
**DISABILITY SUPPORT SERVICES
CONSUMER CONSORTIUM MEETING**

Thursday 18th and Friday 19th March 2010

Summary Minutes

**Brentwood Hotel
16 Kemp Street
Kilbirnie
WELLINGTON**

Facilitator/Member: Venessa Rice, Parent to Parent

Coordinator: Rob Gill, Ministry of Health

Administration: Debbie Webster, NZFDIC

Presenters Day One: Rob Gill – Development Manager Workforce
The Honourable Minister Tariana Turia
Marsha Marshall – Manager Family & Contracting Support
Sue Primrose – ESS Programme Manager
Bronwen Foxx – President, NZFDIC

Presenters Day Two: Anne O’Connell – Group Manager DSS
John Wilkinson – Principal Policy Analyst
Jenny Moor – Manager Service Access Team
Rob Gill – Acting Manager Strategy & Contracting Support

Karen Hyland – Manager Community Living Team

Raewyn Winiata – Development Manager,
Community Living Team

Consortium Members: John Grealley, Autism New Zealand
Simona Mataiti, PIASS Trust
Lena Berger, Rescare New Zealand
Carolyn Weston, Association of Blind Citizens NZ
Wendy Brenkley, Carers New Zealand
Harvey Brunt, Cerebral Palsy Society of NZ
Mathilda Schorer, CCS Disability Action
Jacqui Carlson, CCS Disability Action
Christine Morrison, IHC Advocacy
Lee Rutene, Ngati Kapo o Aotearoa
Merv Cox, Deafblind New Zealand Inc
Karen Pointon, Deaf Aotearoa NZ
Phyllis McPherson, People First
Gayle Cullwick, NZ Down Syndrome Assoc.
Heather Dawson, Hearing Association
Jill Waldron, Muscular Dystrophy Assoc.
Patrick Thompson, Mana Turi o Aotearoa
Wendy Duff, Autism New Zealand
Lolomania Filiai, PIASS Trust
Ngairé Wycliffe, Brain Injury Association

Apologies: Chris Orr, RNZFB
Morgan Smith, People First

In Attendance: Kaeti Rigarlsford, People First

Support persons: Cheryl Cox
Tina Mataiti
Melissa Blackmore
Lingisou Teulilo

Sign Language Interpreters: Harri Harrison, Thornton Peck, Rosie Henley

Key for abbreviations used in minutes

Q = Question P = Point Made R = response

The Consortium started at 9:15 am

Welcome and introductions

Rob Gill welcomed the group, in particular new members Wendy Brenkley of Carers NZ, Heather Dawson of the Hearing Association, Wendy Duff of Autism NZ, John Greally of Autism NZ, Phyllis McPherson of People First and Christine Morrison of IHC Advocacy. The microphone was passed around for members to introduce themselves and housekeeping matters addressed.

Action Points from previous minutes

- Socrates problem – the issue that caused these problems has now been resolved so invoices are not being rejected and payments are going through. To stop this being a problem in the future a report will be prepared at least every two months for all NASCs in the country and the NASCs will be told individually if they have any overdue service

coordinator the MoH will make sure that contract managers follow up where any service co ordination is overdue.

- The GETS website is accessible people need to register to be able to log on to it.
- Launch 14th April for Peak Body Group further details contact Gayle Cullwick at gcullwick@hotmail.com
- Txting Trial Service – organizations waiting for letter from Alison Hearn, Rob responded on behalf of Alison Hearn and asked who does she need to write to? Is there a lead agency? The response received is that a letter needs to go to the CEO/General Manager of each organisation. Rob indicated he could write and send a letter on Alison's behalf.
- Reporting back to the Ministry: Consortium members are to complete annually an appraisal form on the Consortium and between each meeting a record of activity form.

All other action points completed or to be discussed during over next two days.

Consumer Leadership and Training Fund

Rob Gill is the Development Manager responsible for managing the disability workforce programme and he manages the Ministry of Health contract with Te Pou. Te Pou is delivering national training coordination services for the MoH. Applications were received for 2010 from the following organizations SAMS, Standards Plus, People First, DPA, Parent and Family Resource Centre, Parent 2 Parent NZ Inc, Carers New Zealand, CCS Disability Action and PHAB Auckland. The total sum of combined applications for the Leadership Development Scheme and the Consumer Leadership and Training Fund is approximately \$1,113,000.00. The total funding available for 2010 for the consumer scheme is \$834,000.00.

