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**DISABILITY SUPPORT SERVICES  
CONSUMER CONSORTIUM MEETING**

Tuesday and Wednesday 3<sup>rd</sup> – 4<sup>th</sup> November 2009

**Summary Minutes**

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**Hotel Grand Chancellor  
Cnr Kirkbride and Ascot Roads  
Mangere  
Auckland**

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**Facilitator/Member:** Ngaire Wycliffe, Brain Injury Association

**Coordinator:** Alison Hearn, Ministry of Health

**Administration:** Debbie Webster, NZFDIC  
Tanya Wishart, NZFDIC

**Presenters Day One:** Anne O’Connell – Group Manager DSS  
Amanda Hinkley – Policy Analyst  
Anne Bell – Health & Disability National Services  
Karen Smith – Development Manager  
John Wilkinson – Health & Disability Policies

**Presenters Day Two:** Alison Hearn – Strategy & Contracting Support  
Rob Gill – Development Manager Workforce  
Sue Primrose – ESS Programme Manager  
Carmel Daly - Acqumen  
Anne Bell – Health & Disability National Services  
Valerie Smith – Senior Advisor, Disability Policy

**Organization Presentations:** Ngati Kapo Aotearoa NZ

**Consortium Members:** John Grealley, Autism New Zealand  
Kevin Anderson, Brain Injury Association  
Simona Mataiti, PIASS Trust  
Lena Berger, Rescare New Zealand  
Chris Orr, Royal NZ Foundation of the Blind  
Venessa Rice, Parent to Parent  
Carolyn Weston, Association of Blind Citizens NZ  
Jan Moss, Carers New Zealand  
Harvey Brunt, Cerebral Palsy Society of NZ  
Mathilda Schorer, CCS Disability Action  
Jacqui Carlson, CCS Disability Action  
Kim Robinson, Deaf Aotearoa NZ  
Trish Anderson, IHC Advocacy  
Lee Rutene, Ngati Kapo o Aotearoa  
Merv Cox, Deafblind New Zealand Inc  
Karen Pointon, Deaf Aotearoa NZ  
Rainus Baker, People First  
Morgan Smith, People First  
Gayle Cullwick, NZ Down Syndrome Assoc.  
Gillian Smailes, Hearing Association  
Jill Waldron, Muscular Dystrophy Assoc.  
Patrick Thompson, Mana Turi o Aotearoa

**In Attendance:** Christine Morrison, IHC Advocacy  
Kaeti Rigarlsford, People First

**Support persons:** Cheryl Cox  
Tina Mataiti  
Melissa Blackmore  
Bill Dalwood  
Rauwinia Wycliffe

**Interpreters:** Alan Wendt, Harri Harrison, Kerry Locker-Lampson

**Apologies:** Graeme Parish, Hilary Stace, Anne Wilkinson, Lolo Filiai, Jennifer Birch

#### **Key for abbreviations used in minutes**

**Q = Question    P = Point Made    R = response**

Meeting started at 9:00 am

#### **Welcome**

Ngaire Wycliffe welcomed the group, in particular the new members and went over house keeping matters.

#### **Participant introductions**

A special welcome to new members Jill Waldron from Muscular Dystrophy Association, Morgan Smith from People First and Patrick Thompson from Mana Turi o Aotearoa. Also welcomed were John Grealley who is replacing Hilary Stace from Autism NZ and Christine Morrison who will be replacing Trish Anderson from IHC Advocacy.

## Action Points from previous minutes

- Alison to follow up with Pam Henry on emailing links to Auckland based family services to Tina Mataiti.
- NASC - Jenny Moor went on extended personal leave shortly after the last consortium, she has passed her work on to John Wilkinson who has not been able to organize a meeting he will report back at this Consortium meeting.
- National Pacific Plan - Karen Pointon expressed it is difficult to coordinate with all the stake holders to arrange a meeting with Feala Afoa. Karen expressed a desire for a meeting to take place in Poiriua and South Auckland for the Pacific Island deaf community in those areas.
- Mathilda Schorer reiterated the need for any reading material to be sent out in advance as per the terms of reference

All other action points completed or ongoing.

