an Enabling Good Lives Demonstration). This may also include the Person's Nominated Agent. Under a Hosted Scheme the Person is responsible for purchasing Support via a contract or standard employment arrangement.
Personal Budget	The amount of funds a Person is allocated by the NASC that may be used to purchase Disability Supports. A Person can choose how much assistance they require to manage their Personal Budget. This Guideline addresses those individuals who have chosen Hosted Funding Schemes or Direct Fundholding.
Self-employed contractor (also referred to as a contractor)	A self-employed individual who contracts with the Person to provide Supports to the Person.
Self-Managing	The Person (or their Nominated Agent) is responsible for managing the choice of and payment for the Disability Supports they decide to purchase from their Personal Budget. Any such purchasing must be compliant with Ministry Policy and Guidelines.
Supports	Disability Supports purchased by a Person.
Support Worker	An employee or Self-employed contractor who provides Support to the Person.
Third Party Organisation	Any organisation (usually registered for GST purposes as a legal entity) that is independent of the Person and renders an invoice to the Person for payment for Supports provided.
Verification or Verify	The processes involved in establishing whether Personal Budgets expended and Supports purchased are compliant with any obligations or requests associated with that Personal Budget or those Supports.

Source: Ministry of Health, "Guideline for Verification of Supports within Hosted Funding Schemes and Direct Fundholding: Disability Support Services Operational Procedures," 28 February 2017.

More information on individualised funding

Table 5: Flexible Personal Budget Options

Scheme	Availability[48]	Explanation
Individualised Funding (IF)	Across NZ	A hosted scheme where people purchase their own disability supports (usually via employing support workers). People using IF are supported by a Host provider. People using IF (or their Agent) have overall responsibility for managing the budget and managing the quality of the support purchased. People using IF can purchase Home and Community Support Services or the costs of getting a break (respite)
Enhanced Individualised Funding (EIF)	Bay of Plenty only	Hosted scheme similar to IF however, people have a greater scope in what they can purchase. Unlike IF, it is not restricted to HCSS and respite services. People using EIF can purchase disability supports that are goods or services.
Hosted Personal Budgets	Christchurch, Midcentral	Hosted Scheme similar to EIF however funding for supports may come from other government agencies
Choice in Community Living (CiCL)	Auckland, Waikato, Hutt, Otago Southland	Started as an alternative to Residential Services for people who would traditionally require residential services. A flexible option where people are allocated a flexible Personal Budget and work with a contracted provider. The contracted provider takes the role of the Agent and the Host (in individualised Funding) and helps the person decide how the supports are going to be purchased/delivered. In most cases the Provider delivers flexible support. In some cases, the Provider may buy supports on behalf of the person. The provider is responsible for managing the budget and the Ministry manages quality
Flexible Disability Supports (FDS)	Christchurch, Midcentral	Similar to CiCL, however targeted at anybody (regardless of need) who wants choice control and flexibility but doesn't want to manage their budget and quality. Funding may come from multiple government Agencies similar to Hosted Personal Budgets.
Direct Funding	MidCentral, Waikato[49]	Person is funded in advance and directly purchases supports. They may choose to employ/contract support workers or purchase supports from providers. The person has the same responsibilities as in IF

Enabling Good Lives principles

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 takes 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 contributions 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: Ministry of Health, "Where I Live; How I Live Disability Support Services Community Residential Support Services Strategy, 2018 to 2020," Wellington. https://www.moh.govt.nz/notebook/nbbooks.nsf/0/620E44614373A4ABCC258282000810BA/$file/dss-community-residential-support-services-strategy-2018-2020-mar18.pdf

IF purchasing guidelines

Principle One: The Ministry of Health will not increase, or continue to increase, a Person's Budget because they have run out of funding (unless it decides, at its sole discretion, that it is necessary to do so).

Principle Two: People with an identified need for disability supports will still be able to access standard Formal Provider services even if access to a Hosted Scheme is denied or withdrawn.

Principle Three: Any actions taken must ensure that risk to the Person, their whanau or employed support worker is managed appropriately.