The programmes/applicants that are likely to be funded should have contracts by next week. The activities that will be funded include:

- Leadership courses based on Partners and Policy Making
- Consumer and Family training programme to provide weekend workshops for disabled people and families.
- Two day forums in Auckland, Palmerston North and Christchurch on individualised support and mentoring
- Parent support programme – advocacy support course and train the trainers.
- Making basic learning tools for Carers available 24/7 on line.

- Comprehensive mentoring training and coaching package for at least twenty disabled people.

There is one other programme yet to be finalized. Rob will get back to the Consortium on the full outline of what is being offered, and make that information available to the Consortium members. Te Pou will also set up in the near future a web site on the National Training service and will send out regular newsletters promoting the training that's being funded.

Link to Te Pou's website

<http://www.disabilityworkforce.co.nz/page/10-Welcome>

Rob posed the following questions to the Consortium Members:

- What is the Consortiums vision for the Consumer Training and Leadership Fund?
- What types of training does the Consortium consider most important for consumers?
- How would you like Te Pou to provide the information to you?

Minister Tariana Turia

Rob Gill introduced Minister Turia to the Consumer Consortium. Patrick Thompson, on behalf of the Consortium members welcomed the Minister to the meeting, followed by a waiata. The microphone was passed around the Consortium Members to introduce themselves.

The Minister expressed her pleasure at being able to join with the Consortium members at the Disability Services Consumer Consortium.

She was particularly impressed by the Consumer Consortium terms of reference, that diversity and difference will be respected, that commonalities will be sought and collaboration encouraged; that meetings will be run in such a way as to ensure participation and inclusion; and that a commitment will be made to ensure that meaningful advice and information is provided to Disability Services.

She said she has been very influenced by the leadership of people with disabilities who have told her, *nothing about us, without us*. It is implicit in the recognition that people with disabilities and their families know best what they need most. This is a clear direction for Government, to ensure that people with disabilities are able to establish the strategies and individualised plans,

along with individualised funding paths and the full range of assistance they need.

“As the Minister I am determined that Government services will meet the needs of disabled persons as articulated in the *New Zealand Disability Strategy*, and that Government agencies are achieving progress in the implementation of that strategy. We must build on the example of Adam Hall – to do whatever it takes.”

Minister Turia spoke about the newly formed **Ministerial Committee on Disability issues**, as it builds momentum and to make it possible for disabled persons to live everyday lives, in which they have the same access to opportunities, choices, responsibilities and rights that any other New Zealander has. This committee has been functioning since June 2009 and a Chief Executives Group has also be established to gain traction on implementation, and importantly, to follow your lead –to ensure greater collaboration of effort. That Chief Executives Group held its first meeting on the 3 March this year, and the Minister is expecting them to report back to each Ministerial committee meeting from now on in. At the next meeting the Minister is planning that they focus on two key aims:

- to share progress on a new model for disability support
- To achieve greater progress in responsiveness of government to disabled persons.

A new model for Disability Support

Minister Turia acknowledged with appreciation, the input from the Consortium in providing feedback to the Ministry of Health about their perspectives on local area coordination – an approach which she is very supportive of.

The new model that is being created will build on the success factors common to *Local Area Coordination*, as well as emphasizing individualised funding and supported living. The model really picks up on the feedback the Consortium have shared, about supporting disabled persons to do everyday things in everyday ways, even winning a few gold medals along the way. The Minister is really keen to promote opportunities for building up the capacities of whanau, family, community and individuals, including options for support. The focus of the new model will be on helping disabled persons and their families to build a good life for themselves. This may be done in a number of ways - through developing working relationships with Local Area Coordinators; through providing more flexibility over how the funding is used, and giving people more choice and control over the support they can purchase. The Minister is hoping that next time she meets with the Consortium she will have more detail to share, once Ministers have made decisions about the new model.

Responsiveness across Government

The Ministerial Committee has already been briefed by a coalition of disabled people and their families, at a meeting held last October. In that meeting Mark Benjamin, Gary Williams, Graeme Parrish and Cindy Johns raised the call for developing a local area coordination type approach; more flexible needs assessment and an expansion of individualised funding.

The Committee has agreed on three clear priorities:

- **Accessible Aotearoa** – including accepting communities and accessible transport and travel options;
- **Modern disabilities supports** – supports which will include natural support, early intervention, and options to invest in resilient families and self-managing individuals;
- **And contributing citizens** – citizens who can achieve at school and work, to achieve their goals, aspirations and dreams.

The Minister believes that support systems need to be made easier to access and that information should be easier to find. To do this, we are driven by a whole-of-government work programme on disability issues which flow from the Disability Strategy, the United Nations Convention and the Government response to the Social Services Select Committee's inquiry into the Quality of Care and Service provision for people with disabilities.

