

Demonstrating changes to disability support

EVALUATION REPORT
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Acronyms and terms used in this report

CiCL	Choice in Community Living
CMS	Contract Management System
DIAS	Disability Information Advisory Services
DSS	Disability Support Services
EIF	Enhanced Individualised Funding
FAT	Funding Allocation Tool
IF	Individualised Funding
ISP	Individual Service Plan
LACs	Local area coordinators
Level 2	An administrative term to record people who choose to receive ongoing support from a LAC.
MSD	Ministry of Social Development
NASC	Needs Assessment and Support Coordination organisation
Participant	Disabled person or whānau evaluation respondents who have participated in one or more of the New Model initiatives
SPA	Support Package Allocation
UYYS	'Understanding you and your situation' form
Whānau	A disabled person's family

Executive summary

The Ministry of Health (the Ministry) funds support for people primarily aged under 65, who have intellectual, physical and/or sensory impairments. Following the Social Services Select Committee’s report titled Inquiry into the Quality of Care and Service Provision for People with Disabilities (2008) the Ministry was mandated to demonstrate the core components of a New Model for supporting disabled people. The components implemented to date, and their location, are outlined in Table 1.

Table 1: Core components of the New Model implemented by the Ministry

New Model component	Implementation location and start date
<i>Local area coordination.</i> Local area coordinators (LACs) walk alongside disabled people, help them work out what they want from life, help them build community networks	Western Bay of Plenty, late 2011 Eastern Bay of Plenty, early 2013
<i>Choice in Community Living (CiCL).</i> This aims to support disabled people to live independently in their own home, in a way that maximises their legal status and increases choice and control around how they are supported, where they live and with whom. It is intended CiCL will be fiscally neutral for the Ministry.	Auckland and Waikato, late 2012
<i>Enhanced Individualised Funding (EIF).</i> A mechanism that extends a disabled person’s choice and control by enabling them to choose what support they purchase (unlike IF where people are only able to purchase home and community focused services).	Bay of Plenty, early 2013
<i>New approach for collecting information from disabled people and whānau:</i> A new approach has been introduced for disabled people and whānau to provide information that will give an indication of how much money they may receive from Disability Support Services. The new form “Understanding you and your situation (UYYS)” is filled out by disabled people and whānau on their own or with support (as much or as little as they choose). It is an alternative to the traditional approach involving an assessment by a NASC assessor.	Bay of Plenty, late 2013

Local area coordination and Choice in Community Living have previously been evaluated (Evaluate Research, 2012; 2013; 2014). This phase of the evaluation focused on the extent to which the New Model components are:

- contributing to increased choice and control for disabled people over the supports they receive and the lives they live (CiCL, EIF)
- able to be implemented in a fiscally neutral manner (CiCL, local area coordination).

The evaluation was conducted in September - November 2014 and involved 62 semi-structured interviews with 63 disabled people and whānau who are using one or more of the new disability supports, and 28 key stakeholders, a scan of literature on self directed support, and analysis of administrative data provided by the Ministry.

Findings

The findings are presented in three parts: CiCL, EIF, and fiscal neutrality of local area coordination.

Choice in Community Living

Choice in Community Living aims to support disabled people to live independently in their own home, in a way that maximises their legal status and increases choice and control around how they are supported, where they live, and with whom. People eligible for CiCL include those who are in residential care or have a disability support need similar to those living in residential care, are living with family or whānau, and those with current living situations that are unsustainable.

People must be eligible for disability support services funded by the Ministry of Health before they can access CiCL. Once they are assessed as being eligible, disabled people choose a contracted disability support agency to help them develop a plan and support their move into more independent living. There are currently eight¹ CiCL support agencies working in the Auckland and Waikato regions.

Who has engaged?

At the end of July 2014 there were 79 people who had moved into CiCL. Of these, 68 percent were NZ European and 19 percent Māori. The take-up by disabled people living in Auckland was slightly lower (38) than those living in Waikato (41). The cost of accommodation is regarded by stakeholders as one of the factors responsible for the low uptake by Auckland participants.

Prior to CiCL, 39 of the CiCL participants were in residential care, 36 in the community (e.g. in their own home or living with parents) and four in a rehabilitation unit. Most of those who were previously in residential care have moved into a community residential home. Likewise, most of those previously living in the community have remained in the community, either living in their own home or in a private rental.

Disabled people and whānau experiences

Eighteen CiCL participants (disabled people and their whānau) shared their experiences of selecting a CiCL support agency, their living arrangements, selecting and managing support staff, the value of CiCL and management of their CiCL funds.

Most participants said they shopped around for a support agency that worked best for them. Several respondents (including those who have taken up CiCL and those who decided not to proceed) reported that some support agencies have not returned calls in a timely manner or at all. This lack of responsiveness has been a deciding factor when selecting a support agency.

Of the 15 Māori disabled in CiCL, all but two were using mainstream CiCL support agencies. The evaluation included interviews with four of the 15 Māori CiCL participants. Respondents selected a support agency based on its reputation, their responsiveness, and who was offering the best support package.

¹ CCS Disability Action Auckland, CCS Disability Action Waikato, Community Living, Idea Services, Iris, Renaissance, Spectrum Care and Te Roopu Taurima o Manukau.

The interviews indicate there is variability in the quality of support workers used by CiCL participants. Where paid support is working well, one or more of the following are occurring:

- Disabled people and whānau have been involved in determining the kind of skill set and qualities required of their support worker
- Support hours are flexible, determined by the disabled person's needs
- Support workers are 'enabling'. They "support and encourage" but do not take over.
- Where issues arise, support workers and the support agency meet with the disabled person and/or whānau to discuss and find a solution as soon as possible
- Young people have access to support workers of a similar age.

Where paid support is not working so well, participants reported one or more of the following about support workers:

- Staff have a "residential mentality", that is, they "do everything" for the disabled person
- Staff "baby sit" disabled people, e.g. watch TV with a disabled person rather than supporting the disabled person to do household tasks
- Staff lack the required skills, for example not knowing how to use a hoist (resulting in a disabled person being injured)
- Not willing to work at weekends.

The demonstration of CiCL has raised issues about roles and responsibilities of support agencies vis a vis whānau and disabled people. Participants reported having a say in selecting the staff who work with them. However, staff are employed by the support agency, not the disabled person or their whānau. The analysis of interviews with CiCL participants indicates a lack of clarity about whose role it is to manage the performance of staff, despite an expectation that this be specified at the outset. There were also examples of a lack of clarity around responsibilities, for example one participant had not paid his electricity bill, resulting in the power being turned off in his unit. The whānau were upset this had not been picked up by the support agency, yet it was unclear who had responsibility for ensuring day-to-day tasks such as these were undertaken.

Value of CiCL

Participants identified three dimensions of value directly resulting from CiCL as listed below.

Table 2: Value of CiCL for disabled people

Dimension	Examples of value	Resulting in (according to respondents):
Control	Being able to select their own staff Deciding how much of their budget is used for paid support	New learning, e.g. how to state preferences for particular staff
Choice	Flexibility about where they live, and to some extent, who they live with Doing everyday activities on their own, when they choose Deciding who will support them	Freedom to live their own lives in ways they have previously not been able to Being able to stay living in own home Shift in power balance between disabled person and paid staff
Flexible funding	Using funding to achieve personal goals, e.g. involvement in community activities Developing living skills, e.g. managing money Using funding to purchase equipment that reduced the need for overnight care	Feeling fitter, being more engaged and connected with activities in community Increased control and choice

Source: evaluation interviews

A theme that emerged from participants who had previously been in residential care was the sense of freedom they now have, to live their lives as individuals. Whereas in residential care they had had to do activities as part of a group, with little or no choice about participation, four disabled people commented they now have a greater level of choice about what they do and when.

Although the evaluation did not specifically seek perspectives about residential care, the interviews indicate they can be environments where many disabled people do not always have an acceptable level of choice and control over their lives. Participants described disabled people coming out of residential care with institutionalised behaviour. The shift to independent living has required some disabled people to learn, or relearn skills and capabilities. This finding highlights the importance of preparing people for living more independently. An example of where this had been done well was the case of four participants who had previously been involved with the Supported Living initiative. They described how, in Supported Living, and now in CiCL, they had been learning to shop on their own, cook, text on their phones, catch buses and manage their finances. Engaging with CiCL was just another step in their transition toward greater independence. However this was not the case with all the disabled people we interviewed. Whānau participants in particular were critical of paid staff who “do everything” rather than work with the disabled person to develop their ability to live more independently. Access to quality paid support was an issue raised by both whānau and CiCL support agency participants.

Management of CiCL funds

The expected process is that eligible disabled people and whānau are told upfront by the NASC what their disability support budget is for the year. The CiCL support agency appointed by a

disabled person and/or whānau then administers the budget. Support agencies are required to provide regular financial updates to their clients.

Ideally disabled people and whānau have ‘real time’ access to their budget so they have some control over it. Currently only one support agency gives their clients the option to view current financial information online. This agency also provides one-on-one training to clients, if required, to show them how to access and understand the information. Three disabled people and whānau who have engaged with this agency commented this way of managing their funds is working well.

Agencies have been encouraged by the Ministry to explore more creative ways of using CiCL funding allocations with their clients. Examples of how participants are using CiCL for disability support other than paid care are listed in Table 3.

Table 3: How participants are using CiCL for supports

CiCL budget used for:	Examples:
Personal care	Nutritionist engaged to support person to take better care of her health Disabled person enrolled in a three-month weight loss programme
Other home-related supports	Two disabled flat mates pooled resources to fund “enabling” training for their support staff
Support for community-based activities	Disabled person engaged a personal trainer
Items purchased	<p>Bicycle for a person who has anxiety at a level that makes public transport unviable. Also means person is able to work part-time</p> <p>Microwave, so person no longer needs support with cooking</p> <p>Heat pump, so person can remotely control the temperature in room. This has cut down the amount of night support required.</p> <p>Takeaway lunches. Disabled person loves food from his cultural upbringing. Takeaway Asian food is more cost effective than having a support person come in at lunchtime.</p> <p>Internet connection, so person can participate in online training</p>

Source: evaluation interviews

The NASC and provider respondents expressed a concern that the exclusion of transport costs means some disabled people are not able to participate in the community to the extent they would like. The interviews with whānau indicate some families are subsidising their family member’s transport costs. However, not all disabled people have family members who are willing or able to provide this additional level of support.

Is CiCL cost neutral?

Choice in Community Living was expected to be fiscally neutral for the Ministry from the outset. Available data, which is based on DSS allocations (not actual expenditures), shows that allocations have increased for the vast majority of people who joined CiCL from community settings, stayed at about the same level for most people who joined CiCL from residential settings, and decreased for a minority of people who joined CiCL from residential settings. The net effect to date is an overall increase in allocations for disability services.

Actual expenditure data will become available after the Ministry's year-end funding reconciliation process (early 2015). The early 2016 funding reconciliation is likely to yield more robust cost data than 2015 data, as it will include greater numbers of people as well as an extra year's expenditure data. Expenditure data² from the Ministry of Social Development (MSD) was not provided in time to be included in the evaluation.

Reasons why CiCL is not taken up

Interviews were conducted with 13 respondents who had considered CiCL (either for themselves or whānau members) but decided not to proceed. The level of funding available for disabled people with very high needs was the major reason why 10 of the 13 respondents decided not to proceed with CiCL.

A theme across many of the interviews is that "the Ministry" lacks understanding of what is required to support disabled people with very high needs. Respondents said this is epitomized by funding packages that assume it is possible for CiCL to be financially viable if disabled people are prepared to pool resources. Having to pool resources contradicts the values of choice and control.

In addition to the issue of adequate funding, four respondents were of the view that CiCL would put undue stress on their family as they would need to take on more responsibility than they are able to provide. This is identified as a potential barrier for people taking up CiCL, i.e. disabled people may wish to live more independently, but are being held back because family are unable, or unwilling, to assist.

Enhanced Individualised Funding

Enhanced Individualised Funding expands on Individualised Funding which is widely used in New Zealand by increasing the range of service funding areas, and enabling disabled people to decide how they will use their funding allocation to purchase disability supports, products, services and/or arrangements that meet three criteria set out in the Purchasing Guidelines produced by the Ministry. The guidelines are not prescriptive, allowing interpretation on a person-by-person basis according to their individual circumstances and goals. The Ministry has contracted EIF host services ("EIF Host") from Manawanui InCharge to provide coaching and support services to disabled people. Disabled people decide the level of support they want from the EIF Host. That is, they can choose to self-manage (level one) or to purchase additional supports, such as monthly statements, payroll services and completion of tax requirements (levels two and three).

Take-up

The 233 disabled people who have taken up EIF in the period March 2013 to November 2014 represent 14.5 percent of all people receiving DSS support in the Western Bay and 10 percent in the Eastern Bay. Almost the same percentage of Māori and NZ European people receiving DSS support are using EIF - 14 percent of Māori and 13 percent of NZ European. Fifty-seven percent of disabled people have been using EIF for less than 12 months, while 43 percent have been using EIF for 12 months or longer. All disabled people who have come up for an annual review since August 2013, and people new to DSS since this date, are using a self-assessment tool.

² The evaluators requested expenditure data including accommodation supplement, disability allowance, social security benefits, and any other items agreed relevant to this client group. This data was requested in June 2014 but had still not been provided by December 2014.

All but three of the 32 disabled people and whānau we interviewed have chosen the EIF Host to manage the EIF payroll on their behalf. Those who are self-managing are disabled people or family members with relevant work experience, such as running a business or operating a payroll function. A few disabled people said although they are satisfied with the EIF Host managing their payroll at the moment they may become self-managing once they are familiar with EIF processes. One interview was with a couple whose EIF is being managed by a third party as part of a natural supports arrangement.

Being an employer

Disabled people (their parent or caregiver) prefer to employ people known to them, such as whānau, friends and wider networks, rather than having strangers coming into their home. They said they have a greater level of trust in someone known to them. This also acts as an informal risk management strategy. The exceptions are when an age appropriate support worker is required for a young person, or support workers with specific skills are sought e.g. art or business skills. Nine of the 32 participants interviewed talked about problems they were having (or had had) as an employer, such as difficulties recruiting support workers and issues with staff performance.

Purchasing of supports

The disabled people we interviewed are employing support workers for personal care and other home-related supports, and to enable them to participate in community-based activities such as going to the gym, swimming, rock climbing and attending art classes. Items and activities purchased include a mobility scooter, a custom designed riding helmet for a disabled child to attend Riding for the Disabled, swimming lessons, and paying fees and carer costs for a young person to attend a camp for people with disabilities. Four parents have organised (or are in the process of organising) tailored programmes of support for their young adult son or daughter to help their transition from school with the aim of increasing their independence, confidence and skills.

What disabled people value about EIF

Most participants identified one or more dimensions about the value of EIF for them. Nine participants described the value of EIF by comparing it with their past experiences of services from agencies which had been negative. People value being able to choose who they employ as support workers, and how and what they spend their support funds on, described by one person as “being in control and calling the shots.” Five participants value being able to choose what they do in their day, compared to services where they had little choice. Four participants described how being able to choose how their support funds are spent provides more tailored and personalised support arrangements for them.

Difference EIF is making for disabled people

There is consistent support from disabled people and their whānau who are using EIF that the concept of EIF as a mechanism for increasing choice, control and flexibility is sound. Some participants described positive changes that are occurring for them. These changes include reduced social isolation as a result of being involved in more community-based activities, increased independence, increased self-esteem and confidence. Four participants (one disabled person, two sets of parents of disabled children, and a caregiver) said that EIF has not made any difference for them.

Supported self-assessment

The supported self-assessment process is intended to be strengths-based, with the disabled person taking the lead with support from family, friends and/or a NASC assessor (as required). It uses a form ('Understanding you and your situation') which is designed to enable disabled people to tell their story - their situation, who they live with, what they enjoy doing, what they would like to do, and how their impairment(s) impacts on their life.

Ten of the 32 participants we interviewed had used the form - three disabled people, five parents, and two family members. Most said it was helpful having someone to support them to fill out the form such as a NASC assessor. A parent who is new to DSS completed the form with her social worker. The most frequent comments from participants about the form were about its length, the repetitiveness of information requested, and the amount of time it took to complete. While some participants said the form was "okay" or that "the questions were easy to answer", one parent described the form as "a challenge", and another said she felt "bamboozled by it". A disabled person said he felt "confused" by the form. It is not possible to draw any definitive conclusions about the effectiveness of supported self-assessment for disabled people given the small number of participants in our sample who had used the form and the range of their responses.

Getting the most out of EIF

The use of EIF by disabled people is in its early stages, as evidenced by 57 percent of people having used it for less than 12 months. There is evidence that EIF is yet to achieve its full potential for the disabled people we interviewed. Many participants appear to be still getting to grips with what EIF can do for them (this includes participants who were previously using IF). Other stakeholders confirmed this is the case. There are a number of reasons for this. Firstly, the amount of front-end work involved in setting up EIF with disabled people and families was under-estimated by the Ministry and EIF Host. It was assumed that the set-up process would be similar to IF. However the EIF Host describes the set-up of EIF as being more complex, with many disabled people needing substantially more support than IF. This means the amount of resource needed to manage EIF is three to four times greater than IF. This issue was compounded by turnover of staff in the coach role during the first 15 months. The impact of these issues were evident in the interviews, with just under half of the 32 participants either saying they still have questions about how EIF works, or it was obvious to the interviewer that they had knowledge gaps about EIF.

Another significant issue is that disabled people and stakeholders working with them are uncertain about what EIF can be spent on. This is part of a larger issue about how the Purchasing Guidelines are being implemented and interpreted. Stakeholders perceive that a top-down, accountability-driven approach is being used to approve the purchasing of supports, which is 'rubbing up against' the principle-driven approach of the New Model. Part of this concerns the role that the EIF Host is required to adopt in relation to a purchasing request. The Ministry's accountability requirements involve the EIF Host requiring disabled people to 'prove' their need, for example, asking the person to state in writing that they are unable to access the requested purchase from another source. Stakeholders state that this is questioning the disabled person's integrity and treating them as a recipient who has to 'prove' their eligibility for funding. Another issue is that purchasing requests have been turned down by the Ministry or the EIF Host, which the EIF coach, Support Net staff or local area coordinators have encouraged disabled people to apply to purchase. Adverse consequences are emerging from such interpretation issues – the EIF coach, NASC staff and LACs say they are "nervous" and conservative when talking with disabled people about how EIF can be used. Most importantly, some disabled people we interviewed have had their expectations

raised (albeit unintentionally by the EIF coach and/or NASC and /or LAC), which are subsequently disappointed. This is leading some disabled people and stakeholders to the view that the Ministry has 'over-sold' EIF because it does not live up to the promise that disabled people will have more choice in how they spend their support money.

Re-balancing EIF

The findings suggest that an appropriate balance between accountability for the spending of public funds and risk reduction on the one hand (which are the Ministry's responsibilities as a public sector agency), and choice and control of supports for disabled people is yet to be realised. An improved balance could be achieved if EIF requirements and processes are recalibrated with the principles of the New Model. This could be achieved if, (among other things) purchasing decisions about a disabled person's support request are made as close to the individual and their whānau as possible; the current requirement for the front-end 'proof' of need is replaced with a focus on the intended outcomes of the requested support; and potential risk is acknowledged and embraced, rather than avoided.

Local area coordination: fiscally neutral implementation

The purpose of this analysis was to evaluate whether, and under what conditions, local area coordination may be provided on a fiscally neutral basis, and to the extent possible, provide information that can support policy decisions about the future rollout of this initiative, including key areas of disability support funding from which savings might be found to cover the costs of local area coordinators.

To date, data shows an average increase in DSS funding among those who took up local area coordination. However, analysis of individual level records together with commentary from the NASC indicates that, in general, the changes in funding were not attributable to local area coordination.

Furthermore, the data is subject to a number of important limitations. The analysis is based on a small number of people (47), and covers a short time frame,³ whereas impacts of local area coordination may develop over the longer-term as disabled people make progress toward living more independently. The analysis is partially based on Contract Management System (CMS) allocations, which on average tend to be higher than actual payments following the Ministry's end of year funding reconciliation.

Some important potential sources of fiscal savings are not reflected in the data. Available information suggests it is plausible (but not verifiable at this stage) that offsets from deferral/avoidance of high cost disability services including Residential Care and Supported Independent Living, together with unused CMS allocations that might have been taken up in the absence of local area coordination, may be sufficient for local area coordination to be delivered on a fiscally neutral basis.

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

³ The earliest Level 2 approval date among the 47 cases was 24 January 2012, and the data set goes to the full year ended 30 June 2014.

access points. Further elapsed time, together with increased take-up of local area coordination is needed to more comprehensively evaluate fiscal impacts.

Evaluative assessment

This phase of the evaluation examined the extent to which CiCL and EIF are contributing to increased choice and control for disabled people over the supports they receive and the lives they live. It also focused on whether CiCL and local area coordination are able to be implemented in a fiscally neutral manner.

The findings show that the concepts of CiCL and EIF as mechanisms for increasing choice and control of supports are sound. Our interviews with disabled people and whānau indicate that both of these New Model components are still in the initial stages of implementation, with some fine-tuning required. Consequently, the potential of CiCL and EIF for disabled people has yet to be fully demonstrated.

CiCL: The intended outcomes of choice and control were very evident for participants interviewed who had previously been in residential care. They described having a sense of freedom to live their lives as individuals, choosing what they do and when. However the shift to independent living has required some to learn new skills and capabilities (due to having become institutionalised). This highlights the importance of preparing people for living more independently, or else ensuring the appropriate supports are in place. This is supported by overseas literature, for example Fyson et al, 2007 identified that tenants usually regarded money as one of the aspects of living independently they found most difficult to handle.