Reasons to deny access to IF

Access to an IF scheme may be denied or made subject to conditions, in the following circumstances:

- The Ministry and/or NASC and/or the person decide that the level of risk to the person or support workers is too great to safely manage within a Hosted Scheme.
- The person (or their Nominated Agent) does not comply with appropriate laws, for example, those governing employment or health and safety.
- The person (or their agent) employing support workers has had to pay out on more than one personal grievance claim.
- The person has failed to manage the personal budget appropriately, for example:
  - they have purchased supports outside what is allowed within each scheme;
  - the funding allocated has not lasted for the duration of the period funded and there has been no identified change in need.
- The person has been found non-compliant (or is being audited) in their use of the

personal budget, for example claiming for either costs of support that were not incurred or not permitted under the scheme conditions.
- The person has committed any Restricted Act (e.g. theft, fraud, misleading officials).
- The person managing the personal budget is an un-discharged bankrupt.

The final decision on access to hosted funding or any conditions that may be imposed rests solely with the Ministry. An audit may recommend what consequences could be required, and the Ministry will consider any such recommendation.

Source: Ministry of Health (2016), "Disability Support Services Operational Policy: Restrictions on Access to Hosted Budgets," version: 2.0, 23 March.

DSS principles

Principles within DSS provider contracts state that people:

- are individuals who have the inherent right to respect for their human worth and dignity
- have the right to live in and be part of their community
- have the right to realise their individual capacities for physical, social, emotional and intellectual development
- have the same rights as other members of society to services, which support their attaining a reasonable quality of life
- have the right to make choices affecting their lives and to have access to information and services in a manner appropriate to their ability and culture
- have the same rights as other members of society to participate in decisions which affect their lives
- have the same rights as other members of society to receive services in a manner which results in the least restriction of their rights and opportunities
- have the right to pursue any grievance about services without fear of the services being discontinued or any form of recrimination.

Source: Ministry of Health (2018), "Where I live, How I live: Disability Support Services Community Residential Support Services Strategy, 2018 to 2020," March, p.4.

Host provider obligations

Host Providers are expected to monitor each person's expenditure against their personal budget. Monitoring against budget should be done on an ongoing basis so that any problems can be identified early and appropriate plans put in place.

- Where a person is tracking over budget, the Host Provider must have a discussion with the person as to why this is the case.
  - If there is a potential change in need, this should be identified as early as possible and referred to the NASC who will review the person's support needs.
  - Where there is no change in need and/or the increased expenditure wasn't planned, the person needs to put in place a plan to reduce expenditure. The Host Provider can assist with the development of an expenditure reduction plan.
  - Some people are unable to manage a personal budget. This may be for several reasons including an inability or unwillingness to manage a budget. If a person is unwilling or unable to reduce expenditure, the Host Provider should refer this to the NASC.
- Where a person has been found to have purchased items outside what the personal budget has been allocated for (unauthorised purchases) the Host Provider must identify the cost of the unauthorised purchases and address what action needs to be taken in accordance with clause 6.0 of this Operational Policy.

- Examples of unauthorised purchases may include using funding on things that are considered a personal expense or purchasing an item the person has already been told does not fit the Purchasing Guidelines.
- Where a person is suspected of non-compliant or fraudulent activity in relation to their disability support funding, or the Host Provider becomes aware of a Restricted Act by the person or their Nominated Agent, the Host Provider shall notify the NASC and the Ministry's audit team, Audit & Compliance.
- The Host Provider shall have such other obligations as are specified in its Host Provider contract with the Ministry.

Source: Ministry of Health (2016), "Disability Support Services Operational Policy: Restrictions on Access to Hosted Budgets," version: 2.0, 23 March.

Other support services[50]

Disability support service type	Description
Behaviour support services (BSS)	BSSs aim to improve the quality of life for people who have challenging behaviour, making it easier for them to be independent and involved in the community. BSSs work with disabled people and their support networks to develop and implement plans to reduce the impact of challenging behaviour.
Carer support	Carer support is available to full-time, unpaid carers for disabled people, to allow them to take time out for themselves and support them to continue in their caring role. Carer support provides reimbursement of some of the costs of using a support person to care and support a disabled person.
Community residential services	Community residential support services provide disabled people with support for up to 24 hours a day in a home-like setting in the community. This might include help with things like: • shopping • preparing and cooking meals • household chores (eg, clothes washing, cleaning) • personal cares (eg, eating and drinking, getting dressed and undressed, taking a shower) • getting out and doing things in the neighbourhood (eg, going to see a movie). Services are provided in a range of community settings, such as small or large homes, or groups of small homes or flats where disabled people can have their own space and sense of personal belonging.
Community rehabilitation	Community rehabilitation services are provided to disabled people under 65 and aim to help them to maximise their functional independence and participation in society.
Day services	Day services help disabled adults who cannot find work to take part in their community and improve their personal skills, by providing them access to regular meaningful social contact and stimulating activities. Day services include a range of activities, depending on the provider and the individual disabled person's interests and abilities. Activities may include daily living skills, education and learning activities, social activities, and recreation and leisure activities.
Funded family care (FFC)	FFC is Ministry of Health-funded care for eligible disabled people to employ their parents or family members over 18 who they live with to provide them with personal care and/or household management disability supports. FFC cannot be used to pay a disabled person's spouse or partner, or to pay for non-disability supports.