The Minister expressed her hope that through the Ministerial Committee – and the work programme they have set themselves – they are able to strengthen the responsibilities of government agencies in supporting disabled persons.

In the notes inviting the Minister to the Consortium, the Hon. Tariana Turia was asked to address some questions, they are as follows:

- to speak about the plans/role of the newly formed Disability Committee and what are its intentions to implement the select committee findings. And what input do consumers have to this committee?
- What role the Minister may see for the Consortium in her current post as Minister for Disability Issues?

The Minister's responses are as follows:

“And in a way it comes back to your terms of reference – to welcome diversity and to embrace collaboration. I am really keen to know how to engage most appropriately and effectively with the sector. My experience over the last year has shown me areas of duplication and overlap with the potential for confusion or in some cases, some people having disproportionate access to my office, and that doesn't seem right. So I will be keen to hear back from you about any ideas in which I can improve the opportunities that Government has to be accountable to disabled persons and their families. “

“It would be good if I could attend at least two of the Consumer Consortia a year to get feedback on how well we are progressing, I would be happy to do that. I am keen to know how do I engage more effectively with the sector.”

“Two areas I am attempting to progress with the government and I would like your feedback on these:”

- Looking at a human rights commissioner or an ombudsman an independent person that provides reports against what’s happening in the sector, what is being done or not being done.
- A media campaign to help change the attitudes around disabled people.

Consumer Consortium Member Guidelines – Bronwen Foxx

Background

The NZ Federation of Disability Information Centres began co-ordinating and administering the Consumer Consortium for the Ministry of Health in August 2005. The first Consortium meeting we organised was attended by 23 people, including support persons. It was held in Auckland at a total cost of around \$35,000. The last Consortium held in Wellington in November 09 was attended by 30 people at a cost of \$45,000. In both of these cases, the average cost of bringing a person to a Consortium meeting was around \$1,500. This cost includes travel, accommodation, food, disability related costs (including support persons, interpreters and equipment) admin, and consumer honoraria payments.

We appreciate the efforts made by members to keep costs down since we introduced the Guidelines for Expenses last year. We acknowledge that, while we strive to meet everyone’s needs, we are constrained by budget and cannot always achieve the ideal. We believe it is not unreasonable to suggest that, where we cannot meet a person’s individual requirements, the organisation who has nominated that member should take responsibility for ensuring that their nominee’s needs are met. It may be that if we cannot keep within budget that we will have to set a maximum amount per person and if individual costs go over that amount the organisations pay the difference. Would that be fair and reasonable?

The current Consortium Agreement expires at the end of June next year. The Ministry will decide whether it wishes to continue to consult with consumers via the Consortium or not. The main factor that will be taken into account when making that decision will be value for money. We are managing to keep

costs within budget and hopefully, with your help, this will continue. However, the question will be what does the Ministry receive from the Consortium for the amount it is investing? Do you as members believe that you give \$1,500 worth of value to the Ministry each time you meet? What, in your opinion, is it that the Ministry gain from you as a Consumer Consortium member?

It is vital that everyone participates fully in Consortium discussions. It is vital that you read the preparatory material so you can participate in those discussions knowledgeably. It is vital that you complete the annual Consortium Appraisal survey and the Consortium Member Record of Activity form between each meeting as evidence of your participation. It is also vital that you give feedback from your organisation's membership, as well as stating how you have provided them with information from the Consortium meetings. Your organisation has a right to know that you are participating fully and that they are getting something out of having you as their nominee.

We ask you to think about these things. Talk with your organisation about how you are representing them and how they can assist you where we cannot. Participate fully. Help to ensure that the Ministry values your contribution. Accept that we are not able to fund all requirements people may have, but we will do our best to be fair and reasonable.

Individualised Funding Scheme Update – Marsha Marshall

What is Individualised Funding?

- A payment mechanism
- Designed to give people choice and control
- A lot of control or less control and more support
- Currently limited to Home and Community Support Services but plans are to roll out to more disability support services.

Why are we doing this?

- Came out of recommendations from the Select Committee Report
- Disability Strategy
- DSS Strategic Plan
- Review done in 2008
- People like it!

