

# Demonstrating changes to disability support:

Synthesis of evaluation findings 2012—2014

Final report: September 2015

# Contents

<b>Acronyms and terms used in this report .....</b>	<b>4</b>
<b>Executive summary .....</b>	<b>5</b>
<b>About this report .....</b>	<b>11</b>
Evaluation team and approach .....	11
<b>What disabled people said they wanted .....</b>	<b>13</b>
<b>Government's response .....</b>	<b>13</b>
New Model for supporting disabled people .....	15
<b>What happened in the Demonstration .....</b>	<b>17</b>
Approach .....	17
Ministry of Health context .....	18
Summary of New Model components .....	19
Key findings about each New Model component.....	22
Response to the New Model components.....	27
What has changed as a result of the Demonstration .....	29
Key learning about implementation .....	31
<b>Assessment of fiscal neutrality .....</b>	<b>35</b>
Fiscal neutrality of Choice in Community Living .....	35
Potential for local area coordination to be fiscally neutral .....	37
<b>Discussion of key evaluation findings.....</b>	<b>45</b>
Evaluative assessment .....	46
Future challenges.....	49
<b>Conclusion .....</b>	<b>52</b>
<b>References.....</b>	<b>53</b>
<b>Appendix 1: How the New Model and existing DSS system work together .....</b>	<b>54</b>
<b>Appendix 2: People involved in developing outcome challenges.....</b>	<b>55</b>

The authors wish to thank everyone who participated in the evaluation. Tēnei te mihi atu ki a koutou katoa

Mathea Roorda, Mr Martin Sullivan, Julian King, Heather Nunns, Debbie Goodwin, Louise Were and Amy Hogan

## 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
EGL	Enabling Good Lives
FAT	Funding Allocation Tool
LACs	Local area coordinators
LWG	Local Working Group
MSD	Ministry of Social Development
NASC	Needs Assessment and Support Coordination organisation
NHI	National Health Index
NRG	National Reference Group
Kaupapa Māori	Based on Māori values and ways of doing things
Participant	Disabled person or whānau evaluation respondents who have participated in one or more of the New Model components
Tikanga	Custom, practice, procedure
Whānau	A disabled person's family

# Executive summary

This report synthesises the evaluation findings of the Demonstration of the New Model for Supporting Disabled People (the New Model) undertaken between 2012 and 2014. It brings together the evaluation findings about the individual components of the demonstration (Evaluate Research 2012, 2013, 2014, 2015) and examines them in light of the New Model's strategic intent, that is, to increase choice and control for disabled people over the support they receive and the lives they lead, enabling them to live an everyday life. The core components of the New Model included in the evaluation are shown below.

Disabled people and whānau were purposefully placed at the centre of the evaluation focus. Over the two years of the evaluation, 126 disabled people and whānau were interviewed about their experiences of engaging with one or more components of the New Model, of which 60 percent are New Zealand European and 36 percent are Māori.

## *What disabled people said they wanted*

An inquiry into the quality of care and service provision for people with disabilities was instigated by the New Zealand Government Social Services Select Committee in 2006. Some of the key issues identified in the Select Committee's report, presented to Government in 2008, included:

- Current government resource allocation, purchasing and service delivery arrangements unnecessarily limit people's ability to live the life they want
- The system tends to neglect non-government support and mainstream government services, which limits people's choices and results in poor value for money
- Complex cross-government arrangements make disabled people's lives more difficult than necessary
- Residential services unreasonably limit residents' choice and control over the supports they receive and the lives they lead.

## *Government's response*

The Government's response to the Social Services Select Committee report endorsed the Committee's underlying intention to adopt "a citizenship-based model for disability services that is based on improving disabled people's ability to live everyday lives through giving them increased choice and control over the support they receive and the lives they live". The Government's response to the Select Committee's recommendations included:

- directing officials to investigate how local area coordination-type processes might be implemented in New Zealand, and the desirability and feasibility of doing so
- expanding the availability of individualised funding arrangements in which people directly manage the support services they receive
- consultation with disabled people and their families, and with disability support providers, to explore community living choices for people with relatively high support needs
- agreeing that the monitoring of disability services should focus on quality of life outcomes for disabled people, rather than a 'tick-box' approach.

The Ministry of Health was charged with developing a New Model for Supporting Disabled People. The intended outcome of the New Model is to increase choice and control for disabled people over the support they receive and the lives they lead to assist them to live an everyday life. It aims to do

this through (1) a stronger focus on information and personal assistance (2) allocation of funding rather than services (3) more choice and control for people over the supports they purchase, and (4) stronger accountability arrangements.

The New Model includes a number of components, four of which were included in the evaluation as follows.

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### **Components of New Model included in the evaluation**

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*Local area coordinators (LACs)* walk alongside disabled people and families, help them work out what they want from life, help them build community networks. They also work with the community to support the inclusion of disabled people and families.

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*Choice in Community Living (CiCL)* 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.

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*Enhanced Individualised Funding (EIF)* is 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).

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*New approach for collecting information from disabled people and whānau* includes a new form that is filled out by disabled people and whānau on their own or with support. It is an alternative to the traditional approach involving an assessment by a NASC assessor.

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### ***What happened in the Demonstration***

The demonstration was implemented incrementally and in a developmental manner, so that adaption to arrangements and processes could occur over time. The Ministry worked closely with a National Reference Group (NRG) and local working groups (LWG) to implement the New Model. Members of these groups said that while they had been genuinely consulted, they did not regard this process as co-development (page 33).<sup>1</sup> At times the Ministry had to balance the value of their input with time pressures from senior managers and Ministers. The Ministry's willingness to stall progress so that critical issues could be discussed in more depth with the NRG is an indication of the Ministry's commitment to engaging with key external stakeholders.

The original intent of the demonstration was that the New Model would be implemented in its entirety to create system-level change to Disability Support Services (DSS) in the Bay of Plenty. Some way into the demonstration it became clear that the whole-of-DSS system change would not occur. This was due to the New Model operating alongside the existing DSS system in the Bay of Plenty. Instead, the demonstration showed how the individual components of the New Model work, and the extent of difference (if any) they make for disabled people and whānau.

The evaluation findings show that the concepts of local area coordination, EIF and CiCL as mechanisms for increasing choice and control of supports are sound. Overall, disabled people and whānau have responded favourably to the ideas of increased choice and control that underpin the New Model (page 27-31). However disabled people need to see the New Model changes working in practice before giving their full endorsement. There were a number of recurring themes in the evaluation interviews - people's wariness about the motives of the Ministry and politicians in

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<sup>1</sup> For ease of reference, the page number of the relevant page in the report is provided in brackets.

introducing the New Model and uncertainty about whether the New Model will live up to its promises. For some disabled people, this wariness was due to their concern that the New Model might become “another canned initiative”, while others made comments to the effect they had been promised positive changes in that past that had not been delivered. Fear of losing access to current supports can also be a barrier. Some need evidence that the New Model components will make a positive difference for them or their disabled family member before engaging with it.

Considerable resources have been invested in communicating the New Model changes to disabled people and disability stakeholder groups via the Ministry’s website, and other conduits such as workshops and conferences. Despite all these efforts, the evaluation identified people who had not seen or heard any information about the New Model (page 32). This is an indicator of the physical and social isolation of some disabled people. The findings indicate that a relationships-based approach is the most effective approach for conveying information to individual and community groups.

The findings about Enhanced Individualised Funding (EIF) and CiCL indicate that both are still in the early stages of implementation. Of the 233 disabled people who took up EIF in the period March 2012 - November 2014, 123 (57 percent) had been using EIF for less than 12 months, while 93 (43 percent) for 12 months or longer. The early state of CiCL is reflected in take-up figures - at the end of July 2014, 79 people had moved into a more independent living arrangement with support from CiCL (this figure is around half of the Ministry’s forecasted number for the two-year demonstration). Our interviews showed that while some disabled people are ‘ready to go’ with CiCL, other people and their whānau require a significant lead-in time to think about and plan to live independently. Consequently, the potential of CiCL and EIF for disabled people has yet to be fully tested. In the Bay of Plenty, 618 people had been in contact with a local area coordinator (LAC) for information for short-term assistance as at end January 2015. Of this group, 175 have then had an ongoing working relationship with a LAC. The lower than expected take-up of local area coordination in the Western Bay is in large part due to the lack of support from other parts of the DSS sector (page 27). Some DSS service providers and NASC personnel did not tell disabled people and whānau about the support a local area coordinator (LAC) could offer them (page 32).

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 realized (page 34). 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.

### *Changes for disabled people*

Disabled people and whānau were asked what (if anything) had changed for them as a result of using EIF and/or working with a LAC, or living in independent living arrangements with support from CiCL. A range of positive outcomes were described, such as increased flexibility and reliability

of funded supports, more independence and self-confidence, and being more involved in activities in the community (pages 29-31). Such changes are summed up by a disabled person who said: "I'm in control and calling the shots". The significance of these changes must be understood within the context of the daily lives of many disabled people before they engaged with the New Model components. When talking about the difference the New Model components are making for them, disabled people and whānau compared them to previous experiences of DSS services, including the lack of choice about when DSS support was provided and by whom; support workers who had strict parameters about what they could do; unreliable and inflexible services; and residential care eroding some people's sense of self-efficacy.

### *Evaluative assessment*

Our primary evaluative criterion is that disabled people have increased choice and control over the supports they receive and the lives they live. It is not possible to provide a standardised definition for 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. In the early stages of the New Model implementation, the evaluators facilitated a workshop with disabled people (members of the National Reference Group and local working group) and other key stakeholders, to identify expected behaviour, relationship and activity changes (referred to as 'outcome challenges') for four groups: disabled people, the Ministry, whānau and local communities. Our assessment of these challenges is as follows:

*Disabled people:* EIF and CiCL are sound mechanisms for providing disabled people with more choice and control over their paid supports, and the lives they live. Some aspects of these components require fine tuning, while a few other aspects require more significant work. For example, some disabled people require additional support to engage fully with EIF (page 45) and CiCL does not work for people with high and complex impairments who require full-time support (page 31). Disabled people and whānau who have worked with a local area coordinator have been supported to recognise their strengths, and pursue new activities to develop confidence.

*Ministry of Health:* The Ministry has begun a process to design and implement arrangements that align well with the principle of supporting disabled people to live everyday lives through increasing the choice and control they have over the support they receive and the lives they lead. Members of the National Reference Group and local working group in the Bay of Plenty said they had been genuinely consulted, although ideally they would have preferred input into the New Model design "from scratch".

*Whānau:* EIF and CiCL are helping parents to 'give over' their role as carer of their adult child to support workers chosen by them and their child. This is restoring 'ordinary' family relationships (e.g. parent-child) and improving family dynamics. Whānau who have worked with a local area coordinator report changes such as making better decisions, feeling like a better 'mum', developing new networks, finding role models for their disabled child, and changes in the home including how parents are relating to their disabled child.