Of particular concern is that disabled people who require 24-hour care and who are not able to share paid support with others, are currently excluded from CiCL. If all those eligible are to have access to CiCL, then funding packages need to reflect the individual circumstances of disabled people and whānau.

EIF: Disabled people using EIF value are being able to choose who they employ as support workers, how and what they spend their support funds. This has resulted in more flexible and reliable support, enabling people to participate in a wider range of activities particularly in the community. Support funding has been used to purchase items to help with daily living in the home and to pay for community-related activities. Disabled people describe having greater independence and self-confidence, and reduced social isolation.

Some disabled people cannot make EIF work effectively without receiving more intensive support to manage and plan. For EIF to work effectively, it involves the disabled person (who wants to) having the opportunity to discuss their hopes and aspirations, thinking beyond day-to-day care, and then working out how EIF (together with natural supports) might enable them to work towards their goals.

An urgent issue is the need to realign EIF with the principles of the New Model, that is, adjusting the imbalance between accountability and risk reduction on the one hand, and trust of the disabled person, NASC and EIF Host on the other. This trust involves acknowledgement that disabled people know best what support they require to achieve the outcomes they seek, and the NASC

and EIF Host know best how to support them to do this. If this fine-tuning is not done and there continues to be downward pressure on accountability and risk reduction from the Ministry, EIF is likely to fail to achieve its intended purpose of increasing choice and control of supports for disabled people.

Fiscal neutrality of CiCL and local area coordination:

CiCL: Analysis of DSS allocations for people who took up CiCL shows that allocations have increased for the vast majority of people who joined CiCL from community settings, stayed at about the same level for most people who joined CiCL from residential settings, and decreased for a minority of people who joined CiCL from residential settings. The net effect to date is an overall increase in allocations for disability services to those who have taken up CiCL. Actual expenditure data will become available after the Ministry's year-end funding reconciliation process (early 2015). The early 2016 funding reconciliation is likely to yield more robust cost data than 2015 data, as it will include greater numbers of people as well as an extra year's expenditure data.

LAC: DSS allocation and expenditure data does not currently provide a robust basis for determining whether local area coordination can be implemented in a fiscally neutral way. Data analysis was undertaken in the context of early implementation of local area coordination, during a period when it was not fully implemented as part of the intended comprehensive system design. Available data represents a relatively small number of people over a short time frame. The analysis is partially based on CMS allocations, which may differ from actual payments after the wash-up process is completed. Individual people's funding varies considerably as circumstances change, and analysis of individual-level records and NASC commentary demonstrates that in general the funding changes that have occurred since accessing LAC support cannot be attributed to local area coordination.

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

Further savings seem likely if local area coordination is fully implemented in the context of overall system redesign, for example, by reducing duplication and inefficiencies associated with multiple access points. Finally, further elapsed time, together with increased take up of LAC, is needed to more comprehensively evaluate fiscal impacts.

Evaluation findings

This section begins with an overview of the New Model components, followed by a short description of the evaluation approach. The evaluation findings are then presented in three parts:

- Choice in Community Living, including fiscal impacts
- Enhanced Individualised Funding and Supported Self Assessment
- Assessment of the potential fiscal impacts of local area coordination

Overview of New Model components

The Ministry of Health (the Ministry) funds support for people, primarily aged under 65, who have intellectual, physical and/or sensory impairments. Following the Social Services Select Committee’s report titled Inquiry into the Quality of Care and Service Provision for People with Disabilities (2008) the Ministry was mandated to demonstrate the core components of a New Model for supporting disabled people. The components implemented to date, and their location, are outlined in Table 4.

Table 4: Core components of the New Model implemented by the Ministry of Health

New Model component	Implementation location and start date
<i>Local area coordination.</i> Local area coordinators (LACs) walk alongside disabled people, help them work out what they want from life, help them build community networks	Western Bay of Plenty, late 2011. Eastern Bay of Plenty, early 2013
<i>Choice in Community Living (CiCL).</i> This aims to support disabled people to live independently in their own home, in a way that, maximises their legal status and increases choice and control around how they are supported, where they live and with whom. It is intended CiCL will be fiscally neutral for the Ministry.	Auckland and Waikato, late 2012
<i>Enhanced Individualised Funding (EIF).</i> A mechanism that extends a disabled person’s choice and control by enabling them to choose what support they purchase (unlike IF where people are only able to purchase home and community focused services).	Bay of Plenty, early 2013
<i>New approach for collecting information from disabled people and whānau:</i> A new approach has been introduced for disabled people and whānau to provide information that will give an indication of how much money they may receive from Disability Support Services. The new form “Understanding you and your situation (UYYS)” is filled out by disabled people and whānau on their own or with support (as much or as little as they choose). It is an alternative to the traditional approach involving an assessment by a NASC assessor.	Bay of Plenty, late 2013

Evaluation approach

The overall approach for the evaluation of the New Model for Supporting Disabled People (“the New Model”) has taken into account the evolving, adaptive nature of the New Model by focusing on specific components of it as they have been implemented. Local area coordination and Choice and Community Living have previously been evaluated (Evaluate Research, 2012; Evaluate Research 2013; Evaluate Research 2014). This evaluation had a focus on the extent to which the New Model

components are contributing to increased choice and control for disabled people over the supports they receive and the lives they live (CiCL, EIF), and are able to be implemented in a fiscally neutral manner (CiCL, local area coordination).

The evaluation was conducted in September - November 2014 and involved 62 semi-structured interviews about 63 disabled people and whānau who are using one or more of the new disability supports, and 28 key stakeholders, a scan of literature, and analysis of administrative data. More information about the evaluation methodology is included in Appendix 1.

A risk is that our aggregated findings may suggest that (other than obvious differences in the impairments individuals live with), disabled people and their whānau are a homogenous group of people. This is far from the case - among the participants, there are individuals who have lived with disability for a long time, as well as those who have been recently diagnosed. There are parents of young children who are new to Disability Support Service (DSS) and becoming familiar with the public health system. In contrast, there are young adults who were mainstreamed at school and their parents who are highly experienced working with disability supports in the education and health sectors. The participants include disabled people who are connected into the disabled community, and those less connected. Some disabled people rely on government benefits, and others who have access to income from other sources. While the reporting of findings cannot account for such wide-ranging differences among disabled people and their whānau, we trust we have accurately recorded their voices.

In evaluation practice it is important to identify and define the criteria (and standards of performance) against which the programme or policy being evaluated will be assessed. This is done to support evaluative assessments that are explicit, transparent and therefore able to be scrutinised. Our primary evaluative criterion is that disabled people have increased choice and control over supports. It is not possible to provide a standardised definition for each of these terms (or to specify what more or less choice and control mean) because they mean different things for individual disabled people, depending on the nature of their impairment, their individual circumstances and personal goals.

Our evaluation approach places disabled people and whānau at the centre of our focus. This approach recognises that distortions can be generated when initiatives like CiCL or EIF are seen as the principal or exclusive context within which to attribute significance to people's lives. The reality for disabled people and whānau engaged in one or more New Model components is that they may not necessarily differentiate different types of support they are accessing, some of which may not even be part of the New Model.

In this report, the term 'participant' is used for the disabled people and 'whānau' who were interviewed and who have engaged with one or more New Model components. 'Stakeholder' is used for people we interviewed from the CiCL support agencies, EIF Host (Manawanui inCharge), the NASCs, Inclusion Aotearoa, the Local Area Coordinators, Synergia, and the Ministry of Health.⁴ 'Whānau' is used to refer to a disabled person's family members. In some cases the gender, or other demographic details, have been altered to protect the identity of participants and other respondents.

⁴ The Ministry of Health has commissioned Synergia to develop the Funding Allocation Tool, which is discussed later in this report.

Choice in Community Living

Background

The Social Services Select Committee inquiry (2008) found that community residential support services unreasonably limit residents' choice and control over the supports they receive and the lives they lead. For example, in many cases, people living in residential services have little choice over who they live with. Further, because only disabled people live in DSS funded residential services, living with non-disabled people, including family or friends, is usually not an option.

Consultation with disabled people, their families and whānau, and support providers, led to the development of the Choice in Community Living (CiCL) initiative. The initiative aims to support disabled people to live independently in their own home, in a way that maximises their legal status and increases choice and control around how they are supported, where they live, and with whom. People eligible for CiCL include those who are in residential care or have a disability support need similar to those living in residential care, are living with family or whānau, and those with current living situations that are unsustainable.

CiCL involved several changes to the Ministry's residential services' contracting and funding arrangements as follows:

- The Ministry's contracts with CiCL providers cover only the cost of support, rather than the cost of support and living.
- People have the same housing choices that are available to other people (such as being an owner or tenant) and can choose which of several contracted organisations provides them with support, independent of any decision around accommodation.
- People who take up CiCL will have access to independent facilitation-based support to assist them to build a life like other New Zealanders that is more connected to natural supports and the wider community.
- Funding for support will be able to be used more flexibly as people with disabilities (with support as necessary) will be able to negotiate with the provider the particular support that is delivered, as long as it fits within the Funding Allocation Guidelines.
- People can receive the full amount of their main benefit in the same way as other members of the community and are then responsible for their own living costs, e.g. food, housing and utilities.
- People may be able to access the full range of supplementary assistance available through the Ministry of Social Development (MSD). The extent of financial assistance that people are eligible for depends on such things as what assistance they receive through Vote: Health, where they live, what allowable costs they have, and any other income they may have.

The intended outcomes of CiCL include (but are not limited to):

- Disabled people moving to independent living or remaining in their existing home
- Disabled people developing skills and capabilities to support independent living
- More opportunities for relationships, community access and participation, inclusion in cultural activities, and
- Disabled people being able to carry out family and whānau responsibilities.

Demonstration of Choice in Community Living

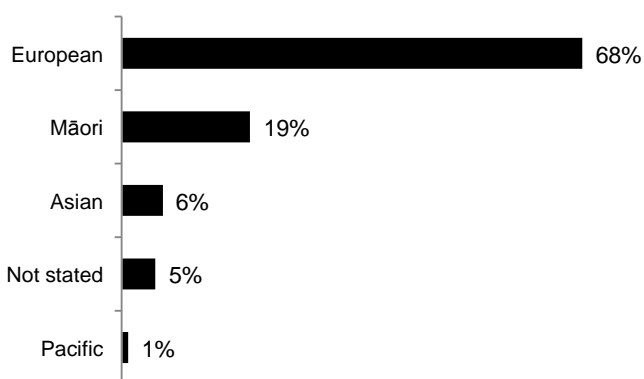
Choice in Community Living has been demonstrated in the Auckland and Waikato regions over a two-year period (late 2012 to October 2014). One of the purposes of the demonstration has been to understand the fiscal implications, particularly across Vote: Health and Vote: Social Development. As with other components of the New Model, there is an expectation that CiCL be fiscally neutral.⁵ The evaluation of CiCL has been in two phases. The first (Evaluate Research, 2013) aimed to help key stakeholders involved in the implementation of the initiative by providing information about how activities were working. This second evaluation is focused on the extent to which CiCL is contributing to increased choice and control for disabled people and whanau, and assessment of fiscal impacts of CiCL.

Who has engaged with CiCL?

Disabled people access CiCL through the Taikura Needs Assessment Service Coordination (NASC) based in Auckland or the Disability Support Link (DSL) NASC in the Waikato. Once people have been assessed by the NASC as eligible for CiCL, they are provided with information about the amount of funding they can access from the Ministry, and given a list of eight support agencies that can help them develop a plan and facilitate their move into independent living. The intention was that people “shop” around for a support agency that worked best for them. The eight support agencies involved in the demonstration are Idea Services, CCS Disability Action Auckland, Community Living, Renaissance, CCS Disability Waikato, Iris, Spectrum Care and Te Roopu Taurima o Manukau.

At the end of July 2014, 79 people had moved into a more independent living arrangement with support from CiCL. This is well below the 150 people the Ministry anticipated would participate during the two-year demonstration period. Of the 79 disabled people, 50 live with an intellectual or learning impairment. As Figure 1 shows, the majority are NZ European (68 percent), while Māori make up 19 percent. There is an even split between males (40) and females (39).

Figure 1: Ethnicity of disabled people taking up CiCL (%)

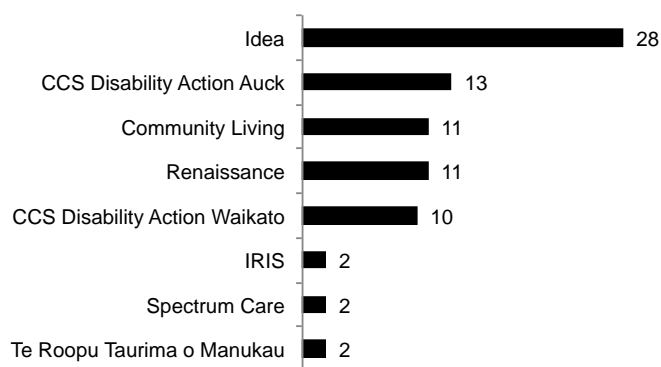


Source: Administrative data on all CiCL participants (as at end July 2014)

⁵ This excludes the cost of implementing the initiative.

Of the eight agencies involved in CiCL, Idea Services has supported 28 (35 percent) disabled people into more independent living arrangements. There are a number of reasons for this. Idea Services has offices in both Auckland and Waikato, enabling their staff to work with people across the demonstration site. A spokesperson for the agency noted they had an existing infrastructure around their Supported Living programme that enabled them to respond quickly to people wanting information about CiCL. Many of those who took up CiCL in the early stages were already in accommodation that could be signed over to them, and they had supports that were largely in place.

Figure 2: CiCL agency selected by disabled person/whānau (n=79)



Source: Administrative data on all CiCL participants (as at end July 2014)

In contrast there has been little uptake of CiCL by participants using Te Roopu o Manukau, Spectrum or IRIS. Different factors have contributed to support agencies' engagement with CiCL. One organisation's services and financial management have been the focus of two Ministry audits and the organisation experienced changes at a governance level during the demonstration. During the Demonstration, another organisation underwent management changes as the organisation was sold. In addition, the implementation of CiCL has been a period of intense learning, particularly for support agencies that have operated under a formal service model. This has been a contributing factor in the performance of at least one of the support agencies involved in the demonstration.

It was anticipated that Auckland would have double the number of participants in CiCL than Waikato due to its larger population. However Auckland has had slightly fewer people (38) in the initiative than Waikato (41). The cost of accommodation is regarded by stakeholders as one of the factors responsible for the low take-up by disabled people living in Auckland. Issues around affordability of the New Zealand private rental market have previously been documented by IHC, 2009.

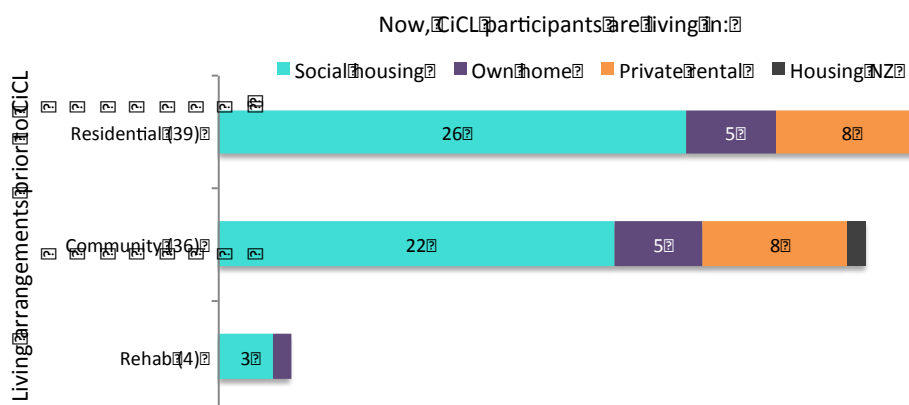
Other potential reasons for the lower than expected take-up of CiCL are discussed in a later section entitled 'Reasons why CiCL is not taken up'.

Living arrangements

Prior to CiCL, 39 of the CiCL participants were in residential care, 36 were living in the community (e.g. in their own, or their parent's homes) and four were in a rehabilitation unit. As Figure 3 shows, most (26) of those who were previously in residential care moved into social housing (such as

Accessible Properties).⁶ Likewise, most of those previously living in the community (31) have remained in the community, either living in their own home or in a private rental.

Figure 3: Disabled people's living arrangements pre and post take up of CiCL



Source: Administrative data on all CiCL participants (as at end July 2014)

In the Waikato, eight percent of disabled people are living in a private rental, compared to 32 percent in Auckland. Just over half of CiCL participants in the Waikato are in social housing, predominantly Accessible Housing owned by Idea Services. Just two percent of CiCL participants are in accommodation managed by Housing New Zealand. This low figure reflects the criteria used by Housing New Zealand to measure housing need (referred to as the Social Allocation System). People who are deemed to be already housed adequately are not eligible for Housing New Zealand properties.

Disabled people and whānau experiences of CiCL

This section reports on the experiences of 18 CiCL participants (disabled people and their whānau) of which:

- half are living in Auckland and half in the Waikato
- 13 are NZ European, four Māori and one of Asian ethnicity.

The findings include participants' experiences of selecting a CiCL support agency, the living arrangements of disabled people, selecting and managing support staff, the value of CiCL, and management of their CiCL funds.

Selecting a support agency

The intended approach is that people and whānau considering CiCL are provided with a choice of CiCL support agencies so they can select one that they feel comfortable working with, and who is able to shape the funding package in a way that meets their specific needs. In the first evaluation

⁶ Housing owned by a non-government-organisation, for example Idea Services

of CiCL most respondents indicated this approach had worked well for them (Evaluate Research, 2013). Similar findings were found in this evaluation. As one respondent said:

I had to renew my carer's support days with (the NASC) and I mentioned to the lady when I rang that there could be an opportunity for (daughter) to move into Supported Living. And so she said to me, "Ah, have you heard about Choice in Community Living?" Which I hadn't so (the NASC) came out and had a big meeting, to explain to us about the Choices programme and how it worked and the next thing we knew was the assessment was being done and we got the go ahead to say yes (daughter) can have this amount of money. (Choice) was explained very well. Yeah we were totally happy...with how it worked. They answered any questions I had, we chose the support agency, we chose, because the house where (daughter) lives...the dad bought the house and they were already using Renaissance so it made sense (for us) to use Renaissance. And they were just amazing – anything we wanted doing or asked questions, they're ringing up all the time and checking things are okay.

Another respondent commented that she had been using Supported Living prior to CiCL. An employee from Idea Services told her about CiCL and how it could help her to live in her own flat. The respondent had wanted her own home for some time so she made the decision to move. She said: "Mum and Dad were so proud of me".

Three respondents identified two issues that limited their ability to select a support agency. First, agencies did not return calls, either at all or in a timely manner, when the disabled person or whānau member tried to make contact. One respondent commented that this was good way to learn about a support agency:

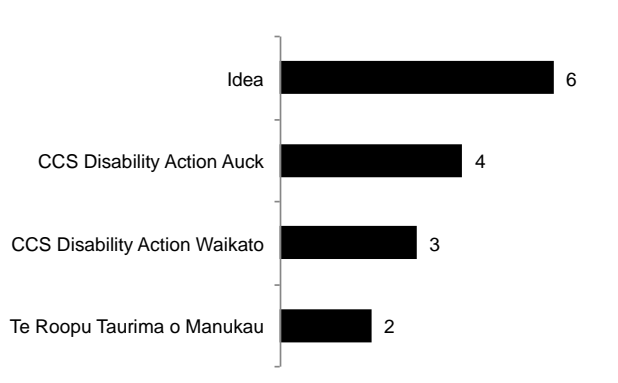
If they don't ring back, that tells you...Communication is vital.

Another respondent said he had called three support agencies. Two did not respond but one, CCS, called back immediately. He said the CCS worker visited to introduce herself and also encouraged him to "check out the other providers to see what was available". The responsiveness of this worker was the reason he chose to engage CCS as his support agency. A CCS stakeholder commented that a number of CiCL participants had come to them because they "returned phone calls and answered questions". However, they reflected that the organisation's responsiveness had improved during the demonstration. Frontline staff had to be informed about the initiative so that people were not turned away when they called to enquire about going flatting.

The second issue relates to disabled people and whānau seeking a kaupapa Māori support agency. As shown in Figure 4, most of the Māori disabled in CiCL have engaged a mainstream support agency. The reasons behind their decision are not known for all participants. It is possible some Māori participants were already working with an agency prior to CiCL and opted to remain with them.

Māori participants interviewed said they selected an agency based on its responsiveness to their needs and who was offering the best support package. One Māori participant was keen to use a non- Māori provider known to them but they did not have a CiCL contract.

Figure 4: Most Māori participants in CiCL have engaged a mainstream disability support agency



Source: Administrative data on all CiCL participants (as at end July 2014)

The experience of one whānau indicated a non-existent relationship between themselves and the CiCL support agency. Five months after signing on to CiCL the whānau did not know the name of the support agency and knew little about CiCL.

Living arrangements pre and post CiCL

Of the 18 respondents interviewed, seven are living in a private rental, seven are renting social housing, two are in units attached to their parents' home, one lives in their own home, and one is in a Housing New Zealand house rented by an extended family member.

Of those in private rentals, four are living in houses owned either by family members, or by a family member of their flat mate. For example, three Auckland women who were living together in residential care saw the opportunity through CiCL to live in their own flat. A family member of one of the women purchased a house with an attached unit. The three rent the main house, while the owner lives in the downstairs unit. Likewise, another respondent moved into a house that was purchased for an acquaintance's disabled daughter. The two women now share the house as flat mates.