IF – then and now

- Accountability frameworks in place

- National consistency in processes
- Increased access nationally (up to 300 people from 129 in 2008)
- Increased eligibility
- Risk management strategies in place: Utilisation vs. Allocation
- More choice of provider

Timeframes – Individualised Funding Scheme Expansion Key Activities and Dates 2009 /10

- **November 2009 onwards:** establishment of Implementation Reference Group (providers, NASCs, Consumer and the Ministry of Health) Development of companion documents for providers and information for consumers
- **November 2009 – January 2010:** Expressions of Interest document developed, interest sought from current HCSS Providers who wish to offer IF.
- **February – April 2010:** Discussion/negotiation with providers to provide IF from May 2010.
- **May 2010:** Formal implementation of a national programme. Delivery of training to NASCs and Providers.
- **2010 / 2011:** Consideration of expansion of IF to other disability supports.

Is IF right for me?

- I want more control over how my supports are delivered
- I want to choose when and how
- I want to choose who
- I am completely capable of making my own choices and being accountable for them.
- I can manage a budget, and perhaps even staff.

What is the down side?

- IF is very complex
- Accountability for long term budget management – no ‘overdraft’
- Risk related to IRD, and employment law must be managed.

How do I get IF?

- Visit a NASC assessment or review.
- For questions or concerns, email: Karen Smith, Development Manager: Karen_Smith@moh.govt.nz or Amanda Bleckmann, Contract Relationship Manager: Amanda_Bleckmann@moh.govt.nz .

Equipment Support Services Update – Sue Primrose

Sue Primrose gave an update on the prioritization work stream of the Equipment and Modification Improvement Programme; this included the work that has been done, who has been involved and what is still planned to do.

Changes to Equipment and Modifications:

Hearing Aids

- No change for children
- Fully funded hearing aids for adults with complex needs
- \$500 subsidy for all other adults

Low Cost Equipment

- Minimum cost raised to \$50.00

Access housing modifications

- Maximum funding of \$15,000.00 for modifications to support people to get in/out and between floors of their homes.

The question was asked ‘Why do some people have to wait for equipment and/or modifications?’ The response was ‘because demand is greater than available budget.’

Current system of prioritization:

- Unfair
- Not transparent
- Open to “gaming” by assessors
- Inefficient
- Focused in mainly on physical safety

Equipment and Modifications Services’ Improvement Programme:

- Assessor Accreditation
- Complex Housing Modifications – liaison with NASC
- Service Outcomes
- Equipment purchase and loan
- Prioritisation

Prioritisation Project Goal – To develop a prioritization system that:

- Means that people who have the greatest and/or most urgent needs can get their services first.
- Is fair and clear to everyone
- Provides value for money within the available budget.

Who's been involved?

- Two consumer groups made up of twenty four people
- Two assessors / health professionals groups made up of twenty six people
- One group overseeing and also participating – consumers, Ministry of Health, NASC, Accessable and Enable New Zealand.

Where are we up to?

Alison Barber from the Ministry of Health has been leading the work which is:

- Based on true life examples of people's needs and situations.
- Using a consensus process (discuss, debate and agree)
- Supported by some special computer software.
- Working out what people think is important and why – called criteria.
- This process gives a 'weighting' (a higher or lower number) to each criteria.
- A 'tool' is being developed – this will give the priority for the person seeking equipment or a housing or vehicle modification.

The four main points – 'criteria'

1. What difference will the equipment or modifications make to your life (or your support people) – 'impact on life'.
2. How much could you benefit?
3. How much will the equipment or modification prevent any injury or deterioration in your disability or situation?
4. How much could you contribute to the cost (yet to be tested).

Impact on Life:

- People will "self assess" – what is the impact on your life of your disability, without the equipment or housing modification?
- Assessors will fill in the other criteria.

A: Current impact of your disability on your physical safety

Which one would you choose?

1. No current physical safety issues
2. Minor harm to physical self or others but high likelihood of happening
3. Significant physical harm possible but low likelihood of happening.
4. High likelihood of significant physical harm to self or others.

B: Current impact of your disability on your ability to self manage

Which one would you choose?

1. No impact – fully independent for all self cares and routine activities
2. Some assisted support required
3. Extensive assistance required i.e. more that 50% for activities of daily living.
4. Fully dependant on assistance for activities of daily living but can communicate.
5. Fully dependant on assistance for activities of daily living and to keep safe including communication.

C: Current impact of your disability on your ability to fulfill roles and responsibilities important to you.

Which one would you choose?

1. No impact.
2. Can undertake most roles and responsibilities of choice, requires assistance in some roles or responsibilities.
3. Requires assistance for most roles and responsibilities of choice.
4. Unable to fulfill roles and responsibilities of choice AND causing high levels of anxiety or distress, and loss of self esteem due to this.

D: Current impact of your disability on the most important relationships to you

Which one would you choose?