*Local communities:* The evaluation findings indicate that natural supports do not often extend beyond immediate whānau. As part of efforts to address this, local area coordinators are working with the community which 'sits' around an individual disabled person. For example, a disabled child was being bullied by his classmates at school. The local area coordinator arranged for an adult



with the same impairment to talk to the children about what life is like for him living with the impairment.

### *Fiscal neutrality assessment*

The evaluation included an assessment of the extent to which CiCL has been fiscally neutral during the demonstration period, and an assessment of the potential for local area coordination to be fiscally neutral in the future.

*Local area coordination:* 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,<sup>2</sup> 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 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 access points. Further elapsed time, together with increased take-up of local area coordination is needed to more comprehensively evaluate fiscal impacts.

*Choice in Community Living:* 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. The 2016 funding reconciliation is likely to yield more robust cost data, as it will include greater numbers of people as well as an extra year's expenditure data. Expenditure data<sup>3</sup> from the Ministry of Social Development (MSD) was not provided in time to be included in the evaluation.

### *Future challenges going forward*

Continuing the transformation agenda on which the New Model is based will require significant changes to existing DSS structures, processes and organisational cultures. Given the substantive nature of such change, it will take time. A potential risk is that having got this far in demonstrating how the DSS system could be transformed, fiscal pressures, efficiency concerns and/or risk

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<sup>2</sup> 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.

<sup>3</sup> 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.

avoidance may alter the 'transforming' agenda to 'tweaking' the existing system, thereby maintaining underlying structures of power and control, with the result that the potential benefits for people with disabilities, their families, and taxpayers, are not fully realised. Another potential risk is that due to financial constraints, mechanisms such as EIF and CiCL are implemented nation-wide without the level of support needed by some disabled people to use them to their potential. A third potential risk is that the transformational vision for disabled people underpinning the New Model may become diluted as new policy priorities emerge for the Ministry. It is vital to the success of the New Model that the transformation of disability supports across government agencies, that had its beginnings in the Social Services Select Committee's report presented to Government in 2008, is sustained.

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.

The New Model demonstration represents the beginning of a transformative change to disability supports in New Zealand. It is important that the transformation of disability supports that had its beginnings in the Social Services Select Committee's report presented to Government in 2008 is sustained. It is equally important that the hopes and expectations of disabled people and whānau about living an everyday life that have been encouraged by the New Model demonstration are not disappointed.

# About this report

This report synthesises the evaluation findings of the Demonstration of the New Model for Supporting Disabled People (the New Model) undertaken between 2012 and 2014. It summarises the key evaluation findings about the individual components of the demonstration (Evaluate Research 2012, 2013, 2014, 2015) and examines them in light of the New Model's strategic intent, namely, to increase choice and control for disabled people over the support they receive and the lives they lead to assist them to live an everyday life. The report begins with an overview of the evaluation approach. The key findings are then discussed under the following headings:

- What disabled people said they wanted
- The Government's response: The New Model Demonstration
- What happened in the Demonstration
- Assessment of fiscal neutrality for Choice in Community Living and local area coordination
- Discussion of key evaluation findings.

## Evaluation team and approach

The Evaluate Research team included people living with impairments, lived experience of disability, and Māori. The team also included academic expertise in disability studies, evaluation expertise, and economic analysis expertise.

The original intention was to evaluate the demonstration of the New Model in its entirety. However during the demonstration it became clear that the existing DSS system in the demonstration site was not being changed to the extent that was originally envisaged (this is discussed further below). Consequently, the evaluation examined each of the component parts of the New Model in respect of the objective to increase choice and control for disabled people over the support they receive and the lives they live. The evaluation also examined the extent to which local area coordination and Choice in Community Living (CiCL) may be provided on a fiscally neutral basis.

The evaluation approach also took into account the evolving, adaptive nature of the New Model demonstration by focusing on specific components at different points in time over the two years of the evaluation. This work was reported at regular intervals to inform the New Model's implementation.<sup>4</sup>

Disabled people and whānau were purposefully placed at the centre of the evaluation focus. Over the two years of the evaluation, 126 disabled people and whānau were interviewed about their experiences of engaging with one or more components of the New Model, of whom four were interviewed twice over the period. Of the 126 participants, 36 percent are Māori, 60 percent are New Zealand European, three percent other and one percent is of unknown ethnicity.<sup>5 6</sup>

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

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<sup>4</sup> Evaluate Research 2012, 2013, 2014, 2105.

<sup>5</sup> A participant refers to a disabled person or whānau evaluation respondents who have participated in one or more of the New Model components.

<sup>6</sup> A detailed description of the methodology can be found in each of the evaluation reports.

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 Services (DSS) and still 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 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.

Over the two years of the evaluation we also interviewed a range of stakeholders in the Bay of Plenty, Waikato and Auckland, including the National Reference Group, Local Working Group, the local Needs Assessment and Support Coordination organisations (NASCs), DSS service providers, and social service providers.

In this report, the term 'participant' is used for the disabled people and 'whānau' (the disabled person's family members) who were interviewed. The term 'stakeholder' is used for people we interviewed who are working with disabled people in variety of roles in the demonstration sites of Bay of Plenty, and Waikato and Auckland (for CiCL only).<sup>7</sup>

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<sup>7</sup> Stakeholders include but are not limited to the Needs Assessment and Support Coordination organisations (NASCs), CiCL providers, the EIF Host organisation, service providers, disability support and advocacy organisations, Inclusion Aotearoa (the organisation contracted by the Ministry of Health to support implementation of the New Model, Local Area Coordinators, Synergia (the company developing the Funding Allocation Tool).

# What disabled people said they wanted

An inquiry into the quality of care and service provision for people with disabilities was instigated by the New Zealand Government Social Services Select Committee in May 2006.<sup>8</sup> The inquiry received 152 submissions from individuals and organisations. Submissions were examined in light of the New Zealand Disability Strategy 2001 which was intended as a guide for the development of disability support by government agencies.<sup>9</sup> The strategy is based on a social model of disability which recognises that attitudinal and environmental barriers created by society hinder the independence and participation of people with impairments.<sup>10</sup> The strategy aims to ensure that New Zealand society is inclusive, enabling people with impairments to be valued and participate in community life to the extent they wish.<sup>11</sup>

The Social Services Select Committee's report was presented to Government in 2008.<sup>12</sup> Some of the key issues identified in the report include the following.<sup>13</sup>

- Current government resource allocation, purchasing and service delivery arrangements unnecessarily limit people's ability to live the life they want
- The system tends to neglect non-government support and mainstream government services, which limits people's choices and results in poor value for money
- Complex cross-government arrangements make disabled people's lives more difficult than necessary
- Residential services unreasonably limit residents' choice and control over the supports they receive and the lives they lead.

## Government's response

The Government's response to the Social Services Select Committee report endorsed the Committee's underlying intention to adopt "a citizenship-based model for disability services that is based on improving disabled people's ability to live everyday lives through giving them increased choice and control over the support they receive and the lives they live".<sup>14</sup> The paper stressed the need to use existing resources in more cost-effective ways rather than introducing major structural change or increasing funding levels. The Government's response to the Select Committee's 22 recommendations included:

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<sup>8</sup> New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disabilities, 2006.

<sup>9</sup> Inquiry into the quality of care and service provision for people with disabilities. Report of the Social Services Committee, September 2008, p.9

<sup>10</sup> The social model of disability is contrasted to the medical model of disability which describes people with impairments as suffering from illness and disease, often requiring medical treatments.

<sup>11</sup> The New Zealand Disability Strategy: Making a World of Difference, Whakanui Oranga. Minister of Disability Issues, April 2001.

<sup>12</sup> [http://www.parliament.nz/resource/en-nz/48DBSCH\\_SCR4194\\_1/cb220d2e3ba25dc33dec0b28b29b30578d110dd5](http://www.parliament.nz/resource/en-nz/48DBSCH_SCR4194_1/cb220d2e3ba25dc33dec0b28b29b30578d110dd5)

<sup>13</sup> Ministry of Health's New Model for Supporting Disabled People. Cabinet Social Policy Committee paper, 15 June 2010 (CAB Min (10) 23/4A).

<sup>14</sup> Government Response to the Report of the Social Services Select Committee on its Inquiry into the Quality of Care and services Provision for People with Disabilities (February 2009), p.1.

- establishing a Ministerial Committee on Disability Issues (“the Ministerial Committee”), to be chaired by the Minister for Disability Issues. The Committee’s purpose is to provide a coherent overall direction for disability issues across government, and to make decisions about the implementation of the work programme arising from the Government response paper
- directing officials to investigate how local area coordination-type processes might be implemented in New Zealand, and the desirability and feasibility of doing so
- expanding the availability of individualised funding arrangements in which people directly manage the support services they receive
- consultation with disabled people and their families, and with disability support providers, to explore community living choices for people with relatively high support needs
- agreeing that the monitoring of disability services should focus on quality of life outcomes for disabled people, rather than a ‘tick-box’ approach.

During 2009 the Ministry investigated the use of individualised funding and local area coordination for disabled people in other countries. This led the Ministry to realise that while introducing local area coordination would be of benefit, such arrangements would not address all of the issues identified in the Select Committee Inquiry. The Ministry reported this to the Ministerial Committee in September 2009 which agreed to the development of a new model for supporting people eligible for DSS funding.

In May 2010 the Ministerial Committee agreed in principle to a paper from the Ministry proposing a new model for managing its disability support funding responsibilities for people with intellectual, physical and/or sensory disabilities (referred to as ‘the New Model’, as described in the following section). The Ministerial Committee also agreed that a demonstration project that included the core elements of the New Model be implemented before decisions would be made on a wider roll-out (referred to as ‘the demonstration’).

The Government identified the following parameters for the New Model demonstration. It was required to:

- be implemented within current DSS baseline funding allocations and be fiscally neutral.
- involve the Ministry of Health only (excluding other government agencies that disabled people and whānau work with such as the Ministry of Social Development for income support and housing, and the Ministry of Education in respect of school-aged children).
- implement local area coordination according to the Australian local area coordination approach.<sup>15</sup>

Baseline research was conducted by independent researchers in early 2011 about the experiences of disabled people and their families with disability support services in the Western Bay of Plenty (Newton, K., Wehipeihana, N., Proctor, E., & Tuagalu, C., May 2011). Twenty-four people with disabilities and their families and whānau receiving non-residential disability support services funded by the Ministry were interviewed. The people interviewed said it was difficult to live a good life, as much of the time they were unable to do everyday things in everyday ways. Some of the difficulties they experienced were beyond the control of the Ministry but others were related to the current disability support services and system. They identified the following as changes that would

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<sup>15</sup> In 2010 the Australian approach to local area coordination was described as being community-based, drawing on community networks and local initiatives. This is in contrast to local area coordination arrangements adopted by some local authorities in the UK where elements of the local area coordination approach have been ‘tacked onto’ existing government systems and structures. Literature suggests that this latter approach is less likely to be successful for disabled people (Broad 2012; Vincent, 2010).

assist them to live a good life: better information and access to information about supports and services; support to access formal and informal (natural) services and supports; more control, flexibility and choice over the disability services and supports they receive; tikanga Māori protocols and practices to be more consistently and broadly exercised within services.