Disability support service type	Description
High and Complex (H&C) Framework services	H&C services provide secure residential facilities for people with an intellectual disability under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. H&C services include: • National Intellectual Disability Secure Services • Regional Intellectual Disability Secure Services • Regional Intellectual Disability Supported Accommodation Services.

Home and community support services (HCSS)	HCSS help disabled people to live at home. They can include:
	
	• household management services, which may include help with:
	  • meal preparation
	  • washing, drying or folding clothes
	  • house-cleaning
	• personal care services, which may include help with:
	  • eating and drinking
	  • getting dressed and undressed
	  • getting up in the morning and getting ready for bed
	  • showering and going to the toilet
	  • getting around the home.

Respite services	Respite services provide short-term breaks for the carers of a disabled person, while also providing a positive, stimulating and worthwhile experience for the disabled person.
Supported living	Supported living services help disabled people to live independently by providing them support with activities such as: • using community facilities (eg, libraries, swimming pools) • shopping, budgeting or cooking • dealing with agencies (eg, WINZ, banks). A support worker works with the disabled person, usually at their home, but also at other agreed places.
Younger people in aged residential care (YPD)	YPD services provide 24-hour residential support in aged care services for people aged under 65 with physical disabilities who require clinical supports not available in community residential support services.

NASCs

NASC	Region	Coverage
NorthAble – Matapuna Hauora	Whangarei	Under 65 years
Taikura Trust	Auckland	Under 65, Auckland
Life Unlimited Charitable Trust	Gisborne	Under 65, Tairawhiti
Disability Support Link	Waikato	All
Support Net Kupenga Hao Ite Ora Tauranga	Tauranga	All
Access Ability Taranaki	New Plymouth	All
NASC Hawke's Bay	Hawke's Bay	All/Hawke's Bay
Access Ability Whanganui	Whanganui	All
Focus	Masterton	All, Wairarapa
Life Unlimited Charitable Trust	Lower Hutt & Upper Hutt	Under 65
Capital Support	Wellington	Under 65, Wellington/Kapiti
Support Works	Nelson	All/Nelson/Marlborough
LifeLinks	Christchurch	Under 65 DSS
Access Ability Otago/Southland	Otago	Under 65, Otago/Southland

Market structure

The table below shows the main players in disability support.

	Functions	Organisations
Ministry of Health	• Funding • Policy • Audit	
NASCs	• Needs assessments to set individual budgets	• NorthAble – Matapuna Hauora, Whangarei • Taikura Trust, Auckland • Life Unlimited Charitable Trust, Gisborne • Disability Support Link, Waikato • Support Net Kupenga Hao Ite Ora Tauranga, Tauranga • Access Ability Taranaki, New Plymouth • NASC Hawke's Bay, Hawke's Bay • Access Ability Whanganui, Whanganui • Focus, Masterton • Life Unlimited Charitable Trust, Lower Hutt & Upper Hutt • Capital Support, Wellington • Support Works, Nelson • LifeLinks, Christchurch • Access Ability Otago/Southland, Otago
Hosts	• Hold funds for individuals • Assess claims on funds • Budget management • Employer support • Job matching • Coaching	• Access Community Health, Nationwide excluding Auckland • Florence Nightingale Agency, Marlborough, Christchurch, Invercargill, Dunedin • Geneva, Nationwide • Healthcare NZ Limited, Nationwide • Home Support North, Northland • Lifewise, Auckland • Manawanui In Charge, Nationwide • Presbyterian Support Northern (Enliven), Auckland, Bay of Plenty • Vision West, Auckland West, Waikato, Bay of Plenty
Workers	• Deliver support services • Approx. 19,000 workers	