1. No impact
2. Can participate to a satisfactory level in most relationships of choice, requiring assistance for some aspects.
3. Requires assistance for most aspects of participating in primary relationships.
4. Unable to participate in primary relationships.

It is a fine balancing act and we have to get it right – so:

- Try the tool out in some places
- Review the trial
- Make any changes that might be needed
- Introduce the tool across the country

A big challenge is to work out how much people could contribute to the cost:

- Low ability to contribute
- Medium ability to contribute
- High ability to contribute

It would be really helpful to give me some ideas of how to work out what people could contribute to the cost and how to determine what they could contribute?

Summary of key points from day one.

- Need to save money!
- **Consumer Training Fund** – Te Pou administering Ministry of Health training fund of \$840 million to be allotted, (\$1.3 million of leadership development funding has been applied for). Next year will be approximately \$750 million. Contracts being allotted this week check out the Te Pou website. October 2010 being the date for submissions for 2011 funding. Consortium Admin to send out information on the courses available.
- **Minister Turia's visit** – The Minister indicated she was keen to come 2 – 3 times per year to the Consortium meeting. That she wants to use the Consortium as a quality assurance group. She has the right vision. She wanted input for a media campaign and ideas around an Ombudsman for disability. Suggestion of an Agency report card – Consortium to grade. Endorsed the Consortiums terms of reference and acknowledged it could be used in other areas to deal with conflict. She endorsed the Consortiums terms of reference as good and a model for conflict resolution.
- **Individualised Funding** – mechanism to give people choice and control. Apart from Manawanui in Charge, they have approved 18 alternative host providers, possibly looking at increasing this to cross over to other agencies. You don't have to take IF it is your choice. Provider has an important networking function reporting monthly for the

first six months. We need more information on quality support after the first six month period

- **Environmental Support Services** – Fairness. Having a group of people having a say produces a much fairer outcomes. What can people contribute? Should people be asked to contribute?

Q. The Consortium website – needs to be updated and could it be used as a way to keep in touch with each other? Could it have a blog site?

R. Admin to check on getting it updated.

Meeting concluded at 4:20pm

DSS Consumer Consortium
Day Two
Friday 19 March 2010
The Brentwood Hotel, Wellington.

Meeting started at 9:10am

Apologies: None

Consortium Meeting / Terms of Reference – Venessa Rice

- **Peak Body Group** – if any members are interested in this they can contact Gayle Cullwick at gcullwick@hotmail.com. It is a Peak Body group made up of providers to lobby government to improve policy and services for people with disability. It has people with disability and their families at their central interest. It is still in its planning stages and I think the Consortium could have input into this.
- **Workforce Action Reference Group:** Lena Berger – as a member of the workforce reference group she has documents from Te Pou, she will send through to admin to circulate to members. Included in this is an assessment form that Consortium members could fill out.
- **University of Auckland Advisory Committee:** Jen Birch has emailed asking if any Consortium member could replace her on the University of Auckland advisory committee. Admin will circulate this to members.
- **MoH presenters providing accessible information:** Frustration expressed at Ministry of Health presenters not giving the Consortium members accessible information especially power point presentations with graphs and charts. Should the Consortium members develop an accessible information policy that the MoH members use that is in a text format along side any pictures? They also need to be formatted in portrait not landscape.
- **.Respite Care:** there was a lot of discussion around the Respite Care crisis in New Zealand. It was suggested the Consortium push this topic with the Ministry. An invitation to be extended to Contract Manager from the Ministry to come to the July Consortium to discuss this topic. It was suggested the Consortium members collate a list of questions to be addressed at that time. It was acknowledged that in the Auckland area there is a large number of children with challenging behaviour that are desperate for respite care, this needs to be addressed.

- **Dates and venue for next meetings for 2010:** It was decided that the next two Consortium meetings for 2010 would be held at the Brentwood Hotel on the 22 – 23 July and 4 – 5 November 2010. It was also suggested that three meetings a year is what is required for the Consortium to function at it's best.

Deloitte Report and 2010 Workplan – Anne O'Connell

Before Anne began her presentation it was noted that for future reference could Ministry presenters please have all documents including power point presentations, formatted in portrait not landscape as landscape formatted documents are not accessible when using a CCTV to view documents.

The Consortium Members introduced themselves to Anne O'Connell, and also to Jenny Moor and John Wilkinson who were in attendance at this session.

The Current Challenges:

1. Present economic conditions and government indications:
 - Future increases to the budget for Disability Support Services likely to be less than in previous years.
 - Demand for and cost of services continues to experience significant upward pressure
2. Within this environment our purchasing framework and service model needs to provide disabled people with the best possible outcomes.

What are we doing?