## New Model for supporting disabled people

The New Model for Supporting Disabled People is based on a social model of disability which understands disability as the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. This means the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others (People with Disability Australia).<sup>16</sup> As this definition suggests, a social model of disability is premised on transformative perspectives about disabled people and communities, such as inclusion, personal development and self-determination (Chenoweth & Clements, 2009).

The intended outcome of the New Model is to increase choice and control for disabled people over the support they receive and the lives they lead to assist them to live an everyday life. This statement expresses the nature and extent of change the New Model is aiming to achieve, namely:

- A focus on the individual disabled person, rather than DSS services and the providers who deliver them.
- A more holistic understanding of the disabled person and their whānau, rather than just focusing on their impairment.
- Transferring power and control from DSS providers to disabled people.
- Moving away from inputs and outputs (i.e. hours of support and support packages) to outcomes (i.e. the difference funded support will make for the individual disabled person).
- Recognition that funded supports can assist disabled people to work towards personal goals and an everyday life (whatever that means for the individual).

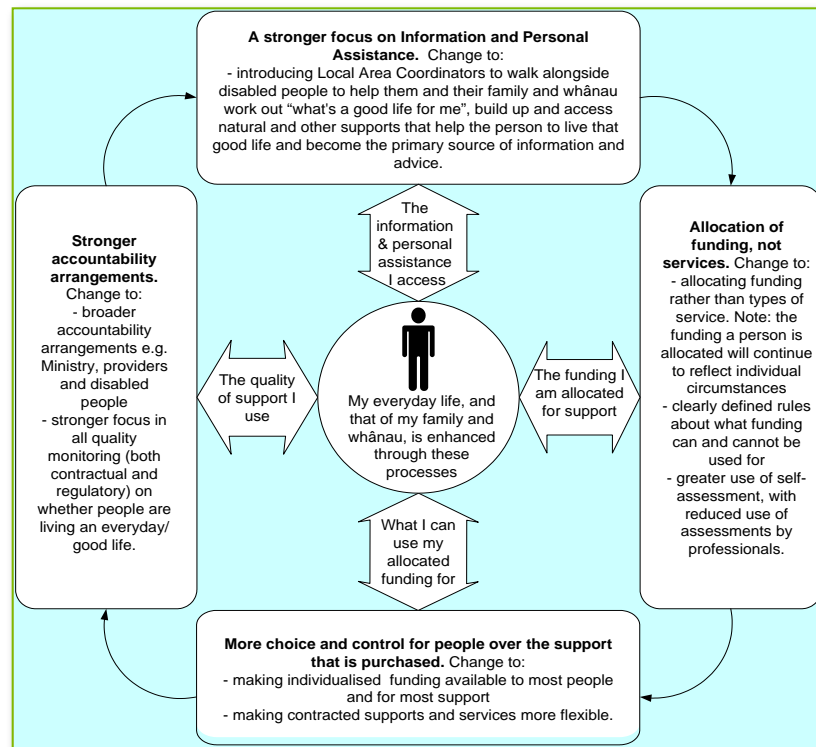
The New Model aims to increase choice and control for disabled people through (1) a stronger focus on information and personal assistance (2) allocation of funding rather than services (3) more choice and control for people over the supports they purchase, and (4) stronger accountability arrangements. Disabled people are placed at the centre of the New Model, as depicted in Figure 1 which was used by the Ministry to communicate the New Model to disabled people, whānau and other stakeholders.<sup>17</sup> Table 1 summarises the intended New Model changes.

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<sup>16</sup> <http://www.pwd.org.au/student-section/the-social-model-of-disability.html>.

<sup>17</sup> <http://www.health.govt.nz/our-work/disability-services/new-model-supporting-disabled-people/updates-new-model-supporting-disabled-people>.

**Figure 1: New Model as depicted by the Ministry of Health (2011)**



**Table 1: Intended New Model changes**

From this:	To this:
Deficit-based approach to disability	Strengths-based approach to disability
Top-down, system-centred	Bottom-up, person-centered, community-level
Rules-based packages of support	Principles-based
Inputs-focused: services to address need	Outcomes-focused: supports to live an everyday life
Disabled people lack opportunities to participate in the community	Disabled people connected into and participate in the community
Professionals are the experts about a person’s impairment	Disabled person is the expert about their impairment
NASC decides how a person’s DSS allocation will be used	Disabled person decides how their DSS allocation will be spent
Service provider decides who, how and when disabled people’s disability supports are provided	Disabled people decide who, how and when disability supports are provided
Focus on paid supports	Natural supports built up to complement paid supports
Disability supports based on a ‘set menu’ of supports	Opportunities for innovation and flexible support, encompassing paid and natural supports



The New Model is part of a broader vision (out of scope of the demonstration project) that includes coordinated disability supports across government agencies, and inclusive communities into which disabled people are well connected.

The Western Bay of Plenty (including Tauranga) was selected for the demonstration for a number of reasons. The region has a diverse population with a relatively high proportion of younger people and a significant proportion of Māori. It also has a mix of urban and rural areas. The demonstration site was extended to the Eastern Bay of Plenty with the introduction of local area coordination in March 2013.

Choice in Community Living (CiCL) was added to the demonstration in late 2012 as it aligned with the New Model programme. The initiative aims to increase the range of community living choices available to disabled people with relatively high support needs. Two sites were selected for the demonstration of CiCL: Auckland and Waikato.

## What happened in the Demonstration

This section discusses the key findings about what happened in the demonstration (September 2011 – July 2014). The section starts with a brief description of the approach which underpinned the demonstration, followed by an overview of the New Model components and their take-up by disabled people. A summary of the key findings is then provided.

### Approach

The design and implementation of the New Model demonstration was based on an approach consisting of three features as follows.

#### *Principle-based*

The New Model is based on the principle of supporting disabled people to live everyday lives through increasing the choice and control they have over the support they receive and the lives they lead.<sup>18</sup> This principle shaped the demonstration's implementation.

#### *Developmental*

The demonstration was implemented incrementally and in a developmental manner. While overseas experience of similar disability change initiatives was drawn upon, the developmental aspect enabled learning and adaption for the New Zealand context to occur. The New Model components were introduced progressively over the two years: local area coordination (late 2011), Choice in Community Living (late 2012), Enhanced Individualised Funding (early 2013), supported self assessment and the Funding Allocation Tool (mid 2013). The rationale for this incremental approach is discussed in the section: "Ministry of Health context", on page 18.

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<sup>18</sup> Ministry of Health's New Model for Supporting Disabled People. Cabinet Social Policy Committee paper, 15 June 2010 (CAB Min (10) 23/4A).

### Co-development approach

The Ministry announced its intention to use a co-development approach to the implementation of the New Model, defined as “a process of working together to explore solutions to problems and other ways of doing things through cooperation”.<sup>19</sup> Two groups were the primary mechanism for such co-development - a National Reference Group (NRG) and a Local Working Group (LWG).

Following a nomination process, the NRG was established in April 2011 to provide strategic input into the planning and implementation of the New Model.<sup>20</sup> The 15 members included people and whānau with experience of physical, intellectual and sensory impairment and complex conditions, and Māori and Pasifika members. People experienced in disability services such as Needs Assessment and Service Coordination (NASC), Supported Living, and Disability Information and Advisory Services (DIAS) were also on the NRG. The NRG met until July 2014, providing strategic advice on the values and principles underpinning the New Model, supported self assessment, stakeholder accountability, self-directed purchasing guidelines, local area coordination, principles of resource allocation and functions, roles and responsibilities and broader workforce issues.

A Local Working Group (LWG) consisting of disabled people and people working in the disability sector in the Western Bay of Plenty was formed in February 2011. The LWG provided advice on the New Model components as they were implemented in the demonstration site, for example, ‘on the ground’ advice on local area coordination based on their knowledge of the area, enhanced individualised funding / host providers, self-directed purchasing, funding allocation, supported self-assessment and roles and functions. During 2011 the LWG met twice a month on average. There were fewer meetings in 2012 (two monthly, on average) as the demonstration project progressed. Members from the Eastern Bay were added to the LWG when local area coordination began in the Eastern Bay in April 2013. By then the Ministry’s need for advice in design and implementation had lessened, and meetings were intermittent.

The experience of NRG and LWG members of co-development is discussed on page 33.

### Ministry of Health context

The New Model Programme Team (“programme team”) consisting of officials from Disability Support Services (DSS) was responsible for implementing the Demonstration Project. The New Model was to be implemented alongside the existing DSS system in the Western Bay of Plenty, and within existing staff baselines. We observed the vision and efforts of the programme team to create the changes underpinning the New Model, despite working on the demonstration project in a part-time capacity (between .3 and .5 FTEs) around their existing roles (with the exception of the programme leader who worked fulltime on the Bay of Plenty project). The programme team was overseen by the New Model Steering Group consisting of senior Ministry officials.

The decision to implement the Demonstration Project in an incremental manner was for practical reasons. Firstly, it was important to continue to offer services and supports for those people who wished to continue using them. Secondly, given the extent of change implicit in the New Model design, it was prudent that the implementation was done in a measured manner. Further,

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<sup>19</sup> The New Model for Supporting Disabled People – The Story So Far. Prepared by Inclusion Aotearoa on behalf of the Ministry of Health, March 2012, p.9.

<sup>20</sup> <http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/new-model-supporting-disabled-people/updates-new-model-supporting-disabled-people>

introducing each of the components progressively was required due to the limited resourcing available for the demonstration. Also as noted above, this incremental approach enabled learning to occur and ongoing enhancements to be made as required.

An unavoidable downside of this incremental approach was that it created a jigsaw effect (the individual components being pieces of the jigsaw). Parts of the jigsaw were in place while other parts were yet to be put in place, creating gaps. For example, Enhanced Individualised Funding started before the Funding Allocation Tool was in place, requiring the NASC to translate service-based allocations into an EIF allocation.

Over the two years of the Demonstration Project, we observed the Programme Team come under pressure from internal and external sources to increase the pace of implementation and speed of take-up by disabled people. Despite limited additional resource, the Programme Team managed this pressure successfully to ensure it did not impact on disabled people.

Further, the co-development approach that the Ministry had committed to with the NRG and LWG required time (this is described further in the section below titled “Co-development”).

## Summary of New Model components

The New Model components included in the evaluation scope are summarised in Table 2. Inclusion Aotearoa was selected in November 2011 (following a tendering process) as the implementation support organisation to help the Ministry to implement the demonstration. Their responsibilities included stakeholder and community engagement, establishing local coordination arrangements (including setting up LAC offices), organising and facilitating meetings of the NRG and LWG, local and national communications, and strategic advice to the Ministry.