"The Ministry of Health provides support for people, mostly aged under 65, with physical, sensory, and intellectual disabilities expected to last six months or more. DHBs provide support mainly for those over 65, and for people with mental-health-related disabilities. DHBs also support people who are expected to be disabled for less than six months. The Ministry of Health is responsible for policy as to what disability support the DHBs fund."[51]

"Needs Assessment and Service Coordination (NASC) organisations allocate most of the Ministry of Health's funding for disability support. NASC contracts are held by various organisations. About half of these organisations are owned by DHBs, and the remainder are community-based trusts or privately owned organisations. NASCs assess, plan, and coordinate tailored packages of support. Each person's disability support needs must be reassessed at least every three years, and their support package is reviewed at least once each year. People with disabilities and their families can, however, ask for their situation to be reviewed or their needs reassessed at any time."[52]

Table 6: Number of Disability Support Services clients, by Needs Assessment and Service Coordination service (NASC), 2018 and 2016[53]

NASC	2018		2016	Change from 2016 to 2018 (%)
	Number	%		
Access Ability – Otago	2,889	7.5	2,855	1.2
Access Ability – Wanganui	562	1.5	534	5.2
Access Ability Taranaki	1,185	3.1	1,099	7.8
Capital Support – Wellington	1,845	4.8	1,635	12.8
Disability Support Link – Waikato	3,426	8.9	3,251	5.4
Enable New Zealand – Manawatu	1,770	4.6	1,650	7.3
Focus – Wairarapa	393	1.0	378	4.0
LIFE Unlimited – Hutt Valley	1,323	3.5	1,283	3.1
LIFE Unlimited Charitable Trust – Gisborne	381	1.0	381	0.0
Life Links – Canterbury	5,384	14.0	4,950	8.8
NorthAble – Northland	1,681	4.4	1,514	11.0
Options Hawke's Bay	1,371	3.6	1,277	7.4
Support Net Kupenga Hao Ite Ora Tauranga	3,063	8.0	2,722	12.5
Support Works – Nelson	1,450	3.8	1,401	3.5
Taikura Trust – Auckland	11,349	29.6	10,856	4.5
NASC subtotal	**38,072**	**99**	**35,786**	**6.4**
NIDCA Auckland	87	0.2	84	3.6
NIDCA Central	59	0.2	73	-19.2
NIDCA Midland	50	0.1	36	38.9
NIDCA South Island	74	0.2	68	8.8
NIDCA subtotal	**270**	**0.7**	**261**	**3.4**
Total	**38,342**	**100**	**36,047**	**6.4**

Endnotes

1 A disability survey by Statistics New Zealand in 2013 found 27% of the working age population in New Zealand has some form of disability. Applied to today's population, this suggests 1,080,000 New Zealanders have a disability.

2 Survey responses in the study were reported in four categories. We calculated net satisfaction as follows. Each response of "Really unhappy" or "Unhappy" counted as -1. Each response of "Happy" or "Really happy" counted as +1.

3 New Zealand Parliament (2008:18).

4 Disability support for people aged 65 or older was later devolved to DHBs.

5 Ministry of Health (2003:4).

6 New Zealand Parliament (2008: 25). MoH (2003:4).

7 Manawanui says 125. Ministry of Health says 129.

8 "99% approval" according to Manawanui, pers. comm.

9 New Zealand Parliament (2008).

10 Ministry of Health, "Flexible Personal Budget Options Allocation Methodology and scope of purchasing Funding in New Zealand," v1.3. Other changes included: IF specification changed to give greater emphasis on accountability and responsibilities. Individualised fees were based on the size of a person's package. The Host fee was paid from the persons support package. An IF training package was created for all IF stakeholders. The IRD confirmed IF is not considered taxable income to the disabled person or their agent when used for services.

11 Further information on the Local Area Co-ordinator model is available at https://www.ndis.gov.au/understanding/ndis-each-state/western-australia

12 Ministry of Health, pers. comm.

13 Funded Family Care allowed some family members to be paid to support people with high very high needs.

14 For further reading on the details of the development of IF after 2008, see Appendix D of New Zealand Productivity Commission, "More Effective Social Services," Final Report, August 2015, Wellington.

15 Reddihough et. al. (2016).

16 Ministry of Health (2018a:6).

17 Ibid.

18 One IF recipient we spoke to said the system still fails to acknowledge that people on IF are contributing to the economy by providing employment. "There's an unspoken attitude that we are a cost to the state, rather than IF being an investment in both the IF user and their employees," he said.

