New Model for Supporting Disabled People: synthesis of Year 1 evaluation findings

December 2012

evalue research

'Thank you' to everyone who participated in an interview for your time and generosity in sharing your experiences and perspectives of the New Model Demonstration Project

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Executive summary

This report is a synthesis of findings from the first year of the evaluation of the New Model Demonstration Project. The evaluation has aimed to help key stakeholders involved in its development and implementation by providing regular information about how activities are working and identifying issues for further consideration. During 2012 the evaluation included three phases of data collection (with reports delivered in April, June and September).

The New Model is being implemented incrementally. While the principles and overarching design of the New Model are Cabinet-mandated, the complex technical details associated with each of the new components (e.g. enhanced individualized funding) are being developed in consultation with a National Reference Group and Local Working Group. Only two components, local area coordination and a supported self-assessment tool, were in place by mid 2012. The slower-than-expected pace has been dictated in part by limited resources allocated to implementing the New Model. Until mid 2012 there was one Ministry of Health official working fulltime on the New Model initiative (there are now two full-time staff),[1] supported by a contracted 'implementation' agency (Aotearoa New Zealand). The Ministry has also been committed to a consultation process with a National Reference Group and Local Working Group. There is broad acknowledgement by all stakeholders that the project would not have progressed to the extent it has without this genuine consultative approach. This has involved working to timeframes that allow for full discussion of critical issues. The high level of trust that now exists between members of the two groups and Ministry staff (see Section 3: *Roles and contribution of the National Reference Group and Local Working Group*) is a major achievement and provides a solid foundation for further work on the New Model.

The first year of the evaluation has focused on the effectiveness of two elements of the Demonstration Project: local area coordination and a self-assessment process/tool. In addition the evaluation described and assessed the implementation of the Demonstration Project, including the involvement of the National Reference Group, Local Working Group and the implementation agency.

Key findings

Local area coordination

To date 27 disabled people/families and whānau have worked with a local area coordinator (LAC) in an active ongoing way. Twelve people provided feedback to the evaluators about their experience of local area coordination. Most state the support they have received has been valuable and can identify initial changes that have occurred as a direct result of working with a LAC. These changes include attending a computer course/planning for tertiary study in 2013, working in a part time voluntary job, attending a gym, developing a home-based income generation project, organising a support group for disabled people and solving transport needs.

Several barriers have been identified as potentially inhibiting the take-up of local area coordination in the Western Bay of Plenty. The first is that some people in the LAC's community view existing support services as the 'right place' for disabled people. A second is that some disability providers in the Demonstration site (particularly management) view LAC as a "waste of resources", replicating work already being done. Despite good information being available on the Ministry of Health's website, many people appear to be uninformed about local area coordination (and the New Model work in general). A third and much more fundamental barrier, is the way in which

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[1] Other Ministry of Health staff are working on the New Model in a part time capacity alongside their usual work responsibilities.

communities engage with and support disabled people. The interviews with disabled people highlight the barriers they face gaining employment and the loneliness and isolation many experience, particularly those living in rural areas without access to regular, easy to access public transport. The barriers to take-up of local area coordination will be explored in more depth in the second year of the evaluation.

Our findings highlight the need for a strategic communications strategy aimed at disabled people, their whānau/families as well as a sustained public campaign to change public perceptions, attitudes and structural barriers to disabled people leading a good life. Many people still are not aware of the different between local area coordination and other types of disability service services. In addition, LAC support can only go so far. The interviews highlight structural and other barriers that prevent disabled people from participating in a 'good life'.

It is still too early to consider the overall effectiveness of local area coordination. The LACs are at an early stage of working with their ongoing contacts. Significant resource has gone into the development of local area coordination; as yet only a small group of disabled people/families have taken up the option to work with a LAC and plan for their future.

Supported self assessment

Support Net (the NASC) began offering disabled people, parents and caregivers the option to do a supported self-assessment (SSA) of their needs in October 2011. The screening process has been revised several times in response to an initially low uptake. One staff member now undertakes an initial screening to decide if SSA is offered to disabled people/families. In the three months May - July 2012, 101 disabled people were considered for a SSA. Sixty were offered a SSA and 36 agreed to this option. Most people who declined a SSA said they preferred to meet an assessor face to face. Support Net does not offer SSA to clients with complex health needs.

Our initial findings suggest SSA may be a more attractive option for people living in rural locations; however the number of people in the Demonstration Project sample is still too low to identify any definitive trends. Those who completed a SSA tend to have strong literacy skills, and be confident and articulate. They liked having the flexibility of completing the assessment in their own time, at their own pace. The SSA does not appear to work so well for those who are less confident about articulating their own, or their child's situation.

Contribution of the National Reference Group and Local Working Group

During 2012 a National Reference Group (NRG) has provided 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. There is wide agreement the NRG has provided strong leadership, exploring future and system-wide strategic change for disabled people.

A Local Working Group (LWG) has provided advice on parts of the New Model as they have been tried in the western Bay of Plenty. This has included 'on the ground' advice on local area coordination based on their knowledge of the area, enhanced individualized funding/host providers, self-directed purchasing, funding allocation, supported self-assessment and roles and functions.

Interviews with members of both groups confirmed they have developed a trusting relationship with key Ministry staff and that genuine consultation is occurring.

Role and contribution of the implementation agency

Inclusion Aotearoa has been contracted by the Ministry to assist with the design, implementation, testing and refinement of the Demonstration Project for the New Model, including identification of risks and issues.

Comments by sector stakeholders during the evaluation interviews indicate Inclusion Aotearoa is generally regarded as credible and trustworthy. This has helped Inclusion Aotearoa negotiate the potential 'fine line' as the implementation agency; that is, working on behalf of the Ministry as a contractor, while also being accountable to the disability sector in an informal sense. Inclusion Aotearoa say this dual accountability has been helped by the integrity of the Ministry's key project staff, and clarity about the respective roles of the implementation agency and the Ministry as they relate to day-to-day-work. Inclusion Aotearoa also appears to have acted as a conduit between the Ministry and some audiences of disabled people. Without their assistance, the Ministry's engagement with some parts of the disability sector may have been problematic.

Understanding the New Model

Lack of understanding about the New Model emerged as a consistent theme in interviews with key informants, people with disabilities and their families/whānau. There are a number of possible reasons for this. Firstly, the New Model is made up of component parts, which may make it complex to understand. The fact that the existing system is currently operating alongside the New Model may add to this complexity. Other than local area coordination and supported self-assessment, other components are yet to be rolled-out. This means that people are trying to understand a theoretical model, rather than one they can experience first-hand.

Although Inclusion Aotearoa has produced ongoing communication material about the New Model which has received positive feedback, the evaluation recommends additional resources be committed to developing a strategic communications strategy.

Summary

Developing an initiative such as the New Model has particular challenges, such as communicating change to disabled people and their whānau at the same time as the technical details are still being worked on, and operating new arrangements (e.g. supported self assessment) alongside existing arrangements. While the change process may appear, to some, to be slow, the first 18 months of the project have set in place a good foundation for fundamentally changing the way the Ministry supports disabled people. The findings highlight the importance of working at a pace that allows for relationship-based, genuine consultation with key stakeholders as well as a developmental approach that values ongoing reflection for the purpose of improvement.

Background to New Model

The New Model

The key objective of the New Model is to support disabled people and their whānau/family to have 'a good life' through greater choice and control over the support they receive and the lives they lead.
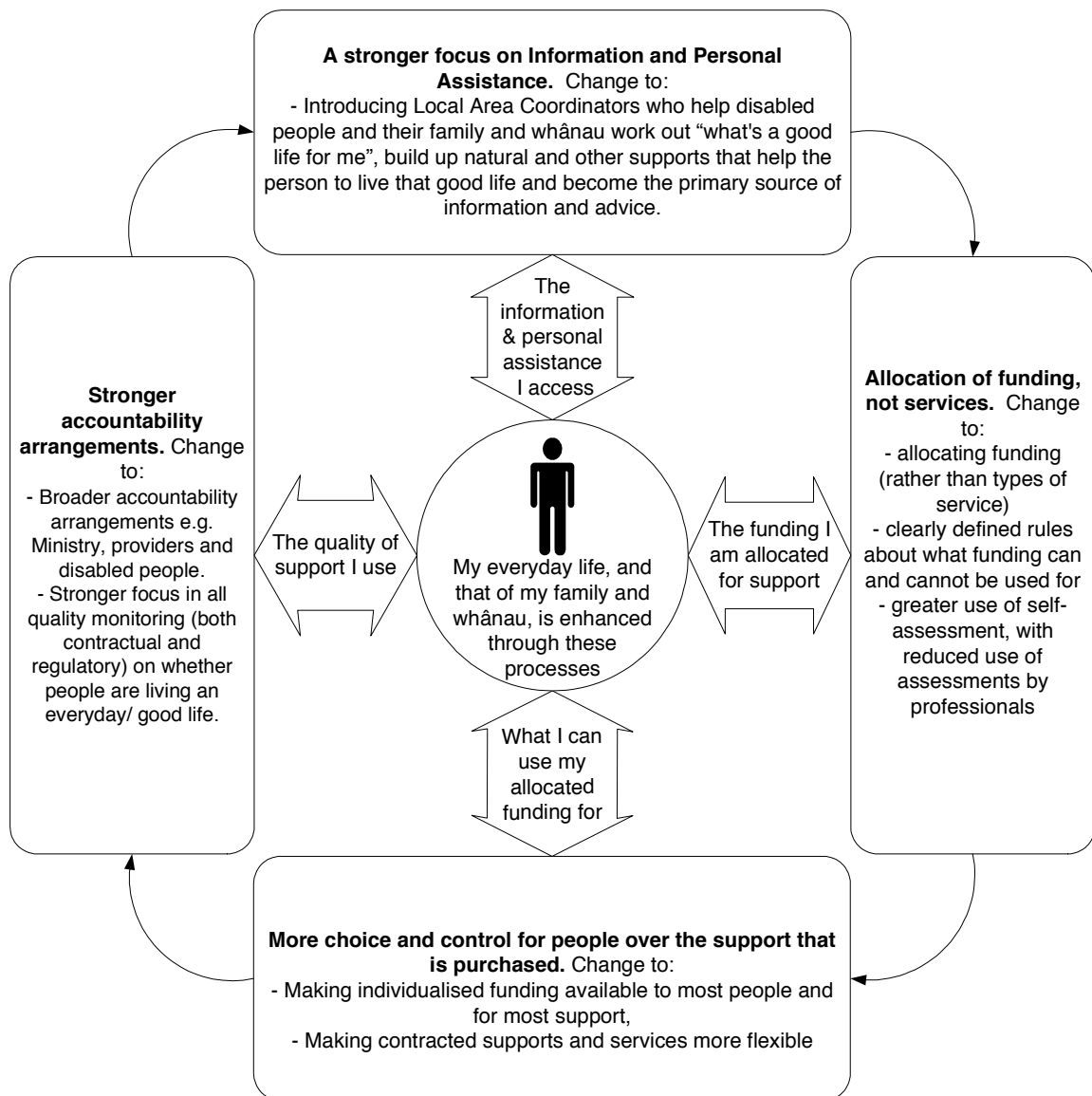
Key elements