## Directorate / DSS Update – Anne O’Connell

Anne introduced herself to the new members and updated the members with what has happened over the past six months of being in the role of Group Manager for Disability Support Services. She has spent a lot of time over the first six months in her role speaking with and listening to consumers and providers. Anne has been looking at cross agency cooperation and the best way to buy services. Anne said the team at DSS is keeping up with the projects they started in the midst of political and economic change.

Disability Support Services has contracted externally with Deloitte to review how their services are being purchased and delivered. The purpose is to have a good look at what the Ministry is doing now, how it could do things better and where to go to from here. Anne is hoping this report will also show how DSS could operate the most effectively. As Deloitte is an international company they have access to other models used in other countries. They are working on a short time frame to have their report ready in the New Year. The outcomes of this review will be listed as recommendations to the Ministry of Health. This report should be available in the New Year. It is possible that as part of the review, Deloitte may seek consultation with consortium members. When the report is ready it will be made available to the Consumer Consortium.

## **Options to improve the health of people with Intellectual Disabilities – Amanda Hinkley**

Amanda introduced herself and updated the Consortium members on this Ministry work programme. The Ministry of Health is currently examining a number of actions to improve the health of people with intellectual disabilities. The Minister of Health agreed to this in June 2009. The actions are organized around the groups of people who can make a difference to the health of people with intellectual disabilities – individuals, their carers and family members, and health professionals (doctors, nurses, community health workers).

Consortium members will most likely be familiar with the report “To Have an Ordinary Life”, produced by the National Health Committee on the lives of people with intellectual disabilities. This work programme has strong links with this report. A copy of this booklet will be sourced and sent out to Consortium members.

Anne Bell has been supporting Amanda’s work by working with Careerforce on the content of the higher level certificate for Service Coordinators. Careerforce established the core foundation level 2 certificates, and have since identified the need for greater training for the Service Coordinators. There is a need to make sure that the people who make decisions in the house, or services coordinators are able to identify the health needs of those people they are supporting. A lot of behavioral problems are based on health needs and not being able to communicate that need. Anne is one of several people working with Careerforce to establish these training programmes.

Amanda would like to create a focus group for her work. Anne will work with Amanda to put out a proposal to be circulated to the Consortium Members for consideration.

If any one wants to contact Amanda directly please email her at:

[amanda\\_hinkley@moh.govt.nz](mailto:amanda_hinkley@moh.govt.nz) or phone: 04 496 2484

## **Individualised Funding/ Respite/ Carer Support – Karen Smith**

### **Individualised Funding**

- A direct payment mechanism for disability supports
- Provides person centered control.
- Empowers disabled people to live ordinary lives, providing choice and control over who provides support, how and when.
- Will be rolled out to HCSS providers during 2010, increasing consumer choice for IF 'hosts'.
- Limited to HCSS at present, but expansion to DSS to be considered in longer term.

### **Timeframes and Key Activities**

November 2009 onwards

- Establishment of Implementation Reference Group (Providers, NASCs, Consumers and the Ministry of Health)
- Development of companion documents for providers and information for consumers.

November 2009 to January 2010

- Expressions of Interest document developed
- Interest sought from current HCSS
- Providers who wish to offer Individualised Funding

February to April 2010

- Discussion/negotiation with providers to provide IF from May 2010
- Delivery of training to NASCs and Providers

May 2010

- Formal implementation of a national programme

2010 / 2011

- Consideration of expansion of IF to other disability supports.

## **Carer Support / Respite**

Progress to date includes:

- Initial discussions with other Carer Support funders
- Agreement for revision of MoH guidelines
- Increase in Out of Family Home Respite services
- Discussing models of respite care with a view to a system wide review

### **Timeframes and Key activities**

December 2009 to February 2010

- Planning and scoping and initiating Carer Support Subsidy Guideline Review

January – February 2010

- Carer Support Subsidy Guideline Review underway

May – June 2010

- Reference Group established
- Respite Services system wide review

### **Implementation Reference Groups**

Individualised Funding

- An implementation Reference Group to be established (November/December 09)
- IRG will develop, endorse Guidelines and external communication information relating to IF expansion.
- Two Consumer nominees/candidates needed
- Commitment required for 6 – 12 month period\
- Meetings will be held in Auckland or by teleconference
- Nominees must agree to be put forward for selection
- Details to [Karen\\_smith@moh.govt.nz](mailto:Karen_smith@moh.govt.nz) by Wednesday 25 November, with short resume and information about relevant skills and experience.