Two young men with physical impairments described the difficulty they had finding a private rental that was wheelchair accessible. They initially met with several real estate agents who they said were not interested in helping them. As one of the men commented:

Obviously we were never going to find something that was set up perfectly for wheelchairs so we were trying to find a place with three or four bedrooms all on one level. And that pretty much restricted us to places we could look at...In the end I actually sent my friend to look at these places and then he told me if they would be worth following up.

When they came to look at the house they are living in, the landlord just happened to be present and agreed to lease the house to them. Even so, the house was not entirely suitable. Initially they had to go back to their family homes to shower as they could not access the bathroom. With the landlord's permission, a family member built an accessible shower in the adjoining garage.

Five respondents are renting Accessible Housing⁷ properties. Another respondent and his wife are renting a kaumātua flat run by a kaumātua service in the Waikato. The couple described their living

⁷ Accessible Properties manage IHC houses throughout New Zealand

situation as “very pleasant”. They have got to know their neighbours and sometimes attend gatherings and barbecues in a central gathering area.

Two respondents live in units attached to their parent’s home. One was previously “unhappily” living in residential care. The CiCL initiative has enabled her to live more independently while still being close to family. The other respondent was already living in a separate unit attached to his elderly parents’ home. The initiative has enabled him to remain living in his unit with paid support.

A third disabled person, in her 50s, was previously in a rehabilitation unit. When ready to leave she was given two options. The first was to be discharged into a residential care facility for the elderly where there would be 24/7 support. The second was to be discharged to her home with an allocation of eight hours carer support per day. She chose the latter as she did not want to live in residential care with elderly people.

Paid support

Disabled people and whānau are able to select their own support staff either from their own networks or by interviewing applicants identified by their support agency. Regardless of how staff are identified, the CiCL support agency is the employer. Table 5 identifies aspects of paid support identified in the interviews that have worked well and less well for CiCL participants.

Table 5: Aspects of paid support that work well and less well

Examples where paid support has worked well	Examples where paid support has worked less well
Disabled person and whānau determine what kind of skill-set and qualities are required for paid support	Staff have a “residential” mentality. They “do everything” for the disabled person
Support hours are flexible, determined by the disabled person’s needs	Staff appear to be “baby sitting”, e.g. watching TV with a disabled person rather than supporting the disabled person to do household tasks
Staff are enabling. They “support and encourage” but do not take over. They are “coaches and mentors”.	New staff arrive untrained, for example not knowing how to use a hoist (resulting in disabled person being injured) or lack experience with undertaking personal procedures.
Support worker and support agency are happy to meet the disabled person/whānau when an issue needs to be worked through (sometimes resulting in a new support worker being appointed)	
Young people being supported by support workers of a similar age	

Source: evaluation interviews

Three CiCL support agency staff also commented on factors that contribute to paid support working well. One respondent commented that CiCL has worked best when disabled people know their support staff prior to moving into a more independent living situation. If they know their staff well, the transition can be quite quick:

But it's a double whammy if the person is going to a new environment and learning to manage new staff. Those who don't have staff on board...have struggled in the first few weeks.

Another respondent from a CiCL support agency reflected that it was difficult to shift the culture within their organisation:

Some staff come from a residential mindset and require a shift in thinking about flexibility. People in Choice may say, "[I] don't want support today, come tomorrow" or "come at a different time". Support agency systems don't always accommodate that.

The organisation has responded by instigating a recruitment drive, looking for people who are new to support but who have "solid life experience and are willing to try new things and consider the contribution they can make to an individual's needs".

Value of CiCL

Disabled people identified three dimensions of value directly resulting from CiCL: having increased control, choice and new opportunities. Table 6 provides an overview of the dimensions based on the interviews with disabled people and whānau. Further description of each dimension of value is then provided.

Table 6: Value of CiCL for disabled people

Dimension	Examples of value	Resulting in (according to respondents):
Control	Being able to select their own staff Deciding how much of their budget is used for paid support	New learning, e.g. how to employ, manage staff
Choice	Flexibility about where they live, and to some extent, who they live with Doing everyday activities on their own, when they choose Deciding who will support them	Freedom to live their own lives in ways they have previously not been able to Being able to stay living in own home Shift in power balance between disabled person and paid staff
Flexible funding	Using funding to achieve personal goals, e.g. involvement in community activities Developing living skills, e.g. managing money Using funding to purchase equipment that reduced the need for overnight care	Feeling fitter, being more engaged and connected with activities in community Increased control and choice

Source: evaluation interviews

Disabled people reported greater control over paid support, included whom they employ and flexibility over when support is provided.

*We control how much of the budget is used, because we get to choose caregiver hours and what not, and we just pass on the working hours to our agency and they pay whatever is needed.
(Disabled person)*

As noted earlier, respondents indicated they have input into the selection of staff who support them. One disabled person commented they have learnt a lot about the selection of staff, while in

another interview, a family member described how they had been unhappy with a staff member. They spoke with the support agency and a replacement was found.

A theme that emerged from respondents who had previously been in residential care was the sense of freedom they now had, to live their lives as individuals. Whereas in residential care they had had to do activities as part of a group, four disabled people commented they now have a greater level of choice about what they did, and when. In this respect, CiCL now means they live a more 'normal' everyday life. As one respondent said:

I love it. I get my own space. I still go out with friends and now I'm doing my own cooking... I have a lady that comes in to help me cook and stuff. I can do my own groceries now. I have a choice when I do my cleaning. I play my own music.

Although the evaluation did not specifically seek perspectives about residential care, the responses from CiCL participants and whānau indicate they are environments where many disabled people do not have an acceptable level of choice and control over their lives. As one respondent said:

When he was in residential care they just bunged him up with so many drugs he was like a zombie, honestly yeah. So he's (now) totally off everything, which is fantastic. So he looks better you know, he's not like a zombie anymore.

One parent described her son moving from home into residential care:

At home (he) was very independent, could shower, get his own breakfast and meals. He did the vacuuming, hanging out washing, going to the shops. (In residential care) he didn't do anything. They occasionally went out in a van riding around, doing nothing constructive.

Several whānau respondents commented that the shift from residential care had required disabled people to learn, or relearn, skills and capabilities. As one said:

... (name of child) is very lazy and that's also a result of residential care ... where if you don't want to do things they don't force you and so you just lie on your bed all day.

Nine disabled people interviewed had never lived in a residential home. Seven were young adults and two were older adults who were living with elderly parents. Residential care was viewed as a last resort option for these whānau respondents, as illustrated by the following comment:

What we worried about with him moving into residential care was, he'd be looked after but we were unsure about the quality of care.

Disabled people who came to CiCL from Supported Living appeared well prepared for more independent living. For example, four disabled people who had previously been in Supported Living, had learnt how to shop on their own, cook, text on their phones, and catch buses. All four are continuing life skills training, including money management and budgeting.

While all disabled people interviewed were positive about the level of choice and control they now had, some whānau respondents expressed concerns about the quality of support their child was receiving, particularly around learning to live more independently. One respondent, for example, did not think enough support was being provided to encourage their son to cook healthy meals:

He looks skinny and that's my main concern.

Several respondents were concerned their disabled family member was not able to articulate their needs, for example if a person was not feeling well they did not have the cognitive ability to ask for

help. Another whānau respondent questioned why the support agency had not helped their family member set up the telephone and organise for automatic bill payments to be set up. They were concerned their family member was not paying his bills on time and incurring additional penalties that he could ill afford. A CiCL official commented such issues were an ongoing challenge for those involved with CiCL. Because the initiative is about shifting power, disabled people may not always make what others (e.g. family or support agency staff) regard as the 'right' choice. Similar issues were identified by Bowey et al, 2005 in that some families wanted their disabled family member to be involved in decisions, but were also concerned they may not always understand the consequences of decisions.

Impact of CiCL on whānau

While most respondents appeared happy with their funding allocation, and the level of support they had in place, one whānau respondent was clearly struggling to cope with her husband who had a physical impairment. The couple described how they opted for CiCL because they wanted to give it "our best shot in our home". The alternative was for the couple to be separated, with the disabled person in permanent residential care. The move to CiCL meant the disabled person's support hours were cut from 24/7 (in residential care) to eight hours a day. The wife described how she returns home from work each day at 5pm and has to:

kick straight into work for dinner, dishes, washing (partner), transferring him to bed. It takes two hours every evening...I've almost chucked it in at times. If I had (paid support) from 8am to 8pm it would work really well. I can come home and have a life. I can treat him as my husband and not as a patient. I wish I could have that – I'm resenting that. Twelve months is coming up so we will be asking for more hours. If we get no more hours, that's when that pressure kicks in, we can't cope.

The whānau respondent commented that they needed someone to help support them to access a range of things, including more funding and following up a housing modification application. They described negotiating the "system" as stressful, and working with their support agency as "taxing".

Roles and responsibilities

The demonstration of CiCL has raised issues about roles and responsibilities of support agencies vis a vis whānau and disabled people. Respondents reported having a say in selecting the staff who work with them. However, staff are employed by the support agency, not the disabled person or their whānau. One respondent reported that two CiCL participants, living in the same flat, had pooled their resources to fund "enabling" training for their support staff. While this is an example of 'creative' use of CiCL funds, it raises a question about who is responsible and accountable for staff training and performance.

Several respondents had experienced changing circumstances in the time they had been living more independently. For example, one person had moved into a two bedroom flat with his partner, but the couple had since broken up. The respondent could no longer afford the flat but was able to move into a new one bedroom flat. His partner had provided a level of natural support that was no longer available. While the disabled person appeared relatively happy with his living situation, his whānau (interviewed separately) had concerns about his ability to manage living independently. Electricity bills, for example, had not been paid and the power had subsequently been turned off. The whānau were unclear about who was responsible in this situation, as they did not believe their family member had the cognitive ability to stay on top of bill payments. Their view was that the support agency should be overseeing these tasks. A stakeholder respondent commented that

responsibilities were expected to be negotiated on a case-by-case basis with the relevant support agency.

Management of CiCL funds

Disabled people and whānau are told upfront by the NASC what their budget is for the year. As one respondent commented: Money is not a secret anymore". The CiCL support agency appointed by a disabled person and/or whānau then administers the budget. Support agencies are expected to provide a summary of funds each quarter to disabled people and/or whānau involved in CiCL.

Only one respondent commented they had not received a financial statement. They said they had no idea how much was left in their family member's budget. In contrast, three disabled people and whānau working with another agency had access to financial information in "real time" and "at anytime" by logging onto a secure online website. A respondent from this agency commented that mostly it was whānau who were accessing financial information. Where requested, the agency has provided one-on-one training to disabled clients to show them how to access their information. Disabled people and whānau working with this support agency commented that this system is working very well for them. One whānau respondent commented:

I can log into it and I can see exactly how much money is left in the kitty.

They are also able to get information if they do not understand the information:

One day when I didn't understand something I just called them and said "what's this? I don't understand this figure? It's nothing that I recognise." And they explained it to me.

Using funds 'flexibly'

The purchasing of CiCL supports, products and/or arrangements must meet criteria as set out in the Purchasing Guidelines produced by the Ministry:^{8 9}

1. The money is spent on disability supports (on things a disabled person needs that they would not need if they did not have a disability).
2. The disability supports contribute towards the achievement of an outcome in the person's individual plan.
3. The disability supports are within the scope of relevant Ministry of Health policies and responsibilities.
4. The disability supports must not be covered by other Ministry of Health funding mechanism (refer Appendix 3).

The Purchasing Guidelines are not prescriptive, allowing interpretation on a person-by-person basis according to their individual circumstances and goals. This approach is intended to give effect to the principles of the New Model, namely, disabled people have increased flexibility, choice and control over the support they buy. Table 7 includes examples of the ways participants are using CiCL for support other than paid care.

⁸ The Purchasing Guidelines are also used for Enhanced Individualised Funding (EIF).

⁹ <http://www.health.govt.nz/publication/purchasing-guidelines-new-model-supporting-disabled-people>.

Table 7: How participants are using CiCL for supports

Dimension	Examples of value	Resulting in (according to respondents):
Control	Being able to select their own staff Deciding how much of their budget is used for paid support	New learning, e.g. how to employ, manage staff
Choice	Flexibility about where they live, and to some extent, who they live with Doing everyday activities on their own, when they choose Deciding who will support them	Freedom to live their own lives in ways they have previously not been able to Being able to stay living in own home Shift in power balance between disabled person and paid staff
Flexible funding	Using funding to achieve personal goals, e.g. involvement in community activities Developing living skills, e.g. managing money Using funding to purchase equipment that reduced the need for overnight care	Feeling fitter, being more engaged and connected with activities in community Increased control and choice

Source: evaluation interviews

Three support agencies interviewed commented that the guidelines were quite flexible, and that the Ministry had encouraged them to explore, with their clients, more creative ways to use CiCL funding allocations. One stakeholder commented:

(The CiCL project staff) have provided a mediating point and also a reality check both ways, holding the Ministry accountable to the commitment (to flexible funding). When necessary they have been happy to challenge the Ministry.

A NASC stakeholder confirmed the Ministry’s commitment to see funding used more creatively. However, their view is that most disabled people want “ordinary things, to be able to do things that everyone else does.” The exclusion of transport costs means that in some cases, disabled people are not able to participate in the community to the extent they would like.

Is CiCL cost neutral?

CiCL is expected to be fiscally neutral for the Ministry from the outset. The data on DSS allocations for people who have taken up CiCL indicates an increase in non-departmental expenditures for disability services. However, the available data is based on allocated (not actual) expenditures. Actual expenditure data will become available after the Ministry’s year-end funding reconciliation process (early 2015). The early 2016 funding reconciliation is likely to yield more robust cost data than 2015 data, as it will include greater numbers of people as well as an extra year’s expenditure data. Expenditure data¹⁰ from the Ministry of Social Development (MSD) which was requested in June 2014 was not provided in time to be included in the evaluation.

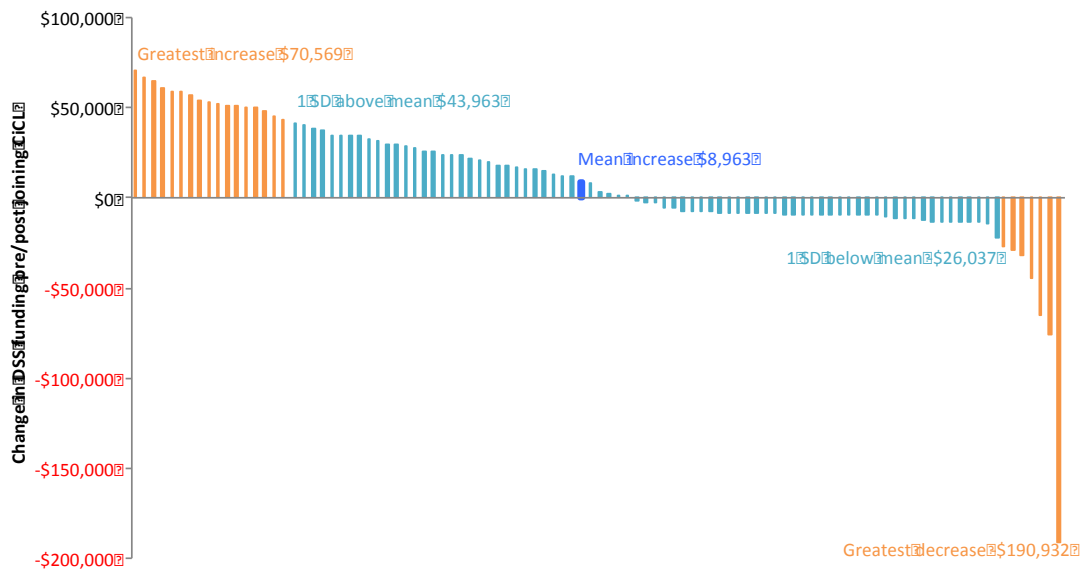
¹⁰ Data requested included accommodation supplement, disability allowance, social security benefits, and any other items agreed relevant.

Changes in DSS expenditure for CiCL clients

The Ministry provided analysis of changes in DSS funding allocations for 101 people who had taken up CiCL as at beginning of November 2014. The data includes all DSS allocations up to and including 4 November 2014. The analysis shows the change in annualized funding allocation pre and post starting CiCL.

As Figure 5 shows, changes in funding allocations varied widely, from a \$190,000 reduction to a \$70,000 increase. The average change in funding package was an increase of \$8,963, with a standard deviation of \$35,000.

Figure 5: Change in annualised DSS allocation after starting CiCL



Some first allocations included an initial \$2,000 transition package. These are not recorded consistently in the data (sometimes they are recorded on a separate line and sometimes built into the standard package). In order to derive an estimate for ongoing costs, transition packages have been excluded where they could be identified. If any unidentified transition packages remain in the data, these would skew the mean upwards but not by a significant amount.

An apparent reduction in funding allocation of around \$10,000 (+/-50%) is seen for approximately one-third of the CiCL clients. These cases are thought to be affected by a work-around NASC have used to remove client contributions for accommodation costs and represent a change in allocation, not a true reduction in payment: As a transitional measure in the absence of the Funding Allocation Tool, the Ministry of Health instructed NASC to manually subtract the client contribution from the rate calculated by the Transparent Pricing Model (TPM). However, true accommodation costs are generally higher than the client contribution, and clients are still being paid for accommodation under the residential funding model.

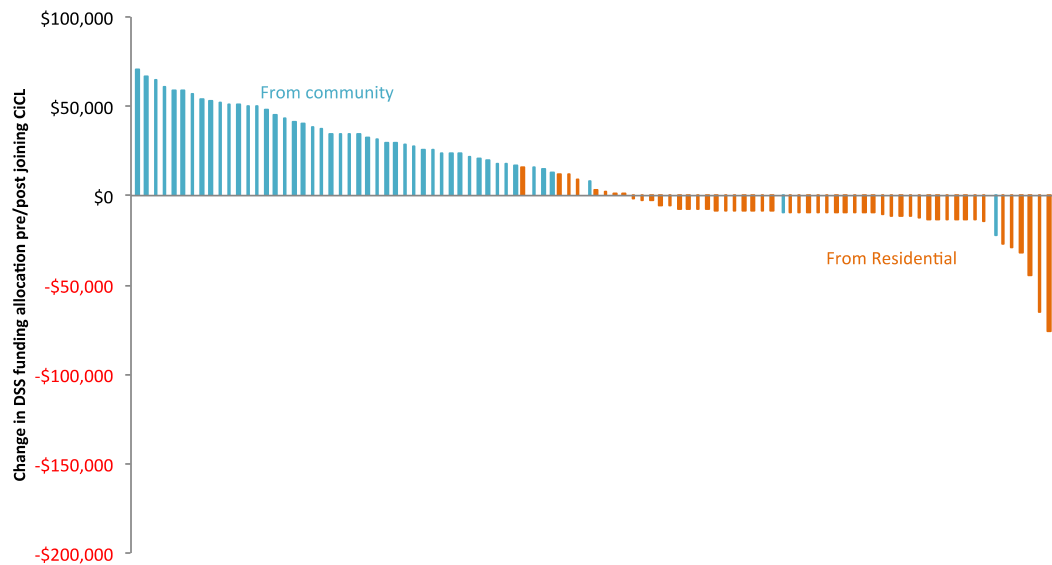
The change in DSS funding differs markedly depending whether the client joined CiCL from a community or residential setting (Figure 6):

- Nearly all of the increases in funding allocations were to people who joined CiCL from community settings (an average increase of \$34,778); and

- Nearly all decreases in funding were people coming from residential settings (an average decrease of \$14,417; note, however, that as explained above, the apparent reduction is skewed downward by the removal of client contributions from funding allocations and may not be a true reduction in payment). For the vast majority (around three quarters) of those who joined CiCL from residential settings, it is likely that there has been no material change in DSS expenditures.

This general pattern was seen for both NASCs.

Figure 6: Change in DSS allocation after taking up CiCL, community vs. residential



More substantive reductions in funding allocations are seen in a handful of cases, and it is likely that these are the only cases that will show real reductions in expenditure after the year-end funding reconciliation process, when accommodation costs are taken into account.¹¹ These savings are likely to be attributable to CiCL enabling the person to move into their own home.

For people who joined CiCL from community settings, a possible explanation for the funding increases seen is thought to be that CiCL has provided people with an option of living independently from family members who were previously caring for them.

Actual expenditures (which will become available after the year-end funding reconciliation) tend to be lower than allocations, so may show a lower average increase for people who joined CiCL from community settings. For people who joined CiCL from residential settings, the average reduction is likely to decrease (bringing the change in funding close to cost-neutral for most of these people) when actual accommodation costs are taken into account. The early 2016 wash-up is likely to yield more robust cost data than that in 2015, as it will include greater numbers of people as well as an extra year's expenditure data.

¹¹ The \$190,000 outlier is a person who was previously funded at a rate of \$813 a day for approximately five years prior to joining CiCL, then moved to a lower rate of funding. This is likely to represent a real saving attributable to CiCL by enabling the person to move out of residential care and into their own home.

In addition to the costs analysed above, there is an administrative cost associated with CiCL. The Ministry currently does not have access to cost information on CiCL. Total funding amounts are known, but not how they are broken into delivery of support, facilitation, etc. nor how many FTE are being funded in support agencies.¹²

Reasons why CiCL is not taken up

Interviews were conducted with 13 respondents who had considered CiCL (either for themselves or whānau members) but decided not to proceed. At the time they were considering CiCL, five disabled people were in residential care, seven were living with parents and one in their own home. Of these:

- 10 are NZ European, two are Māori and one is of Pacific ethnicity
- eight live in the Waikato, five in Auckland.

Inadequate funding was the major reason why 10 of the 13 respondents decided not to proceed with CiCL. This was particularly the case for people who required fulltime support:

(Son) would have had to live with at least three others with similar high needs to get 24/7 care. However, this would not have resulted in appropriate access to the community as staff ratios would still have been 1:3 at the best of times.