19 Ministry of Health (2018b). There are also rules around payments to family. Recipients can only pay a resident family member to provide household management and personal care supports is the disabled person is assessed as having 'high' or 'very high' needs. Recipients cannot pay resident family members to provide respite.

20 Children under 7 cannot be diagnosed with an intellectual disability. There may be children over 7 who are not yet diagnosed.

21 NASCs are owned by DHBs or are community-based trusts or private organisations. NASCs also provide needs assessments for other types of support such as Aged Care. NASC organisations hold contracts with the Ministry of Health and DHBs.

22 The funder may be a District Health Board or the Ministry of Social Development. However, in most cases the funder is the Ministry of Health.

23 Recipients can go back to their NASC for an assessment when enduring changes in need occur.

24 Provided a government commitment not to use underspending to reduce budgets is credible, which it appears is the case.

25 Source: pers. comms. Manawanui, Ministry of Health.

26 Ministry of Health, "Flexible Personal Budget Options Allocation Methodology and scope of purchasing Funding in New Zealand," v1.3.

27 Ibid.

28 Ministry of Health, pers. comm.

29 However, IF does not eliminate bureaucratic interactions on setting budgets. A third party, NASCs, must still set the budget which can be a source of friction.

30 Not all people with agents need supported decision making. The Ministry of Health is doing work to enable people with no capacity for decision making to still exercise some choice depending on their ability and capacity. Some people, mostly parents, will get a PPPR (The Protection of Personal and Property Rights Act gives authority to the Family Court to appoint people to protect personal and property rights) or a guardianship order which eliminates the need for supported decision making.

31 Australian Productivity Commission (2011:353).

32 Statistics New Zealand (2014).

33 Australian Productivity Commission (2011:389-90).

34 Dovetail (2015:16). Dovetail states, "[w]e observed IF users tend to simultaneously receive IF and non-IF services, with the proportion of non-IF services reducing over the first few years of transition (such as carer support, respite and behaviour support) due to their circumstances or commissioning arrangements in place."

35 An agent is an individual who is authorised to make decisions on behalf of the services recipient. The Ministry of Health defines an agent as: "An individual (chosen by the person) who is most closely involved in helping the person with their care and decision making and is able to make decisions on behalf of the person that relate to managing the person's supports. This individual will be identified through the assessment process." See Ministry of Health (2018b:9).

36 We understand changes made after we spoke to Lisa mean ACC serious injury and disability support funding are more aligned.

37 Fleming et. al. (2019).

38 By contrast, traditional HCSS is a fortnightly allocation.

39 Questions about what spending is permitted still arise under IF. Decisions on whether spending is permitted is decided according to the four purchasing criteria. The job of adjudicating whether a purchase is permitted sits with the host provider.

40 Carer Support is a type of respite support in New Zealand. There are different types of respite. Carer Support is an old version of respite which is defined as a "subside" to help the carer pay to get a break. Carer Support is funded at a low rate. In the past, Carer Support was difficult to use because respite had to be purchased in 24 hour blocks with only $75 funding, with the difference to be made up by the services recipient. However, Carer Support has become more flexible in recent years. MoH is allowing people to aggregate days, providing greater flexibility and allowing it to be used more effectively. Other kinds of respite include IF and fully funded residential respite.

41 MoH's position is that decision making should be as close as possible to the disabled person.

42 Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 orders or s141 of that Act for children.

43 Australian Productivity Commission (2011:391-2).

44 Australian Productivity Commission (2011:392-3).

45 New Zealand Productivity Commission (2015: Chapter 11).

46 Australian Productivity Commission (2011:361).

47 Poll et. al. (2006).

48 DHB Boundaries can be found at ihttps://www.health.govt.nz/new-zealand-health-system/key-health-sector-organisations-and-people/district-health-boards/location-boundaries-map

49 Direct Funding in Waikato is being managed through the Ministry of Social Development but is using Ministry of Health Funding.

50 Ministry of Health (2018), "Demographic Report for Clients Allocated the Ministry of Health's Disability Support Services," Wellington. P111-113.

51 Select Committee 2008: 18.

52 Select Committee 2008: 21.

53 Ministry of Health (2018), "Demographic Report for Clients Allocated the Ministry of Health's Disability Support Services," Wellington, p. 18.

"The current policy question asks if people with disabilities should be allowed self-direction. This report will help answer a different question – why should anyone be denied self-direction?"

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