Carer Support / Respite

Pending DSS approval, proposed activities are:

- A Reference Group to be established early 2010 to inform Respite Services Review
- Two Consumer nominees/candidates needed
- Commitment required for approximately twelve months

- Nominees must agree to be put forward for selection
- Details to [Karen.smith@moh.govt.nz](mailto:Karen.smith@moh.govt.nz) at any time, with short resume and information about relevant skills and experience.
- Ministry will call for nominations through formal communication channels.

## Local Area Coordination Model – John Wilkinson

This session is about how Local Area Coordination-type processes might be implemented in New Zealand.

The Government Response to the Social Services Select Committee’s “Inquiry into the Quality of Care and Service Provision for People with Disabilities” said that the Government had asked officials to investigate how Local Area Coordination-type processes might be implemented in New Zealand, and the desirability and feasibility of doing so. The Ministry of Health is currently carrying out that investigation.

Local Area Coordination is an approach to supporting disabled people and/or their families. It involves Local Area Coordinators developing working relationships with disabled people and their families, in order to help them plan their lives and select and receive supports and services. Local Area Coordinators ask the basic question “what is a good life for you?” In helping people build that good life, there is a strong focus on developing natural and community supports, but they also help disabled people to access government funded supports. They provide information similar to what the Disability Resource Centres already do in NZ. They help people advocate for themselves.

Questions John asked the Consortium members to consider:

- How could we implement Local Area Coordination-type processes in New Zealand?
- What are the good things about Local Area Coordination that we would like to keep if it is implemented in New Zealand?
- What are the things about Local Area Coordination that we wouldn’t want to keep if it is implemented in New Zealand?
- What are the good things about our current way of doing things that we don’t want to lose?
- What sorts of things could we consider when we are developing New Zealand’s approach to implementing Local Area Coordination-type processes?

[John.wilkinson@moh.govt.nz](mailto:John.wilkinson@moh.govt.nz)

## **Consumer Organisation Presentations – Ngati Kapo o Aotearoa Inc**

Christine Cowan Executive Officer of Ngati Kapo O Aotearoa gave a presentation about her organization.

The name Ngati Kapo was given by an original founder and kaumatua from Christchurch. The organization was born in 1981 at a Hui for blind Maori and whanau. Between 1981 and 1990 the interest amongst blind Maori in being a part of Ngati Kapo grew quickly, so that by 1990 there were approximately ten groups around the country and they became an incorporated society.

Membership to Ngati Kapo is only to any people who support blind Maori persons. They only represent blind Maori; however the membership is open to all people able bodied or disabled. The organization is consumer led and driven. They retain consumer directive through the organizations governance. Ngati Kapo is a national Maori disability organization. They are also a provider of Maori DIAS services.

### **Base Services:**

- Work to assist blind Maori and their family to advocate for themselves
- To provide information to the members, for empowerment and to enable them.
- Peer support – to provide support to each other
- Policy Advice – advise the government

### **New Services (developed over the last nine years):**

- Research and development – growing Maori blind, vision impaired, a lot of Maori children are not being diagnosed until they are nine years of age.
- Public Awareness
- Workforce Development – for Ngati Kapo members to find meaningful employment

### **The Work we do:**

- Education – work with the Blind Learning Education Network of New Zealand.
- Representation on disability councils, or groups like the Consumer Consortium
- DIAS – disability information services

- Social Services – assist in development on policy around Maori disability.
- Whanua Ora – the well being of family.