The design of the New Model has the disabled person (and their whānau/family) as its centre. There are four key elements (refer Figure 1):

1. **Improved access to information and personal assistance** for people and their whānau through local area coordination arrangements (described in more detail below).

2. **Allocation of funding with greater flexibility over how the funding is used** (rather than prescribed types and levels of services). This involves allocating indicative dollar values of support (reflecting the disabled person's individual circumstances), and greater use of self-assessment.

3. **More choice and control for people over the support that is purchased** through making individualised funding available to most people and for most supports, and making contracted supports and services more flexible and focused on outcomes.

4. **Broader accountability arrangements** to include the responsibilities of the Ministry, and disabled people and their whānau/family, and a stronger focus in all quality monitoring (contractual and regulatory) on whether people are living an 'everyday/good life'.

The Western Bay of Plenty (including Tauranga) was selected as the first site to demonstrate the New Model for a number of reasons, including having a diverse population with a relatively high proportion of younger people and a significant proportion of Māori. The region also has a mix of urban and rural areas. On 17 December 2010, a community hui was held to formally welcome the Ministry of Health and Inclusion Aotearoa to the region. The Minister of Health officially launched the Demonstration Project on 23 August 2011.

Figure 1: The New Model (source: Ministry of Health)

A stronger focus on Information and Personal Assistance. Change to:
- Introducing Local Area Coordinators who help disabled people and their family and whânau work out "what's a good life for me", build up natural and other supports that help the person to live that good life and become the primary source of information and advice.

Stronger accountability arrangements. Change to:
- Broader accountability arrangements e.g. Ministry, providers and disabled people.
- Stronger focus in all quality monitoring (both contractual and regulatory) on whether people are living an everyday/ good life.

The information & personal assistance I access

The quality of support I use

My everyday life, and that of my family and whânau, is enhanced through these processes

The funding I am allocated for support

Allocation of funding, not services. Change to:
- allocating funding (rather than types of service)
- clearly defined rules about what funding can and cannot be used for
- greater use of self-assessment, with reduced use of assessments by professionals

What I can use my allocated funding for

More choice and control for people over the support that is purchased. Change to:
- Making individualised funding available to most people and for most support,
- Making contracted supports and services more flexible

Methodology

The Ministry requested a developmental evaluation approach to respond to the evolving, adaptive nature of the New Model and to mirror the Ministry's 'co-development' approach with disabled people, their whānau/families, community and other stakeholders.

The evaluation aimed to provide 'real time' information about how the Demonstration Project's activities and processes were working, and to identify areas for improvement and development.

Originally the focus for 2012 was to describe and assess:

- the effectiveness of the elements of the Demonstration Project (i.e. the self assessment process/ tool, local area coordination, funding allocation tool and self directed purchasing), and
- the implementation of the Demonstration Project, including the co-development approach.

Based on a discussion with the Ministry in April 2012, it was agreed to refine the evaluation foci for the remaining period in 2012 on:

- the effectiveness of two elements of the Demonstration Project, namely local area coordination (LAC) and the self assessment process/ tool, and
- the implementation of the Demonstration Project, including the co-development approach and the implementation agency.

Evaluation approach

The evaluation approach is based on Outcome Mapping (OM).[2] Four guiding principles underpin the this approach:

1. People and organisations drive change processes. The problem to be tackled, the aims of the project and the indicators of success are defined in terms of changes in the behaviour of these stakeholders (called project partners[3]).
2. Continuous learning and flexibility. OM emphasises that most effective planning, monitoring and evaluation activities are cyclical, iterative and reflexive.
3. Co-development approach. By involving stakeholders in the planning and monitoring process and emphasising reflection, participation incorporates valuable perspectives and fosters two-way accountability and responsibility.
4. Nonlinearity and contribution. OM recognises that change is not the result of 'inputs' controlled by a funding organisation but is the result of a complex web of interactions between different stakeholder groups.

The first task involved co-developing with key stakeholders in a workshop (held in December 2011) the following:

- a vision for the New Model.
- a mission statement describing how the New Model ideally intends to support the vision.
- outcome challenges and progress markers. These describe the changes key stakeholders expect to see key groups (called 'project partners') making. The project partners include: disabled people, whānau, the Ministry/LACs/NASC/providers and local community/iwi.

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[2] http://www.outcomemapping.ca/resource/resource.php?id=184

[3] The following project partners have been identified for this evaluation: disabled people; whānau of people with disabilities; Ministry of Health/LACs/NASC/providers; local communities/iwi.

Appendix 1 (outcome mapping for the New Model) provides the vision and mission statement developed by the workshop participants.

Data collection

Data was collected in three phases during 2012. Table 1 provides a summary of the stakeholders[4] interviewed over the year.

Table 1: Summary of stakeholder interviews 2012

Stakeholders	Focus of data collection			
	Local area coordination	Supported self assessment	Co-development	Implementation agency
Disabled people/whānau /family (33)	x	x		
Support Net staff (6)				
NRG members (14)			x	x
LWG (10)			x	x
Local area coordinators (4)	x		x	
Inclusion Aotearoa (2)			x	x
Ministry of Health staff (4)	x	x	x	x
Other stakeholders		x		

Other data included monthly LAC reports and administrative data (to July 2012), Support Net administrative data on people considered for a Supported Self Assessment (SSA), minutes of NRG and LWG meetings, Inclusion Aotearoa reports to the Ministry, and communications material about the New Model.

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[4] Some stakeholders were interviewed more than once.

Findings

This report is a synthesis of findings from the first year of the evaluation of the New Model Demonstration Project. The evaluation has aimed to help key stakeholders involved in its development and implementation by providing regular information about how activities are working and identifying issues for further consideration. During 2012 the evaluation included three phases of data collection (with reports delivered in April, June and September).

The findings are presented in four sections:

1   Local area coordination - experiences of the local area coordinators and disabled people/families who have worked with a local area coordinator
2   Supported Self Assessment (SSA), including experiences of disabled people/families who have completed a SSA
3   National Reference Group and Local Working Group contribution to the development of the New Model and implementation of the Demonstration Project
4   The role and contribution of the implementation support agency (Inclusion Aotearoa).

(1) Local area coordination

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.[5]

Four local area coordinators (LACs) were appointed in August 2011 to work in the Western Bay of Plenty. Their first months in the job were spent receiving training in the new role, developing and extending their networks. By November 2012 they had worked with 203 people, of which 27 were ongoing contacts. The ethnicity of disabled people who had contact with a LAC is recorded in Table 2, although it should be noted ethnicity data was not recorded for 50 percent of contacts.

Table 2: Ethnicity of LAC contacts*

Ethnicity	No.
Maori	21
NZ European / New Zealander	48
Tongan	1
Fijian	1
Australian	1
English	1
Not stated	74
Total	147

Source: LAC Report (as at 12 November 2012)

* Includes LAC contacts in database only

[5] Local Area Coordination Manual, 1 December 2011

LACs experience working with disabled people/families

In June 2012 the LACs were asked to describe their work and their perspective about:

- what difference (if any) they think local area coordination is making for the disabled person/their family
- what is helping (or getting in the way) of the person/family moving towards their goals.

Figure 2 is an overview of LACs' responses. The circle to the left identifies the issues and barriers faced by some people when the LAC first comes into contact with them. The middle circle describes the LACs' work with people and organisations, and the last circle describes LACs' perspectives of the changes that have occurred for some disabled people and family members.