- Deloitte Limited has undertaken a review of our current purchasing.
- Developing a proposed new model of support services – John Wilkinson.

What is guiding this work?

This development work has been influenced by:

- NZ Disability Strategy
- UN Convention of Rights
- Select Committee report and Government response

And discussed with:

- Disabled people and their families
- Disability support providers
- The Disability Support Services Consumer Consortium

The Review of our Purchasing:

Deloitte were asked to recommend short and medium term solutions around:

- Getting better value for money
- Continuation of a stable and predictable business environment
- Select Committee report and Government response

Their findings are:

- DSS Funding is experiencing a steady increase in spend with relatively same budget
- Some providers are having difficulty sustaining funding levels
- The Ministry is not always getting best value for money

Some of the Issues:

- MoH and NASC understanding of the NASC role
- Poor data – and data provided to the MoH not always analysed.
- Inconsistent and unclear policy and procedures
- Inconsistent applications of policy, tools etc
- Under – monitoring of providers
- Not holding NASC's and providers accountable

Draft Recommendations:

Short Term Goals:

- Get consistency around support packages
- Decrease NASC and Provider performance variation
- Improve relationships with NASC and Providers
- Increase Cost efficiency and MoH's ability to forecast future needs
- Get disabled people and their families more involved at key decision stages and in supporting other disabled people

Medium Term Goals:

- Allow more flexible support to be delivered to clients
- Achieve nationally consistent purchasing approach and price bands
- Increase the value delivered from monitoring and auditing
- Develop a "whole of Government" approach

Next Steps

- Finalising the Deloitte report
- Developing paper for Ministerial Committee on the new Service Model
- Ongoing development of other services

Anne commented that 30% of the people use 70% of the resources; this raises the question why do you have one system that fits all? It was suggested this is a chance to change the system to fit the needs.

There are clear trends in the data that packages are a lot higher than in the past. Deloitte was not able to receive data from Socrates because that data was not mature enough; Socrates has not been running long enough. Other

comments made were that Provider outcomes are not monitored well enough and there is a greater need for accountability. The Ministry will begin to do a benchmarking of providers.

Local Area Co ordination Model Update – John Wilkinson and Jenny Moor

Jenny Moor and John Wilkinson introduced themselves to the members. Jenny thanked the Consortium for the feedback from the last Consortium in November 2009 around the LAC model. Jenny acknowledged that it was Consortium member, Lena Berger's, request at a past Consortium meeting that the report to the Ministerial Committee on Disability Issues, on the investigation of LAC type processes has been made publicly available.

The following information was presented by John Wilkinson. It records in text form what was contained in a series of diagrams.

2010 Service Development – Health and Disability National Services National Health Board Business Unit 2010

Development of proposed new Service Model:

As part of our ongoing development work, Disability Support Services has been working on a proposed new model of support for disabled people.

“Supports for Living: Outcomes Framework”

High level outcome:

- Disabled people have the ordinary opportunities, choices, responsibilities and rights that other people living in New Zealand have and;
- Are able to participate in activities in similar ways to people at similar stages of life.

Living an Everyday Life

Listed are some activities that are important to many disabled people. These activities are not listed in any particular order and there will be many others that are important to some disabled people that are not listed.

Like other New Zealanders, I have the same opportunities, choices, rights and responsibilities to decide:

- What happens in my own home
- What I do with my time and money
- What I do during the day and the risks I take
- Who I have relationships with
- Who supports me and how I am supported
- Where I live and who I live with
- How I am involved in the community
- The paid and unpaid work that I do

Support for Disabled People to Live an Everyday Life

New Zealand Disability Strategy's Vision – People with impairments can say they live in 'A society that highly values our lives and continually enhances our full participation.'

High Level Outcome for Disabled People (from "Improving Long-Term Disability Supports: Maintaining Momentum") – Disabled people have the ordinary opportunities, choices, responsibilities and rights that other people living in New Zealand have. This means being able to participate in the following areas of life in similar ways to other people at similar stages of life:

- Learning and applying knowledge
- Civic Life
- Home and community life
- Relationships
- Paid and unpaid work

Disabled people's ability to overcome any challenges and barriers they face to participating is influenced by a wide range of factors. Disability support funded by the Ministry of Health is only one of them. The Factors include:

- Personal skills, assets and resources
- Natural support networks
- Community and NGO services
- Ministry of Health funded support
- Mainstream government services
- Environment and society
- Other government supports