Several whānau respondents commented they were already financially supporting their disabled family members, for example by contributing to transport costs. The additional costs of CiCL were considered too high for them to take on as well. Two respondents said they would have had to subsidize the additional cost of support by an estimated \$200 per week. One respondent said the NASC had suggested installing an alarm bell as an alternative to paid support. However they said their son did not have the level of comprehension required to push a bell if he required help.

A theme across many of the interviews is a perspective that officials lack understanding of what is required to support disabled people with very high needs. Whānau participants said this is evident in funding packages that assume it is possible for CiCL to be financially viable if disabled people are prepared to pool resources. The following vignette describes one whānau's situation, where there appears to be a mismatch between the goal of CiCL and what is required to make it happen.

My husband and I were tiring and felt we were just too old to provide a quality of life that Louie (aged 18 years)¹³ deserves. My husband was Louie's main carer but he'd had an injury that left him unable to do the things Louie enjoyed and needed. So we began to explore what was out there to support him. Putting his impairment aside, he functions between the ages of six and 18, but he really wants to live on his own.

We got a caravan onto our property for him to develop his independence while still being able to feel secure. He had two hours of care a day. The carer was there to help him learn to cook and clean up after himself. But this didn't happen. She just came in and did the cooking. Then one day we went into his cabin and we realised how much support he actually needs. There were faeces smeared around the caravan as he'd had an accident in the night and didn't know what to do.

¹² The 2012 'Functions, Roles and Responsibilities' report noted that "Financial information is not collected by the Ministry of Health in a way that provides separation between functions and roles that can also be used to determine facilitation or management costs from support services or functions within support services" (p. 7).

¹³ Not the person's real name.

So we tried Supported Living. He was placed with a couple who had long-term addiction issues. Within a week Louie had lost all his money, was drunk every day and physically unwell.

Louie requires overnight support as we have found that it is not safe to leave him on his own. He requires support to stay on top of his personal cares and to help him make good choices. We spoke with the NASC about CiCL. However, it was clear there would not be enough funding under this initiative for him to be appropriately supported overnight.

He is now in residential care where he has no power. When we visit and suggest something he says: "I have to check with the staff." It's not bad, but it's not set up for Louie to be the best he can be.

Likewise, another respondent was living in a wheelchair accessible rental property when she heard about CiCL. Her health was steadily deteriorating and she could no longer manage on her own. She said the NASC presented CiCL as an option where she would be able to stay in her home with the support she required.

But then the NASC came back and said she'd got it all wrong. They could only offer 48 hours support a week. This would pay for someone to come from 9-11am, then from 2-6pm. It would mean being put to bed at 6pm and left until 9am the next morning.

For a while she contemplated staying in her home while accepting she would lose some independence. However, her health then deteriorated to the point where living at home no longer seemed like a viable option.

Related to the issue of adequate funding, four respondents were of the view that CiCL would put undue stress on their family. One respondent commented that CiCL might be better suited to disabled people with a functioning extended family, who could provide the additional support required. He said that if anything went wrong while his family member was in CiCL "it would be my problem, no one else's", whereas in residential care, the responsibilities were shared with the support agency. This issue of additional stress on whānau was evident in some of the interviews with people who had taken up CiCL, as discussed in a previous section entitled 'Impact of CiCL on whānau'.

The literature on CiCL-type initiatives in the UK, US, Australia, New Zealand and Canada identify a number of barriers to eligible people transitioning to more independent living that may help to explain the lower than expected take-up of CiCL. These barriers include:

Private rentals:

- The quality and accessibility of suitable private rental accommodation in New Zealand (CRESA, 2007).
- People with disabilities may find it more difficult to obtain rental accommodation than other people, even after factors such as income are allowed for (McDermott Millar, 2005)
- Of utmost importance in any housing arrangement is the availability, flexibility and diversity of affordable and purpose appropriate housing options (Fisher et al, 2008).

The disabled person:

- Older disabled people feel they need to remain at home to care for elderly parents (Shaw et al, 2011).
- Disabled people may feel anxious about how their families will feel if they leave home (McGlaughlin et al, 2004).
- People do not verbalise their wishes to avoid conflict with family members (Bowey et al, 2005).

- Feel powerless because they feel they have little choice, and decisions are made by professionals or family members (McGlaughlin et al, 2004).
- Lack confidence about how they will cope living independently (McGlaughlin et al, 2004).
- Concerns about personal safety in the community (Shaw et al, 2011).

Family:

- Anxiety about “letting go”, feelings of guilt (Bowey et al, 2005).
- Parents’ perceptions that their adult child lacks the required functional skills to live independently (Shaw et al, 2011).
- Concerns about personal safety in the community (Shaw et al, 2011).
- Concern about the availability and quality of supports (Bowey et al, 2005).
- Concern about the possibility of social isolation (Shaw et al, 2011).
- While wanting the family member to be involved in decisions, the family is concerned that s/he may not always understand the consequences of decisions (Bowey et al, 2005).

Providers:

- Staff can be either be facilitators of inclusive living, or gatekeepers from inclusive living (Fisher et al, 2008).
- Lack of strategic planning which acts as a barrier to agencies working together in a holistic manner (Jordan, 2012).

How could CiCL work better?

This section discusses how CiCL could work better for disabled people in Auckland and the Waikato. Two inter-related topics are discussed: supporting disabled people with very high needs, and developing skills to live more independently.

Supporting people with very high needs

From the outset CiCL was intended to increase the range of community living choices that are available to disabled people with relatively high support needs. However, the evaluation findings indicate that this policy objective is incompatible with the funding packages allocated to eligible disabled people who require greater levels of support and who may not be able to live with others. The interviews with whānau indicate there is interest in taking up CiCL but it is viable only if the disabled person is willing to live with at least one other person with similarly high needs. The interviews identified CiCL participants who have had no, or limited, choice about who they live with. There are people who would like to take up CiCL but, because of their impairment, need to live on their own with support. While electronic alternatives to paid support may work for some, it is not a viable option for everyone.

In some cases the level of support is placing additional stress on families who want more “normal” relationships with their disabled family members. Funded support enables them to step back from the carer role and be a parent or partner. Alternative, the Ministry may need to be more frank about who is, and who is not, eligible for CiCL.

Developing skills to live more independently

Developing the skills required to live more independently has been identified as an important outcome of CiCL but is not always being achieved. As one whānau respondent described:

In residential care Allen¹⁴ didn't have to do anything. Everything was done for him, even the planning of the day was thought out. So now all of a sudden he's by himself and in the beginning that was very hard for him, you know, to know what to do with his freedom. But a year down the track (after starting CiCL) he's not managing on his own. I still find that if there's no staff on in the morning he won't have breakfast, he won't have lunch ... one night we went around and the staff were cooking. We said: "Alan should be cooking". The staff member said: "Oh no, we made a deal, I'll do the cooking and he does the dishes". But they're missing the point; they are supposed to be mentoring him...you know, you can say: "You wash the vegetables and I'll peel the potatoes" or whatever, but you do it together. So I find it really difficult that after a year he is still not capable – oh we can cook a meal but then it's only instant noodles.

The need for quality support workers is obviously wider than just CiCL. However, because this initiative is working with disabled people who have high, or very high needs, or who are transitioning from residential care to their own homes, it is particularly important that quality support is in place. This finding is supported by overseas literature. Fyson et al., 2007, for example, identified that staff who have previously worked in residential care often described their new role as more challenging. In particular, it was difficult for some to learn how to stand back and sometimes let tenants learn from their own mistakes. In addition, a person's support needs will change as the individual does. This requires that agencies providing supported living services organise themselves in ways that are flexible and responsive to changing needs. Support staff must be willing to wear many hats and play different roles at different times. For example, a staff member may help an individual learn how to travel independently to a site where they will begin to work as a volunteer (the role of a teacher) and later that day provide the individual with assistance in showering (the role of personal assistant) (NYSACRA, 2009).

Currently missing from the CiCL initiative is an independent local area coordinator-type role that can support disabled people and whānau with negotiating the "system" and assist with longer term planning. Most respondents commented they had participated in developing a plan with their support agency. However, for some participants there was little evidence that plans were being followed through. This is a catch 22 situation. While plans are meant to be participant-directed, those same participants may lack motivation to develop new skills and capabilities – in part because the support network is operating in a way that is incongruent to the vision of CiCL and/or people, over time, have adopted institutionalised ways of operating. In addition, ongoing support of the type provided by LACs is not free: CiCL support agencies must recoup their costs so presumably would charge disabled people for LAC-type support. In summary, there appears little evidence to demonstrate the accountability of the support service to the participant and their whānau.

¹⁴ Not the person's real name

Enhanced Individualised Funding & Supported Self-Assessment

This section begins with an overview of self-directed supports from an international perspective as background for the findings about EIF and supported self-assessment. This is followed by background information about Enhanced Individualised Funding (EIF) and supported self-assessment.

Self-directed supports: international perspective

The Ministry of Health commissioned a literature review of Individualised Funding in 2009 (Bennett, 2009). Evaluate Research undertook a scan of literature post-2009 to inform the evaluation findings. This section provides an overview of this literature, with a more detailed discussion provided in Appendix 2.

Terms used

The term 'self-directed' support is an umbrella term describing arrangements whereby individuals can choose the way their support budget is spent, enabling them to have greater levels of control over how their support needs are met, and by whom (Alakeson, 2010; Manthorpe, Hindes, Martineau, Cornes, Ridley, Spandler, Rosengard, Hunter, Little & Gray, 2011). Countries use a range of terms to describe such arrangements - direct payments or individual budgets (UK), personal budgets (Netherlands, Germany), self-directed care (US), flexible funding and self-directed funding (Australia). A Scottish Government report notes that the term 'self-directed supports' focuses attention on the person, rather the system of delivery as is the case with terms such as 'direct payments' (Manthorpe et al., 2011). For this reason, the term 'self-directed support' is used in this summary of the literature scan.

Premises

Self-directed support is premised on the following.

- Disabled people are the best people to know what supports they require to achieve their goals and live 'a good life' (Junné & Huber, 2014).
- Disabled people control how their funded supports are spent to best meet their needs (Manthorpe et al., 2011).
- Funded supports are individualised and tailored for the disabled person, their circumstances and goals (Alakeson, 2010).
- The focus is on the intended outcomes of funded supports (Duffy, 2009).

Development of self-directed support

Self-directed support began in 1995 in the US where Medicaid (the social health care programme for low income families and individuals) trialed an initiative named 'Cash and Counselling' for disabled people and seniors eligible for Medicaid services (O'Keeffe, 2009). People managed their budget and chose services to meet their personal and home care needs (Alakeson, 2010). As its name suggests, the initiative included compulsory counseling to provide information about self-direction and personal-centred planning.

In the last 20 years, self-directed support has become a mechanism for funding and delivering health and social care arrangements for disabled people, the elderly, and mental health consumers in the US, UK, Netherlands, Austria, Germany and Sweden (Alakeson, 2010). Self-directed support was introduced into adult social care in England in 2007 as part of a broader social policy of personalisation (Beresford, 2014) (This term is defined in Appendix 2). For this reason, UK research done about self-directed supports may include the elderly, mental health users as well as disabled people. In Australia, the state of Western Australia has the longest history of self-directed supports for disabled people (from 1988), followed by Victoria (from early 2000's), more recently South Australia and Queensland.¹⁵

Background to Enhanced Individualised Funding

Purpose

Enhanced Individualised Funding is a mechanism to enable disabled people to have greater choice, control and flexibility over how their disability support allocations are used and the supports they buy. It is a key component of the New Model as it is intended to enable disabled people to purchase supports that will help them to achieve their goals and live 'a good life' (however they define a 'good life' for themselves).

Enhanced Individualised Funding builds on Individualised Funding (IF) which has been operating nationally since 2009. Individualised Funding enables people who have household management and personal care allocations to decide how and when their supports are delivered, and by whom.¹⁶¹⁷ Enhanced Individualised Funding expands on IF by:

- increasing the range of service funding areas included in EIF (listed in Appendix 3), and
- enabling disabled people to decide how they will use their funding allocation to purchase disability supports, products, services and/or arrangements that meet three criteria set out in the Purchasing Guidelines (explained below).¹⁸

Enhanced Individualised Funding was introduced into the Bay of Plenty in late 2012, with the first disabled people taking it up in March 2013. Initially EIF was offered to those people already using IF as it was assumed they would be familiar with flexible arrangements. The decision was subsequently made to offer EIF to other disabled people in the Bay of Plenty. As with IF, EIF is offered to disabled people who are perceived by the NASC assessor as being able to manage a budget or who have an agent to do so on their behalf.

EIF Host

The Ministry contracted EIF host services ("EIF Host") from Manawanui InCharge (Manawanui) to provide coaching and support services to disabled people. The host provides a mandatory level of service (level 1) which includes:¹⁹

¹⁵ www.pc.gov.au/__data/assets/pdf.../28-disability-support-appendixd.pdf.

¹⁶ Home Management and Personal Care make up the service funding area 'Home and Community Support Services' (HCSS).

¹⁷ The Ministry commissioned an evaluation of Individualised Funding in October 2011 from Synergia.

¹⁸ Dated October 2013. www.health.govt.nz/

¹⁹ Manawanui is one of 12 IF hosts. Unlike the other IF providers, Manawanui is solely focussed on providing IF and EIF support and is independent of service provision.

- working with the disabled person to develop an Individual Service Plan which details the use of funded supports²⁰
- supporting the person with advice on the management of support staff and budgets
- receiving information from the person that verifies the delivery of the support services (such as timesheets or expense claims)
- making sure the person is fully informed of their entitlements (and any limitation on those entitlements)
- ensuring that all expenditure is within the Purchasing Guidelines
- assisting and coaching the person in managing their funding budget and ensuring that expenditure is within funding limits and no over expenditure of allocated budget is incurred
- reviewing at regular intervals how the person is managing with the support arrangements to ensure the provision of the services meets the needs of the person
- ensuring that appropriate administrative processes are complied with and appropriate records kept.

The disabled person decides the level of support they want from the EIF Host. They can choose to self-manage (level one) or to purchase additional supports from the EIF host, such as monthly statements, payroll services, completion of tax requirements (i.e. PAYE, Accident Compensation Corporation employer levies and KiwiSaver contributions), membership of the Employers' Association, additional budgeting tools, help with recruitment (levels two and three).

The EIF Host works on a cost recovery basis, based on the amount of Disability Support Services (DSS) funding the disabled person is receiving and the service level they have chosen. The fees for disabled people to be charged for the provision of level one EIF services are specified by the Ministry in the EIF Host service specification, as shown in Table 8. The EIF Host may determine the fees to be paid for additional supports beyond level one.

Disabled people who chose to use EIF are required to sign a service agreement with the EIF Host which specifies the respective responsibilities of the two parties. Accountability for the appropriate expenditure of EIF funds lies with the disabled person or their agent/representative and the EIF Host. Supports and purchases must be delivered and verified as being in compliance with government policy by the disabled person and the EIF host before the Ministry will pay the support agency who in turn pays the carer or reimburses the disabled person.²¹

Table 8: Rates for provision of EIF services level one

Client package amount per week (average over allocation period/week)	Percentage rate clients are charged for expenses incurred within each payment period
\$0 - \$499	6%
\$500 - \$1,100	5.5%
\$1,101 and over	4.75%

²⁰ The Individual Service Plan is required to be completed within two weeks from the confirmed start date for the delivery of support to the person.

²¹ EIF Host Service Specification, 2 August 2012.

The primary interface between the EIF Host and the disabled person is via the EIF coach. The coach is responsible for coaching disabled people how to manage their own supports, including their obligations as an employer and spending funding within the parameters set out in the Purchasing Guidelines (explained further in the section ‘Purchasing guidelines and panel’). Initially the EIF coach role was a .5 FTE position (20 hours/ week) which was later increased to a 30 hour/ week role, supported by a full-time EIF manager (a new position in the EIF Host organisation). The EIF manager approves EIF purchase requests in conjunction with the EIF Host CEO (other than those requests that are required to be approved by the Ministry, discussed below.)

EIF key players: roles and responsibilities

As context for the findings that follow, Table 9 provides a brief overview of the roles and responsibilities of the EIF Host, the NASC and the Local Area Coordinator (LAC) in relation to working with disabled people who want to use or are using EIF.

Table 9: Overview of roles and responsibilities of LAC, NASC and EIF Host in relation to EIF

LAC	NASC	EIF Host
Support disabled people in their planning to identify personal goals and desired outcomes	Support disabled people to do supported self assessment	Confirm how disabled people are going to use funding to meet their goals
Work with disabled people to identify and develop natural supports to replace or complement paid supports	Discuss indicative allocation with disabled people in light of their goals and desired outcomes	Coach people how to manage their own support allocation
If requested, assist with recruitment of support workers e.g. job descriptions, suggesting recruitment options such as linking into community networks	Confirm the allocation with disabled people	Explain employer obligations and set up processes
If requested, working with disabled people to problem solve and identify solutions for support issues	Carry out annual reassessment and reviews	Carry out annual reviews
If requested, crisis management when support arrangements fall down.		Provide additional EIF-related services (e.g. payroll) as requested by the disabled person

Purchasing Guidelines and Panel

As noted above, the disabled person is primarily responsible for ensuring support money is used for its intended purpose and only in ways that are consistent with the Purchasing Guidelines.²² The EIF Host is also accountable for appropriate expenditure of funds. The EIF Host is required to repay any funding to the Ministry that has not been used for the purposes for which it was allocated.²³

In situations where an EIF Host is uncertain about a proposed purchase using EIF funds, the EIF Host submits the request to the Ministry. This involves completing a form which provides an overview of the disabled person's current situation and support needs, details the proposed purchase and how the purchase meets the three purchasing criteria.²⁴ A Purchasing Panel considers whether the proposed purchase is in line with the guidelines and makes a recommendation to the Group Manager Disability Services who makes the final decision on whether the funding can be used as proposed.²⁵ The Terms of Reference for the panel lists the membership of the panel as being made up of the New Model Programme Leader, the Disability Policy Manager, one of the Disability Support Services team managers, two disabled people (external member) and a family/whānau (external member). The three external panel members are yet to be appointed.

Background to supported self-assessment

Two themes in the submissions to the Social Services Select Committee Inquiry into the Quality of Care and Services Provision for People with Disabilities were that disabled people and whānau know best what support they require, and they want less assessment by professionals. A review was commissioned by the Ministry of Health in 2010 to investigate self-assessment models, practices and tools within a disability supports setting.²⁶ The definition of self assessment used in this report is: "A process in which a person uses information about their goals, circumstances and environment as the basis for decision-making about their future actions and needs for assistance" (Qureshi, 2006 cited in MacDonald, 2010, p.19). The review led to the development of a form to facilitate supported self-assessment that was trialed in the Bay of Plenty from October 2011. The NASC assessors 'translated' the information from this form to identify an individual's Support Package Allocation (SPA). The early use of supported self-assessment (SSA) by disabled people was evaluated by Evaluate Research in 2012.²⁷ At that point 60 people had been offered a SSA and 36 had agreed to this option. Those who completed a SSA tended to have strong literacy skills, be confident and articulate. They liked having the flexibility of completing the assessment in their own time, at their own pace. Most people declined a SSA because they preferred to meet an assessor face to face.

In August 2013 further work was done on supported self-assessment to support the development of the Funding Allocation Tool (FAT), which is a technical tool to replace the SPA.²⁸ The FAT is

²² Service Agreement between Manawanui-InCharge and the disabled person.

²³ Ministry of Health Service Specification Enhanced Individualised Funding, dated 2 August 2012.

²⁴ The form must be endorsed by the NASC and EIF host provider.

²⁵ DSS Purchasing Guidelines Review Panel Terms of Reference, dated 12 September 2012.

²⁶ Self Assessment Models, Practice and Tools within Disability Support Services, Carol MacDonald, November 2010.

²⁷ New Model for Supporting Disabled People: Synthesis of Year 1 evaluation findings, October 2012.

²⁸ Synergia has been contracted by the Ministry of Health to develop the Funding Allocation Tool.

designed to make the allocation of funding to address unmet need more objective and transparent. This work led to a new self-assessment form titled 'Understanding you and your situation' (UYYS), the information from which is linked directly into the FAT. The form was developed by a working group of people with both lived and/or work experience of assessment in the disability sector. As its title suggests, the UYYS form encourages the disabled person to communicate what is important about the whole of their life, not just the part that relates to DSS funding. The form is divided into four parts:

- Section One focuses on the disabled person's general details - who they are, their impairment(s) and living situation.
- Section Two is about the disabled person's story - their situation, who they live with, what they enjoy doing and what they would like to do.
- Section Three is about how their impairment(s) impacts on their life.
- Section Four is about the other supports they may be receiving, both funded and natural.

The NASC emails or posts the UYYS form and an information sheet about it (supplied by the Ministry) to the disabled person who is asked to fill in some or all of the form. It is suggested that they may want to have a family member, LAC or other person support them to complete the form. If they prefer, an assessor will support them to fill in the form.

The application of the information from the UYYS form into the FAT produces an indicative funding amount. This is then discussed by the disabled person and the NASC service coordinator to identify what supports the person may want to purchase (i.e. the discussion starts with a dollar amount, rather than a list of services as is the case for disabled people not receiving EIF).

The intended differences between a traditional assessment and a supported self-assessment are summarised in Table 10.

Table 10: Differences between traditional assessment and supported self-assessment

Traditional assessment	Supported self assessment
Deficit based	Strengths based
The NASC assessor facilitates the assessment with the disabled person.	The disabled person and whānau take the lead. They can either complete the form themselves, or get support from friends and family or the NASC to do so.
The assessment is usually done in one session.	The disabled person and whānau are encouraged to take time to think through their responses, completing the form over a period of time, at their own pace
The assessment usually occurs during office hours. This may mean the assessment is done with one parent if the other is in paid work.	Disabled people and whānau can work on the information at a time that suits them, and with people they want to support them.