Figure 2: Overview of local area coordination in the Western Bay of Plenty at June 2012
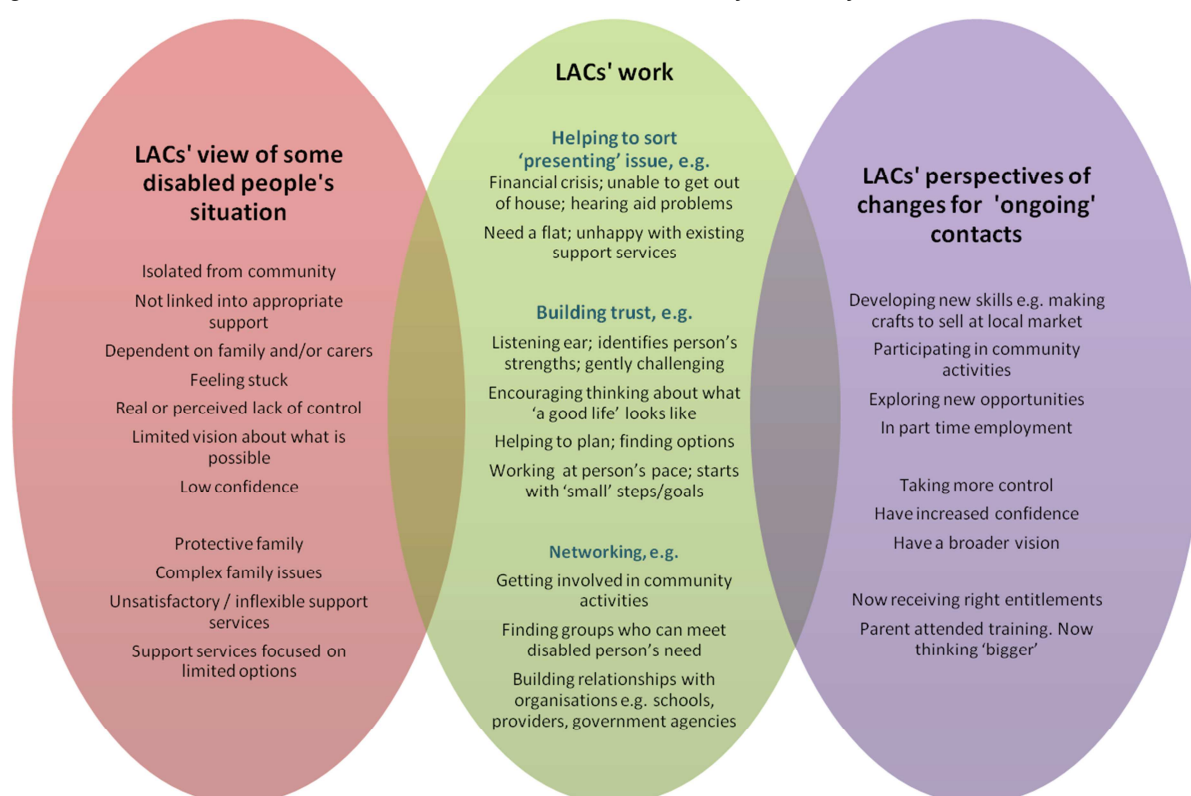
The LACs identified two emerging issues that may act as barriers to the success of local area coordination in the Western Bay of Plenty. The first is that some people in the LAC's community view existing services as the 'right place' for disabled people. The second is that some disability providers (particularly management) view LAC as a "waste of resources", replicating work already being done.

The following vignette describes how a LAC began working with a person who is an ongoing contact, and illustrates how the LAC helped to sort an initial issue as the first step. It also demonstrates the importance of working at the person's pace and the value of building a relationship. The vignette also shows how local area coordination can trigger actions by other people/organisations.

When Brenda* and the LAC first met, Brenda was in "crisis mode". She was in debt and had sought support from a budget advisory service and a social worker. The social worker knew about local area coordination through personal contact with a LAC.

Brenda held off meeting with the LAC as she was busy supporting family members. Having someone else come in at that point would have been too much, so the LAC told her the door was always open, and to make contact when she was ready.

Several months later, life had settled down and Brenda arranged to meet the LAC. As she told her story it was clear her previous experiences had undermined her confidence. During the 1.5 hour meeting the LAC offered to make coffee; Brenda commented it was a long time since someone else had made her a drink.

Sorting out transport was clearly a high priority. Brenda relied on a mobility scooter to get out and about. However, since having a "slight tip" on a hilly road she had not been able to get back on her scooter. She had few friends, was housebound and felt isolated. The LAC suggested she organise for someone to do a safety check, which would involve observing Brenda as she used her scooter. However, this turned out to be unnecessary. After their meeting, a relative offered to fix a flat tyre on the scooter. Brenda then got back on her scooter of her own accord.
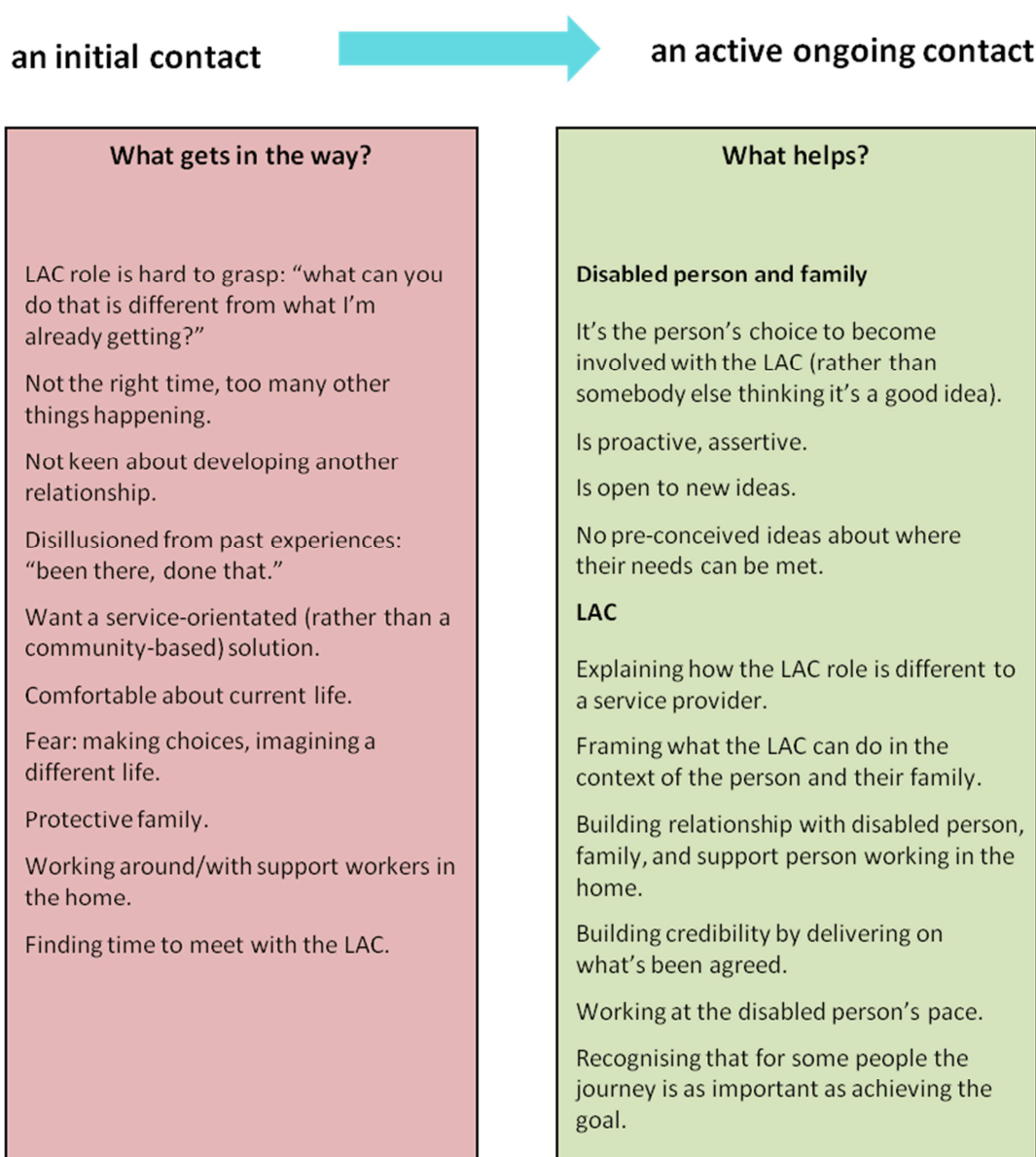
At their second meeting, Brenda volunteered more information about her family situation. The LAC encouraged Brenda to meet with Work and Income to review her current entitlements. At Brenda's request, the LAC came as a support person. A follow up appointment was made and this time Brenda opted to go to Work and Income alone. A few weeks later she was offered a temporary part-time job.

Brenda's scooter is now regularly seen by the LAC at the local shopping centre. Reflecting on the change she has seen since she first began meeting with Brenda, the LAC said: "Her head is up, she is engaged, she makes eye contact. She is frustrated she is on a benefit, but she is more confident than when I first met her."

'Brenda' is a pseudonym, not the person's real name.

We also asked LACs about the process for people to transition from an initial contact to an ongoing contact. Figure 3 shows 'what helps' and 'what gets in the way' of an eligible person becoming an active ongoing contact, based on the experiences of LACs as at June 2012.

Figure 3: Transitioning to an active ongoing contact

an initial contact → **an active ongoing contact**

What gets in the way?

LAC role is hard to grasp: "what can you do that is different from what I'm already getting?"

Not the right time, too many other things happening.

Not keen about developing another relationship.

Disillusioned from past experiences: "been there, done that."

Want a service-orientated (rather than a community-based) solution.

Comfortable about current life.

Fear: making choices, imagining a different life.

Protective family.

Working around/with support workers in the home.

Finding time to meet with the LAC.