**Table 2: Core components of the New Model included in the evaluation scope**

New Model component
<p><i>Local area coordination</i> implemented in Western Bay of Plenty late 2011; Eastern Bay of Plenty, early 2013</p> <p>The purpose of local area coordination is to support people who have a disability and their families to access community opportunities that will enhance the capacity of the person with a disability to build supportive relationships, to enhance family and whānau life, and to participate in and contribute to the life of their community. Local area coordinators (LACs) walk alongside disabled people, help them work out what they want from life, help them build community networks. They also work with the community to support the inclusion of disabled people and families.</p> <p>The desired outcomes of local area coordination are that disabled people and/or their families and whānau:</p> <ul style="list-style-type: none"> <li>• receive support that reflects a strength-based approach, is flexible enough to meet changing needs and supports valued roles for the disabled person</li> <li>• have natural supports around them to assist them achieve their vision and their goals</li> <li>• have access to community support which is appropriate to their needs and goals</li> <li>• receive quality support and services</li> <li>• have better access to relevant information about available support, services and funding.</li> </ul>
<p><i>Enhanced Individualised Funding (EIF)</i> implemented in Bay of Plenty early 2013</p> <p>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).</p> <p>EIF 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 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).</p>
<p><i>New approach for collecting information from disabled people and whānau</i> implemented in Bay of Plenty, late 2013</p> <p>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. It is an alternative to the traditional approach involving an assessment by a NASC assessor.</p>
<p><i>Choice in Community Living (CiCL)</i> implemented in Auckland and Waikato, late 2012</p> <p>It 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.</p> <p>People eligible for CiCL include those who are in residential care or have disability support needs similar to those living in residential care, who live with family/whānau or where their current living situation is unsustainable. People must also be eligible for disability support services funded by the Ministry of Health (the Ministry).</p> <p>People access CiCL through the Taikura Needs Assessment Service Coordination (NASC) based in Auckland, or the DSL NASC, based in the Waikato. Once people have been assessed by the NASC as eligible, they are provided with information about the amount of funding they can access from the Ministry, and a list of support agencies in their area who can help them develop a person-centred plan and support their move into independent living.</p> <p>CiCL involved changes to the Ministry's residential services' contracting and funding arrangements as follows:</p> <ul style="list-style-type: none"> <li>• The Ministry's contracts with CiCL providers cover only the cost of support, rather than the cost of</li> </ul>

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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.
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#### *Funding Allocation Tool (FAT)* implemented in the Bay of Plenty, mid 2013

This is a technical tool to replace the Support Package allocation used by the NASC to determine funding allocations. The FAT is designed to make the allocation of funding to address unmet need more objective and transparent. The information on the UYYS links directly into the FAT. Note: the FAT was out of scope of this evaluation.

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#### *Purchasing Guidelines and Panel* implemented mid 2013

The purchasing of supports, products and/or arrangements in respect of CiCL and EIF must meet criteria as set out in the Purchasing Guidelines produced by the Ministry:<sup>21</sup>

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.

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. A Purchasing Panel is responsible for the Purchasing Guidelines and considering purchasing requests submitted by the EIF Host or CiCL provider on behalf of a disabled person. The intention was that the panel be made up of Ministry officials (the New Model Programme Leader, the Disability Policy Manager, and one of the Disability Support Services team managers), two disabled people (external members) and a family/whānau (external member). As at the end of 2014 the three external panel members had yet to be appointed.

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. (The EIF Host is also accountable for appropriate expenditure of funds). In situations where an EIF Host or CiCL provider is uncertain about a proposed purchase, a request is submitted to the Purchasing Panel. 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. 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.

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<sup>21</sup> <http://www.health.govt.nz/publication/purchasing-guidelines-new-model-supporting-disabled-people>.

## Key findings about each New Model component

This section provides an overview about the key findings for each component of the New Model that were included in the evaluation focus.

### *Local area coordination*

The Minister of Health formally launched the New Model in the Western Bay on 23 August 2011. Local area coordination was the first component to be demonstrated. Three local area coordinators (LACs) located in Te Puke, Tauranga City, Bethlehem and a LAC Supervisor in Katikati began working in September 2011. The LACs were initially contracted as independent contractors to the Ministry of Health. This arrangement was subsequently changed when Inclusion Aotearoa became the LAC employer in March 2013.

In September 2012 the demonstration site was extended to the Eastern Bay of Plenty. An experienced LAC manager was recruited from Australia and began work in March 2013, based in the LAC office in Whakatane. A total of 7.5 FTEs were allocated to the LAC and manager positions and a part-time administration assistant. Four LACs worked in the Western Bay and three new LACs (2 FTEs) plus the manager began work in the Eastern Bay in April 2013. One LAC was based in Opotiki, another worked out of the Whakatane office, and the third was rurally-based. In mid 2014 the role of Inclusion Aotearoa as the implementation organisation for the demonstration ended. Following a tender process, Imagine Better was contracted to provide local area coordination across the Western and Eastern Bay of Plenty, and Lakes District.<sup>22</sup>

In the first two years (September 2011 – end June 2013), 248 disabled people had been in contact with a LAC (i.e. received Level 1 support) and 68 people had an ongoing working relationship with a LAC (referred to as 'Level 2 support'). By January 2015, the number of people engaged with Level 2 support had increased to 175.

Despite significant publicity efforts by the Ministry and local area coordinators (e.g. 'grass-roots' communication strategies such as information in doctors' waiting rooms, flyers sent to schools and published stories from those using LACs), the evaluation findings indicate that local area coordination was not widely known across the disability community. The most recent interviews with disabled people and whānau (July-August 2014) identified people who did not know about local area coordination despite having worked with the NASC and EIF Host. We heard about situations where the person may have found working with a LAC useful, such as helping people having difficulty recruiting support workers. Of particular concern were at least three families in challenging situations who may have benefitted from working with a LAC if they had been told about local area coordination by the NASC or EIF Host. The lower than expected take-up of local area coordination is also due to the lack of support from other parts of the DSS sector (explained further in the section 'Disability sector: reaction to the New Model').

The evaluation findings indicate that the practice of local area coordination in the Demonstration Project was aligned with the original Australian approach, specifically:

- 1 The values-based practice of LACs which is based on a charter and set of principles.
- 2 The LACs are locally-based and work out of community bases.

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<sup>22</sup> <http://www.imaginebetter.co.nz/lac>

- 3 Opportunities and solutions are determined and driven by disabled people and whānau in their time, rather than a 'top-down' approach based on a menu of options.
- 4 Employment and accountability arrangements support person-centered, community-based practice.

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

Eight dimensions of value are identified from interviews with disabled people who had or are using local area coordination, including people developing their own vision of a good life; recognising their own strengths; getting information about what is available; making use of, and building on networks; strengthening their voice; taking practical action for change; taking up new opportunities in the community; accessing enhanced individualized funding and support services.

### *Enhanced Individualised Funding*

The 233 disabled people who had 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 were using EIF - 14 percent of Māori and 13 percent of NZ European. Fifty-seven percent of disabled people had been using EIF for less than 12 months, while 43 percent had been using EIF for 12 months or longer. All but three of the 32 disabled people and whānau we interviewed had chosen the EIF Host to manage the EIF payroll on their behalf. Those who were 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.

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.

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.



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.

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.

### *New approach for collecting information from disabled people and whānau*

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. 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 trialled 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 Evalue Research in 2012. 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. The FAT is 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 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).

Ten of the 32 participants we interviewed in September - October 2014 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. The most frequent comments about the form were about its length, the repetitiveness of information requested, and the amount of time it took to complete. Participants provided a range of responses - one said the “the questions were easy to answer”, while others called the form “a challenge” or “confusing”. It is not possible to draw any definitive conclusions about the effectiveness of the new process for disabled people given the



small number of participants in our sample who had used the form and the range of their responses.

### *Choice in Community Living*

The Choice in Community Living (CiCL) initiative was developed after consultation with disabled people, their families and whānau, and support providers. People eligible for CiCL include those who are in residential care or have disability support needs similar to those living in residential care, who live with family/whānau or where their current living situation is unsustainable. People must also be eligible for disability support services funded by the Ministry of Health (the Ministry).

People access CiCL through the Taikura Needs Assessment Service Coordination (NASC), based in Auckland, or the DSL NASC, based in the Waikato. Once people have been assessed by the NASC as eligible, they are provided with information about the amount of funding they can access from the Ministry, and a list of support agencies that can help them develop a person-centred plan and support their move into independent living. The NASC allocates a funding package<sup>23</sup> for each person moving to CiCL. This funding is paid to the provider, to be used to commission a range of different types of disability support for the person according to their plan.

An expectation by the Ministry was that the eight CiCL support agencies share ideas and resources during the demonstration project. This occurred through regular meetings that brought together not just agency staff, but also staff from the two NASCs, Ministry of Health, Ministry of Social Development as well as the CiCL Project Manager. Support agency respondents reported that these meetings were useful and involved “open and transparent conversations”.

At the end of July 2014, 79 people had moved into a more independent living arrangement with support from CiCL (this figure is well below the Ministry’s forecast of 150 people participating during the two-year demonstration). 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.

Eighteen CiCL participants (disabled people and their whānau) agreed to be interviewed about their experiences. 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.

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<sup>23</sup> The guidelines on what funding can be used for are based on three criteria: 1) they are a disability support; 2) they contribute towards the achievement of outcomes that are identified in a person’s individual support plan; and 3) they are within the scope of relevant Ministry policies and responsibilities.

- 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.

Participants identified three dimensions of value directly resulting from CiCL, namely, control (e.g. being able to select their own staff), choice (e.g. doing everyday activities on their own, when they choose), having flexible funding (e.g. using funding to achieve personal goals, such as being involved in community activities). 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, participants 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. Whānau and CiCL support agency 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 that “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.

## *Purchasing Guidelines*

Two issues have arisen regarding the Purchasing Guidelines - the first issue concerns their implementation, and the second is about their interpretation. Both issues can be regarded as 'teething' issues associated with the introduction of new requirements and processes, and as such need to be worked through with the relevant parties.

The first issue concerns the role that the EIF Host is required to adopt in relation to a purchasing request. The Ministry's accountability requirements of the EIF Host require the EIF Host to get 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. A stakeholder described the impact 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'". This issue is 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.

Secondly, 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 the NASC and/or the EIF coach and/or the LAC regard as being within the Purchasing Guidelines, which has subsequently been turned down by the Purchasing Panel 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).

## *Response to the New Model components*

The response to the New Model is discussed from two perspectives - disabled people and whānau, and the disability sector in the Bay of Plenty.

### *Disabled people and whānau*

Overall, disabled people and whānau have responded favourably to the ideas of increased choice and control that underpin the New Model. Since the evaluation focus was on the New Model components, our interviews with disabled people and whānau did not seek any information about DSS services. However in the course of telling their story about their experiences of local area coordination and/or EIF or CiCL, people talked (unprompted) about their experiences of DSS services and residential care. Recurring themes were about inflexible and unreliable services, lack of appropriate DSS services for school-leavers who had received mainstream schooling, the impact of institutional living on personal capability, and poorly trained carers and/or carers who lack

understanding of a strengths-based approach. Some disabled people had had such negative experiences of DSS services that they had chosen to opt out of funded support (some of whom had opted back into DSS support as a result of working with a local area coordinator).