Who has engaged with EIF?

This section examines EIF up-take in the Bay of Plenty. Over the period mid-January 2013 to mid-November 2014, 233 disabled people took up EIF. This represents 10 percent of all people receiving DSS support in the Eastern Bay and 14.5 percent in the Western Bay (Figure 7). Ninety-three (43%) have been using EIF for 12 months or longer, and 123 (57%) have been using EIF for less than 12 months.

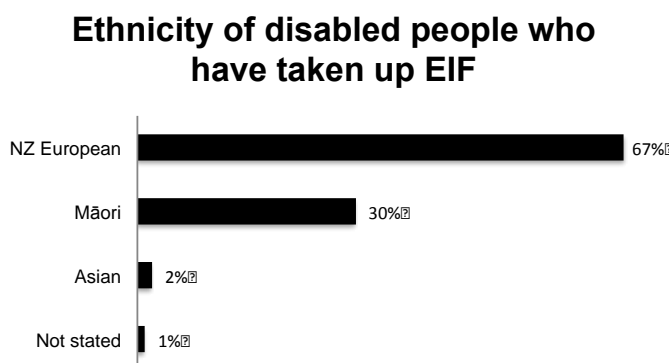
Figure 7: Disabled people using EIF in the Bay of Plenty



Source: NASC database

Of the 233 disabled people who have engaged with EIF, 67 percent are NZ European and 30 percent Māori (Figure 8). Only one person of Pacific Island ethnicity has taken up EIF.

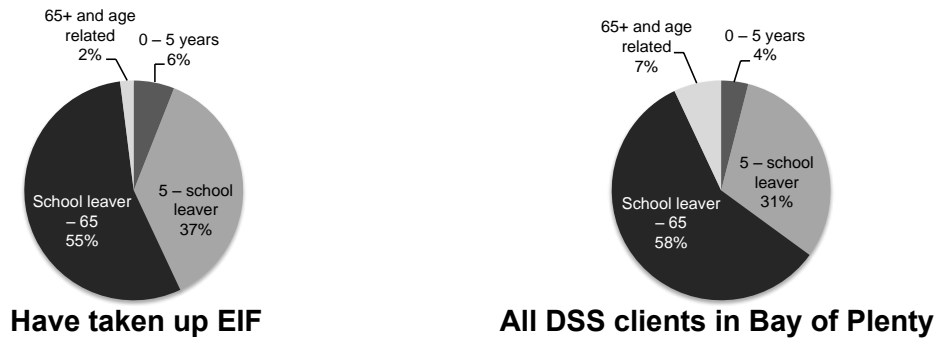
Figure 8: Ethnicity of disabled people who have taken up EIF



Source: NASC database

The ages of people who have taken up EIF are similar to the ages of all DSS clients in the Bay of Plenty (Figure 9). The only significant difference is that six percent more disabled people in the group aged five to school-leaver are using EIF than the same age range for all disabled people using DSS.

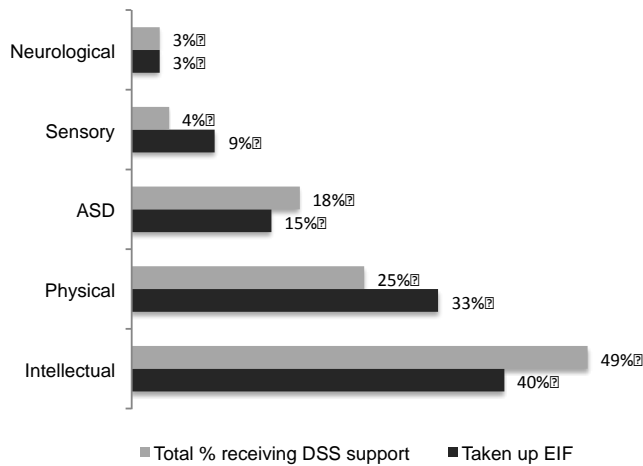
Figure 9: Age of people who have taken up EIF compared with all those receiving DSS support



Source: NASC database

When compared to all disabled people with the same impairment receiving DSS, proportionally more disabled people with sensory or physical impairments have taken-up EIF than people with other impairments (Figure 10).

Figure 10: Impairment type of disabled people who have taken up EIF compared with total DSS



Source: Ministry of Health administrative data

The minimum EIF allocation is \$840 per annum and the maximum is \$320,690 per annum. Removing the outliers, the mean amount is \$22,094 per annum and the median is \$14,830 per annum.

Disabled people's experiences of EIF and supported self-assessment

This section presents the findings of interviews with 30 disabled people and their whānau (about 32 disabled people) about their experiences and perspectives of EIF and supported self-assessment. Of the 32 disabled people in the evaluation sample:

- 30 are using EIF
- 2 are not using EIF
- 21 used IF before receiving EIF
- 11 are working (or have worked) with a LAC
- 12 live in the Eastern Bay and 20 in the Western Bay
- 13 are NZ European, 19 are Māori
- 8 are aged 18 or under, and 24 are aged over 18.

Of the 30 disabled people who are using EIF, 11 have been using EIF for more than 12 months, 15 for six to 12 months, and one for five months or less. (Data was not recorded for three people).

Managing EIF

All but three of the disabled people (their parent or caregiver) we interviewed have chosen the EIF Host to manage their EIF payroll. Those who are self-managing are disabled people or family members with relevant work experience, such as running a business or operating a payroll function (two previously used IF). A few disabled people said they are satisfied with the EIF Host managing their payroll at the moment but may become self-managing once they feel familiar with EIF processes. One interview was with a couple whose EIF payroll is being managed by a third party as part of a natural supports arrangement.

Employing and managing support workers

Disabled people (their parent or caregiver) prefer to employ people known to them, such as whānau, friends and wider networks, rather than having strangers coming into their home. They said they have a greater level of trust in someone known to them:

It is better to have people you know, your friends and family. We are private people and it gives us control over who comes into our home. It gave us the power. Julia²⁹ is able to choose her carers" (previously IF).

In one case a support worker resigned from a service agency to continue supporting the disabled person.

The exceptions are when an age appropriate support worker is required for a young person, or support workers with specific skills are sought e.g. art or business skills. Four disabled people said they are paying (or want to pay) their support workers higher hourly rates because they value them.

²⁹ Not her real name

Nine disabled people or parents talked about problems they were having (or had had) employing support workers, as summarised in Table 11. Five of these participants previously used IF. The disabled person's location is shown.

Table 11: Summary of participants' employment-related issues

Employment-related issues	Description
Difficulty finding suitable support workers. (None of the five people on the right are working with a LAC.)	<ul style="list-style-type: none"> • People receiving Work and Income benefits don't want to be employed as support workers because it will impact on their entitlement (previously IF, Western Bay) • People don't want to work unless they are paid under the table (Eastern Bay) • The level of care needed for the disabled person's needs is hard to find. Support workers are trained but then leave because they find it too hard (previously IF, Eastern Bay) • "Advertising for 24 hour care is going to be the biggest hurdle ...there aren't many people who want jobs" (Western Bay) • Finding the caregivers is what I need most help with (previously IF, Western Bay)
Employing age-appropriate support workers for disabled teenagers	Turnover due to support workers leaving school and getting fulltime employment or leaving town to attend university (2 participants, both previously IF, both from Western Bay)
Support workers' performance	Two disabled people had employed a non-resident family member (a grandson and a niece) whom they had to ask to leave because of poor work (2 participants, one from Western Bay and the other from Eastern Bay, previously IF).
Carer support wages	Carer Support (a DSS funding stream) is tax free (\$76 for a 24 hour period) but when it comes into EIF, it is regarded by the IRD as income and taxed. This means that it is impossible to find people to do carer support because the hourly rate is so low (Western Bay, previously IF)

Source: evaluation interviews

How EIF is being used

Most the 30 disabled people who are receiving EIF have employed their own support workers to provide the particular types of support they want.

Table 12 provides examples of how some participants are using their EIF funding. Four parents have organised (or are in the process of organising) tailored programmes of support for their young adult son or daughter to help their transition from school with the aim of increasing their independence, confidence and skills.

At least five participants who are using EIF are continuing to use an existing service agency for Supported Living services and/or carer support and/or respite care. This means they either have a service allocation and an EIF allocation, or they are choosing to contract privately. There are a range of reasons disabled people using EIF continue to use agency-based services, as follows:

Disabled people or whānau choice

- Agency-based services may be working well so there is no reason to change them. For example, a parent of a disabled adult said that her daughter's friends attend the same programme.
- Disabled people and families may feel uncertain whether EIF will work for them or will continue long-term so they want to maintain relationships with a support agency. A parent said: "I retain a foot in both camps because I wasn't sure how it would work". Such anxiety about EIF was confirmed by the NASC: "There is still some anxiety among disabled people about EIF - 'is it as good as it seems? Is it going to last?'"
- For busy parents or those with younger children who are new to DSS support, using an agency may be less stressful and time consuming than becoming an employer. A parent said they needed " ... more headspace to actually think about what needs to be done for [name of son]"
- Carer Support (\$76 per 8 to 24 hour period) is regarded as a subsidy and is therefore non-taxable income for the person providing the support. However when Carer Support is transferred into EIF, the Inland Revenue Department (IRD) recognises it as taxable income. This makes it difficult for disabled people and whānau using EIF to find carer support workers for such a small amount of money. Therefore disabled people and whānau may choose not to take carer support into EIF.
- When respite care is transferred into EIF, the number of allocated hours is calculated into a total dollar value. This dollar value buys a lesser amount of respite care from a support agency because the support agency bills the disabled person the actual cost of such care. Therefore disabled people and whānau may choose not to take respite care into EIF. (Currently, respite care agencies are bulk-funded by the Ministry for disabled people who are not using EIF. This bulk funding arrangement enables efficiencies of scale and competitive pricing which has the effect of reducing the actual per-person cost of respite care. However such cost reductions are only applied for people not using EIF).
- Disabled people and whānau may feel familiar with the current system (even if they may not be satisfied with it), especially in situations involving complex disabilities.
- Disabled people with a small number of support hours per week may feel that becoming an employer is not worth the time and effort involved so chose to continue to use a service.

System-related

- Insufficient time and/or information may have been provided to the disabled person and whānau by the EIF Host or NASC to enable them to understand the options and opportunities that EIF offers them (this is discussed below).

Some disabled people have used some of their funding allocation to purchase items or fund activities related to their goals and personal situation. Some have used their funds to 'top-up' funding from other sources to enable them to buy a better quality product (if this was deemed consistent with the Purchasing Guidelines)

Table 12: How participants are using EIF for supports

Use EIF for:	Examples:
Personal care	<ul style="list-style-type: none"> ● Daily care of her feet means that the disabled person no longer needs six weekly visits to the podiatrist at \$60 per visit (previously funded by Work and Income).
Other home-related supports	<ul style="list-style-type: none"> ● In addition to providing personal care, the support worker uses any down-time between support tasks to do gardening which means that the disabled person no longer has to pay a gardener. ● Support worker assists with weekly shopping and then they have lunch together ● Support worker helps with budgeting and paying bills ● Support workers help the disabled person and his two disabled flatmates to live independently ● The support worker does lawn mowing and section maintenance
Support for community-based activities	<ul style="list-style-type: none"> ● Support workers do activities with the disabled person such as going to the gym, swimming (2-3 times a week), rock climbing, mini golf, ten pin bowling, attending art classes, going shopping, visiting the library, going to the hairdressers. ● Carer travelling and providing support to disabled person while on holiday overseas. ● Support person helps disabled person to make dolls for sale.
Items/activities purchased	<ul style="list-style-type: none"> ● A custom designed riding helmet for a disabled child to attend Riding for the Disabled ● Annual fee for high usage of the ambulance ● A special swing for a disabled toddler ● Mobility scooter ● Hoist ● iPad; Tablet for the disabled person to communicate with his partner who works away from home for long periods. ● Upgraded hearing aids and batteries ● A device which translates phone calls into text which will be helpful for the person's job ● Paying for swimming lessons ● Paying fees and carer costs to attend church camp for people with disabilities.

Source: evaluation interviews

What disabled people value about EIF

Most participants identified one or more dimensions of the value of EIF for them, as listed below. Nine participants described the value of EIF by comparing it with their past experiences of services which had been negative.

- *“In control and calling the shots”*: Disabled people value being able to choose who they employ as support workers, how and what they spend their support funds on (7 participants).
- *Increased options and choice*: Disabled people value being able to choose what they do in their day (5 participants).
- *Tailored supports*: Being able to choose how support funds are spent results in more tailored and personalised support arrangements (4 participants).
- *Improved matching of support workers*: EIF enables a better match between support workers and disabled people’s needs e.g. age appropriate, support workers’ personal attributes, support workers with skills in particular areas e.g. art, crafts (3 participants).
- *Quality purchases*: Disabled people are able to use EIF funds to add to the funding available via the Equipment Modification Service to purchase a higher quality of equipment or specially designed equipment (3 participants).
- *Flexibility and reliability*: Disabled people are able to alter support worker hours from one week to the next, for unforeseen and other circumstances. If they do not need some support hours one week, they don’t have to use the hours (4 participants): “EIF has made that so much easier as I now have that flexibility without having to work around an agency’s agenda. One support worker lives nearby and goes home at 7.30pm. If I need her, I can phone and she will come back”.
- *Flexibility for support workers*: Disabled people say that EIF also provides greater flexibility for their support workers e.g. if the support worker is sick, they can make up their hours later (2 participants).
- *Holistic support*: The support worker can do whatever the disabled person requires e.g. climb a ladder to change light bulbs, cut toe nails. This is in contrast to agency staff who were limited in the tasks they were allowed to do (1 participant).

Some participants described positive changes that are occurring for them as a result of using EIF. These are summarised as follows:

- Reduced social isolation as a result of being involved in more community-based activities (3 participants). “A couple of weeks ago I went to do my shopping, the first time in three to four years. It was amazing, it really was. When you have to shop from a pamphlet or a computer, it’s really limiting. The isolation is huge. I used to leave at 8am and be back at 5.30pm. It’s gone from all that to 24/7 [at home] - it’s been a huge change. I get to go to the hairdressers now, it’s a bonus.”
- Increased independence (2 participants): “I do feel like I’m in charge again. I felt [when in hospital] I was losing my independence. Thought I’d never feel that independence again. Now I’m in charge of my care, to the extent that I’m able”
- Planned transitions from school for young people which is building independence and skills, and keeping the young person connected with their peer group avoiding social withdrawal (2 participants).
- Increased self-esteem and confidence (2 participants) e.g. disabled people are now able to catch the bus by themselves.
- In a better position financially (2 participants) e.g. before EIF, the parent had to get loans to pay for swimming lessons for her disabled child.
- Reconnecting with whānau by attending family reunions (2 participants).
- Moved into own home (2 participants).
- Feels empowered (1 participant).

- Positive child-parent dynamics (1 participant): Age appropriate support workers are helping the mother to 'step back' from her young adult son: "It's not appropriate for him to be stuck with his mother all the time and his behaviour was reflecting that. He was becoming more withdrawn because he's a very social young man so I didn't want to go into a downward spiral of him becoming socially withdrawn as well. So going onto EIF sort of stopped problems before they arose." (previously IF)
- The disabled person's child is now going to school. Previously the child was kept home because there was no-one else to push the disabled person's wheelchair or get it in and out of the car when the person needed to go into town (1 participant).
- A mother with a very young child who has an impairment can get her housework done while the child is being cared for, so the time she spends with her child is quality time (1 participant).

An EIF user network group has met monthly since February 2014. The group started with support from the Eastern Bay of Plenty LACs but is now coordinated by disabled people. Some of the positive outcomes are that disabled people are supporting each other and support workers are being shared so they have sufficient hours:

A lot of those parents, caregivers, they actually feel connected together because they have something in common. They help each other with their timetables ... also our assistants don't have enough hours to keep them going. So we collectively pooled them together so that they all get work (previously IF)

Four participants (one disabled person, two sets of parents of disabled children, and a caregiver) said that EIF has not made any difference for them. The caregiver said she did not realise that her relative who is disabled had been transferred from IF to EIF. As a result, \$3000 of annual funding was not utilised.

Choosing not to use EIF

We were not asked to interview disabled people who had considered EIF and decided not to use it. However in the course of our interviews about disabled people's experiences of using the new form, we interviewed two people where this was the case. A parent whose child is using IF decided against EIF because of the risks associated with being an employer, such as employee performance management and other employer responsibilities. The parent described EIF as another layer of stress in an already stressful household caring for a very sick child: "There's a lot of danger when you start employing someone ... Someone's going to get screwed and it's probably the families" (Eastern Bay). A disabled person decided against EIF because people who attend the support agency's activities are friends.

Supported self-assessment

This section summarises disabled people and whānau experience of supported self-assessment, specifically using the UYYS form. As noted above, while disabled people and whānau are encouraged to fill in some or all of the UYYS form themselves, they may ask a family member, friend or a NASC assessor to support them to do it.

Ten participants had used the UYYS form - three disabled people, five parents, and two family members. Most participants said it was helpful having someone to support them to fill out the form such as a NASC assessor. A parent who is new to DSS completed the form with her social worker.

The most frequent comments from participants about the UYYS form were its length, the repetitiveness of information requested, and the amount of time it took to complete. While some participants said the form was “okay” or that “the questions were easy to answer”, one parent described the form as “a challenge”, and another said she felt “bamboozled by it”. A disabled person said he felt “confused” by the form. One parent said she had not been able to bring herself to open the envelope containing the form because it felt so thick and considered that it was just another form to be filled out.

Two parents spoke positively about being able to provide information they think important to convey in their own words. One said she felt she could express herself more, she could put more detail in it, and talk more to how she handled things with [name of child]. “It is a thousand times better than the previous one which was just yes or no answers”. The other parent who had support to complete the form said:

It was good to have the opportunity to put things in our own words and see it written in our own words.

When asked about the form, a few people could not recall whether they had used it. This may reflect the fact that disabled people are required to complete a lot of documentation so the form may be regarded as just another piece of paper to be filled out.

It is not possible to draw any definitive conclusions about the effectiveness of supported self-assessment for disabled people given the small number of participants in our sample who had used the form and the range of their responses. This range is reflected in the following information about the form’s use supplied by the NASC. Approximately:

- 20 - 25 percent of disabled people/parents of children complete the form themselves or with whānau, friends etc.
- 25 - 30 percent of disabled people/parents of children starting filling in the form themselves (or with whānau, friends etc) and then ask Support Net for support to complete it.
- 50 percent of disabled people/parents of children choose not to fill in the form themselves and ask Support Net to do it with them.

Based on their experiences, NASC staff suggested disabled people and whānau may require support to complete the form if they

- are too busy and/or tired to do the in-depth thinking that answering the questions involves.
- appreciate face-to-face contact with an assessor.
- have literacy issues so find it helpful to have an assessor present.

In addition, NASC staff said deficit-based assessment is evident in the education and medical systems, so thinking in a strengths-based way may take some adjustment and time.

How could EIF work better?

This section discusses how EIF could work better for disabled people in the Bay of Plenty. Three topics are discussed: getting the most out of EIF; understanding the purchasing of supports; collaboration among key players.

Getting the most out of EIF

The use of EIF by disabled people is in its early stages, as evidenced by 57 percent of people having used it for less than 12 months. There is evidence that EIF is yet to achieve its full potential for participants. Many disabled people and whānau interviewed appear to be still getting to grips with what EIF can do for them (this includes participants who were previously using IF). It was also confirmed by stakeholders. Five factors are identified as contributing to this as yet unrealised potential, as follows.

Preparing the ground for disabled people to use EIF

According to stakeholders, some disabled people and whānau have been quick to see the potential of EIF to achieve personal goals such as increased independence and community involvement. We found evidence of this among some participants, for example, a parent said:

EIF has been absolutely fantastic for us because [name of son] has gone right through regular schooling and our family philosophy has been that he is fully included in our family life ... and so [EIF] is providing support that enables us to have him fully independent in the community (previously IF).

Another parent described using EIF to develop a programme for their daughter's transition from school (previously IF).

Other disabled people may be in a different 'space' when they begin to consider EIF. For example, some may have low expectations about support as a result of receiving second-rate services from agencies or have constrained perspectives from years of restricted choice. Three stakeholders talked about the significant shift in attitude that EIF may involve for some disabled people, particularly those who have not used IF:

Disabled people have been in a position where they have had no control - they have been told by their support agency 'you'll have a support worker from 3 to 4pm on Tuesday'. Now they are told 'you have funding of \$15,000 - go for it'.

EIF is a very daunting prospect ... [Some disabled people] don't know where to start, it takes a shift in thinking.

Some disabled people are not using EIF to the max ... They need support to understand how they could use it. They don't know what EIF could do for them - they don't get the possibilities it offers.

Another stakeholder described the importance of up-front support for EIF to work well:

EIF is money which means nothing without [the disabled person having] a sense of self determination. Without this, people go for what is safe and what they already know. EIF can be innovative but it takes time.

Consequently, some disabled people may benefit from up-front support which encourages them to think beyond their current situation, visualise what a 'good life' means for them, and plan how their funding allocation could help them achieve their goals and complement natural supports. This will enable them to make the most use of the potential that EIF offers. While such visioning and planning is one of the roles of the LACs, we interviewed people who did not know about local area coordination. This is discussed further below.

EIF coach role

The role of the EIF coach involves discussing with people how they are going to use their allocation, explaining employer obligations and processes, and coaching people how to manage their own supports. The amount of front-end work involved in setting up EIF with disabled people and families was under-estimated by the Ministry and EIF Host. It was assumed that the set-up process would be similar to IF. However the EIF Host describes the set-up of EIF as being more complex, with many disabled people needing substantially more support than IF. As a result, the amount of resource needed to manage EIF is three to four times greater than IF.