The key principals we live by:

- We operate under the articles and the principals of the Treaty of Waitangi
- What we give to our people – we support our people

**Ngati Kapo O Aotearoa – We may be blind but we have Vision.**

[www.kapomaori.com](http://www.kapomaori.com)

0800 770 990

**Ministry of Health Disability Services Consumer Consortium  
and the University of Auckland Graduate Advisory Group –  
Jen Birch**

Jen was unable to attend the November Consortium; she did submit a written report with information on this project which was distributed to the members at this Consortium. The main points from Jens report are:

- Auckland University School of Counseling, Human Services and Social Work: Graduate Diploma Education Disability Support – first meeting was held 31 August 2009, the programme co-ordinator is Kathy Martindale.
- Courses taught semester one were: HUMSERV 202 (practice course) and DISABILITY 313 (theory course)
- Courses taught semester two were: HUMSERV 211 (theory course) and HUMSERV 304 (practice course)
- Course to be taught semester one 2010: HUMSERV 301

Jens notes from that meeting:

- Jenny Moor and Rod were present. Jenny commented this diploma course is a pilot; there will be an evaluation of it. It is a part-time course. Two or three full cohorts of students go through, twenty students per cohort.
- At present it is very difficult to do the course if one is NOT working for a NASC. Our group discussed how other potential students could

participate (which was thought to be desirable) e.g. workers from RNZFB, Deaf Aotearoa, Mental Health, ACC.

- The student and their employer need to work together if the student is to do the course, i.e. requirements are time off, support and encouragement, coaching and mentoring. There is the need to engage employers' co-operation in achieving student retention and passes.
- Category A EFT. – corresponds to Bachelor degrees. Teacher training equals 1 EFT, (different funding)
- What are the measures of success? Retention of students; passes; practice in the workplace.

If anyone would like more information they can contact Jen Birch directly.

Jen Birch, [jenbirch@actrix.gen.nz](mailto:jenbirch@actrix.gen.nz) , [www.aspergers.co.nz](http://www.aspergers.co.nz)

PO Box 17-426, Greenlane, Auckland

**Meeting concluded at 4:30pm**

## **DAY TWO – Wednesday 4 November 2009.**

### **The Brentwood Hotel, Wellington.**

Meeting started at 9:05am

**Apologies:** Simona Mataiti for part of the morning.

#### **Forums / Fono / Hui – Alison Hearn**

From the funding the New Zealand Federation of Disability Information Centres receives from the Ministry of Health they organise the Consumer Consortium and also the Forums / Fono / Hui. The Forums / Hui / Fono held earlier this year produced an action plan which list action points to be dealt with. Alison's role is to look at what came out of the Forums and has to be accountable to the Ministry of Health for those actions.

Alison asked the members several questions around the Forums, Hui and Fono. And she asked for suggestions on key topics. Having done this three times now, where could there be improvement? Is doing the same thing again right? What do the members think of the idea of getting the local and regional MoE, MSD, MoH, ACC representatives together on a panel where consumers could ask specific questions? This would have a cross agency type appeal.

#### **Consumer Training and Leadership Fund 2008 – 2009 – Rob Gill**

The Consumer Training and Leadership Funds were created with the following priorities:

- Family
- Flexibility
- Workforce
- Information

From those priorities came the vision that disabled people can live in their home and take part in their community in the same way other New Zealanders do.

## **2008 – 2009 CTL Fund**

\$500,000.00 was allocated to:

- Foster leadership for disabled people by disabled people
- Assist disabled people to become more confident to manage their own supports.

Five organizations were awarded contracts following a request for proposals.

- CCS Disability Action
- Deaf Aotearoa NZ
- People First Christchurch
- Standards and Monitoring Services (SAMS)
- Standards Plus and Up2date

## **Limits and Requirements**

Funding was a one-off through to June 2009. Nationwide access was encouraged. Training was to be led by disabled people.

Requirements:

- Training so people can confidently manage their supports
- Meetings/hui were value for money
- Strict financial record keeping
- Follow-up support for learners
- Monitoring of learning outcomes

## **Findings**

There was no formal evaluation because contracts were short-term.

Findings have been drawn from:

- Performance Monitoring Reports
- Contract relationship management
- Sector feedback

There have been benefits. These benefits align to goals of the DSS group.

Consequences:

- Further funding has been found for initiatives in 2010
- We have learned some important lessons
- Rules for the fund will change as a result (for example – timing of service deliver, secretariat support, listing on GETS website)

## **The 2010 CTL Fund**

Register interest for 2010 funding by 2pm on Friday 13 November 2009. For details go to the GETS website <http://www.gets.govt.nz>  
Previously funded providers can apply again but must disclose all funding still available.