Ministry of Health – Possible Support Delivery Framework

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

- ***The information and personal assistance I access*** – Information and personal assistance, which includes: general information about living with a disability. Someone to talk to. Someone who can develop a relationship with me and helps me to clarify my goals and to build up

and access all types of support to help me to achieve my goals.
Someone who can help me build a community of support around me

- ***The funding I am allocated for support*** – Allocation of MoH funding, which focuses on: allocating support in ways that are consistent with the objective and principals. Funding may be one off and short-term, intermittent, ongoing, or specialized. The level of scrutiny will increase with the cost and risk of packages.
- ***What I can use my funding for*** – MoH purchasing, which includes: implementing a direct funding arrangement so that people can arrange supports themselves, and contracting for supports and services that people elect to use.
- ***The quality of support I use*** – Accountability, which focuses on providing assurance that the Ministry of health is achieving its objective and operating in ways that are consistent with its guiding principals

Guiding Principles

- Choice and Control
- Outcome Focus
- Value for money
- Accountability
- Relationship based
- Fiscally responsible

Key elements or parts of the proposed model

- Information and personal assistance
- Ministry of Health Responsibilities – allocation of funding, purchasing, accountability.

Information and Personal Assistance

Information to help you plan and meet your goals from various sources:

- Internet sites and information sheets
- Church and community groups
- Government and local agencies
- Someone who can help you be clear about your goals and put you in touch with people or groups who can support you.

Ministry of Health Responsibilities

Funding processes which focus on:

- Supports that fit the principles
- Based on agreed personal plan

Providing flexibility for how you can purchase services through:

- Direct or Individual Funding
- Centrally contracted arrangements.

The following questions were asked of the Consortium members after the presentation:

What do you see as being good from this proposed model?

Responses:

- I like the model as it builds on the family/whanau. I like that it gives the person choice.
- The way it links people into their community. No agency covers that.
- It acknowledges the complexity of current DSS system. And that it is based on the disabled person they are on top.
- The holistic approach, being able to approach all other services for the person.
- It is person centered allocation of funding that the person is given all the information on their package. Question on accountability should that be extended to the provider?
- The LAC - the point should be made that the disabled person be involved in this role where possible.

What do you see as not so good?

Responses:

- Not everyone accesses the internet, or are involved in church or community groups and not everyone can manage their own care due to nature of their disability.
- Need to ensure a smooth transition between models, identify any barriers there might be in transition.
- Be courageous in transition.
- Accountability – wording
- Wording ‘what’s a good life for you’ to be incorporated
- Improve model to be accessible in its format – more useful to have plain language, remove barriers like getting information in advice, communication needs are met.
- If the model helps to reduce waiting lists and funding issues.

What are the good things we currently do, that you don’t want to lose?

No Response

After what has been described today are there other things that need to be considered?

Reponses:

- Name for new model
- Keep your eyes on the rural communities
- DHB’s all have different processes and systems; I assumed that because their funding comes from the MoH they would have the same services and systems. This creates real problems for consumers. Can the MoH give the DHB’s guidelines to have consistency across the country for disabled people and the accessing of services?

- In communities that are not connected as seems to be the trend in urban area, how is this model going to work?
- Are contracts to providers under this system going to be wider and more flexible?
- Where there is specific expertise required and there are limited providers for those services how are you going to encourage competition when we don't have enough qualified and experienced staff? (a challenge for the workforce future)
- I hope you keep in mind the great need out there for residential services.
- I think you need to cover the rural area as that's where a lot of people are missing out. I know of one individual who waited 18 months for an assessment.
- Willingness to experiment and pilot our own thing is not a bad thing.

Any further comments or responses to these questions can be sent through to Jenny Moor and John Wilkinson.

The most significant next step is to go to the Ministerial Committee that Minister Turia chairs in May and hope to have a proposal around the model leading to demonstration sites. We'd like to build something that we have seen from overseas but build into it NZ ideas. John reminded people that the material is still in draft, was presented today with the agreement of the Minister's office, and is not for wide distribution, nor to be viewed as Government policy.

Residential Services for People with a Physical Disability Project Stage 2 – Raewyn Winiata

Karen Hyland introduced herself to the members as the Manager of the Community Living Team, and Raewyn Winiata Development Manager for the Community Living Team. Raewyn presented on the Residential Services for People

Longstanding Issue

- Past projects – short term gains but not able to be sustained.
- Not coordinated at a national level
- Work cannot be done in isolation without a concurrent focus on service development nationally

Proposes a number of recommendations

- To be undertaken to divert younger people from entering aged care facilities
- Improve the situation for people who remain in residential services.