The positive changes that the New Model represents are supported by disabled people and whānau we interviewed. However they need to see the New Model changes working in practice before giving their full endorsement. There were a number of recurring themes in the interviews - people's wariness about the motives of the Ministry and politicians in introducing the New Model and uncertainty whether the New Model will live up to its promises. For some disabled people, this wariness was due to their concern that the New Model might become "another canned initiative", while others made comments to the effect they had been promised positive changes in that past that had not been delivered. Some need evidence that the New Model components will make a positive difference for them or their disabled family member before engaging with it. This was the case with some whānau who investigated CiCL but decided against it once they realised the DSS allocation would not provide the level of care they believed was required for their family members.

### *Bay of Plenty disability sector*

There is an active and long established disability sector in the Western Bay consisting of formal and informal networks.<sup>24</sup> Some DSS providers and others in the sector perceived the introduction of the New Model as the Ministry being critical of the performance of the current DSS system and providers. Their view was that the Ministry did not value the work of providers or recognise their efforts to align their practices to a social model of disability (for example, some DSS providers said they were already offering local area coordination-type services).

This resulted in a high level of criticism on the part of many DSS providers and other people working in the sector in the Western Bay, aimed in the most part at the Ministry rather than the New Model per se. This negative reaction was described in some of our interviews with other stakeholders who reported examples of "patch protection" behavior by some DSS providers, particularly in relation to offering disabled people and whānau the option of local area coordination.<sup>25</sup> Such less than positive reactions are not surprising given the DSS sector is based on a competitive purchasing model which fosters competitive behavior among providers, including provider 'ownership' of individual disabled people.

A different response occurred in the Eastern Bay where many disability-related and social services are provided from bases out of the area, such as Tauranga and Rotorua.<sup>26</sup> Stakeholders talked about the lack of services for people in the Eastern Bay, especially those living in rural areas. There appeared to be a much greater level of collaboration and cooperation among stakeholders in the Eastern Bay. In particular, the local NASC staff support local area coordination and work collaboratively with the LACs. Stakeholders from social service organisations in the Eastern Bay (whose clients include disabled people) described local area coordination as much needed for disabled people in the area.

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<sup>24</sup> Such networks include the Western Bay Disability Support Trust consisting of 25 member organisations which holds monthly meetings for disabled people and people working in the sector in the Western Bay of Plenty.

<sup>25</sup> This was confirmed by local area coordination referral data examined by the evaluators in mid - 2013. In the period from mid-2011 when local area coordination started to 30 June 2013, DSS service providers (including the NASC) had referred half the number of people to a LAC compared to other service providers (i.e. those who do not receive DSS funding).

<sup>26</sup> Community Profile of the Eastern Bay of Plenty. Prepared for the Ministry of Health by Inclusion Aotearoa, June 2012.

## What has changed as a result of the Demonstration

### *For disabled people*

Our interviews asked disabled people and whānau about what (if anything) had changed for them as a result of using EIF and/or working with a LAC, or living in independent living arrangements with support from CiCL. Table 3 illustrates some of the changes described. These changes are summed up by a disabled person who said: “I’m in control and calling the shots”. As noted above, the New Model components are still in the early days of implementation so the changes described may not be reflective of change that may occur over time.

The significance of the changes summarised in Table 3 must be understood within the context of the daily lives of many disabled people before they engaged with the New Model components. When talking about the difference the New Model components are making for them, disabled people and whānau compared them to previous experiences of DSS services, including the lack of choice about when DSS support was provided and by whom; support workers who had strict parameters about what they could do; unreliable and inflexible services; and residential care eroding some people’s sense of self-efficacy.

We made a noteworthy observation while interviewing disabled people and whānau about their experiences of local area coordination. In telling their stories, the LAC’s role was visible but not at the forefront, indicating disabled people and whānau had strong ownership of their ideas and decisions about how they want to live their lives.

**Table 3: Changes for disabled people**

Local Area Coordination	Enhanced Individualised Funding	Choice in Community Living
Developing their own vision of a good life, recognising their strengths.	Improved quality of funded support i.e. flexibility, reliability, improved matching of support worker and disabled person.	Freedom to live their own lives in ways they have previously not been able to e.g. doing everyday activities on their own, when they choose
Taking practical action for change e.g. completed a computer course, seeking paid employment, exploring a micro-business, finding a flat on Trade Me.	Improved family dynamics e.g. adult son no longer spends long periods at home with his mother.	Being able to stay living in own home
Participating in community-activities e.g. participating in netball, athletics, bowls, gym, singing, cycling club. Joined and taken up a role in a Neighbourhood Watch group.	Living a more active life outside the home e.g. going to the gym, ten pin bowling, swimming lessons, rock climbing.	Shift in power balance between disabled person and paid staff
Learning how to make decisions for themselves and increased independence e.g. learning how to catch the bus, moved out of parents’ home and into a flat.	Reduced social isolation, reconnecting with whānau.	Learning new skills e.g. how to employ and manage staff

Increased self-confidence e.g. presented at a forum for disabled people, attending Toastmasters, participated on interview panel.	Planned transitions for young people from school to build independence and confidence.	
For whānau of disabled people Gaining new ideas and extended horizons e.g. information about options, becoming part of new networks, meeting other parents and role models for family member.	Purchasing items and activities e.g. a custom designed riding helmet for a child to participate in Riding for the Disabled; a mobility scooter; a device that converts phone calls into text which will be helpful in the person's job.	

### *For Māori disabled*

*Local area coordination:* Two principles which underpin local area coordination are aligned to Māori values and ways of doing things. Firstly, local area coordination is based on a partnership relationship between the disabled person, their whānau and the LAC, and the authority of the whānau is respected. Secondly, local area coordination is local - the LACs have connections and networks into the community. These factors explain in part the positive response by disabled people, whānau and stakeholders to local area coordination in the Eastern Bay of Plenty. This was evident in the number of disabled people using local area coordination when it was introduced into the Eastern Bay in early 2013. In the first seven months, 117 people received Level 1 support and 26 Level 2 support. Of the 26, more than half (16) were Māori.

Another reason for the positive response is that local area coordination is seen by stakeholders as filling a gap in support for disabled people in the Eastern Bay, particularly for those living in rural and remote communities. Local area coordination has been embraced by Māori stakeholders in the Eastern Bay as being another “tool” to achieve their goal of assisting whānau. Such endorsement is illustrated in the following comments:

*The local area coordinators are a god-send as there is a huge gap in the area.*

*It's been a long time coming, some support for our disabled whānau.*

*Local area coordination is another kaupapa that's come along that enhances what I'm already doing.*

Three of the original LACs are Māori with ties to local iwi and hapu. Following a change in employer in mid-2014, there are now two LACs working part-time who are Maori, both of whom are based in the Eastern Bay. The LAC located in Opotiki works out of the Whānau Ora Services office. This enables a supportive and collaborative approach when working with individual whānau, and ease of referral.

*Enhanced Individualised Funding:* When compared to all disabled Māori receiving DSS support, slightly more disabled Māori have taken up EIF (14.6 percent) than disabled people who are New Zealand European (13 percent). The flexibility provided by EIF in the way support funds can be spent is helping disabled people to become involved in community activities that they (and their whānau) could not otherwise afford. For example, a parent talked about using DSS funds to pay for swimming lessons for their disabled child, whereas in the past the parent had to get a loan to pay for lessons. Two disabled Māori had reconnected with whānau as a result of attending family



reunions that they otherwise would not have been able to attend due to the nature of their impairment. People have also used their support funding to buy equipment that is not available through the Equipment Modification Service (or to purchase a higher quality of equipment than what is available). For example, a person with a hearing impairment has purchased a device costing around \$300 that translates phone calls into text. This is very helpful for his part-time job as he is otherwise unable to use the phone at work.

*Choice in Community Living:* Of the 79 people who have moved into a more independent living arrangement with support from CiCL (as at the end of July 2014), 19 percent<sup>27</sup> are Māori. Most have engaged a mainstream support agency rather than the only kaupapa Māori support agency available in the demonstration. The reasons behind their decision are not known. It is possible some Māori disabled 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 the best support package available.

### *For people with high and complex impairments*

The level of support funding available for CiCL means it works less well for those people with high and complex impairments, who require fulltime support and who, because of their impairment, are not able to share support worker with another person. If they are to use CiCL, they need to have a private source of income to top-up their support allocation. This has the effect of excluding disabled people who would like to move into their own home but cannot access funding from whānau or other sources to do so. Disabled people who are able to share a support worker have a limited choice about who they live with, as they need to find somebody who can also share a support worker.

### *At the system-level*

The demonstration has identified people with impairments who were previously not known to DSS, or who had previously withdrawn from receiving DSS funding because of dissatisfaction with DSS providers. The latter situation was the case for one disabled person and parents of two children (from different families) who were interviewed about their experiences of local area coordination. At some stage in the past all had chosen to “opt out of the system” because of their negative experiences of providers. One parent described the limited choices offered by providers: “... services generally work for what’s good for services, rather than what’s good for a person and their family ... they offer what they do”. The other parent was critical of the approach and quality of support staff: “(they) are not paid very well and so don’t have much nous or common sense”.

## Key learning about implementation

The following key learning about implementing the Demonstration was identified from the findings from interviews with disabled people, their whanau, and local stakeholders.

### *Take-up by disabled people takes time*

Any initiative instigated by a government agency has result targets and other accountability requirements to achieve within defined timeframes. Officials are required to demonstrate that the initiative is making a difference for the target groups(s). However such timeframes may not be appropriate for the people to whom the initiative is targeted, and the extent of change the initiative

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<sup>27</sup> Nation-wide, Māori made up 16.2 percent of DSS clients in 2013.

is aiming to bring about. The Demonstration Project was under pressure to 'prove' its effectiveness in what was a relatively short timeframe given its significant goals.

While the Ministry of Health, the LAC, the EIF Host or the CiCL provider may claim the New Model is a "good" thing, the disabled person and whanau need to be reassured that the New Model component(s) will benefit them in their particular circumstances, and not lead to undue stress and risk (financial and personal) for them. We interviewed some disabled people and whanau who had been early adopters of local area coordination and/or EIF and/or CiCL because they could immediately see how it could be of benefit to them. Other disabled people and whanau said it was a significant step for them to "get their heads around" the New Model components. This is an indicator of the substantive change implicit in the New Model. We interviewed some families who had considered CiCL or EIF for their family member but eventually decided against it for reasons associated with their specific circumstances. Disabled people also explained that some people are reluctant and lack confidence to try new things due to years of restricted choice. Our interviews showed that some disabled people and their whānau require a significant lead-in time and support to think about their goals, and to consider and plan new support arrangements to assist them live more independently. It may be some time yet before there are sufficient numbers of disabled people engaging with one or more of the New Model components, and the impact of the changes can be more robustly assessed.