## **Important Considerations**

Participants must be involved as users (including families and carers), or providers, of disability support services funded by the Ministry of Health.

Value for money must be demonstrated.

Special consideration will be given to improving health outcomes for people with disabilities and their carers.

## **What drives this?**

Our shared goal to:

- Build leadership capacity within the DSS consumer population.
- To improve outcomes for people who use disability support services funded by the Ministry.

## **Discussion**

This presentation is a briefing during a competitive funding process; therefore answers to all questions must be made public through the GETS website.

By sharing answers to your questions with all potential respondents we prevent some from being advantaged over others.

All enquiries must be made to Susan Fernandes during the ROI period to stay within the Ministry's procurement rules.

*Questions to the consortium members from Rob Gill, to be responded to at the next Consortium.*

- *What is the Consortium's vision for the future of the Consumer Training and Leadership Fund?*
- *What types of training does the Consortium consider most important for consumers?*

[rob\\_gill@moh.govt.nz](mailto:rob_gill@moh.govt.nz) Phone: 09 580 9111

## **Alison on TXTing Service on behalf of Julz Britnell**

This has not been trialed as yet, Julz would like some formal nominations from organizations that would like to trial the txting service. She has two questions for the Consortium on the TXTing service:

1. How can we trial the txting service?
2. What shall we trial it on? And who would do it?

The auto reply cues are:

- Complaints
- Equipment and Hire issues
- Hours – information on DSD
- How to get the DSD DVD
- How do I get pamphlets and information

The Association for Blind Citizens and RNZFB, Deaf Aotearoa, Hearing Association has indicated they might be able to trial the service. Those members concerned to talk to their organizations. Alison will write a formal request to these organizations and thank them for agreeing to participate.

## **Points of Interest for members from Alison Hearn**

- The Human Rights Commission put out a media release around proposed new wording which they believe will water down the basic human rights, around the affordable housing act. There is a bill before parliament that proposes the restrictive covenants that are in place be removed which they believe will not benefit those on low income. Check out their website.
- Deaf Aotearoa newsletter mentioned the funding they received from Ministry of Health, thank you.
- The Office for the Community and Voluntarily Sector has a regular E-newsletter with new publications and meetings and is a good reference point for members.
- Statistics NZ have put out disability travel and transport survey results – check out website.
- The NZFDIC has new information packs published with Ministry of Health DSS fact sheets and NASC flow charts, available at your local DRC. Check out the NZFDIC website [www.nzfdic.org.nz](http://www.nzfdic.org.nz)

## **Minister Tariana Turia**

Minister Turia was unable to make today's session, and sent her apology to the Consortium members.

Roger Jolley took a moment to inform the members of a Maori Disability Symposium to be held at the Copthorne Oriental Hotel in the Nicholson room on Wednesday 11 November from 9:30am – 3:30pm. They will be looking at:

- Maori Disability Issues
- Planning a National Maori Disability Conference

For more information call Roger Jolley at [roger\\_jolley@moh.govt.nz](mailto:roger_jolley@moh.govt.nz) , 04 496 2358 or 021 421 683

For those unable to physically attend there will be a teleconference available from 1 – 3pm.

## **Environmental Support Services – Sue Primrose and Carmel Daly**

### **1. Background**

The Ministry of Health is developing new ways of working out if a person can get support for equipment or modifications to their home or vehicle and, if so, how much support they can get and how long they might have to wait for these services.

### **2. Why we are doing this work**

This is important work as the amount of money available for these services will always be limited and we need to make sure that it is used in the best possible way to support disabled and older people, and the people who care for them. This means that their needs can be met as fairly as possible and that people can understand how decisions have been made, even if they miss out. It also means that the government gets good value for the money it spends on these services.

### **3. Types of applications**

Half (50%) of the applications for equipment cost less than \$1000 and costs can vary widely. For example the cost of walking frames ranges from \$130 to \$5000 and the average cost is \$240. We can improve the way we buy the frames to get better deals. In the future there may be only two or three types of frames available, however it will mean more people can get the equipment they need and more quickly. This type of equipment is called 'common' and 'standard'.