What helps?

Disabled person and family

It's the person's choice to become involved with the LAC (rather than somebody else thinking it's a good idea).

Is proactive, assertive.

Is open to new ideas.

No pre-conceived ideas about where their needs can be met.

LAC

Explaining how the LAC role is different to a service provider.

Framing what the LAC can do in the context of the person and their family.

Building relationship with disabled person, family, and support person working in the home.

Building credibility by delivering on what's been agreed.

Working at the disabled person's pace.

Recognising that for some people the journey is as important as achieving the goal.

In September 2012, the LACs described their visioning and planning activities with disabled people and their families. The Local Area Coordination Manual sets out the key features of the visioning and planning approach to be used by LACs with ongoing contacts. Building on the LAC principles, the approach emphasises that disabled people and their families are best placed to determine their goals and plans. A personalised, strengths-based and flexible approach is used (Appendix 2 provides more information about this approach).

The LACs identify two important foundations for facilitating a visioning and planning process with a disabled person – building a relationship of trust with the person, and one or more of their parents (as appropriate); and developing an understanding of the person, their current life, their family relationships/dynamics and current support arrangements.

The LACs use their judgment about the best way to introduce visioning and planning to a person and their family. For some people, an unstructured, informal approach (without referring to the

words 'visioning' or 'planning') is more appropriate, for example over a cup of coffee. Such conversations happen over a number of visits. For some people, thinking about what a 'good life' means for them is not easy and/or they have a narrow perspective. For example, one young person's idea of a 'good life' was a 'typical' teenage response (watching TV all day). For other people, the challenging nature of their current circumstances means it is hard for them to envisage a different future. Other people who may be service-orientated may view their 'good life' as receiving as much support as possible.

Where LACs are using an unstructured, informal approach, they judge the right time to suggest writing up the disabled person's ideas into a plan. There have been some negative responses to the suggestion of a plan, particularly from families with histories of working with agencies who regard a plan as a bureaucratic requirement. A LAC reported:

> *The parents of an ongoing contact are not so much resistant, but rather express apathy about the idea of a plan. Their daughter has been in the system for a long time and they have done a million plans. They know that if you are involved in services, you have to do a plan, which is then usually ignored. It's just more of the same old, same old.*

Another LAC described a family member's response to the idea of a written plan:

> *When I mentioned to the disabled person 'shall I put that into a plan?', the mother rolled her eyes. So the notes went into the back of my notebook and a plan was never signed off.*

In contrast, other people have been keen to start working on their plan immediately. For one ongoing contact, the plan appeared to provide a framework for the person to understand the LAC's role. Although the initial plan was relatively short and superficial, the LAC reported that it was useful because it stimulated more in-depth thinking and discussion with the person.

The format of plans developed to-date has been flexible, based on what suits the individual person. For example, the plan for a person with an intellectual disability uses clip art. The LAC has recently realised that while the 'picture' plan was appropriate for the disabled person, a bullet point list would work better for his mother. A second LAC said a person responded well to the plan template in the Local Area Coordination Manual because she is a systematic sort of person.   Another LAC commented that the plan template lends itself to a flexible approach – it is sufficiently broad that it does not 'lock' people into a specific format, and is specific in that it covers off the components of a plan.

A LAC described how the plan was useful for a person who was starting to use Individualised Funding (IF) to employ a support worker. The person used information from the plan to identify activities the support worker would be involved in. This information was then recorded in the support worker's job description and employment agreement.

This incident demonstrates the level of trust that has developed between the person and the LAC. The IF Host had visited the person and left forms to be filled out. The person rang the LAC asking for help to do this (the LAC got the impression the person did not find the IF Host helpful and was overwhelmed by all the information provided). The person knows two other people who use IF, but preferred to ask the LAC for help.

Regardless of how a plan has been developed (via an informal, unstructured approach, or using a more structured method) or its format (words/pictures), the LACs agree that the plan is a means to an end, rather than an end in itself. The process of thinking through their ideas has been more important for people rather than the plan as a 'product'. While a written/visual plan may be helpful for some people, it may be less appropriate for others.

Engagement with the community

Much of the LAC's work in the first six months involved establishing new links or strengthening existing links with individuals and organisations in their local community. This has included schools and early childhood centres, GPs and other health providers, disability and advocacy organisations, iwi organisations, the Pasifika network, business networks, service organisations, and community-based groups. The key aspect of this engagement has been to explain the New Model and the role of the local area coordinator. The LACs' experiences provide three important insights for introducing local area coordination into other areas, in particular:

- establishing community networks and building the LAC profile takes time.
- the importance of face to face interaction in building relationships and rapport in the community.
- the importance of LAC activities being aligned with community-based expectations and practices i.e. 'the way things are done around here'. For example, the protocols for people to 'enter' a small community.

Disabled people and parents' experience working with LACs

This section describes the experiences of 12 people who have used (or are using) local area coordination in the Western Bay of Plenty demonstration site. Seven are disabled people, and five are parents of a disabled person (one of a young child and four of adults).[6] Nine were working with a LAC when they were interviewed. Of the remaining three, one had their presenting issue solved and decided to put further contact with the LAC on hold until another issue arises. Two others (a disabled person and a parent) are reluctant about having further contact with the LAC because they are dissatisfied with their experience to-date.

The findings from the interviews are presented under the following headings:

- Context for local area coordination: experiences of disabled people and parents
- Contacting a local area coordinator: how and why
- How local area coordination is understood
- Changes for disabled people and families
- Unmet expectations
- Value of local area coordination
- Nine month snapshot of local area coordination.

Context for local area coordination

While talking about their experiences of local area coordination, disabled people (or their parents) described aspects of their life as a disabled person (or parent). These descriptions form part of the context for the findings that follow.

Two disabled people said they are uncomfortable out in 'the world' because people do not treat them nicely and either ignore or stare at them. They feel society "just doesn't get it" and they are not valued. They are frustrated at being unable to get paid work despite having worked in voluntary, part-time roles most of their adult life:

> *I want to know what it feels like to have paid work.*

Two other disabled people described the loneliness and isolation they experience. Such isolation is more pronounced for people living in rural areas without public transport:

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[6] The disabled people are "on-going contacts", a term used by the Demonstration Project to describe people who are eligible for DSS-funded services.

> *When you are disabled, you are very isolated.*

A parent described being upset by the public's negative attitude and discrimination towards people with (*name of disability*).[7] Another parent wants more supports for parents of disabled children that do not focus on therapy or care of their child.

Previous experience of DSS-funded services provided a context for some people to think about their experience of local area coordination. Ten of the 12 disabled people in this study appear to have some experience of using DSS-funded services (currently or in the past), while two others appear to be relatively new to DSS-funded services. A disabled person and two parents expressed dissatisfaction with current or past services.

Contacting a local area coordinator: how and why

Disabled people and whānau /family members found about local area coordination from a range of sources as outlined in Table 3.

Table 3: How people find out about local area coordination

Sources	No.
Via parent or other close personal contact	4 (3 x disabled people; 1 x parent)
Service provider	3 (2 x parent; 1 x disabled person)
School	1 (parent)
Health and disability advocate	1 (disabled person)
Counsellor	1 (disabled person)
Work and Income	1 (disabled person)
NASC	1 (parent)

Only one disabled person and one parent had prior knowledge about local area coordination when they first made contact with a LAC. Six disabled people and two parents said they knew nothing about the LAC role and what to expect. Two other parents said they thought a LAC was a service provider.[8] The low level of awareness about local area coordination was also identified as an issue in a 2010 PriceWaterhouseCoopers study on Western Australia's Local Area Coordination. [9]

Despite a general lack of knowledge and expectations, seven people said they had a specific reason for making contact with a LAC as listed in Table 4. Five people did not identify a specific reason - all are disabled people who were referred or recommended to a LAC by a third party i.e. a parent (3), a service provider (1), a counselor (1).

Table 4: Reasons for initial contact with a local area coordinator

Initial reason for contacting a local area coordinator	No.
Help to establish a social group for young disabled people	1 (disabled person)
Help with transport needs	1 (disabled person)
Assistance with adult child's transition from school	1 (parent)

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[7] The name of the disability is not specified to protect the identity of the parent.

[8] The remaining disabled people and parents did not comment about their prior knowledge and expectations of LACs.

[9] PricewaterhouseCoopers (2010). Disability Services Commission: Local Area Coordination Consultation Project.

Seeking support as a parent of a disabled young child	1 (parent)
Seeking accommodation for adult child	1 (parent)
Finding opportunities for adult child to socialise and be occupied	1 (parent)
Help for adult child to become more independent and gain employment	1 (parent)
No reason given	5 (disabled person)

How local area coordination is understood

As noted above, 10 people had no prior knowledge about local area coordination and initially did not know what to expect. As a result of their experiences of working with a LAC, disabled people described local area coordination in the following ways:

· A bridge between disabled people and local networks/agencies (3)

· Ideas and suggestions, help and encouragement (3)

· Help with goals related to work, hobbies and enjoyment in life (2).

One disabled person described what he likes about what the LAC does:

> *It's building relationships and referring people to other networks that I like about the LAC.*

Three parents described local area coordination as a source of ideas, information and options and one person as "someone else to turn to". One parent said despite still being unsure about the LAC's role, she finds the LAC's input helpful:

> *To me all of this is helpful because I have never been in this situation before and don't know what is out there … so the LAC looks into things for me.*

People were asked for suggestions about how local area coordination could be improved. The only suggestion came from a parent who wants the LAC to have regular contact with her adult child.