### *Getting information to some disabled people and whanau can be difficult*

Considerable resource has been invested in communicating the New Model changes to disabled people and disability stakeholder groups via the Ministry's website, and other conduits such as workshops and conferences. A range of resources have been produced such as stories about disabled people who have used a New Model component. The Ministry has also disseminated information to disabled people via DSS service providers. At a local level, the LACs made significant effort (which is ongoing) communicating local area coordination through community-level conduits such as local media, schools, doctors' waiting rooms, community groups and other community-based networks, neighbourhood leaflet drops, as well as via government agencies and NGOs working in their area. Despite all of these efforts, during our interviews in August-October 2014 we talked to disabled people in the Bay of Plenty who had not seen or heard any information about the New Model (even though they had had contact with the NASC or EIF Host). This can be seen as an indicator of the physical and social isolation of some disabled people. It may also reflect a lack of internet access by low income families and those living in rural areas.

### *Coordinating New Model components and existing DSS system is problematic*

The New Model components are operating in parallel with the existing DSS system in the Bay of Plenty. While significant efforts were made by the Ministry to coordinate the existing system and the components (local area coordination, in particular), the interviews with disabled people indicate they were not coordinated from their perspective. An example of the Ministry's efforts to coordinate the components is shown in a diagram developed with input from the NRG and LWG (Appendix 1). The diagram titled 'the disabled person's pathway' was designed to show how the New Model components fit with existing services.<sup>28</sup> This diagram illustrates how operating the New Model components alongside the existing system provides additional complication to an already complex disability system, and how confusing this may be for disabled people and whānau. The findings

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<sup>28</sup> The New Model for Supporting Disabled People – The Story So Far. Prepared by Inclusion Aotearoa on behalf of the Ministry of Health, March 2012, p.4.



show that efforts to align local area coordination with the existing system have not been not successful (described in the section 'Disability sector: reaction to the New Model').

The interviews indicate the New Model components and the existing system were also not coordinated in respect of day-to-day functions and relationships among people working in the DSS sector in the Western Bay, despite considerable efforts by the Ministry to facilitate such collaboration. This was particularly evident in respect of some NASC personnel working in the Western Bay and the local area coordinators (despite efforts by the LACs to do so). The reasons for this are not clear. A possible reason is that some NASC personnel view local area coordination as duplicating their information-giving role. This was not the case in the Eastern Bay where NASC personnel (from the same NASC) and the local area coordinators work well together, and in Waikato and Auckland where the two NASCs work collaboratively with CiCL providers.

### *Using a locally-based implementation organisation was beneficial*

Having a locally-based organisation to assist with implementing the demonstration project was beneficial in a number of ways. The site for the demonstration project had not been decided at the time the implementation support agency was being selected. It was fortuitous one of the directors of Inclusion Aotearoa lives in the Bay of Plenty. This physical presence was very helpful, given that the Project Manager and other Ministry personnel involved in the demonstration were based in other locations. Inclusion Aotearoa came to the project with established community contacts and local knowledge of the area which were very valuable for engaging local communities and stakeholders with the New Model activities. The local presence of Inclusion Aotearoa made face-to-face contact with local stakeholders easier and enabled timely responses to issues, as required

Further, Inclusion Aotearoa acted as a conduit between the Ministry and parts of the sector. Throughout the evaluation, we heard many comments about the distrust and suspicion with which the Ministry is viewed by some groups of disabled people, and skepticism towards the new approach to supporting disabled people. Inclusion Aotearoa acted as an effective conduit between the Ministry and some audiences of disabled people. Without the assistance of an implementation agency in this facilitative role, the Ministry's engagement with some parts of the disability community may have been problematic.

### *Co-development*

The NRG and LWG were interviewed in mid-2012 and again in mid-2014 about the co-development process and the difference members perceived co-development was making to the New Model's implementation. While not wanting to under-value the approach the Ministry was using to involve them, most NRG and some LWG members did not share the Ministry's definition of co-development. For many members, the term means working together with equal influence, having input into the New Model's design "from scratch", and being able to significantly influence the end product. Rather, members described their role as advisory or working in a developmental capacity to refine the New Model components, a process which could be more appropriately described as genuinely consultative. In their interview in mid-2014 NRG members expressed frustration about:

- not receiving feedback from the Ministry about the outcomes of their advice.
- having to rely on the Ministry to get information about what was happening in the Demonstration Project.

- not having opportunities to communicate and discuss issues with the LWG (except on one occasion).
- not having input into the evaluation design.

Members of the LWG were of a similar view that their role had been consultative rather than co-developers.

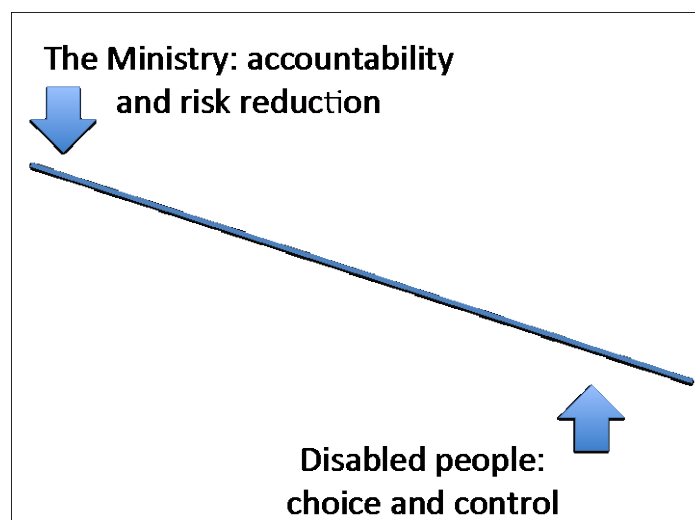
From the Ministry's perspective, the NRG provided strong leadership and important input into exploring system-wide, strategic change. At times Ministry staff had to balance the value of NRG input with time pressures from senior management and Ministers. On a few occasions the NRG was successful in halting work when it felt extra time was needed to discuss critical issues. Similarly, the LWG provided important local contextual knowledge which helped to shape how implementation occurred.

### *Balance between accountability/risk reduction and choice and control*

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 2). 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 2: Balance between choice and control and accountability/risk reduction has 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.

## Assessment of fiscal neutrality

This section provides an assessment of the extent to which Choice in Community Living has been fiscally neutral during the demonstration period, and an assessment of the potential for local area coordination to be fiscally neutral in the future.

### Fiscal neutrality of Choice in Community Living

CiCL was 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 was based on allocated (not actual) expenditures. 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 data<sup>29</sup> from the Ministry of Social Development (MSD) which was requested in June 2014 was not provided in time to be included in the evaluation.

#### *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.

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. 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.

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<sup>29</sup> Data requested included accommodation supplement, disability allowance, social security benefits, and any other items agreed relevant.

An apparent reduction in funding allocation of around \$10,000 (+/-50%) is seen for approximately one-third of the CiCL clients. These cases are the result of a work-around NASCs 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:

- 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.

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.<sup>30</sup> 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.

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.<sup>31</sup>

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<sup>30</sup> 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.

<sup>31</sup> 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).

## Potential for local area coordination to be fiscally neutral

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 temporally<sup>32</sup> (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).

Available evidence was examined 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. Retrospective data analysis was undertaken to compare DSS expenditures and unit costs for disabled people accessing Level 2<sup>33</sup> support, before and after they started working with a LAC. The following steps were followed.

1. A list of people who accessed Level 2 support was produced, including their National Health Index (NHI) number (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

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<sup>32</sup> To further clarify, the reasons 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.

<sup>33</sup> Level 2 refers to people who choose to receive ongoing support from a LAC.

receipt of DSS included 4 receiving National Travel Assistance (NTA) only; 15 not in Socrates (a national database of the Ministry's DSS clients and service providers); and 6 not active in Socrates. Of the remainder it is conjectured (but cannot be verified) that some may be people with unused CMS allocations. These are allocated by client but cannot be tracked to this level.

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).

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). The analysis included a mix of actual retrospective costs, and CMS allocations which are made prospectively and, 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.

### *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.

1. 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.<sup>34</sup> 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 whose DSS funding reduced after taking up LAC, searching and review of individual CCPS and Socrates 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 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.

## 2. 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.

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<sup>34</sup> <http://www.health.govt.nz/your-health/services-and-support/disability-services/other-peoples-stories/new-model-people-stories>



- 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.<sup>35</sup> 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.

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. It is possible that 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 \$6,200 per client (\$433,000/70).

### 3. 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:

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<sup>35</sup> 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.



- 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 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 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.<sup>36</sup>
- Four other increases were attributed to unspecified “increased needs” and for the remainder, the reason was unclear.

### *Reducing duplication and inefficiency in disability services*

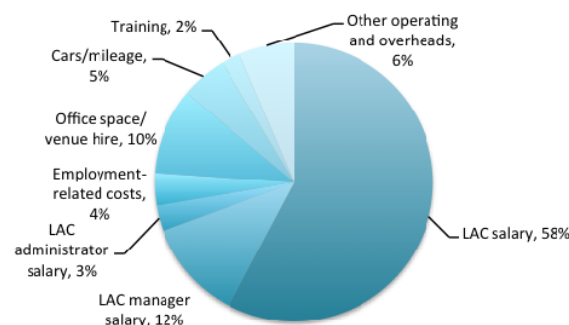
Over the longer term, local area coordination might contribute to sector efficiencies and related fiscal offsets – for example, by reducing duplication and inefficiencies associated with multiple access points (e.g., NASC and DIAS). Such effects cannot be quantified from available data. However, relevant 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 3. 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).

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<sup>36</sup> 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.

**Figure 3: Cost of LAC delivery**



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.<sup>37</sup>
- 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.<sup>38</sup>
- 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

<sup>37</sup> 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.

<sup>38</sup> 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).

its costs, adding around one per cent to gross domestic product and saving \$20 billion per year by 2035” (p. 28).<sup>39</sup>

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):

*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.

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<sup>39</sup> [http://www.ndis.gov.au/sites/default/files/documents/annual\\_report\\_2013\\_14.pdf](http://www.ndis.gov.au/sites/default/files/documents/annual_report_2013_14.pdf)

- 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.

## Discussion of key evaluation findings

This section discusses some key implications of the evaluation findings for the New Model.

### *New Model change is yet to be fully realised*

The original intent of the demonstration was that the New Model would be implemented in its entirety to create system-level change in the demonstration site. This was to include structural changes identified as a result of the Review of DSS Functions, Roles and Responsibilities completed in late 2012.<sup>40</sup> Instead, the demonstration has shown how the individual components of the New Model work, and the extent of difference individual components are making for disabled people and whānau. This whole-of-system change did not occur for a number of reasons. The amount of resource involved in creating such change and the length of time required are greater than the resource and time that was available for the demonstration project. Further, while the demonstration of the New Model started out as a discrete project, it was subsumed into the Enabling Good Lives approach in September 2012 following a decision of the Ministerial Committee.<sup>41</sup> The decision to incorporate the New Model into EGL meant that some of the work done in the demonstration (such as the Review of DSS Functions, Roles and Responsibilities) was 'put on hold' until Enabling Good Lives progresses. This means that the potential of the New Model changes are yet to be fully realised. This is discussed further on page 51 "Maintaining Transformation Agenda".