Another resource-related factor is the area covered by the EIF coach in the demonstration site - from Katikati in the north to Opotiki in the east, and encompassing communities in the southwest of the region such as Kawerau. This area is geographically large and diverse, encompassing urban, rural and remote communities.

The under-estimation of the resource required for EIF was compounded by staff turnover. Two people were recruited for the coach role, both of whom subsequently left the position. Individualised Funding coaches and other staff from the EIF Host filled in as EIF coach between appointments. During this time the LACs also worked with some individuals to help them understand EIF and what was required. A new coach was appointed in September 2014.

The pressure on the coach role was compounded by the decision to start using the new Funding Allocation tool with disabled children under 15 years of age (this occurred from mid-2013). The EIF Host was not consulted beforehand about this decision. Many of these children receive small funding allocations (e.g. around \$3000 per annum). This resulted in enquiries from parents asking about how the funding could be spent on purchases of items, at a time when the EIF coach was very busy working with disabled people with larger allocations wanting to purchase supports.

While 12 participants expressed satisfaction with the support provided to them by the EIF Host (nine of whom had been using EIF for between 10 and 15 months), others were less satisfied. The resourcing issues described above are reflected in the comments of some disabled people who describe the coach as always being in a rush and unable to spend sufficient time with them, and being difficult to contact by phone or email.

Among our participants were people who require tailored face-to-face EIF coaching because of their impairment or personal circumstances. A disabled person who had previously used IF described her difficulties understanding how EIF works:

When I was first given the red folder [about EIF] it was mind-boggling, it was too much. When you've had [name of disability], drip-feed it [information]. I'm ok if I can ask questions, I can understand, but when they [the EIF coach] is gone ... I don't even know the difference between IF and EIF, what is it?" (19, previously IF).

A parent new to DSS who was stressed at the time the agency called to explain EIF in a phone conversation said:

I couldn't get my head around how the funding worked. I wasn't in the best frame of mind around then, so maybe I wasn't taking it all in on the phone. The most basic principles, I couldn't get my head around" (16).

This parent had been sent a DVD about EIF but had not had time to watch it. The parent has since had a face-to-face meeting with the EIF coach and now understands how EIF works.

Many participants (both Māori and NZ European) place great value on a personal relationship with their coach. Developing such a relationship has been impossible given the limited amount of time the EIF coach has had to work with individuals and the turn-over of coaches (some disabled people said they have had contact with three coaches and other staff filling in the coach role).

Information gaps about EIF

Just under half of the participants either said they had questions about EIF or it was clear in the interview that they had knowledge gaps about EIF. Some participants said they have had insufficient face-to-face time with an EIF coach to enable them to fully understand how EIF can work for them. Four participants said they have had had no face to face contact with a coach. Three participants said they have not received any written information about EIF. Only a few participants could recall seeing a copy of the Purchasing Guidelines. A significant information gap concerns what EIF can be used for in respect of purchases and activities (this is discussed further in the section 'Understanding what EIF can be spent on').

Understanding what EIF can be spent on

This section describes another factor that is contributing to the as yet unrealised potential of EIF for some disabled people. Due to the adverse impacts that are emerging, it is discussed as a separate section. The issue concerns the interpretative nature of the Purchasing Guidelines, specifically, how the guidelines are being implemented and interpreted.

Implementation

Two issues about the implementation of the guidelines are identified and the implications described.

The first issue concerns how some purchasing decisions are being made. When EIF started in early 2013, the EIF Host made all purchasing decisions and referred requests to the Purchasing Panel when they were unclear about a request. From late-2013, the Ministry required the EIF Host to refer all purchasing requests outside of IF parameters to the Purchasing Panel which was resource intensive and time consuming. This process continued until early 2014 when, following discussions with the EIF Host, the Ministry agreed to the current decision-making process. The EIF Host is now required to:

- submit any purchasing requests that are not a service, or would not be covered by a service, to the EIF/IF Manager in the Ministry for approval. If this manager is unable to make a decision, the request is forwarded to the Purchasing Panel.
- supply a list of all approved purchases to the Ministry.

The second issue concerns the role that the EIF Host is required to adopt in relation to a purchasing request. The Ministry's accountability requirements involve the EIF Host requiring disabled people to 'prove' their unmet need, for example, asking the person to state in writing that they are unable to access the requested purchase from another source. Stakeholders state that this is questioning the disabled person's integrity and treating them as a recipient who has to 'prove' their eligibility for funding. According to a stakeholder, this has the effect of the EIF Host acting as "the purchasing police" which adversely impacts on its relationship with the disabled person and their whānau. This 'message' that disabled people cannot be trusted to spend EIF funds appropriately was compounded by a EIF Host monthly newsletter (August 2014) which was referred to by some participants we interviewed. It stated: "All the funders have statutory rights to look at your bank accounts and spending patterns without your consent, or ours, or even your knowledge. If they see anything remotely suspicious they can do an audit on you and again you may not be aware." The impact is described by a stakeholder as "Families are having to fight for things and then they give up because it's just too hard". Another stakeholder said: "It comes down to trust - surely there is enough evidence to trust disabled people to make decisions for their life?" Another commented: "The message [from the Ministry] is that disabled people are in control and have increased options. Then they are told 'you can't do that'".

These two implementation issues are inconsistent with the principles underpinning the New Model. Stakeholders interpret the Ministry's requirements as the Ministry not trusting disabled people to choose the support they need, and not having confidence in the NASC and EIF Host to do their work effectively.

Interpretation

The EIF Host, NASC and LACs understand that the interpretative nature of the guidelines on a person-by-person basis means there is no one 'correct' answer to the same purchasing request from two or more disabled people. Rather, each request must be considered individually based on the person's circumstances and the outcomes they are seeking to achieve. Confusion and uncertainty have arisen when a disabled person has made a purchasing request which Support Net and/or the EIF coach and/or the LAC regard as being within the Purchasing Guidelines, which has subsequently been turned down by the Ministry or the EIF Host. Disabled people and stakeholders' confusion and uncertainty is the result of not understanding the reasoning and rationale behind the decision. The EIF coach/Host, NASC and LACs need this understanding so they can apply the same reasoning to other purchasing requests (as appropriate). Table 13 provides examples of decisions that have caused confusion for disabled people and/or stakeholders. A significant limitation of this table is that the evaluators have not had access to all of the information that would have been available to the EIF Host or Purchasing Panel on which they based their decision. Despite this limitation, these examples demonstrate the need for disabled people and stakeholders to understand the reasoning behind a negative decision. These examples also illustrate the impact on disabled people.

Table 13: Examples of purchasing decisions that have caused confusion

Declined purchasing requests	Response from the disabled person/ whānau and/or stakeholders
A disabled person had been supported by Support Net, the EIF coach and the LAC in his goal to visit family he had not seen for a long time. The LAC had assisted in locating a van with a hoist to hire. A request to use EIF funds for the van hire was turned down by the EIF Host on the basis that other family members could bring the disabled person's mother to see him.	The disabled person's response to the decision was as follows. ³⁰ "I have been planning this all year and to be turned down after having such hopes raised is nothing short of cruel. I have gone from a position of planning a 'life' to feeling totally discriminated against just because I don't fit the model with my unusual disability ... I don't see the point of having a budget if I can't use it. The only thing enhanced is my disappointment"
Parents of two disabled children wanted to purchase a wendy house for one of the children so that other children would visit to play.	The family said they were offended by the letter from the Ministry which stated they should 'contact the LAC so that their daughter can access the community'. The idea of the wendy house was for exactly that, so her friends would come over and she would socialise, and [name of disabled child] likes being outside. It also took into consideration their son's need for quiet time in the house due to his impairment. They felt the Ministry did not know their circumstances, they were not told to include all this information in the application and they would have been happier if they had received a phone call from the Ministry to clarify any further details, as stated on the form.
A person had a medical condition that was exacerbated by the cold and damp so requested that EIF funding be used to install a HRV system.	A stakeholder's cited this as an example of a decision made by the Purchasing Panel that is difficult to understand given the substantial health

³⁰ Permission was provided by the disabled person to include this information in the report.

The request was declined by the Purchasing Panel as the applicant's condition is a chronic, long-term condition (chronic conditions are not covered by EIF).	benefits for the person, and cost savings in healthcare.
A disabled person is unable to use public transport because of anxiety. The person's family wanted to use the EIF funding for the person to firstly learn to ride a scooter and then to purchase one. The request was declined.	A stakeholder's response to the decision was as follows: "The disabled person is allowed to use their funding for taxi fares which doesn't make sense given that the person lives in a rural location. Plus using a taxi is doing nothing to enhance the person's independence."

Source: evaluation interviews

Adverse consequences are emerging from such interpretation issues. Most importantly as example one illustrates, some disabled people we interviewed have had their expectations raised (albeit unintentionally by the EIF coach and/or NASC and/or LAC), which are subsequently dashed. This is leading some disabled people and stakeholders to the view that the Ministry has 'over-sold' EIF because it does not live up to the promise that disabled people will have more choice in how they spend their support money.

A second consequence concerns the impact of the confusion and uncertainty about purchasing on the work of the EIF coach, Support Net and the LACs. A stakeholder said: "We've encouraged disabled people to apply for some purchases that we regarded as no brainers but they were turned down by the Ministry". Another stakeholder said they are "nervous" when speaking with disabled people about EIF because they don't "want to lead families down a path of expectation". Another stakeholder said such uncertainty makes working with families "very stressful ... (it's) a hard place to be in." Given their lack of certainty about what purchases will be approved, the EIF coach, Support Net and LACs are now more likely to take a conservative approach when talking with disabled people about what EIF may offer them. They are less likely to encourage disabled people to be innovative for fear of raising expectations that may be subsequently disappointed.

Collaboration among key players

The Ministry has made considerable efforts to facilitate effective working relationships and collaborative processes among the key players involved in EIF - the NASC, EIF Host and LACs. The relationships and processes were formalised in a memorandum of understanding between the three organisations.³¹ A working group of managers from the organisations was set up which has met monthly (or more frequently when required) to address issues as they have arisen. Joint training workshops were held in March, July and November 2013 with staff from the three organisations to encourage working together in a complementary and collaborative way.

Despite these activities, there is evidence that such relationships and arrangements are yet to be fully achieved. As noted above, we interviewed people who had not been told about local area coordination. During our interviews we heard about situations where the participant may have found working with a LAC useful, such as in recruiting support workers. Of particular concern are at least three families who may have benefitted from working with a LAC if they had been informed about local area coordination by the NASC or EIF Host, as follows.

³¹ Memorandum of Understanding, dated 12 March 2013.

- A disabled young person who recently left school had been attending a day programme but had decided to stop. He had been mainstreamed through school and according to his parent “was a bit freaked out with the diverse disabilities he came across at [name of agency], including some quite challenging personalities.” The parent said she would welcome some ideas to help her think about her son’s future.
- A caregiver needs help to find support workers for a disabled child with complex needs. The caregiver reported that the level of care required is difficult to find. Support workers are trained but then leave because they find the work too hard.
- A family with disabled children moved into the region and started on EIF. The parent said they spent many hours (58 meetings and over 100 hours making phone calls) finding out about and contacting the key medical and education people to set up the supports for her children. The parent said she had expected she would have been referred to a LAC.³²

This lack of collaboration is particularly evident between some NASC personnel working in the Western Bay and the LACs, despite the LAC’s efforts to do so. The reasons for this are not clear. A possible reason is that some NASC personnel view the LACs as duplicating their information-giving role. This view is shared by two stakeholders (who do not work at the NASC and who are not LACs). One stakeholder described the NASC in the Western Bay as having “vested interests”, while another said:

For EIF to work better, the NASC, the LACs and the coaches need to work together. Some in the NASC don’t like the theory of LACs. The buy-in is not there.

The effective working together of these key players also involves their interaction with the disabled person, each of which results in a plan as listed below. The support plan produced by the NASC and Individual Service Plan produced by the EIF Host are part of these organisations’ contractual requirements with the Ministry.

- Personal Plan (LAC): developed by the disabled person with support from the LAC expressing their personal goals. The plan may be written up or may be expressed in non-verbal ways e.g. a drawing, diagram.
- Support Plan (NASC): specifying their overall goals for the purposes of identifying appropriate supports based on the UYYS form.
- Individual Service Plan (ISP) (EIF Host): specifying the support arrangements that will meet the goals identified in the Support Plan.

While the Support Plan and Individual Service Plan are used for different purposes by the NASC and EIF Host, they inform each other. The Support Plan and the ISP for the purposes of EIF is illustrative of existing processes and documents being used for new ways of working. It may be appropriate to investigate whether the information collected in these two plans could be reconceptualised, with the person’s agreement, into one document which serves the purpose of the NASC and EIF Host (with the personal plan being appended to this new document).³³ This would help to address the concern that has been expressed by disabled people that the planning required by DSS and other parts of the health and education sectors is excessive and repetitive.

³² There is no formal referral process required to work with a Local Area Coordinator.

³³ The document could be designed so that confidential information for use by the NASC is recorded in a way to maintain confidentiality.

Local area coordination: fiscally neutral implementation

The purpose of this analysis was to evaluate whether, and under what conditions, local area coordination may be provided on a fiscally neutral basis, and to the extent possible, provide information that can support policy decisions about the future rollout of local area coordination, including key areas of disability support funding from which savings might be found to cover the costs of local area coordinators.

Methods

The following methods were used for the analysis of local area coordination included in this evaluation:

- retrospective data analysis to identify whether, and in what ways, DSS expenditure has changed for disabled people accessing support from a LAC to-date
- prospective qualitative analysis (including reference to past reports and studies from New Zealand and overseas) to clarify the conditions under which future fiscal savings from local area coordination may be increased, and key sources of those potential savings
- use of existing case examples illustrating individual circumstances in which the various fiscal impacts might be seen.

Potential for local area coordination to become fiscally neutral

As with other aspects of the New Model, local area coordination is based on transformative philosophical perspectives about disabled people and communities. These perspectives are based on a social model of disability and incorporate inclusion, personal development and self-determination (Chenoweth et al., 2009).

Desired outcomes, as defined in the LAC Manual (2013, p. 23) include disabled people and/or their families and whānau:

- receiving support that reflects a strengths-based approach, is flexible enough to meet changing needs and supports valued roles for the disabled person
- having natural supports around them to assist them achieve their vision and their goals
- having access to community support which is appropriate to their needs and goals
- receiving quality support and services
- having better access to relevant information about available support, services and funding.

Additional outcomes, as identified by Bennett and Bijoux (2009, p. 12) include:

- increased opportunities for valued relationships
- security for the future
- improved functioning, health and wellbeing
- enhanced self-sufficiency and competence
- better engagement with the community
- enhanced socialization and social networks

- increased employment and income
- increased choices
- increased control
- increased contribution to family, community and society.

Based on these intended outcomes, the potential for local area coordination to be provided on a fiscally neutral basis stems partially from the potential to reduce people's need for disability services and supports, and ensuring people do not access higher cost supports and services than necessary, by:

- linking them to natural and/or community supports
- supporting and encouraging them to plan and pursue job opportunities, set up their own business or study for a qualification
- supporting and encouraging them to live as independently as possible, in their own home
- adopting an intentional preventative focus (Broad, 2012) and crisis management (when unexpected events occur).

If local area coordination is successful in these ways, these effects could manifest in people exiting various forms of DSS support (e.g. residential care, Supported Living), or deferring or avoiding the need to take up such supports in the future.

While reductions in DSS payments/allocations may be identified in DSS data, and linked temporally³⁴ (if not causally) to people taking up local area coordination, the deferral or avoidance of future costs is not recorded or tracked in routinely collected data, and there would be a number of practical and conceptual barriers to doing so.

For other individuals, local area coordination might serve to increase people's uptake of services and supports that meet their needs, In terms of administrative costs of providing local area coordination, some portion of LAC work may offset work in the sector that was already being done by others (e.g. NASC). Over the longer term, local area coordination might also contribute to sector efficiencies and related fiscal offsets, for example, by reducing duplication and inefficiencies associated with multiple access points (e.g. NASC and DIAS).

The following sections examine available evidence to make evaluative judgments about the extent to which these effects may be seen at the current time, and the potential for further fiscal offsets in the future.

Changes in DSS funding after accessing LAC support

Retrospective data analysis was undertaken to compare DSS expenditures and unit costs for disabled people accessing Level 2³⁵ support, before and after they started working with a LAC. The following steps were followed.

³⁴ To further clarify, the reasons why DSS payments go up or down are not always known. Engagement with a LAC is just one possible reason amongst many. If DSS payments go up or down just after starting work with a LAC that is an indication it might be related to local area coordination, but not necessarily. If payments go up or down after some time working with a LAC then it may or may not be attributable to local area coordination.

³⁵ Level 2 refers to people who choose to receive ongoing support from a LAC.

1. A list of people who accessed Level 2 support was produced, including NHI (where known), name, date of birth, LAC commencement and exit dates (the information provided to the evaluators did not include personal details about individuals).
2. The Ministry of Health extracted DSS data from the Client Claims Payment System (CCPS) and CMS for the listed individuals for the five years pre local area coordination, and post local area coordination.
3. Details of 138 people from the Bay of Plenty who had received Level 2 support were identified. Of these, 102 (74 percent) were in receipt of DSS and 36 (26 percent) were not. Those not in receipt of DSS included 9 with unused CMS allocations; 2 with no allocation; 4 receiving National Travel Assistance (NTA) only; 15 not in Socrates (a national database of the Ministry's DSS clients and service providers) or CMS; and 6 not active in Socrates.
4. Data was extracted for 99 people whose NHI was known and who had a CCPS and/or CMS payment in the last six years. Of the 99, 47 had pre and post data suitable for analysis, including 29 who had exited local area coordination and 18 still receiving LAC support.
5. Data analysis was conducted to examine changes in DSS costs 'pre' (the fiscal year before they were approved for Level 2) and 'post' (the fiscal year after they were approved for Level 2 support). This includes annualized payments made through the CCPS and allocations through CMS (actual expenditures tend to be lower than CMS allocations, but won't be known until after the year-end wash-up process).

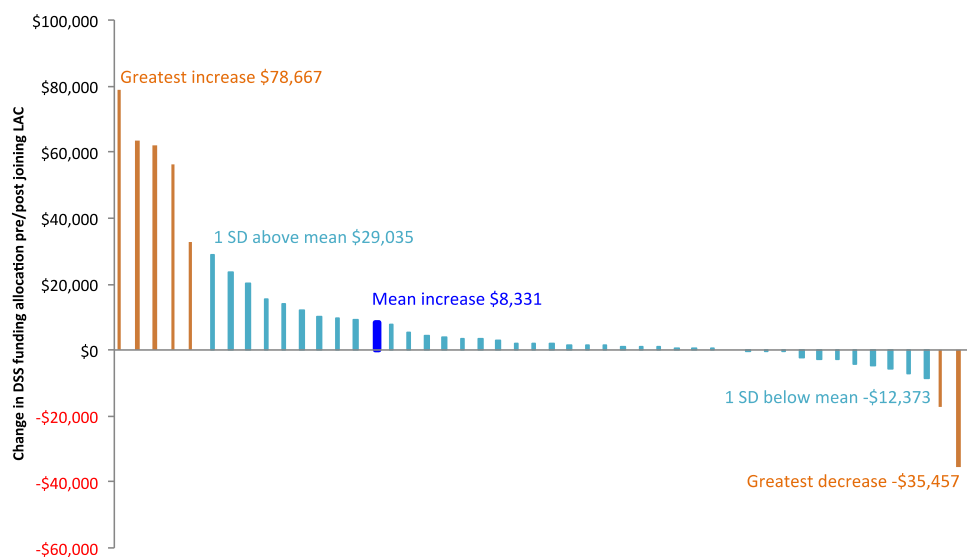
As Figure 11 shows, the changes in funding/allocations varied from a \$78,000 increase to a \$35,000 reduction. The average change was an increase of \$8,331 with a standard deviation of \$20,704. The vast majority (70 percent) of these people's DSS funding after accessing LAC support remained within +/- \$10,000 of their pre-LAC level.

It is not possible to conclude much from this analysis. Analysis of individual circumstances (detailed below) indicates that the changes in funding are generally not attributable to local area coordination. Furthermore, the analysis is based on a small sample of people (47) over a short time period (the earliest Level 2 approval date among the 47 cases was 24 January 2012, and the data extract covers the period up to the fiscal year ended 30 June 2014). It is also partially based on CMS allocations, which on average tend to be higher than actual payment levels after the year-end financial reconciliation.

Disability Support Service payments are increased or decreased for individuals for many different reasons that may be unrelated to the implementation of local area coordination. The data displays general volatility, showing that DSS funding can vary considerably as people's circumstances change. Analysis of annual changes in funding across the six fiscal years from 2009 to 2014 for the 99 LAC recipients in the data extract shows that in 32% of cases, funding increased or decreased by +/- 50% or more from one year to the next, and in 17% of cases the year-on-year change was +/-100% or more. In a further 21% of cases funding started from a zero base (so a percentage increase could not be calculated). Overall, one in five of the 495 year-on-year funding changes exceeded +/- \$10,000. The data does not indicate to what extent changes in DSS funding for LAC recipients may be attributable to LAC or other factors.

It should be also noted that responsibility for allocation of funding is a NASC role. Local area coordinators have no influence over funding decisions.

Figure 11: Change in DSS funding pre and post approval for Level 2 LAC support



Possible fiscal effects of using local area coordination

Three possible fiscal effects of using local area coordination are discussed in this section, two of which have the effect of reducing use of DSS funding, and one which has the effect of increasing use.