Changes for disabled people and families

The focus of most people's comments was about changes that had happened or are going to happen as a result of their contact with a LAC. Respondents identified a number of changes[10] that had occurred already as result of their interaction with a LAC.

Changes for disabled people included:

• Attending a computer course/planning tertiary study in 2013 (two people)
• Working in a part time voluntary job
• Attending a local gym
• Developing a home-based income generation project
• Organising a support group for disabled people
• Solving transport needs so can go shopping and other places
• Referred to a housing provider for housing needs.

Changes for parents included finding accommodation for an adult child and visiting early childcare centres/kindergartens to assess suitability for child.

People described other activities that are still in progress. These include:

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[10] Two people reported more than one change.

- forming a committee of disabled people to lobby for transport services for the area around Te Puke
- working to source funding for accommodation and travel costs to get treatment at a city-based residential rehabilitation facility[11]
- sourcing funding e.g. for one-on-one support at a workplace.

Unmet expectations

One disabled person and two parents expressed dissatisfaction with local area coordination. The disabled person said the LAC lacked local knowledge, networks and tools. When one of the parents understood the LAC role, she expected the LAC would help to identify the individual's and family's goals, and provide ideas and resources about how to achieve them. She had been told (by an unnamed source) she had to choose between using a service provider or a LAC, so she subsequently approached a service provider for assistance. Although the parent's expectations of local area coordination were obviously unmet, it would appear she was seeking a service solution for her immediate issue.

Another parent said she is disappointed with what the LAC has done to-date. She described the LAC as:

> *not moving fast enough … there is not a lot of doing … the whole idea is fantastic but there are not enough actions backing up the words.*

Value of local area coordination

During the interviews, 10 people made comments about what they value about local area coordination. These are summarised in Table 5.[12]

Table 5: Respondents' views about the value of local area coordination

Value of local area coordination	No. of people
Disabled people's comments	
Quality of the relationship with the LAC (listens, trustworthy, patient, helpful)	6
Feel empowered, increased confidence (to work towards their goals, to be in the community)	4
Feel supported by the LAC	4
LAC is a sounding board, helps to generate ideas, explore options	2
LACs' local knowledge and networks	2
LAC encourages person to get medical help if feeling unwell	1
LAC's 'can do' attitude	1
Parents' comments	
LAC provides information about what is available, provides new ideas and options	3

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[11] The person's accommodation and travel expenses used to be met by the facility. The person said she has been told by the facility that this funding is no longer available.

[12] This includes a comment made by a parent about something the LAC had done, despite expressing overall dissatisfaction with local area coordination.

LAC researches options (this is valued by one parent because she has preschoolers and has limited time)	2
LAC relates well to the disabled person	2
Feel supported by the LAC/is someone to turn to	2
LAC is a sounding board	1

Two disabled people described the value of the local area coordination for them. The first person is developing a home-based income generation project.

> *I have been with the health system for a long time … I know I will not be a millionaire … (name of LAC) is giving me hope to be in a better position than where I am now.*

> *I've only been with the project for three months and my (name of issue)[13] has been sorted out, just like that. And now this – my plan to study next year … having someone to work with is very empowering … I want to be more useful for the community, giving back something to the community so at the moment I am preparing for tertiary education.*

As indicated above, six disabled people value the quality of the relationship they have with a LAC. One person said:

> *There was another guy from another organisation, he was trying to rush me, he was unrealistic and he didn't want to listen to me. My LAC listens to what I am saying and doesn't rush me … you don't feel pressured (6)*

These findings provide a snapshot of the experiences of some disabled people and parents in the first nine months since local area coordination began in the Western Bay of Plenty. The experience of nine of the 12 people interviewed has been positive. Their presenting issues have been addressed and they are now thinking about what changes they want to work towards in the future. The quality of the relationship formed between the disabled person and/or parent and the LAC has created a good foundation for future activities.

The one disabled person and two parents who expressed dissatisfaction with aspects of local area coordination emphasise the importance of LACs being equipped with local knowledge, networks and tools, as well as working at a pace that is suited to the particular individual. The findings also highlight the importance of communicating the role and place of local area coordinators: who are they, where do they 'fit' in the disability sector and what do they do?

(2) Supported Self Assessment

Support Net began offering disabled people, parents and caregivers the option to do a supported self assessment of their needs in October 2011. Initially the uptake was limited so at the end of November 2011 it was decided to extend SSA to reviews (reassessments). Support Net also offers SSA as an option to parents/caregivers with children who have ADHD (attention deficit hyperactivity disorder).

In the first four months (up to 16 February 2012) SSA questionnaires were sent to 32 disabled people. They included 10 adults (aged 18 or over) and 22 children. Several SSA questionnaires were completed by parents/caregivers for more than one child. Each of the four Support Net staff

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[13] The name of the issue is not provided to protect the identity of the person.

involved in the Demonstration Project was involved in screening disabled people for SSA. The option was not offered if staff considered the disabled person had complex needs, or the person completing the questionnaire did not have the required English language or cognitive skills.

In May 2012 Support Net revised the screening process. One staff member has responsibility for undertaking an initial screening to decide if SSA is offered to disabled people/families. Support Net has also started recording the number of people considered for SSA and, where appropriate, reasons for declining.

SSA uptake

In the three months May - July 2012, 101 disabled people were considered for a SSA. Of the 18 people living in rural locations who were offered a SSA, most (14) took up this option (Table 6). In comparison, only half of those living in Tauranga/Mt Maunganui agreed to complete a SSA. This finding indicates SSA may be a more attractive option for people living in rural locations; however the numbers of people in the Demonstration Project sample are still too low to identify any definitive trends.

Table 6: Where Support Net clients live

Geographic location & no of SSA clients	Offered SSA	Accepted SSA
Katikati (4)	1	1
Papamoa (9)	6	4
Tauranga/Mt Manganui (73)	42	22
Tauranga rural (6)	6	5
Te Puke (7)	5	4
Waihi Beach (1)	0	0
Not known (1)	0	0

'Complex health issues' was the main reason recorded for 36 people not being offered SSA as an option. Other reasons included people being in hospital, not having any natural supports, and being unable to write.

Of those offered the SSA option, 24 declined and 36 agreed to complete a SSA. Four people were unable to be contacted by Support Net so were referred back to an assessor for follow up. One person had their assessment changed to a review. Table 7 shows most supported self assessments have been completed by people of European/other descent. Of the 48 who were offered a SSA, 32 (67%) took up this option. Maori and Pacific people were more likely to decline a SSA, although again, the numbers are too small to show any definitive trend.

Table 7: Ethnicity of clients considered for SSA

Ethnicity	Not offered SSA	Offered SSA	Accepted SSA	Declined SSA	Could not contact or changed to review
Maori (14)	7	5	1	4	2
European/other (71)	20	48	32	16	3
Pacific (3)	2	1	0	1	0
Asian (1)	1	0	0	0	0
Not recorded (12)	6	6	3	3	0
Total (101)	36	60	36	24	5

Most people (22) declined a SSA because they preferred to meet an assessor face to face. One person further commented they had no energy to complete a SSA, one wanted the assessor to attend "so I can understand too"; and the third commented they had more than one child with a disability. This finding suggests it is important to provide clients with the option to complete either a supported self-assessment or a more traditional assisted assessment. A comprehensive UK survey of user experience of assessment in community care supports this approach.[14]

Of the 101 people considered for SSA, 57 were aged 18 or over and 38 were children.[15] An analysis of SSA uptake by age showed no distinct trends.

User experience of supported self-assessment

This section outlines the experiences of 11 respondents (disabled people and parents/caregivers) who opted to complete a SSA.

Most respondents commented they completed the SSA over several days, usually writing one section at a time. Respondents said it took them between 45 minutes and four hours to complete the questionnaire. Three respondents (all parents/caregivers) described themselves as articulate or highly literate, confirming the appropriateness of screening for English language skills. As one parent commented: "(the process) hinges on strong literacy and confidence of self expression".

The data identified a number of 'high lights' (aspects of the process that worked well for respondents). Two respondents also described the 'down side' of doing a SSA which we describe as 'low lights'.

High lights

Most respondents commented they liked having the flexibility to complete it in their own time, at their own pace. For those who are in paid work, doing a SSA means they can complete it over time, at home and involve the other parent/caregiver. The following two vignettes reflect the approach taken by most of the respondents:

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[14] Challis, D., Brand, C., Abendstern , M., Clarkson, P., Hughes, J., O'Shea, S., et al. (2009). Self- Assessment in community care: Are service users satisfied? Discussion Paper, M214, PSSRU, University of Manchester.

[15] Age is not recorded for six people.

One disabled person (being reassessed) said they spent approximately four hours completing the questionnaire. The person pottered around the house, thought about 'bits and pieces' and then wrote at the dining room table. The person thought carefully about what to say. Their partner spent a few minutes completing the carer's section.

A parent (new assessment) found the process of doing the SSA "therapeutic" as it provided a forum to explain her history, organise her thoughts and formulate a potential future for her child. Doing it herself made it easy to be "candid and frank" about her experiences and expectations. She completed the questionnaire over several days, sitting for short periods and thinking carefully about each section. She described never having been asked to put her perspective forward before; she had low expectations about support and assumed that what she was "enduring" was normal.

One respondent involved a non-family member (their child's caregiver) in the process by "brainstorming" ideas:

> as (the caregiver) knows the family intimately and has an understanding of (the child's) behaviour.