### *New Model - financial implications*

Choice in Community Living was expected to be fiscally neutral from day one. The findings indicate that this is being achieved for people moving from residential settings to living independently. However, CiCL has also opened up an opportunity for disabled people already living in the community (e.g. with family members) to live independently. The findings indicate that additional funding will need to be found if this option is taken up by significant numbers of disabled people in the same situation. Further research may be required to estimate the numbers of people eligible to take up CiCL and potential costs.

Our analysis included an assessment of the potential for local area coordination to be fiscally neutral in the future. The 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 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 design.

### *Importance of support for disabled people to use New Model components*

The evaluation findings confirm the soundness of CiCL and EIF as mechanisms for disabled people to have increased choice and control of supports they purchase. Some aspects of CiCL and EIF require fine tuning (as detailed in the EIF and CiCL reports), while a few other aspects require

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<sup>40</sup> An externally commissioned report was completed in April 2012 to identify the impact on existing functions and roles in light of the New Model changes. A Framework Redesign Working Group was formed in late 2012 made up of people working in the DSS sector which did further work on the topic.

<sup>41</sup> Enabling Good Lives (EGL) emerged following the devastating Christchurch earthquake (in February 2011) when local disabled people, families, and a group of providers worked together to ensure disabled people were supported in the earthquake's aftermath.

more significant work. An aspect discussed in this section is the importance of support for some disabled people to get the most of EIF or CiCL.

Some disabled people and whānau are quick to see the potential of CiCL and EIF to achieve personal goals such as increased independence and participation in the community. For other disabled people, these mechanisms are not of themselves sufficient - they need support to recognise how EIF or CiCL can be used to make a difference for them, and support to make such things happen. This may be the result of people being risk-averse to receiving second-rate services from agencies, having constrained perspectives from years of restricted choice, or experiencing the negative effects of institutional care. Other disabled people require support to instigate and do new things due to the nature of their impairment. The nature and length of this support will be different for individuals - while some may need short-term support, others may benefit from more intensive input over a longer period of time.

There is some evidence that when local area coordinators have supported disabled people thinking about using EIF, the disabled person has been more 'ready' for their meeting with the EIF Host to discuss support arrangements,<sup>42</sup> and the EIF set-up has been relatively straight forward. There is also some evidence of the difference **not** having support makes for some people and whānau thinking about or using EIF – some people have a limited understanding of how they can maximise its use for them and the set up process has been less straightforward. In respect of disabled people and whānau using EIF, we interviewed five whānau who could have benefitted from local area coordination support with difficulties they were having in recruiting workers.

In the case of CiCL, much of the support provided to-date is on the front-end, that is, setting up independent living arrangements. As local area coordination does not operate in their regions, disabled people wanting ongoing support to plan for and work towards personal goals must pay for it through their DSS allocation.

## Evaluative assessment

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 creates 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 the supports they receive and the lives they live. It is not possible to provide a standardised definition for 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. In light of this, at the beginning of the demonstration a workshop was held with disabled people from the Western Bay of Plenty, DSS providers, NASC and Ministry personnel to identify outcome challenges for each of the groups involved in the demonstration - whānau, the Ministry/NASCs/providers, local communities/iwi (the workshop attendees are listed in Appendix 2). The outcome challenges describe the expected outcomes from the New Model changes for each of the groups involved in the demonstration (Table 4).

There are three limitations about using the outcome challenges for the evaluative assessment. Firstly as noted above, system-level change was not demonstrated in the Bay of Plenty as intended. Rather, individual components of the New Model were implemented. A second limitation

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<sup>42</sup> Such 'readiness' for EIF includes disabled people having thought about their goals and how their support arrangements can be used to achieve them.

(also described above) is that EIF, CiCL and local area coordination were not fully tested in respect of the difference they may make for disabled people. A third limitation is that some of the New Model changes described in the outcome challenges were not designed to happen in the demonstration, for example, the changes identified for local communities and iwi in Table 4. Despite these limitations, the outcome challenges provide a suitable platform for the evaluative assessment of the demonstration.

**Table 4: Evaluative assessment of outcome challenges**

Outcome challenges	Evaluative assessment
<p><b>Disabled people</b></p> <p>The New Model intends to see disabled people stepping / rolling outside their comfort zones. They take on opportunities when they can. They have identified and are participating in new relationships with communities of interest. They are working for their living. They are supported to deal with the 'crap', for example dealing with being an employer and with big transitions in their lives. They access support that gives them choices and control and which nurtures their wairua tanga / spiritual wellbeing. They have leadership roles and are working with other project partners, including government, to co-develop elements of the New Model.</p>	<p>EIF and CiCL are sound mechanisms for providing disabled people with more choice and control over their paid supports, and the lives they live. Some aspects of CiCL and EIF require fine tuning, while a few other aspects require more significant work</p> <p>CiCL does not work for people with high and complex impairments who require full-time support.</p> <p>A range of positive changes are reported by people who have used local area coordination, EIF and CiCL including increased flexibility and reliability of funded supports, more independence and self-confidence, and being more involved in community-based activities.</p> <p>Some disabled people require additional support to engage fully with EIF in particular. It was expected that local area coordinators would provide such support to disabled people and whānau, including those thinking about or using EIF. This did not occur to the extent expected in the Western Bay of Plenty due to low referrals from other parts of the DSS sector and a lack awareness of local area coordination by disabled people.</p> <p>Disabled people and whanau who have worked with a local area coordinator have been supported to recognise their strengths, and pursue new activities to develop confidence (including courses, using skills to gain income e.g. face painting at a community event, volunteering e.g. Neighbourhood Watch group, and moving out of parents' home into a flat.)</p> <p>The findings have shown that the lack of paid employment opportunities in the Bay of Plenty for disabled people mean that those who wish to work are unlikely to achieve this aim.</p> <p>There is some evidence of disabled people taking up leadership positions, e.g. on NRG and LWGs. However, during the timeframe of the evaluation no disabled people were appointed to the Purchasing Guidelines Panel.</p>
<p><b>Ministry of Health</b></p> <p>The New Model intends to see the Ministry contract more flexibly. Contract specifications have been developed with disabled people and cut across current 'service types'. The Ministry has outcome-focused contracts and relationships and is</p>	<p>The Ministry has begun a process that aligns well with the values of human rights and equality that underpin the social model of disability. The components implemented as part of the New Model have resulted in increased choice and control for the majority of disabled people who have engaged with</p>



<p>monitoring against outcomes. They have done their homework about what works. Their homework is based on research and research outcomes. These outcomes have been co-developed with disabled people and other project partners as relevant. They are designing the New Model with a consistent philosophy which allows people to exercise choice and control. Policy and funding are coherent and consistent. There are clear policy guidelines. Ministry staff are taking and sharing risks. The Ministry has a leadership role. They stay the course. The Ministry is sharing fiscal responsibility and accountability. The Ministry makes it easier for people to get support. Staff are culturally competent. They know about disability and are committed to working with disabled people. Their focus is on people living ordinary lives. They support Māori to support Māori disabled people, whānau and their communities. The Ministry keeps good records, including statistics and other information.</p>	<p>one or more of the New Model components.</p> <p>The Ministry was directed by the Government to implement local area coordination as per the original Australian approach. This has occurred.</p> <p>The Ministry made considerable efforts to coordinate functions and relationships among people working in the DSS sector in the Western Bay. Despite these efforts, the local NASC staff did not facilitate disabled people's access to local area coordination. In contrast, the NASC staff involved with CiCL have worked closely with the Ministry and providers to support disabled people into their own homes.</p> <p>The Ministry worked closely with a National Reference Group and local working groups to implement the New Model. Members of these groups said they had been genuinely consulted by Ministry officials, although ideally they would have preferred input into the New Model design "from scratch".</p>
<p><b>Families/whānau</b></p> <p>The New Model intends to see families / whānau get to the "stage of accepting" in order (for disabled people) to begin their life journey (for me, by me). Families / whānau access timely and relevant information. They are supported to have ordinary expectations of their children. They know how to support their child to live an ordinary life. Families / whānau have resilience. They spend less time battling bureaucracy and fighting for fundamental human rights. They are confidently choosing the 'inclusive option'. They are promoting the autonomy of young disabled adults. They invest equally in the lives of all their children. They are celebrating their disabled child's life and successes. Families are supporting other families. More whānau are involved in the life of their disabled family members.</p>	<p>EIF is being used by some parents of school leavers and young adults to create age-appropriate support arrangements intended to build their young person's confidence and independence.</p> <p>EIF and CiCL are helping parents to 'give over' their role as carer of their adult child to support workers chosen by them and their child. This is restoring 'ordinary' family relationships (e.g. parent-child) and improving family dynamics.</p> <p>Whānau who have worked with a local area coordinator report changes such as making better decisions, feeling like a better 'mum', developing new networks, finding role models for their disabled child, and changes in the home including how parents are relating to their disabled child.</p>
<p><b>Local communities / iwi</b></p> <p>The New Model intends to see local communities / iwi more connected to disabled people. The community recognises, and is engaging, disabled people in leadership and other valued roles. Local communities adapt, so disabled people can be included. Schools educate and welcome all children. The local community is educated about, and aware of, different disabilities. Local councils have policies so houses, community buildings and marae are accessible. Buses are accessible to all. There is a wide pool of committed, community-based support workers.</p>	<p>The local area coordinators are working with the community which 'sits' around a particular disabled person. For example, a disabled child was being bullied by his classmates at school. The local area coordinator arranged for an adult with the same impairment to talk to the children about what life is like for him living with the impairment.</p> <p>The interviews indicated that natural supports do not often extend beyond whānau (discussed below in the section 'Natural support')</p>



## Future challenges

The New Model represents the beginning of a potentially transformative change in the way disabled people are supported to live everyday lives through DSS supports. This change involves a range of issues which will test and challenge existing ways of thinking and working by the Ministry and the DSS sector. This section identifies some of the future challenges raised by the findings.

### *New Model assumptions*

The New Model is underpinned by some assumptions about external factors, as listed below. The evaluation findings question some of these assumptions. The issues identified here will need to be considered in the future development of DSS supports.

- Funded supports will be complemented by natural supports.
- Whānau are willing and able to provide natural supports.
- Paid employment opportunities are available for disabled people who wish to work.
- Suitable and affordable accommodation is available for disabled people in the place they want to live.
- The DSS sector will be responsive to the New Model.

### *Natural supports*

One of the goals of the Enabling Good Lives initiative (in which the New Model demonstration now sits) is that disabled people “will make more use of natural supports”.<sup>43</sup> An examination of the nature and role of natural supports in complementing paid supports was out of scope of this evaluation. However the following observations about natural supports can be made from our interviews with disabled people and whānau.

- Whānau are the primary source of natural supports which include time, input and money.
- Some disabled people do not have whānau who are willing and able to provide natural supports.
- Some whānau are worn down and exhausted from supporting their disabled family member over a long period of time. They may also feel worn down by dealing with “the system”.
- Having a family member in the role of ‘carer’ means some disabled people are not able to have ordinary relationships with their whānau, e.g. relate to their partner as just a partner, or just as a parent.
- It is hard to find and maintain natural supports for disabled people with complex impairments.
- Age-appropriate natural supports are important for older children and young adults.