Reducing utilisation of disability services and supports

Local area coordination could potentially reduce some people's need for disability services and supports. For a person accessing LAC support, this may not occur immediately, but may be achieved after linking them into natural and/or community supports, and planning toward living more independently.

The potential to reduce need for disability supports and services is illustrated in some of the *New Model People Stories* on the Ministry of Health website.³⁶ For example:

- Leanne enrolled in a six-month Certificate in Computing and Business Administration, with encouragement and support from her LAC. Subsequently, the LAC helped link Leanne with work opportunities, which led to Leanne taking up two volunteer roles.
- Kelvin has started to turn his hobby, making fishing flies, into a business, with support from his LAC.

For the people shown in Figure 11 whose DSS funding reduced after taking up LAC, searching and review of individual CCPS and CMS records, together with commentary provided by NASC, did not reveal any common patterns or trends that might be attributed to local area coordination. In two instances (including the case with the greatest reduction in DSS funding) the apparent reduction was in fact temporary, and was followed by an increase in CMS allocation in the subsequent year as needs increased. The second-greatest reduction was not associated with any identifiable

³⁶ <http://www.health.govt.nz/your-health/services-and-support/disability-services/other-peoples-stories/new-model-people-stories>

change in payment type or circumstances. Of the smaller reductions (all under \$10,000) one person had moved from Household Management and Personal Care to Enhanced Individualised Funding and another had taken up Individualised Funding; others reflected general decrease of need.

It is expected that for many people, engaging with a LAC is a transitional need. Local area coordination is intended to help people move to a more independent state. For those who had exited LAC, reasons for exiting were looked up in the LAC database. Analysis of free-text comments indicates that there were many individual reasons for exiting, but in approximately one quarter of cases, the person's life had improved to the extent that they no longer required LAC support. Other common reasons for exiting, collectively accounting for around half of the exits from local area coordination, included not seeing a current role for LAC in their life (without specific mention of their circumstances having improved), not wanting to engage or having minimal or no contact with LAC.

Deferring or avoiding future need of disability services and supports

Another potential effect of local area coordination is reduction in the uptake of future high cost supports. For example, a value for money review of LAC in Western Australia (Bartnik and Psaila-Savona, 2003) noted the "capacity of LAC to facilitate access to self-help and low-intensive resources, potentially negating or delaying the need for more (long-term) intensive supports." Significant areas of possible savings (as well as better outcomes for people with disabilities) include avoiding or deferring the need for residential care, and not using or not increasing Supported Living, Home-Based Services, and Carer Support Subsidy.

For example, in the *New Model People Stories* on the Ministry's website:

- Tania was assisted by LAC to move into her own home following the death of her parents and the sale of their family home. Formal support is available if needed, but so far Tania has not required it. She has also started doing voluntary work.
- Stephen, who is on the Autism spectrum, was assisted by the LAC to go flatting and lead a more independent life away from his mother, and was able to take up voluntary work, which he sees as a way back into the workforce.

Costs deferred or avoided are not identifiable in DSS data.³⁷ Another way to investigate these effects is to consider what *might* have happened for LAC clients if they had not engaged with LAC. To this end, the LACs reviewed case notes for 70 clients out of the 99 individuals represented in the data (the remaining 29 were not known to current LACs due to the recent change of employer). Of the 70, LACs identified 7 people (10%) who may have gone into Residential Care if they had not received support from a LAC, and a further 3 (4%) who could have required Supported Independent Living or a group home in the absence of LAC support. Based on average costs per person in 2012/13 for Residential Care (\$56,994) and Supported Independent Living (\$11,375) the estimated value of these notional savings is \$433,000.

³⁷ Hypothetically, given sufficiently large numbers of LAC users, and a statistically matched sample of non-LAC users, it may be possible to detect a net difference between the two groups. This line of inquiry is worth investigating in future years when greater numbers of people have taken up LAC and a longer period of time has elapsed for effects to become apparent.

Additionally, 24 cases out of 70 (34%) were identified where no increase in Carer Support or other DSS funding was foreseen. It is not possible to determine to what extent this may be attributable to LAC or other factors, nor to estimate the value of any such savings. However, in some of these cases it might be that access to LAC has helped to alleviate the need for further funding. This would be consistent with the intended role and functioning of LAC.

It is also interesting to note that there were 36 cases (26% of the total sample of 138 people) where LACs were working with people who were receiving no DSS funding – including 9 people with unused CMS allocations. The value of allocations for these people was not provided (as they were outside the 99 who had payments in the last six years). However, the average CMS allocation for the 99 was \$16,000. Applying this figure to the 9 would imply approximately \$140,000 in unused CMS allocations. As LAC becomes more embedded and well known within the system, it is possible that over time this number could increase.

Although not providing a sound basis for forecasting purposes, identified notional savings associated with deferral of Residential Care, Supported Independent Living and with people who have not used any of their CMS allocations average out to \$7,200 per client ($\$433,000/70 + \$140,000/138$).

Increasing utilisation of disability services and supports

One of the impacts of local area coordination may be to facilitate access to funding that people had not previously been using. For example, this might be one factor behind take-up of EIF for some LAC clients. While the immediate effect of such cases is to increase DSS costs, such cases represent an increase in the effectiveness of the disability support system to meet needs by ensuring people receive appropriate supports.

Moreover, in the longer term, such investments (together with local area coordination are intended to maximize people's ability to achieve the outcomes summarized above and may therefore ultimately lead to reduced or delayed need for DSS supports and services downstream. Such effects are not measurable over the short term and, once they have occurred, would be highly problematic to attribute.

Uptake of EIF through local area coordination is evidenced in some of the *New Model People Stories* on the Ministry's website. For example:

- George had a degenerative illness and required a power wheelchair for mobility. He lived in an isolated area in the Bay of Plenty. Before he started using EIF he found it hard to get good caregivers to come to his home. With LAC assistance he was able to choose and employ the assistants he wanted. Local area coordination also helped connect George more closely with his community. (Note: George has since died. His story is still shared with permission of his whānau.)
- Melanie, a mother of three who has vision impairment, has been able to gain greater independence through the use of EIF and employing her own part-time staff.

For the 18 people shown in Figure 11 above whose DSS funding increased the most after taking up local area coordination (ranging from increases of \$4,000 to \$78,000), searching and review of individual CCPS and CMS records, together with commentary provided by NASC, suggests that a variety of individual circumstances contributed to these increases which in the majority of cases are not attributable to LAC. Key examples included:

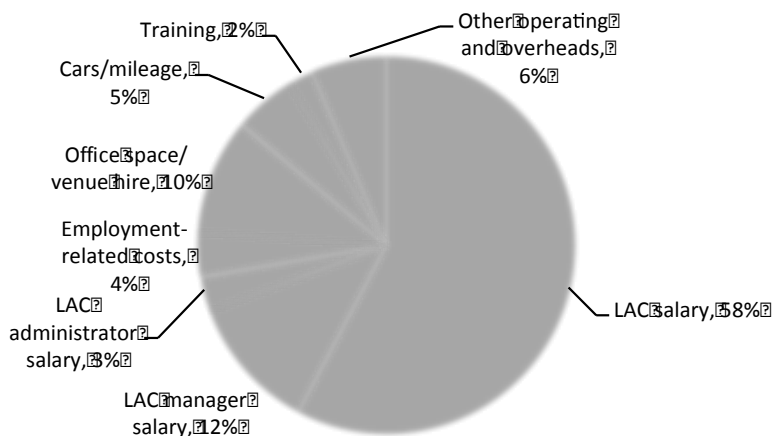
- Six people (33%) had taken up EIF at some time after using LAC. In two of these cases, people had not been receiving any DSS payments prior to starting LAC. In another two cases EIF did not account for the funding increase shown as it had been taken up in a subsequent period to that reflected in the graph.
- Three of the larger increases (ranging from \$15,000-24,000) were attributed to changes in circumstances involving loss of natural networks (one who moved to a different area, one who moved away from home, and one with a “lack of informal supports”).
- Two of the 18 people had moved into Residential Care, including one with National Intellectual Disability Care Agency (NIDCA) involvement.³⁸
- Four other increases were attributed to unspecified “increased needs” and for the remainder, the reason was unclear.

Reducing duplication and inefficiency in disability services

Over the longer term, local area coordination might contribute to sector efficiencies and related fiscal offsets – for example, by reducing duplication and inefficiencies associated with multiple access points (e.g., NASC and DIAS). Such effects cannot be quantified from available data. However, relevant considerations are set out below.

Annual costs for local area coordination in the Eastern and Western Bay of Plenty totaled \$629,027 or \$109,000 per front-line FTE. This figure includes an average allocation for management, administration and overhead costs as shown in Figure 12. Additionally, there were one-off setup costs of \$65,000 for LAC in the Eastern and Western Bay of Plenty. Advice from the Ministry indicates that these costs are comparable to those of NASC. This could not be further explored through direct or detailed comparison. The 2012 *‘Functions, Roles and Responsibilities’* report noted that “Financial information is not collected by the Ministry of Health in a way that provides separation between functions and roles that can also be used to determine facilitation or management costs from support services or functions within support services” (p. 7).

Figure 12: Cost of LAC delivery



³⁸ NIDCA is a national agency for those covered under the *Intellectual Disability (Compulsory Care and Rehabilitation) Act* or civil clients with similar needs, who are likely to be among higher cost clients.

Local area coordination may already be reducing workload in other parts of the system – therefore part of the cost of providing this initiative may not be an additional cost to the system. There is no clear basis for estimating these offsets.

Local area coordination may achieve further savings in the future, in the context of overall system redesign, which has not been implemented to-date. Examples of such savings include:

- existing people working with LAC strengthening their natural and/or community supports, becoming financially independent through work, and/or moving to independent living arrangements, which may be more readily achieved when the system is functioning as intended.
- improving outcomes and costs for people who are not currently receiving LAC, as more people take up LAC.
- increased efficiency in the ratio of LAC FTE to clients with the growth of the approach and LACs gaining competence and efficiency in their roles over time.³⁹
- longer-term savings from LACs' direct work with communities (as distinct from individuals and family/whānau) which, over time, might mean that some disabled people can be supported in the community, reducing demand on funded services.⁴⁰
- offsets from system improvements under best practice implementation of LAC e.g., potential to reduce duplication and inefficiencies associated with multiple access points and people accessing higher cost support/services than necessary.

As an example of the efficiencies that might be achieved with full implementation of LAC as part of a more comprehensive system change, the 2014 Annual Report of Australia's National Disability Insurance Agency (NDIA) notes, "As detailed in reports by the Productivity Commission and PriceWaterhouseCoopers, the long-term economic benefits of the NDIS are estimated to exceed its costs, adding around one per cent to gross domestic product and saving \$20 billion per year by 2035" (p. 28).⁴¹

Overseas experience also highlights the criticality of comprehensive system change to enable local area coordination to work effectively. For example:

To be successful, individualised support and funding needs to be embedded in a new paradigm of disability and community building capacity of individuals, families and communities (Chenoweth & Clements, 2009). This includes a good system for allocation of individualised funds with block funding, local area coordination so that local needs and preferences shape services, implementing changes in phases to ensure infrastructure supports separate from the service system, implementation of alternative quality systems, universal access and utilising a blend of formal and informal supports under best practice models. (Twentypages Ltd, 2012, p. 43-4)

The likely consequences of implementing LAC without comprehensive system change was noted by Bennett (2009, p.14; cited in Twentypages Ltd):

³⁹ The WA value for money review of LAC (Bartnik and Psaila-Savona, 2003) found that the ratio of staff supporting people with disabilities improved over time. Overseas experience as well as previous evaluations (Evaluate Research 2012; Evaluate Research 2014) also shows that it takes time for LACs to become fully effective in their roles – e.g., to develop role competencies and community networks.

⁴⁰ The community building aspect of LAC has been documented as being the most difficult aspect of LAC to achieve (Stalker, Malloch, Barry, & Watson, 2008; cited in Twentypages Ltd, 2012).

⁴¹ http://www.ndis.gov.au/sites/default/files/documents/annual_report_2013_14.pdf

A primary implication is that without wider change the importation of LAC- type processes would result in a duplication of roles and responsibilities which would also be likely to add to bureaucracy and potentially cause confusion amongst service users and service providers.

In the context of the Demonstration, local area coordination was, in effect, added on to the existing system. The March 2014 evaluation of LAC (Evaluate Research, 2014) noted that local area coordination is operating in parallel with, or as a 'tack on' to the existing system. While efforts have been made to coordinate local area coordination and the DSS system, these services are not yet coordinated from the perspective of disabled people, and in day-to-day functions and relationships between LACs and others working in the sector. This affected take-up of local area coordination as well as potential to reduce duplication and inefficiencies within the system, throughout the Demonstration.

A similar finding was documented in a 2012 comparative stock take and analysis of *Functions, Roles and Responsibilities and the New Model for Supporting Disabled People* (Twentypages Ltd, 2012, p.7) which concluded:

There are overlaps and duplication of some functions, roles and responsibilities across approaches, supports and services. This is particularly so in person centred planning and facilitation roles. This can make life more complicated for disabled people and their family and whānau and add costs to the system.

Key issues limiting the potential for local area coordination to work with maximum efficiency include the following.

- Effectively, local area coordination was offered to people in the Bay of Plenty as an option (rather than a systemic approach with LACs as the first point of contact) in the context of an existing system where people were still actively engaged with, and understood the gateway to DSS to be information through DIAS and services/funding through NASC.
- During the implementation of local area coordination there were not the working connections between LACs and the NASC that were anticipated, and which should occur in the future.
- Existing support agencies in the region did not feel they had been adequately consulted, and in some cases believed they were already providing local area coordination. As a consequence, the take up of LAC was not facilitated by NASC as effectively as it could have been.
- Stakeholders have not shared a cohesive view about the respective functions, roles and responsibilities of LAC and NASC.
- Structural arrangements for local area coordination have been subject to some uncertainty and change, with strong polarized opinions across stakeholders (internal and external to the Ministry) as to the need to have a separate and new infrastructure for LAC or whether in fact current infrastructure should be improved and changed (Twentypages Ltd, 2012).
- LAC contracting arrangements have changed, and the transition to a new support agency may have had some impact on effectiveness of local area coordination, at least in the short term, given the relational nature of the role.

Conclusion

This analysis has been undertaken in the context of early implementation of local area coordination, during a period when it was not fully implemented as part of the intended comprehensive system design. Available data represents a relatively small number of people over a short time frame. The analysis is partially based on CMS allocations, which may differ from actual

payments after the wash-up process is completed. Individual people's funding varies considerably as circumstances change, and analysis of individual-level records and NASC commentary demonstrates that in general the funding changes that have occurred since accessing LAC support cannot be attributed to local area coordination.

Furthermore, there are sound reasons, related to the intended functions of local area coordination, to anticipate fiscal savings that will not be shown in the data e.g. negating or delaying the need for expensive supports such as residential care. Available information indicates that offsets from deferral/avoidance of high cost disability services, together with other unused CMS allocations that might have been taken up in the absence of LAC, could potentially offset increases in DSS funding.⁴²

Further savings seem likely if local area coordination is fully implemented in the context of overall system redesign, for example, by reducing duplication and inefficiencies associated with multiple access points. Finally, further elapsed time, together with increased take up of LAC, is needed to more comprehensively evaluate fiscal impacts.

⁴² Although not providing a sound basis for forecasting purposes, identified notional savings associated with deferral of Residential Care, Supported Independent Living and with people who have not used any of their CMS allocations average out to \$7,200 per client ($\$433,000/70 + \$140,000/138$).

Learning from the New Model demonstration

This section identifies the implications of the New Model demonstration components for wider implementation.

Choice in Community Living

Choice in Community Living is intended to give disabled people an alternative option to residential services. It was expected that, through CiCL, eligible disabled people would have the same housing options as other people, have increased choice about which provider supports them and the way in which they are supported, and be eligible for a wider range of social welfare benefits, as other people are. It was also expected that disabled people would have greater choice over who they live with.

The evaluation findings indicate CiCL is working well for people who have sufficient supports around them to live more independently. These supports include adequate funding to purchase paid support, support workers who are enabling in their approach and whānau who provide both natural support and, in some cases, additional financial support for transport and other costs. The initiative is working for people with very high needs when they are willing to share accommodation with other disabled people with very high needs, so that resources can be pooled.

Choice in Community Living works less well for people who have high needs, require fulltime support and who, because of their impairment, are not able to share a house with other disabled people. People with very high needs who are able to share accommodation have limited choice over who they live with.

The roles of disabled people, vis a vis whānau and support agencies are not always clear. While arrangements will differ depending on the circumstances of each person, the evaluation findings indicate this is an aspect of CiCL that needs to be strengthened. Where arrangements are in place, they may need to be proactively revisited as people's circumstances change.

Enhanced individualised funding

Any new policy initiative, especially one of this size and significance, will require adjustment and ongoing fine-tuning. Three areas for fine-tuning are identified: better alignment of EIF with the principles of the New Model, maximising the potential of EIF for disabled people, and identifying and mitigating potential risks for disabled people from using EIF. Lastly, areas requiring further work and possible topics for investigation in the future are identified.

Areas for fine-tuning

Better alignment with New Model principles

As a public sector agency, one of the key drivers for the Ministry is accountability for the use of public funds and the management of perceived risk. Any use of funding that is not regarded as appropriate or failure to manage risk will come under close scrutiny by Government and the media. Alongside this, the Ministry has committed to increasing choice and control for disabled people through the New Model.

The findings suggest that an appropriate balance between accountability and risk reduction on the one hand, and choice and control for disabled people is yet to be realised (Figure 13). This is reflected in how the EIF Host is being required to implement the Purchasing Guidelines, that is, requiring disabled people to ‘prove’ that the requested support is appropriate for them. This has the effect of refocusing support onto front-end inputs, rather than on the intended outcomes of the support. It also places disabled people in the position of having to prove they are ‘worthy recipients’ of their requested support. The imbalance is also reflected in the Ministry’s requirements for the EIF Host to refer ‘out of the ordinary’ requests over \$500 and all requests over \$1000 to the Ministry for approval.

Figure 13: Balance between accountability and risk reduction vs choice and control yet to be realised



An improved balance between accountability and risk reduction on the one hand, and increased choice and control on the other could be achieved if EIF processes and requirements are recalibrated with the principles of the New Model. The following are suggested as ways of enabling this to happen.

- Purchasing decisions about a disabled person’s support request are made as close to the individual and their whānau as possible. It is not possible to capture in writing all of the details and subtleties of a person’s (and their whānau) situation and circumstances for consideration by an individual or group (such as the Purchasing Panel) who are ‘at a distance’.
- The current requirement for the front-end ‘proof’ of need is replaced with a focus on the intended outcomes of the requested support.
- The current level of scrutiny by the Ministry on purchasing requests over \$500 is relaxed.
- Potential risk is acknowledged and embraced, rather than avoided.

Maximising the potential of EIF for disabled people

Enhanced Individualised Funding is described as a mechanism for disabled people to have control and choice over the supports they purchase. It can also be understood as operating as a process. The EIF process may happen quickly for some disabled people, and at a more measured pace for others. The process involves disabled people thinking about the area(s) in their life that they want to give priority, and considering how they could use their support funding to do so. While some disabled people will immediately articulate their ideas, others may need up-front support and time to do so. If this is the case, such support needs to happen before any conversations about the technical details of employer responsibilities and administrative processes (although these need to

happen early in the process so disabled people understand the implications at the outset). The following enhancements will facilitate the EIF process:

- A pre-EIF visit(s) from a LAC to those who have expressed an interest in EIF to 'prepare the ground', specifically, talking with disabled people about their aspirations (rather than funding), encouraging them to think beyond their day to day lives and current support arrangements, and working out how natural supports can be fostered to complement funded supports including EIF.
- Increased resourcing for the EIF coach role (particularly for rural areas) so they can spend more time in face-to-face contact with disabled people and whānau explaining the technical details of how EIF works.
- Combining and streamlining of the three plans into one document which is 'owned' by the disabled person and whānau.
- Improved coordination between the NASC, EIF Host, and the LAC.
- Extension of the contractual requirement for the EIF coach to set up EIF with a disabled person within two weeks of a referral from the NASC. While this timeframe may be appropriate for some disabled people and whānau, others need more time to process the information and think about their goals.
- More support for disabled people and whānau in the recruitment of support workers (via LACs) and employment contracts (if amendments to the standard contract are required, via the EIF Host).

Identifying and mitigating potential risks for disabled people from using EIF

There are potential risks for disabled people arising from their role as employer of staff, such as staff management issues, employment disputes, exploitation and abuse (including financial, physical and sexual abuse) and health and safety. The extent of this potential risk is evident in the Service Agreement between the EIF Host and the disabled person which states: "The disabled person is responsible for complying with all laws and other relevant New Zealand legislation in their role as an employer or principal (the party to the contract that engages the other party (the contractor) to perform work or provide goods and services)." The potential for exploitation is demonstrated in a situation described by a stakeholder where a disabled person using EIF is said to have paid a considerable sum to a private company to provide recruitment services.

Given the relative newness of EIF, potential risk is an as yet untested area. Informal risk management is already occurring - as noted above, many disabled people and whānau we interviewed said they prefer to employ people known to them or someone recommended by their wider network. Consideration could be given to other risk management approaches that may be appropriate, for example, police checks on prospective employees who are not personally known to the disabled person and whānau.

The issue of risk for EIF users requires on going monitoring and research as EIF is implemented in new regions and more disabled people take it up.

Implications for NASC practices

The focus of this evaluation has been on disabled people's experiences and perspectives. In this section we turn our attention to the NASC, the impact of the New Model on their way of working, and the implications for NASC practices in the future.