The respondent said this process worked because they could think about the questions "holistically". They believed information would have been missed out if they had been interviewed. This finding mirrors Rabiee and colleagues (2008) findings.[16] UK study in which users reported the self-assessment process to be holistic and encourage people to think creatively about what they wanted to achieve.

The experiences of three people are described in the following vignettes to provide a richer understanding of the process from the perspective of those completing the SSA. Initials (not from their real names) are used to protect respondents' identities.

Experience of "M" and "P"

"M" is a young adult who has an intellectual disability. M's mother, "P" is the primary caregiver. "M" said they completed the SSA questionnaire on their own and found it "easy". There was nothing they didn't like about doing it and hoped they could do the next assessment by themselves. It was clear from the interview they enjoyed feeling involved with the assessment, but also that they did not necessarily understand what it was for.

"P" said she was the one who "comprehensively" completed the SSA. While she was supportive of M being involved, she noted that if they had completed it themselves they would not get any support. She also said "it would not be positive for M to have a full awareness of what effort is put into supporting them..."

"P's" experience completing the questionnaire was that it took "ages and ages" and was "too big to do (all) at once". She worked her way through the questionnaire by completing some parts, then putting it down and returning to it later. She had rung Support Net for assistance at one point and found them to be "responsive". It was useful to have them involved, noting people "need to feel reassured that the change in style of assessment will not negatively impact (on a person getting their needs met)".

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[16] Rabiee, P., Moran, N., and Glendinning, C. (2008). Individual budgets: Lessons from early users' experiences. British Journal of Social Work, 39, 918-935.

She liked the concept of SSA as it was clearly attempting to assess disability needs without being negative:

"In general, disability needs assessments are emotionally traumatic experiences for parents of disabled people, primarily because they force the individual to think about everything in life which is difficult".

Overall, "P" was cautious about viewing SSA as a positive move. "A lack of clear government commitment to difference, equality and equity" has led her to generally distrust changes in needs assessment processes. "P's" view is that when any change is implemented, parents become nervous that the change could become a tool for making their lives worse.

Experience of "G"

"G" is a parent of a disabled child. Support Net had made contact with her several years ago. "G" had been reluctant to engage believing she could cope independently. Recently she had significant health issues of her own and a specialist encouraged her to contact Support Net. She said her daughter had "specific needs and caring for her requires an intimate knowledge of her idiosyncratic behaviour and interests". The child has trouble sleeping and sleeps with her parents, although in her own bed.

She completed the SSA on her own and described the process as "therapeutic". It provided a forum to explain her history, organise her thoughts and formulate a potential future. She completed the questionnaire over several days, sitting for short periods and thinking carefully about each section. She had never been asked to put her perspective forward before; she had low expectations about sources of support.

As she did not have to "face" anyone she said it was easy to be candid and frank. She is happy writing information and found it easy to express herself on paper. The person from Support Net had done an "excellent" job explaining SSA.

Experience of "B"

"B" has a physical disability and lives with her husband "F" and children. Her husband is her main carer. Both parents are actively involved in their children's lives and supporting their activities. They have discouraged their children's involvement in "B's" care to ensure a clear role distinction between parent and child.

"B" has been "frustrated" at the lack of recognition of "her own expertise". Much of her advice around service requirements, especially medical, has been ignored. The SSA provided an opportunity for her to express her understanding and experience. .

Support Net contacted her by phone at the time her reassessment was due and asked if she would like to do a SSA. She spent approximately four hours completing the questionnaire, "pottering around the house thinking about bits and pieces and then writing at the dining room table". She thought carefully about what to say. "F" spent a "few minutes" completing the carer's section.

"B" has been "in the system" for many years and felt she was repeating a lot of information Support Net already knew about her. She found the need to re-describe her physical condition frustrating.

Lowlights

The lowlights describe the 'downside' of doing a SSA, as perceived by two respondents. These included the impersonal nature of the questionnaire (as opposed to having an assessor visit them face to face) which appeared to be related to a concern they might understate their (or their children's) needs and potentially miss out on support. Both concerns are also noted in overseas studies on self-assessment (Challis et al, 2008; Rabii et al, 2008).[17] [18]

A respondent and his wife (interviewed as a couple) described being "proud and private people who don't like asking for help". Both said they tended to underestimate the needs of the disabled partner. They said they would have appreciated help from Support Net (to complete the questionnaire) but no-one rang them. In future they would prefer someone to visit "and chat with us. It's much nicer to sit down and talk with someone about what we're going through."

A second respondent opted not to complete the SSA, in part because she was concerned she would not complete it to her child's "best advantage". When she received a follow-up call from the assessor she was relieved and agreed to go ahead with a regular reassessment.

> *It's amazing how little (support) you get and you just don't know what you can get until someone comes along.*

Having the assessor come to her home helped her feel "someone cares" and that "you're not alone".

(3) Roles and contribution of the National Reference Group and Local Working Group

This section examines the roles the National Reference Group (NRG) and Local Working Group (LWG) have had in contributing to, and influencing decision-making about the Demonstration Project. The findings are discussed in two parts: NRG involvement and LWG involvement.

National Reference Group involvement

A National Reference Group (NRG) was set up in early 2011 to provide strategic input during the planning and implementation of the Demonstration Project and the development of New Model. The NRG comprises 14 people including disabled people, family/ whānau with experience of disability, Maori and Pacific members and people experienced in disability services.[19] The NRG met six times between April 2011 and June 2012. Members' experiences of the NRG can be divided into two phases: the first three meetings (between April and August 2011) and the meetings held since November 2011.

NRG respondents described an initial period (the first three meetings) where many members expressed a lack of clarity about their role. In part this related to an expectation (articulated by six members) that the NRG would have a major influence over the shape of the New Model. As one person said: "I thought we were coming to the New Model as a clean slate". The Ministry's use of

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[17] Challis, D., Clarkson, P., Hughes, J., Abendstern, M., Brand, C., O'Shea, S., et al. (2008b). Enhancing the efficiency and effectiveness of assessment in community care. Vol. IV: Self Assessment pilot projects: Concluding observations. Discussion Paper, M180, PSSRU, University of Manchester.

[18] Rabiee, P., Moran, N., and Glendinning, C. (2008). Individual budgets: Lessons from early users' experiences. British Journal of Social Work, 39, 918-935.

[19] Sixteen people were selected for the NRG. Paul Gibson was unable to take up the position as he was appointed Disability Rights Commissioner. One member attended the first three meetings only.

the term 'co-development' to describe how they planned to work with the NRG further fuelled their expectations about the extent to which they would be involved.

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

> We thought we had an opportunity to get the bull by the horns, but in fact…were just tampering around the edges because the framework had already been determined by the Ministry.

Heavy agendas in the first three meetings also contributed to members' confusion about their role. As one member described:

> The Ministry (wanted) us to comment on a bunch of stuff without any real time spent organizing what the group was there to do, how it was supposed to do it or a clear understanding about what the New Model was.

One NRG member resigned after attending three meetings due to lack of confidence in the process and investment in input.

In the fourth meeting, concerns were raised by members and discussed with the Ministry representatives in a frank and open forum. This discussion was described by those in attendance as pivotal in building understanding between NRG members and Ministry staff. Members reported it became apparent the Ministry "did not have all the answers" and was seeking genuine input into the design and implementation of the New Model. Reflecting on more recent meetings, one NRG member commented:

> (We have) now evolved as a group. The dialogue has become more genuine. Members are working alongside the Ministry and providing real input.

An analysis of comments from members who have attended meetings in 2012 indicates most think the NRG has had strategic input into the design of the New Model, particularly in recent meetings. A few members disagree:

> *If you had an expectation that you would be significantly influential in how this New Model would be shaped that would have been incorrect because the parameters in which the NRG has been working are way too narrow.*

Most respondents' comments indicate trust in those representing the Ministry. As one person commented:

> …there has been a genuine desire to share information and ideas. This has meant free and frank conversations have been able to occur…The conversations inside the room have gone beyond the usual public sector conversations. I give them (Ministry staff) credit for that. The mark of the group is that that hasn't been broken.

The issue of heavy agendas has also been addressed. At the fifth meeting the agenda focused on just two issues, allowing for more in-depth discussion.

Overview and value of NRG input
Minutes of NRG meetings show the group has provided strategic advice on:

- Values and principles underpinning the New Model
- Supported self assessment

- Stakeholder accountability
- Self-directed purchasing guidelines
- Local area coordination principles, and links with Whānau Ora
- Principles of resource allocation
- Functions, roles and responsibilities and broader workforce issues.

Members further described their involvement as:

- challenging assumptions, for example that there will not be a single solution for everyone and that while the focus is on empowering individuals "we need to factor their family into the equation".
- thinking about the New Model in the context of what else is happening that is aimed at similar outcomes, such as Whānau Ora and Enabling Good Lives.

Ministry officials commented the NRG has provided strong leadership "exploring future and system-wide, strategic change". At times the Ministry has had to balance the value of NRG input with time pressures from senior management and Ministers. NRG members reported they had been successful in stalling progress when they felt extra time was needed to discuss critical issues:

> Without the NRG the New Model would have been (developed) in haste without due consideration being given (NRG member).

Likewise a Ministry staff member commented the project would not have progressed to the extent it has without a genuine consultation approach which "commits us to working at the pace of the NRG (and LWG)".

What is not working so well?
There was little consensus about aspects of the NRG that are not working so well. Issues raised by some members are regarded as working well by others. A consistent message was the importance of ensuring all voices are heard equally. Two members commented the size of the group makes it challenging to get a "balanced" view and at times, they do not feel their view is heard. They suggested a smaller group might have been able to achieve more than a group with "a far wider spread of agendas". Another commented:

> Some people have strong relationships with the Ministry. I feel what they say is given more weight than people not in the 'inner sanctum'.