### *Paid employment*

Some of the disabled people we interviewed have personal goals that include paid employment. They were frustrated at being unable to get paid work despite having worked in voluntary, part-time roles. Many had worked with disability providers to find employment but with no success. As a result, their goal of paid employment is unlikely to occur without significant attitudinal changes on the part of employers.

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<sup>43</sup> Disability Action Plan Summary, 30 October 2012. Available from <http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/what-is-enabling-good-lives.html>

### *Suitable and affordable accommodation*

The supply of affordable private rentals in Auckland may have contributed to the lower than expected take-up of CiCL in this region. Recent changes in the Government's eligibility criteria for social housing may exclude some disabled people who wish to live independently from their parents or other family members and do not want to live in a property provided by a disability-related housing provider.<sup>44</sup> Accessing suitable and affordable accommodation will continue to be an issue in urban regions given the current demands on the private rental and increasing rents.

### *Responsive DSS sector*

As described above, while the NASCs and DSS providers involved in CiCL were responsive to the New Model changes, this was not the case with some of the DSS sector in the Western Bay of Plenty. Getting some NASCs and DSS providers 'on board' with the New Model changes (in addition to building their capacity) could be a significant task for the Ministry.

### *Coordinated and coherent disability system*

The Government has recognised that the currently system of funding disability supports makes the lives of disabled people and their whānau more difficult than necessary.<sup>45</sup> In September 2012 Government announced its intention to create a cross-government disability system to address this issue.<sup>46 47</sup>

Our interviews with disabled people and whānau have reinforced this need, particularly given the level of stress experienced in some households on an on-going basis. The extent of complexity of the current disability system is illustrated in an interview with a parent of a family with two disabled children who had recently moved into the Bay of Plenty. The parent said they had 58 meetings and spent over 100 hours in phone calls to set up supports for the children (this family did not know about local area coordination). Other disabled people and whānau described being worn down by their experiences of working with the disability system. A few parents of older children said they had learnt (often through trial and error) how to "navigate" the system to get the "right" supports for their young person. We also interviewed people who are new to disability supports and still trying to understand the system, and how they can make it work for them or their child.

### *Recognising and reconciling differing priorities and perspectives*

The New Model is an ambitious policy initiative in terms of its size, significance and potential impact. In considering the future of the changes inherent in the New Model, it is important that the differing priorities and perspectives of disabled people and Government (described in the following paragraphs) are acknowledged, debated and attempts made to reconcile them to the greatest extent possible. Writing about the implementation of complex policy in New Zealand, Eppel, Turner & Wolf (2013, p.191) make the following observation to which we have added (see italicised text): " ... understanding of policy problems and solutions will lack coherence if boundaries, *values and priorities* identified and maintained by different policy participants are ignored".

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<sup>44</sup> The Government's Social Allocation System criteria give priority to social housing applicants who lack accommodation or who are living in accommodation that is deemed unsustainable due to overcrowding or the physical condition of the accommodation.

<sup>45</sup> Ministry of Health's New Model for Supporting Disabled People. Cabinet Social Policy Committee paper, 15 June 2010 (CAB Min (10) 23/4A).

<sup>46</sup> Disability supports are currently funded by eleven government sectors which have different eligibility policies.

<sup>47</sup> <http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/what-is-enabling-good-lives.html>

For disabled people and whānau, the New Model represents the beginning of a vision in which the DSS system is transformed to have greater alignment with the values of human rights and equality which underpin the social model of disability. The intent of the New Model represents a long-awaited change in which power and control of supports are with disabled people, rather than professionals. The intended New Model changes also reflect changes to disability supports that are occurring in other western democracies. The disability community in New Zealand is waiting to see whether these promised changes which had their beginnings in the Select Committee Inquiry will come to pass or whether they are policy rhetoric.

The Government is facing increasing fiscal pressure on the funding of DSS supports. There are increasing numbers of New Zealanders with impairments due to New Zealand's aging population. In 2013, almost a quarter (24 percent) of the New Zealand population was identified as disabled, a total of 1.1 million people. Māori and Pacific people had higher than average disability rates (after adjusting for differences in ethnic population age profiles) - Māori 32 percent and Pacific 26 percent.<sup>48</sup> The priority for policy-makers is ensuring that the New Model changes can be implemented in a fiscally neutral way and do not place more pressure on available DSS funding.

The challenge for policy-makers is to continue working with the disability sector to identify and implement transformational approaches to DSS supports that are sustainable - fiscally sustainable from the point of view of Government, and sustainable for disabled people in that they have the level of supports they require, and power and control over them

### *Maintaining transformation agenda*

Continuing the transformation agenda on which the New Model and Enabling Good Lives are based will require significant changes to existing DSS structures, processes and organisational cultures. Given the substantive nature of such change, it will take time. The potential risk is that having got this far in demonstrating how the DSS system could be transformed, fiscal pressures, efficiency concerns and/or risk avoidance may alter the 'transforming' agenda to 'tweaking' the existing system, thereby maintaining underlying structures of power and control. Another potential risk is that due to financial constraints, mechanisms such as EIF and CiCL may be implemented nation-wide without the level of support needed by some disabled people to use them to their potential. A third potential risk is that the transformational vision for disabled people underpinning the New Model may become diluted as new policy priorities emerge for the Ministry.

### *Challenges for the Ministry*

As a government agency, the Ministry is responsible and accountable for the appropriate use of public funds, and management of real and potential risk. The changes inherent in the New Model will challenge the 'top-down' approach to delivering DSS supports and its associated accountability approaches. The Ministry is not alone in this situation. Changes are occurring to public management in New Zealand, including a new relationship between government and the users and providers of public services, which create new challenges for government agencies (Ryan, 2013). In respect of the implications of the New Model changes for the Ministry, the challenges include:

- focusing on the outcomes of DSS support, rather than inputs or outputs

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<sup>48</sup> 2013 Disability Survey. [http://www.stats.govt.nz/browse\\_for\\_stats/health/disabilities/DisabilitySurvey\\_HOT2013.aspx](http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOT2013.aspx)

- creating systems (including contracting and performance management) that foster a more tailored approach to DSS services
- producing practice-based resources for NASCs and DSS providers to foster good practice approaches based on a social model of disability
- creating incentives that foster collaboration among DSS providers
- recognizing that failure may occur (and learning from such instances)
- creating new accountability approaches and structures which achieve an appropriate balance between risk management and trust.

## Conclusion

The New Model demonstration represents the beginning of a transformative change to disability supports in New Zealand. It is important that the transformation of disability supports that had its beginnings in the Social Services Select Committee's report presented to Government in 2008 is sustained. It is equally important that the hopes and expectations of disabled people and whānau about living an everyday life that have been encouraged by the New Model demonstration are not disappointed.

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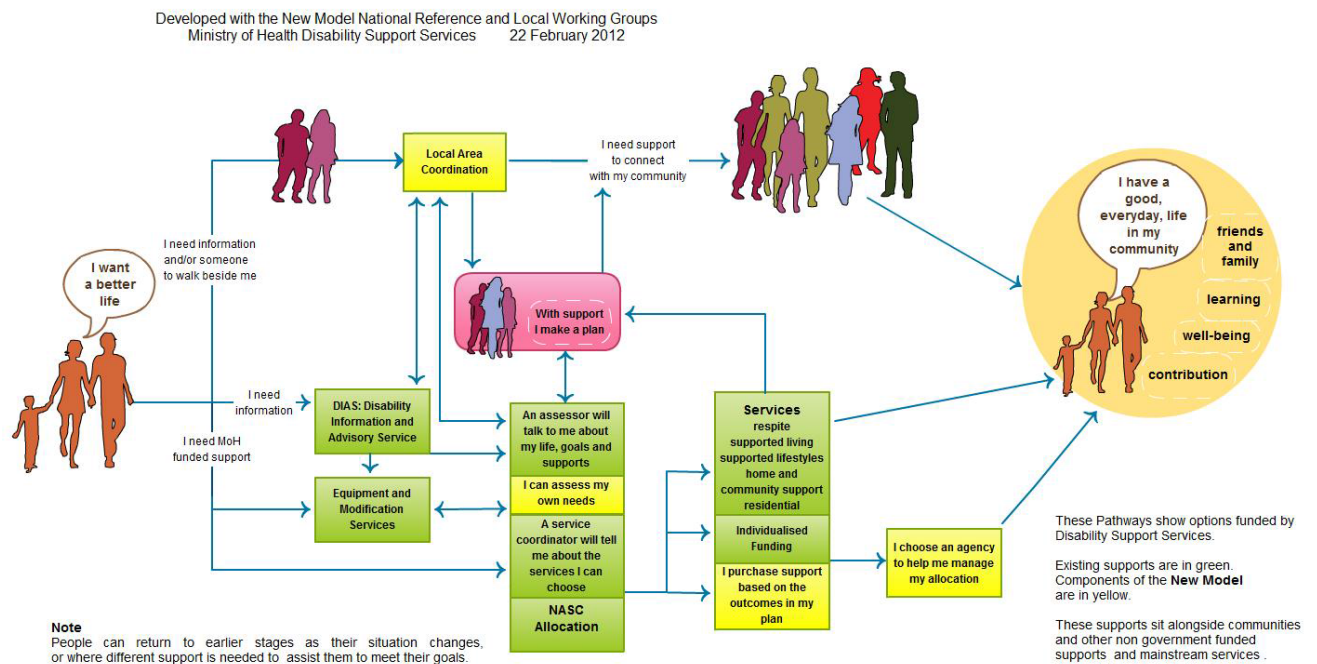
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# Appendix 1: How the New Model and existing DSS system work together

Source: The New Model for Supporting Disabled People – The Story So Far. Prepared by Inclusion Aotearoa on behalf of the Ministry of Health, March 2012



## Appendix 2: People involved in developing outcome challenges

Lorna Sullivan	CE Standards Plus / National Reference Group
Dale Johnson	CCS Disability Action
Rena Savage	Local Working Group
Lyndsay Tahitahi	Local iwi / Local Working Group
Ruth Gerzon	Inclusion Aotearoa
John Wilkinson	Principal Policy Analyst, Ministry of Health
Jenny Moor	Programme Manager, Ministry of Health
Rowanne Janes	Senior Quality Analyst / Team Leader evaluation and accountability work stream New Model, Ministry of Health
Chris Petch	Contract Relationship Manager, Ministry of Health
Roger Jolley	Senior Advisor Māori, Ministry of Health
Terry Hibbert	Project Manager / Team Leader for Allocation and Purchasing New Model work stream, Ministry of Health
Rhondra King	Group Manager, National Quality
Tonty Te Amo	Kaumatua
Don Sorrenson	Support Net (NASC manager), NASC
Feala Afoa	Ministry of Health

Other people who provided input included National Reference Group members Philip Patston and John Taylor. Bronwyn Foxx was invited to the workshop but was not able to attend.