Living at home option

- Improve the continuum of disability support services to ensure that people with a physical disability who have high and complex need, can continue to live in their own home.
- Develop and procure more physical disability residential services to ensure a continuum of age appropriate residential services would provide support over a lifetime as disabled peoples needs change.
- Review of the service specification to ensure the service specification accurately reflects the levels of care and needs of disabled people and the Ministry expectations.

Priorities

- What other priorities could the team address which could feed into the residential services projects?
- Consumer input – who and how? Looking at having provider forums in April 2010. Possibly have Consumer focus groups in Auckland and Christchurch to involve people living in residential services. Perhaps a national reference group?

Raewyn also presented the following facts:

- July 2009, 757 younger people were in aged care across the country, the medium age of those young people was 16 years. The average age of older people in aged care is 82 years.
- Residential services for people with physical disabilities in local communities the average age is 47 years, there are currently almost 400 Government supported young people in those services.

Summary of day two key points

Consumer Meeting:

- Dire need for respite and residential care – asked to be addressed at next meeting.
- Peak Body for consumers?
- Power point presentations and graphics – text only no graphs.

- Dates and venue for next meetings 22 – 23 July and 4 – 5 November in Wellington at the Brentwood Hotel
- Action point – invite Contract Manager to discuss respite care (Natasha Gardner?)

Anne O'Connell – Deloitte Report:

- Full report available soon
- 30% of the people gets 70% of the funds
- Need to improve relationships between NASCs and providers and more flexible funding
- Include disabled people and their families more involved in their decisions
- Improved systems for monitoring and auditing

LAC – John Wilkinson and Jenny Moor:

- Move towards what constitutes a good life
- Looking at the framework it is a person centered calling it 'Person Centered Choice and Control'
- Request for feedback from presenters
- Choice of language from service to support
- Accountability extends to providers as well
- Cover for the rural sectors

Consortium meetings inclusiveness:

- Form from admin asking members what their communication needs are
- Large group sessions in morning and small group work in the afternoon
- Have the Consortium meeting in the afternoon as people get more involved and holds attention.
- Getting equipment needs right
- Breaking into small groups will cost more as have to book more rooms
- Some speakers wanted small groups but after seeing the room lay out decided against it, need to consider room lay out.
- Don't want cost to ourselves out of the consortium – two rooms' means two lots of interpreters and two hearing loops.
- Splitting into small groups with different speakers relating to that interest group. Although members can't be in two places at once if they have more than one interest areas.

Residential Care for People with Physical Disabilities:

- Variations across the country and spoke about three of the nine options.
- Young people living in aged care services – this needs to be addressed immediately.
- There are huge gaps in the system across the board and need for improvement.
- Increasing supports may include nursing care and registered nurses may be available
- 757 young people in aged care and once they are in it is difficult to get them out.

- Thanks to Rob, Venessa and Debs for running a smooth session

Venue for next meeting: Wellington

Facilitators for next two Consortiums: July – Chris Orr, November – Tina & Simona Mataiti.

Meeting closed at 4:00pm

CONSORTIUM ACTION POINTS To be completed by next meeting

ACTION POINTS	PERSON RESPONSIBLE
Rob to check if NASCs are able to enter new dates into Socrates before old dates expire as this was raised as causing the problems with breaks in services to consumers.	Rob Gill
Launch 14 th April for Peak Body Group further details contact Gayle Cullwick at gcullwick@hotmail.com	Members
Consortium Member Guidelines	
Create new members pack with guidelines of responsibilities include templates for reporting back	Admin
Update Consortium website and explore the possibility of including a member blog on the site	Admin
Individualised Funding	
Find out why Merv Cox (DeafBlind) application for reference group was not acknowledged or responded to	Marsha Marshall
Minister Turia asked for Lee Rutene's service issues to be looked at.	Rob Gill / Marsha Marshall
Consumer Training and Leadership Fund – Te Pou	
Consortium Admin to send out information on the courses available. Members can also access Te Pou website for further details www.disabilityworkforce.co.nz	Admin

Texting Service Trial	
Rob on Alison's behalf will write a formal request to the CEO or General Managers of the Association for Blind Citizens, RNZFB, Deaf Aotearoa, and the Hearing Association asking for their participation in a TXTING service trial.	Rob Gill
Consumer member meeting	
Workforce reference group – circulate survey form for members to complete	Admin
University of Auckland Advisory Committee – need replacement Consumer member, Admin to circulate information from Jen Birch	Admin
Accessible information for Consortium meetings – remind Ministry presenters text only power points and landscape not portrait formatting.	Admin
Invite MoH contract manager for Respite Care to attend next consortium	Members/admin
Send out a short form asking for members to describe their communication needs.	Admin

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