Several NRG (and LWG) members commented the payment for attending meetings does not value their input:

> The Ministry lacks understanding of the amount of effort required – reading material before the meeting which we are not paid for.

Local Working Group involvement
A Western Bay of Plenty local working group (LWG) was set up in February 2011 to assist the Ministry. Its role includes:

- giving advice on parts of the New Model as they are tried in the Western Bay of Plenty
- reflecting on how well the New Model is working and how it might help disabled people live a good live
- suggesting changes that might improve the Demonstration Project

- sharing information with people and organisations in their networks.

By December 2011 the group had met 15 times (on average twice a month). There were fewer meetings in 2012 (three in the first six months).

The LWG began with 15 members. The death of two LWG members, Rena Savage and Peter James in early 2012 left a significant gap.

Overview and value of LWG input
Minutes of LWG meetings show the group has provided "on the ground' advice on:

- Local area coordinator (LAC) selection and placement in specific communities development done by Ministry
- Enhanced individualized funding/host providers
- Self directed purchasing
- Funding allocation
- Supported self assessment
- Roles and functions
- Disabled person pathway

Members identified a number of aspects that have worked well from their perspective. They include:

- Members' commitment to the work. As one member said: "There is a lot of energy and passion for change".
- Opportunities to meet in different forums, for example doing small group work either within a larger LWG meeting or outside the meeting. Members also appreciated the opportunity to talk for part of a LWG meeting without the Ministry present. One person commented there was a "real opening up" in the room when this occurred.
- Members report they have developed a trusting relationship with key Ministry staff. Respondents referred to Ministry staff as "upfront, insightful" and "engaging actively with (the LWG)".
- Realistic timeframes. Members commented the extended timeframe for implementing local area coordination enabled them to be "genuinely" involved.

Comments from three LWG members indicate they expected to be working more closely with the local area coordinators than has been the case, for example problem-solving issues or leading disability awareness training.

(4) Role and contribution of the implementation support agency

This section provides an overview of the work of Inclusion Aotearoa as the implementation support agency for the Demonstration Project in the Western Bay of Plenty. This is followed by key findings about the implementation support agency's work in relation to:

- sector credibility
- being a conduit between the Ministry and parts of the sector
- resourcing and pace of work
- physical presence

- community engagement
- LAC accommodation
- strategic communications strategy

Inclusion Aotearoa was appointed as the implementation support agency in mid-November 2010 following a tendering process.[20]   The role of Inclusion Aotearoa is to assist with the design, implementation, testing and refinement of the Demonstration Project for the New Model, including identification of risks and issues.[21]

An overview of the work completed by Inclusion Aotearoa from the end of 2010 to mid-2012 is included in Appendix 3.[22] Its early work focused on establishing the relationships and infrastructure required to support the introduction of the Demonstration Project into the Western Bay of Plenty. This included community engagement activities, and establishing and facilitating the Local Working Group. Inclusion Aotearoa was also tasked with recruitment of four local area coordinators, organising training, professional and cultural supervision for these staff.

Following the initial establishment phase in the Demonstration site, Inclusion Aotearoa's work focused on establishing and facilitating the National Reference Group, and the development of specific areas of the New Model, such as Enhanced Individualised Funding and the Purchasing Guidelines. Inclusion Aotearoa has also provided information about the New Model to the disability sector through summaries of the meetings of the National Reference Group and Local Working Group, and other material (e.g. frequently asked questions) posted on the Ministry of Health and Inclusion Aotearoa websites.

Sector credibility

Comments by sector stakeholders during the evaluation interviews indicate that Inclusion Aotearoa is generally regarded as credible and trustworthy. The directors' experience supporting and working in the disability sector, and lived experience of disability (in the case of one director) contribute to how Inclusion Aotearoa is perceived. This credibility appears to help Inclusion Aotearoa negotiate the potential 'fine line' as the implementation agency, that is, working on behalf of the Ministry as a contractor, while also being 'accountable' to the disability sector in an informal sense. Inclusion Aotearoa say that this dual accountability has been helped by the integrity of the Ministry's key project staff, and clarity about the respective roles of the implementation agency and the Ministry as they relate to day-to-day work.

Conduit between the Ministry and parts of the sector

Since the evaluation began in early 2012, the evaluators have heard many comments about the distrust and suspicion with which the Ministry[23] is viewed by some groups of disabled people, and skepticism towards the new approach to supporting disabled people. Inclusion Aotearoa appears to have acted as a 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.

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[20] The request for proposals was advertised on the Government Electronic Tendering website in July 2010.

[21] http://www.health.govt.nz/our-work/disability-services/new-model-supporting-disabled-people/updates-new-model-supporting-disabled-people

[22] A detailed account of the work can be found in the annual report of Aotearoa Inclusion (July 2011).

[23] This refers to the Ministry as a whole, rather than individuals working within the Ministry.

Resourcing and pace of work

Until around mid-2012, there was only one person from the Ministry working fulltime on the project (there are now two full-time staff members). Other Ministry staff are working on the project around their existing duties. These resourcing constraints, together with the short implementation timeframe for the Demonstration Project has meant Inclusion Aotearoa has had to be responsive to meet implementation timeframes.

Physical presence

At the time the implementation support agency was being selected, the site for the Demonstration Project had not been decided.[24] It was fortuitous one of the directors of Inclusion Aotearoa lives in the Bay of Plenty. This physical presence has been helpful, given that the Project Manager and other Ministry personnel involved in the Demonstration Project are based in other locations. It has made face-to-face contact with local stakeholders easier and enabled timely responses to issues, as required. Inclusion Aotearoa came to the project with established community contacts and local knowledge of the area.

Community engagement

At the end of 2010 and early 2011, Inclusion Aotearoa began a process of community engagement in the Western Bay of Plenty with disabled people, consumer groups, public health organisations (who are also Whānau Ora providers), Maori, Pasifika, local government and other stakeholder groups. This engagement was done via individual, face to face meetings. These efforts were evidenced at the hui held in December 2010 to welcome and bless the Demonstration Project to the Western Bay of Plenty which was attended by over 100 people, many of whom were disabled people and their whānau/family. These initial community engagement efforts have been further expanded using information about local networks provided the Local Working Group.

Although this relationships-based approach to community engagement is resource and time intensive, Inclusion Aotearoa describe it as being essential for building a deeper understanding of how to engage with a particular community, particular Maori communities. This relationships-based approach also helps to stimulate interest in the New Model in a way that more passive forms of communication (e.g. email) may not.

LAC accommodation

Inclusion Aotearoa's effort in locating accommodation for the four local area coordinators has provided useful learning for future sites. This experience has reinforced the importance of knowing how a particular community 'works' before selecting an office site, and locating the office in a high visibility setting with foot traffic. However the affordability and availability of such locations means that trade-offs often have to be made.

Strategic communications strategy

Inclusion Aotearoa provides communication material about the New Model as the work of the NRG and LWG is progressing. Members of both the NRG and LWG commented the summaries have been useful for sharing with their networks: "They are readable, usually well put together". Despite the summaries, some members expressed concern that many people in the disability sector

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[24] Having a physical presence in the area was not a selection criterion for the implementation agency. The tender for the implementation agency referred to two or three possible sites and required those submitting proposals to confirm being able to work in whichever areas were selected.

appear "uninformed" about the New Model work. This is of concern as it has the potential to create uncertainty and anxiety about the changes, particularly among disabled people and their families.

Appendix 1: Outcome Mapping for New Model

Vision

1. The vision for the New Model is based on the NZ Disability Strategy, the UN Convention on the Rights of Persons with Disabilities and comments from participants at the workshop.

DRAFT VISION

Our vision is: In New Zealand disabled people say they live in a society that 'highly values our lives and continually enhances our full participation, and expectations to learn, work and engage in social structures as part of social and economic life. Disabled people are treated equitably, regardless of gender, age, cultural background, type of disability or when and how the impairment was acquired. They have the opportunity to choose where they live. Buildings, roads, transportation and other indoor and outdoor facilities including schools, housing, medical facilities and workplaces are accessible. Their interdependence with others is recognised and valued, especially their relationships with family, friends, whānau and other people who provide support. People in the community are non judgmental. Disabled people are valued for what they bring and contribute to communities. Their abilities are valued and not questioned. The diversity of disabled people, including their cultural backgrounds, is recognised and there is flexibility to support their differing aspirations and goals. Māori define and provide for their own priorities for participation and are delivering their own disability services. Disabled Māori and Pacific participate in their communities and access disability support in culturally appropriate ways. People focus on support, not services. Disabled children and youth lead full and active lives. Disabled people have access to information about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, supports and facilities. They have access to a range of affordable in-home, residential and other community supports, including personal assistance necessary to support living and inclusion in their community. They have the opportunity to participate in decision-making processes about policies and programmes, including those that directly concern them. New Zealand legislation, policies and other activities enhance the lives of disabled people. Disabled people are influencing change in all areas of society; leading a social change away from disability towards accessibility. Disabled people are accepting responsibility for self determination and community development. They are in leadership roles and are promoting each others' values and uniqueness.

Mission statement

2. The mission is that 'bite' of the vision statement on which the New Model is going to focus.

DRAFT MISSION

We will know the New Model is working when … disabled people are working towards achieving their dreams. They have autonomy and are able to determine their lives. They have real life more choices about how they live their lives. Their wairua tanga/spiritual wellbeing is nurtured. We see more disabled people in socially valued roles (paid and unpaid), and as leaders throughout society. Their roles and contributions are valued. Communities are connected to, and welcoming of, disabled people. Family, whānau and others in the community are recognised as significant natural supports.