The introduction of supported self-assessment and the UYYS form is described by NASC staff as involving a "mind shift" which is altering the way they think and practice. This change is described as significant because it has involved 'undoing' years of using a deficit-based approach in their work. Assessors and service coordinators say they are now working with disabled people in a much more positive way which respects the disabled person's knowledge of their disability and their unmet need, allowing them and their family to be in control. While acknowledging that the NASC is the funder, the new way of working makes staff feel that they have a more equal relationship with disabled people. However this change is not happening quickly or easily and is on-going, as is described by a NASC assessor:

She was the first to use the UYYS form. She struggled with the new way of working which surprised her because she felt that her mindset was aligned to a social model of disability. She thought she was already there. She would talk about it at staff meetings with the other assessors who would look at her strangely. But when they started working with the new form they said to her 'I now know what you were talking about'.

The extent of the difference between working in the traditional way and using a strengths-based approach was described by an assessor as follows:

At a recent staff team meeting, one of the assessors talked about her experience of using the old needs assessment again [MSD and Ministry of Education require the traditional assessment.] She talked about how hideous it was using the old form and how negative and draining it was. She said it felt like she was invading the disabled person's space.

Another assessor described about how the NASC's approaches are changing:

How we think has changed. We didn't realise the extent of this change in thinking until we transferred a client (who isn't using EIF) to another NASC. This NASC had a prescriptive approach saying what the person could and couldn't do. They were budget-bound. They blocked things left, right and centre. We used to be like that but not any longer. We're still working on it but until this transfer happened, we didn't realise how far we'd come.

According to the Support Net staff we interviewed, other NASCs will need time, resource and support from the Ministry to move towards this new way of thinking and practicing in order for EIF and self-assessment to be effective for disabled people.

Other issues

The evaluation has identified other issues requiring attention, as summarised below.

About disabled people:

- *Carer support and respite care:* Disabled people and whānau who are considering EIF and who currently receive carer support and/or respite care should be told about the implications of transferring these into EIF i.e. carer support payments become taxable for the person providing the support; disabled people get less value from respite care when it is included in EIF.
- *EIF and ORS funding:* Parents of teenagers who still enrolled at school and are gradually transitioning out of school are seeking clarification about how EIF and Ongoing Resourcing

Scheme (ORS) funding paid to schools by the Ministry of Education can be used together e.g. the teen may attend school for three days a week and then use EIF for a tailored transition programme for the other two days.

About the EIF Host:

- *Working with disabled people with smaller funding allocations:* The cost recovery feature of the EIF Host business model does not work well in respect of disabled people with smaller funding allocations who (i) may require a similar amount of support as a person with a larger allocation and/or (ii) use their funding allocation for purchases only. It may be appropriate to explore a different approach to supporting people with smaller funding allocations.
- *Monthly EIF expenditure statements:* All disabled people using EIF should receive a monthly statement, regardless of the service level they have chosen. We interviewed four people (who should have done so) who said they either had not received any monthly statements or had received one statement in 12 months. They were unable to determine how much funding they had used. Some said they had failed to use significant portions of their annual allocations because they had been conservative in their spending.

About the Purchasing Panel:

- *Membership of the Purchasing Panel:* The Purchasing Panel Terms of Reference state that membership of the panel will include three external members - two disabled people and a family/whānau member. These members are yet to be appointed.

Topics for future investigation

Given that EIF is in its initial stages, further investigation of how EIF is working and its impacts could be undertaken in the future. The evaluation has raised the following questions:

- What difference is EIF making for disabled people and whānau in the longer term?
- To what extent are user-led arrangements for managing EIF developing? e.g. disabled people managing EIF for other disabled people? Shared carer arrangements developing among disabled people? Whānau working together to form a combined family trust to manage EIF for their family members?
- To what extent are natural support arrangements for managing EIF occurring?
- How can more peer support arrangements be facilitated (similar to the Whakatane group)?
- What innovative support arrangements are occurring?
- How is potential risk being managed by disabled people? What risk-related issues have occurred? What has been learnt from such issues?
- Are any negative impacts for disabled people and whānau emerging from their use of EIF?
- What impact is EIF (and IF) having on the carer workforce? e.g. casualisation of the carer role?
- What impact is EIF (and IF) having on the service support agency sector?

Evaluative assessment: summary

This phase of the evaluation examined the extent to which CiCL and EIF are contributing to increased choice and control for disabled people over the supports they receive and the lives they live. It also focused on whether CiCL and local area coordination are able to be implemented in a fiscally neutral manner.

The findings show that the concepts of CiCL and EIF as mechanisms for increasing choice and control of supports are sound. Our interviews with disabled people and whānau indicate that both of these New Model components are still in the initial stages of implementation, with some fine-tuning required. Consequently, the potential of CiCL and EIF for disabled people has yet to be fully demonstrated.

CiCL: The intended outcomes of choice and control were very evident for participants interviewed who had previously been in residential care. They described having a sense of freedom to live their lives as individuals, choosing what they do and when. However the shift to independent living has required some to learn new skills and capabilities (due to having become institutionalised). This highlights the importance of, in some cases, preparing people for more independent living. A culture shift is also required by some support agencies and support staff to ensure support is enabling and facilitative.

Of particular concern is that disabled people who require 24-hour care and who are not able to share paid support with others, are currently excluded from CiCL. If all those eligible are to have access to CiCL, then funding packages need to reflect the individual circumstances of disabled people and whānau.

EIF: Disabled people using EIF value being able to choose who they employ as support workers, how and on what they spend their support funds. This has resulted in more flexible and reliable support, enabling people to participate in a wider range of activities particularly in the community. Support funding has been used to purchase items to help with daily living in the home and to pay for community-related activities. Disabled people describe having greater independence and self-confidence, and reduced social isolation.

Some disabled people cannot make EIF work effectively for them without receiving the level of support they need to do so. For EIF to work effectively, it involves the disabled person (who wants to) having the opportunity to discuss their hopes and aspirations, thinking beyond day-to-day care, and then working out how EIF (together with natural supports) might enable them to work towards their goals.

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

Fiscal neutrality of CiCL and local area coordination:

CiCL: Analysis of DSS allocations for people who took up CiCL shows that allocations have increased for the vast majority of people who joined CiCL from community settings, stayed at about the same level for most people who joined CiCL from residential settings (when client contributions for residential accommodation costs are taken into account), and decreased for a minority of people who joined CiCL from residential settings. The net effect to date is an overall increase in allocations for disability services to those who have taken up CiCL. Actual expenditure data will become available after the Ministry's year-end funding reconciliation process (early 2015). The early 2016 funding reconciliation is likely to yield more robust cost data than 2015 data, as it will include greater numbers of people as well as an extra year's expenditure data.

LAC: DSS allocation and expenditure data does not currently provide a robust basis for determining whether local area coordination can be implemented in a fiscally neutral way. Data analysis was undertaken in the context of early implementation of local area coordination, during a period when it was not fully implemented as part of the intended comprehensive system design. Available data represents a relatively small number of people over a short time frame. The analysis is partially based on CMS allocations, which may differ from actual payments after the wash-up process is completed. Individual people's funding varies considerably as circumstances change, and analysis of individual-level records and NASC commentary demonstrates that in general the funding changes that have occurred since accessing LAC support cannot be attributed to local area coordination.

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

Further savings seem likely if local area coordination is fully implemented in the context of overall system redesign, for example, by reducing duplication and inefficiencies associated with multiple access points. Finally, further elapsed time, together with increased take up of LAC, is needed to more comprehensively evaluate fiscal impacts

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Appendices

Appendix 1: Methodology for qualitative interviews

The interviews with disabled people were conducted by Evaluate Research team members with lived experience of disability and/or who are skilled in interviewing disabled people, and have appropriate Māori cultural expertise.

Informed consent

A plain English information sheet about the evaluation was emailed/mailed to people identified in the initial sample frame requesting an interview. This was followed up by a phone call by an interviewer. People who agreed to be interviewed were invited to have people supporting them through the interview process. In the Bay of Plenty, parents of younger children were interviewed, and teens were interviewed with a parent present. In many cases the parent also contributed to the interview.

At the start of the interview, the interviewer provided verbal information about the purpose of the evaluation, use of the respondents' information and confidentiality. Participants had the opportunity to opt out at any stage of the interview. Participants were asked to sign a consent form. The interviews were written up and emailed/posted to the participant. Participants were invited to amend the interview notes if they wished and return them to the interviewer.

CiCL evaluation sample (disabled people and whānau)

In total, 34 interviews were conducted about 31 disabled people who had either taken up CiCL (18) or considered CiCL but decided not to proceed (13).

The Ministry provided the evaluators with a list of disabled people who had taken up CiCL. An initial sample frame was drawn up which included Māori and Pākehā/other people, Auckland and Waikato based, and people with a range of impairments. Of the 18 respondents who had taken up CiCL, half were living in Auckland and half in the Waikato. Thirteen were NZ European, four Māori and one of Asian ethnicity. Eleven respondents had previously been in residential care. Of the 18 interviews, 13 were with disabled people on their own or with family members present and five with family members only.

Key staff from the two NASCs provided a list of people who had seriously considered CiCL but decided not to proceed. Twelve whānau respondents and one disabled person were interviewed about their reasons for not taking up CiCL. They included 10 Pākehā, two Māori and one Pacific Islander. Respondents' type of impairment were as follows:

Impairment	Number of disabled people
Intellectual	17
Physical	10
Physical and intellectual	2

CiCL participants were interviewed face to face. Several whānau respondents were interviewed by telephone.

Bay of Plenty evaluation sample (disabled people and whānau)

The Ministry provided the evaluators with a password-protected list of disabled people who are using EIF. An initial sample frame was drawn up which included Māori and Pākehā/other people, and people with a range of impairments. Efforts were also made to include those who are new to DSS and those who have had previous experience of DSS support and services.

Twenty of the disabled people who were interviewed live in the Western Bay and 12 in the Eastern Bay. Their age, gender, ethnicity and type of impairment are as follows.

Age (years)	Female	Male
0 – 5	0	1
5 – school leaver	5	4
School leaver – 65	13	7
Age not recorded	1	1

Ethnicity	Number of disabled people
Māori	19
NZ European	13

Impairment	Number of disabled people
Intellectual disability (ID), type not specified	14
Neurological	8
Physical	5
Autistic Spectrum Disorder (ASD)	2
Sensory	1
Not specified	2

Stakeholder interviews

Interviews were conducted with 28 stakeholders as follows:

Stakeholders	Focus of data collection (and number of stakeholders interviewed)		
	Local area coordination	EIF/Supported self assessment	CiCL
NASC staff		2	2
Local area coordinators*/manager	1	5	
Inclusion Aotearoa		2	
Synergia		1	
EIF Host		3	
CiCL support agencies			3
CiCL project manager			1
Ministry of Health staff	3	3	2

* Conducted as a group interview

Coding and analysis

Coding and initial analysis of all interviews was done using NVivo (qualitative data analysis software). The initial analysis was discussed by all of the interviewers in a workshop. Further analysis was then completed by one of the evaluation team.

Peer review

All aspects of the evaluation (the work plan, interview topic guides, draft reports) were peer reviewed by members of the evaluation team.

Limitations

There are a number of limitations associated with this evaluation, as follows.

- Not all impairment types are equally represented in the sample of disabled people, despite efforts to do so in the initial sample frame.
- Despite the initial group of disabled people starting to use EIF in early March 2013, the evaluation findings show that EIF is still in its early stages of implementation. Therefore the outcomes reported in this report may not represent the full potential of the new arrangements to improve outcomes for disabled people and their whānau. One of the risks of identifying outcomes early in this ambitious change to disability supports is that some of the intended positive changes are not seen until more time has passed.
- Our interviews focused on disabled people who are using EIF. Other than two people interviewed who had decided not to use EIF, we do not have any significant insights into the reasons for such decisions.

Appendix 2: Literature scan

A scan of literature on self-directed support was undertaken to inform the evaluation findings. Given the amount of literature on this subject, priority was given to (i) evidence-based reports and peer-reviewed papers (ii) papers published in 2009 or later (a literature review was done for the Ministry of Health in 2009 (Bennett, 2009)). The scan focused on:

- disabled people's experiences of using self-directed supports
- what helps/hinders the effectiveness of self-directed supports for disabled people
- outcomes of self-directed supports for disabled people.

The research

Recent research about the experiences of users of self-directed support ranges from smaller-scale qualitative studies, to survey-based studies involving a range of users such as disabled people, mental health consumers and the elderly. Two nation-wide research projects have been done in the UK about self-directed supports. The first is the Individual Budgets Evaluation Network project (known as IBSEN) which evaluated the piloting of individual budgets in 13 local authorities across England between 2005 and 2007.⁴³ Users of individual budgets included disabled people, mental health consumers, and elderly people. The second is a national survey (referred to as the POET survey) by 'In Control', a charitable organisation which works "for an inclusive society where everyone has the support they need to live a good life and make a valued contribution".^{44 45} The third national POET survey has recently been completed involving 4,000 disabled people and their carers about their experiences of using self-directed support.

Personalisation

The term 'personalisation' appears in much of the literature about self-directed support. The UK Government has defined the term as follows: "A personalised system is one which is fair, accessible and responsive to individual needs of those who use services and their carers and one where users should be able to live independently, exercise control over their own life, and to participate as active and equal citizens in community life." (HM Government, 2007 cited in Manthorpe et al., 2007, p.12).

Some authors describe the meaning of 'personalisation' as ambiguous and contested (Beresford, 2014; Kendall & Cameron, 2013; Manthorpe et al., 2011). Such ambiguity reflects differences in the ideologies of the disabled people's movement and governments (Kendall and Cameron, 2013). For disabled people, personalisation means a "commitment to user control, involvement and empowerment" (Beresford, 2014, p.19). For governments, its meaning is grounded in neo-liberal philosophy (Junne & Huber, 2014), and managerialism and consumerism (Beresford, 2014). Such differences in meaning and interpretation are at the core of tensions underpinning the different 'agendas' of governments and disabled people in respect of self-directed support (Kendall & Cameron, 2013).

⁴³ The evaluation used a randomised controlled trial method.

⁴⁴ <http://www.in-control.org.uk/>

⁴⁵ Written in full, the POET survey is the Personal Evaluation Outcomes Tool.

Importance of context

Examination of the research findings indicates that self-directed support arrangements cannot be properly understood without consideration of the context within which such arrangements operate (Manthorpe et al., 2011). Laragy (2010) compared research on self-directed support arrangements for disabled people in four countries - Australia, Sweden, England and Scotland. She identifies important macro contextual factors as the country's values and expectations, the political context, and the resources provided. Micro contextual factors include how self-supported arrangements are configured, and the extent to which disabled people have a choice of supporting organisations and are involved in personal planning decisions.

Arrangements for self-directed support

The literature indicates that there are a number of potential arrangements for delivering self-directed supports, such as the following:

- A cash model in which people are given cash with few, if any, parameters for its use (Alakeson, 2010). This approach appears to be being used in some states in the US and in Germany (although it appears Germany may now have replaced this arrangement).
- Self-directed support is delivered by the government agency (federal, state, local) with statutory responsibility for disability support. For example, in the UK 433 local authorities are responsible for the delivery of disability supports in their area.
- An intermediary, independent agency is contracted by government agencies to provide brokerage services to disabled people (Duffy & Fulton, 2011).

Outcomes for disabled people

Studies examining the outcomes for disabled people from using self-directed supports are generally positive on measures such as enhanced social participation and overall satisfaction with life. For example, a US study based on a randomised controlled trial found that users of Cash and Counselling (i.e. disabled people who are eligible for Medicaid funding) in three US states were more likely to report overall satisfaction with life, than Medicaid recipients not using Cash and Counselling (Carlson, Foster, Dale & Brown, 2007). Cash and Counselling is described as being the most flexible of the US consumer directed programmes. Users may modify their care or homes, purchase household appliances, set the wage rate of workers, hire family members, hire workers to do household tasks as well as personal care, and use a small proportion for incidental expenses (ibid). Laragy (2010) reviewed social participation outcomes for disabled people in research studies done in Australia, Sweden, England and Scotland. The study found that self-directed support enhanced social participation regardless of impairment across all research examined.

Contributors to positive outcomes

Despite the generally positive correlations between self-directed supports and outcomes for disabled people such as enhanced life satisfaction, research has identified factors that may mitigate such positive results. An Australian study (Spall, McDonald & Zetlin, 2005 cited Laragy, 2010, p.132) found that social participation outcomes for people with a disability did not improve with the use of flexible funding. The poor outcomes were attributed to insufficient funding and a lack of availability of information and support. Results from the 2014 POET survey (In Control) identified associations between positive outcomes for users of self-directed supports and the following:

- People's experience of the process of setting up and managing a personal budget. People who found the process of getting and managing a personal budget easy were nearly three times more likely to report good outcomes.
- Whether people's views were included in this process. They were nearly twice as likely to report good outcomes as those who said their views were not included in the process.
- People had help to plan their support.
- People knew how much money was in their budget.

Facilitators and barriers

A review of research was commissioned by the Scottish Government to identify facilitators and barriers to the take-up and development of self-directed support. The authors note that barriers and facilitators are sometimes linked, for example, a lack of information is a barrier and accessible information is a facilitator. The study's findings are summarised below (Manthorpe et al., 2011, p.7-8).

Facilitators

- *For users of self-directed support:* Information needs to be accessible and widely available; Comprehensive support for users (and their carers) when they are thinking about change and want might be needed over time; Social networking among users to help share ideas and experiences; Plans to deal with possible emergencies.
- *For practitioners and carers:* Training and skill development so they can be better equipped to work with the new way of working.
- *System-level:* Clarity about the policy for users, carers and practitioners to understand what the changes are intended to bring about; Realistic action plans to translate aspirations into working practices.
- *Management and leadership:* Self-directed support champions to help with start-up and addressing issues as they arise.

Barriers

- *For users and carers:* The administrative burden of self-directed support may be too great; Users (carers) do not always want the responsibility of managing their own money or supports; Employment of support workers may be problematic; Employment of family members may not be easy or best; Funding allocation systems and the rules on expenditure are not always clear to users and carers.
- *Practice and practitioner levels:* Existing staff are concerned about their jobs and roles in the light of self-directed support; Fear that self-directed support may worsen working conditions for support workers or families.
- *Legal and procedural frameworks:* These may not be clear and result in users worrying about accountability and blame; Rules may vary and change, leading to confusion.
- *System-level:* Insufficient publicity and information; If the local third sector is not actively involved then practical and peer support for individuals may be insufficient; Processes and procedures can seem under-developed leading to uncertainty and confusion.

Real and potential limitations

Alongside the benefits of self-directed supports for disabled people identified in research, other authors highlight real and potential limitations of self-directed supports, such as the following.

- Boxall, Dowson & Beresford (2009) identify the potential for governments to use self-directed support to maintain the existing level of disability funding or to reduce it. This will leave the disabled person to meet the rising costs of their supports.
- Duffy & Fulton (2009) note the emergence of new professional roles and services designed to help disabled people to use self-directed support. These authors express the need for caution in professionalising roles that do not require it. They advocates for community-based approaches to provide such support, such as peer and community networks.
- While self-directed payments offer choice and control for disabled people in determining their support arrangements, there has been no real shift in power which still remains with the funder (Kendall & Cameron, 2013).
- Based on research done on self-directed supports in Germany, Junne & Huber (2014) state that such support transfers risks (specifically, risks associated with financial liability and liquidity) to disabled people. Similarly, Beresford (2014) writing about direct support arrangements in the UK suggests financial risk is being transferred to the disabled person and their family away from the government and the service support agency.
- There is potential risk associated from moving from 'enforced collectivism' which underpins traditional disability service provision, to 'enforced individualism' that may be associated with self-directed supports (Roulstone and Morgan, 2009, cited in Kendall and Cameron, 2013, p.3). Without adequate support, self-directed support could lead to social isolation, and issues of equity and access for disabled people (ibid).

Sustainability

Manthorpe et al., 2011 note that research on self-directed support focusses on implementation and less on the sustainability of self-directed funding and arrangements. They recommend that research be undertaken on effective ways for users of self-directed support to sustain positive outcomes over time.

Self-directed support does not of itself create change

A theme highlighted in the literature is that self-directed support arrangements do not of themselves create change towards greater choice and control for disabled people. Writing about risk enablement and safeguarding in the context of self-directed support, Carr (2011, p.131) emphasises the need for system-wide change: "It cannot be a bolt on solution to existing systems that do not have the person at the centre". A similar observation is made by O'Keeffe (2009, p.viii) in a report reviewing the implementation of the Cash and Counselling replication project by 12 US States: "It can take a long time for a state's care system to make a paradigm shift to a system that allows participants to have maximum control over the services they receive."

Appendix 3: Funding areas included in EIF

The funding areas included in EIF are those that are:

- assessed by the NASC. Areas that require assessment by another professional are excluded from EIF

and/or

- funded by the Ministry of Health. Any funding area that is funded by another agency such as the Ministry of Social Development (MSD), Ministry of Education, or District Health Boards (DHBs) is excluded.

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Table 14: Funding areas included and excluded in EIF

Included in EIF	Not included in EIF
<ul style="list-style-type: none"> • Home and Community Services • Supported Living • Carer Support • Respite (facility-based/in home respite) • Residential Services budgets 	<ul style="list-style-type: none"> • Equipment and Modification Services - assessment is done by a range of professionals such as occupational therapists and audiologists in DHBs, Behaviour Support Service, Child Development Service. • Behaviour Support Services - a Ministry of Health service that work with a disabled person and their support network to reduce the impact of a person's challenging behaviour. • Child Development Services - a Ministry of Health service providing early intervention for preschool children who have disabilities or are not achieving developmental milestones. • Day programmes - most are funded by MSD. Some are funded by the Ministry of Health but are not included in EIF • Orthotics - this is funded by the DHBs.