A smaller number of people need a 'complex' solution. This means that the equipment or modification has extra features and it may have been designed especially for them and usually this costs more.

### **4. Assessors knowledge and skills**

The way we work out what support a person can get will be matched to the level of skill and knowledge assessors have. This means that when a solution costs more or it needs to be especially designed for a person, the assessor will need to have more skills and knowledge. Some of the areas that we are looking at are:

- Wheelchairs and seating
- Communication assistive technology
- Housing modifications
- Vehicle modifications

This is a very large area of work and we are working with assessors from across the country.

## **Prioritisation Framework - A Consensus Building Process:**

### **Goals**

- To develop a fair and transparent system for prioritizing access to equipment and modification services.
- To fairly meet greatest needs within the available resources.
- To manage the budget well and achieve value for money.

### **Stage One**

- Total of four workshops in Auckland and Christchurch (two were for consumers with 24 participants; two were for assessors / health professionals, EMS providers – Enable and Accessable, and NASC with 26 participants)
- People were asked to rank 29 case studies in order of priority i.e. who did they think should have the higher priority to receive services.
- Discuss factors or values that influenced decision making.

Two case studies were looked at and discussed at the workshops.

## **Themes from the workshops**

Overall, same themes from all four workshops (in draft and in no particular order)

- Current condition: Impact on Life
- Benefit
- Prevention / Risk of deterioration
- Ability to contribute to self funding: purchase and maintenance.

### **Current Condition: Impact on Life**

Ability to:

- Maintain the safety of the person (physical and psychological)
- Maintain the safety of others (physical and psychological)
- Self manage and maintain or regain independence e.g. mobility, self cares
- Fulfill responsibilities
- Maintain and support carers (if appropriate)
- Maintain or build dignity, self esteem

### **Benefit**

Need to consider the amount of benefit (magnitude), quality and how long (duration)

Examples:

- Did other options fail
- How likely is it that the option will provide the desired benefit
- Will reverse / maintain any part of the disability
- Will it reduce the impact of disability on self or others

### **Prevention / Risk of Deterioration**

Examples:

- What is the history of the person's disability
- What is the likelihood of deterioration
- Can the deterioration be prevented
- What is the impact of any likely deterioration

### **Ability to Contribute to Purchase and Maintenance**

- Needs more discussion
- Will be linked to high, medium or low ability to self fund / contribute

- Options being explored are increased use of income and Asset testing, increased use of Community Services Card and thresholds

## **Stage Two**

- Starts next week
- Intensive work with reference group to test and develop priority assessment criteria and to develop relative weightings for each criteria
- New prioritization tool will be piloted in the New Year.
- Following evaluation and approval by the Ministry, it will then be implemented throughout New Zealand.

## **Interface with NASC**

Disability Services has two main service areas:

- Equipment and modification services
- Support services (managed by NASC)

Interface between the two areas will be strengthened to:

- Coordinate/integrate planning for a person
- Get best use of resources/budgets

Focus will be on:

- People with behavioral needs
- High cost services
- Degenerative conditions (quickly changing needs)

## **Home Service Agreements and Residential Services Booklets – Valerie Smith and Anne Bell**

Anne Bell attended the Consortium on behave of Karen Hyland to respond to any questions around Home Service Agreements. Anne had provided the Service Specification on Community Residential Support Services – Intellectual Disability, recommending reading page seven of the service spec.

She also posed two questions for the Consortium members:

1. What do you think should be included in the home agreements and how could the Ministry and providers make this agreement more meaningful (if necessary)
2. Do you think the Ministry should develop a template to guide providers about what should be in the home agreement?

Valerie Smith introduced herself to the members and explained the journey of the Residential Support Services Booklets. She saw a need for people going into Residential Services and their families a few years ago and the booklet has come to fruition and is now at the distribution stage. Val thanked the Consortium members for their input into the booklet. The booklets have been distributed to Disability Resource Centre's around the country and to NASC's. Around ten thousand copies of the plain language version have been printed for distribution as this version has proved the most popular. Valerie welcomes any feedback from Consortium members; she believes there may be room for improvement on this first version.

**Meeting closed at 4:30pm**