The New Model is about a fundamental paradigm shift in power and control, and in the nature and shape of support for disabled people. Disabled people choose those (paid and unpaid) who will journey with them to achieve their dreams.

Project partners

3. At its essence, change is accomplished by, and for, people. Therefore, the focus for our evaluation is on changes in behaviour, activities, and relationships – especially those who are working directly with the Demonstration Project (called project partners). We have identified the following project partners for the Demonstration Project:

    - Disabled people
    - Families/whānau of people with disabilities
    - Ministry of Health/LACs/NASC/providers. These are the people who have the power to promote, block, or otherwise influence how disabled people are reached and affected. The common denominator is the Ministry. Some other influences affect the behaviour of Ministry staff, but political requirements, policy, contract specs, contract management, compliance and auditing are within the sphere of the Ministry.
    - Local communities/iwi

4. The following are strategic partners. These are people the project partners may be working with, but do not necessarily want to change. The project partners may want an alliance with them to achieve their objectives, but they are not trying to change their behaviour.

    - Disabled persons' membership organisations
    - Human Rights Commission/Disability Commissioner

Outcome challenges and progress markers

5. One outcome challenge has been drafted for each project partner. These outcome challenges relate to the New Model, not just the Demonstration Project.

6. The outcome challenges were developed by asking participants:

    - Ideally, in order to contribute to the vision, how will the project partner be behaving or acting differently?
    - What new relationships will have been formed?
    - How will existing ones change?

7. The progress markers represent a change model for each project partner. They advance in degree from:

    - Expect: the minimum one would expect to see the project partner doing as an early response to the New Model's basic activities
    - Like: what it would like to see them doing, and
    - Love: what it would love to see them doing if the New Model was having a profound influence.

8. The evaluation will not be monitoring all the progress markers - just those that relate to the key components of the Demonstration Project. The suggested progress markers to be monitored in 2012 are indicated in right hand column.

9. The outcome challenges and progress markers will be updated over the course of the evaluation to ensure they remain relevant.

Outcome challenge for disabled people
Outcome challenge A: The New Model intends to see disabled people stepping 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.

Expect to see disabled people:

1	Deciding, with LACs, the level of responsibility they want to take on (e.g. finding their own supports)
2	Being assertive and when appropriate, non-compliant
3	Participating in ways they have previously not been able (e.g. paid work in their communities)
4	Sharing their knowledge with whānau, hapu, iwi
5	Accessing flexible support easily (less bureaucratic)
6	Participating in iwi development activities
7	Not 'putting up' with appalling services
8	Accessing individualised funding
9	Members of the National Reference Group providing strategic input into the planning and implementation of the New Model elements and their suggestions being taken on board
10	Members of the Local Working Group providing advice and assistance into the planning and implementation of the New Model elements and their suggestions being taken on board
11	Influencing national policy through participation in cross-government forums

Like to see disabled people:

1	Disabled people managing services such as LACs, NASCs

Love to see disabled people:

1	Disabled people in Ministry policy positions making liberating changes and innovating new responses to disability/accessibility support systems

Outcome challenge for the Ministry of Health/LACs and NASC/providers

Outcome challenge B: 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 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.

Expect to see:

1	LAC outcomes**
2	LACs providing information about local area coordination to local iwi/Māori groups
3	Ministry implementing 'stronger, broader' accountability mechanisms that are consistent with risk (less 'red tape')
4	Ministry contracting more flexible services (based on soft accountability and high trust) that are focused on outcomes
5	Ministry investing in technology (information systems, communication, web based solutions) that are accessible for disabled people
6	Ministry producing clear information about what funding can and cannot be used for
7	Ministry staff meeting with leaders in the disability sector to have regular conversations about issues
8	Ministry using co-development processes with the National Reference Group and Local Working Group that includes sharing of information, and taking members' advice and suggestions on board
9	Ministry developing policies that are clear and consistent with the NZ Disability Strategy
10	Ministry handing over authority to Māori organisations to provide support to disabled Maori

Like to see:

1	Ministry funding flexible support that meets the needs of individuals

Love to see:

1	Ministry allocating resources to people that can be carried over 12 month periods

** Through local area coordination, disabled people and/or their families and whānau:

- receive a service that reflects a strengths-based approach, is flexible enough to meet changing needs and supports valued roles for the disabled person

- have natural supports around them to assist them achieve their vision and their goals

- have access to community services which are appropriate to their needs and goals

- receive quality support and services

- have better access to relevant information about available services, supports and funding.

LAC Outcomes (from draft LAC Manual, December 2011, p.16).

Outcome challenge for families/whānau
Outcome challenge C: The New Model intends to see families/whānau supported so they are able to support family members. 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.

Expect to see families/whānau:

1	Articulating positive messages about their disabled family/ whānau members in the media
2	Calling on grandparents and extended family/ whānau to help with support
3	Accessing ordinary supports, e.g. schools, playcentres, kohanga
4	Including disabled people in activities at the marae
5	Connecting with other families/support groups and organisations

Like to see families/whānau:

1	Identifying opportunities for intellectually disabled family/ whānau members to learn more

Love to see families/whānau:

1	Assisting other project partners to develop pre-birth and neo-natal information and supports for family/whānau
2	Participating in clinicians' training on live possibilities on disability

Outcome challenge for local communities/iwi
Outcome challenge D: 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.

Expect to see local communities/iwi:

1	Linking any Whānau Ora work to the New Model
2	Identifying key people and networks
3	Meeting with LACs
4	Participating in the demonstration of the New Model
5	Establishing varied types of support for disabled people to access
6	Identifying opportunities for more people to get involved in supporting disabled people
2	Implementing the Council's Disability Plan

Like to see local communities/iwi

1	

Love to see local communities/iwi

1	Integrating the New Model with Whānau Ora

Appendix 2: local area coordination principles

Source: Local Area Coordination Manual, 1 December 2011, p.14-15

1. As citizens, disabled people have the same rights and responsibilities as all other people to participate in and contribute to the life of the community.
2. Disabled people and/or families supporting a person with a disability are best placed to determine their own goals, and to plan for the future either independently, as a family, or supported by advocates of their choice.
3. Families, friends and personal supports are the foundations of a rich and valued life in the community.
4. Disabled people and their families have natural authority and are best placed to be their most powerful and enduring leaders, decision makers and advocates.
5. Maori disabled are recognised as tangata whenua. Their aspirations, rights and needs will be met in ways that support their identity, beliefs, values and practices as individuals within whānau.
6. The aspirations, rights and needs of diverse cultural groups are understood and respected in ways that support their identity, beliefs, values and practices.
7. Access to information that is timely, accurate and available in appropriate formats enables people to make appropriate decisions and to gain more control over their life.
8. Communities are enriched by the inclusion and participation of disabled people, and these communities are the most important way of providing friendship, support and a meaningful life to disabled people and/or their families and carers.
9. The lives of disabled people and/or their families are enhanced when they can determine their preferred supports and services and control the required resources, to the extent that they desire.
10. Services and supports provided through Local Area Coordination complement and support the primary role of families, carers and communities in achieving a good life for disabled people. These services and supports should not take over or exclude the natural supports that already exist or could be developed.
11. Partnerships between individuals, families and carers, communities, governments, service providers and the business sector are vital in meeting the needs of disabled people.
12. Disabled people have a life-long capacity for learning, development and contribution.

Appendix 3: overview of the implementation agency's work areas

Work area	Outputs
Preparatory work	• Community profile of Western Bay of Plenty written • Input into the Baseline Research
Stakeholder and community engagement	• Community Engagement Plan developed and updated • Key people and organisations in the Western Bay of Plenty contacted and information about the Demonstration Project provided • Database of Western Bay of Plenty contacts and national stakeholders created and updated • Organised and facilitated a community hui which included a Powhiri, and Maori and Pasifika blessings to welcome the Demonstration Project into the Western Bay of Plenty (17 Dec 2010) • Organised the LAC launch by the Minister of Health (23 August 2011) • Facilitates sector stakeholder meetings
Local Working Group & National Reference Group	• Systems and documentation prepared for nominations and selection of LWG and NRG • Assisted the Ministry with the selection of LWG and NRG members • Assists the Ministry with the planning of LWG and NRG meetings, including developing 'real life' scenarios for members to discuss specific topics • Undertakes pre-meeting briefings for LWG and NRG members, as required • Facilitates meetings, writing of minutes, and providing other secretarial support for LWG and NRG • Runs pre-meeting briefings for LWG and NRG meetings, and supporting individual members as appropriate • Arranges members' travel for meetings
Local Area Coordination	• Recruitment processes and documentation completed (e.g. job description • Physical infrastructure set up (offices, computers, phones, signage etc) • LAC policies and administrative systems developed • LAC brochure and fact sheet produced • Identified and contracted training for LACs, including overseas experts on LAC arrangements. • Produced LAC Manual • Professional/practice/management supervision arranged for LACs
Communications	• Summaries of the work of LWG and NRG meetings written and made available on the Ministry of Health and Inclusion Aotearoa websites • Other updates, information and FAQs about the New Model developed and made available on the Inclusion Aotearoa and Ministry websites • Presentations and other material about the New Model developed for use by the Ministry at sector conferences and other forums
Strategic advice	• Advice how to engage with specific parts of the sector • Advice about specific aspects of the New Model • Risk identification