
**DISABILITY SUPPORT SERVICES
CONSUMER CONSORTIUM MEETING**

Monday 4th, Tuesday 5th and Wednesday 6th October 2010

Summary Minutes

**Brentwood Hotel
16 Kemp Street
Kilbirnie
WELLINGTON**

Facilitator: Alison Hearn, Ministry of Health (Day One)
Jill Waldron, Muscular Dystrophy (Day Two)
Robert Martin, People First (Day Three)

Coordinator: Alison Hearn, Ministry of Health

Administration: Debbie Webster, NZFDIC
Tanya Wishart, NZFDIC

Presenters Day One: Anne O'Connell – Group Manager DSS
Feala Afoa – Manager of Pacific Development
Brennan Gracie – Te Pou
Roger Jolley – Manager of Maori Development
The Honourable Minister Tariana Turia

Presenters Day Two: Karen Smith – Development Manager Family and
Community
Natasha Gartner – Contract Relationship Manager

Jenny Moor – Development Manager Service Access Team

John Wilkinson – Principal Policy Analyst

Presenters Day Three: Elliot Lloyd-Jones – Contract Analyst

Anne Bell – National Health Board Business Unit

Deafblind New Zealand Presentation

Alison Hearn – Manager, Strategy & Contracting Support

Consortium Members: John Greally, 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

Chris Orr, RNZFB

Robert Martin, People First

Venessa Rice, Parent 2 Parent

Neville Strong, NZ Down Syndrome Association

Glennis Wilson, Brain Injury Association

Apologies:

Ngaire Wycliffe, Brain Injury Association

Merv Cox, Deaf Blind (for part of day one)

Gayle Cullwick (day one)

In Attendance:

Kaeti Rigarlsford, People First

Ross Brererton, DPA

Catherine Cox

Support persons:

Cheryl Cox

Tina Mataiti

Melissa Blackmore

Lingisou Teulilo

Martyn Waldron

Sign Language Interpreters: Stephanie Awheto and Rosie Henley

Key for abbreviations used in minutes

Q = Question P = Point Made R = Response

Day One of the Consortium started at 9:05 am

Welcome and introductions

Alison Hearn welcomed the group, in particular new members Neville Strong of NZ Down Syndrome Association, Robert Martin of People First and Glennis Wilson of the Brain Injury Association. Due to unforeseen circumstances the facilitator scheduled for this meeting had to cancel at the last minute. The Consortium members were asked if were happy for Alison Hearn to facilitate the meeting and a request for volunteers was made. Jill Waldron agreed to facilitate day two and Robert Martin day three of the Consortium. It was also confirmed that an additional person was required as a runner for one of the microphones. The Members agreed that Catherine Cox could perform that role at this Consortium.

Alison went over the agenda and the microphone was passed around for introductions.

DSS Draft Strategic Plan 2010 – 2015 - Anne O’Connell

Anne O’Connell presented the Disability Support Services Final Draft Strategic Plan for 2010 – 2014. The plan was provided to the members for reading prior to the meeting. The vision is that ‘Disabled people and their families and whanau live in their homes and take part in their communities in the same way that other New Zealanders do.’ This vision was established in the 2008 – 2010 plan and continues through to the 2010 – 2014 draft.

This strategic plan builds on the 2008 – 2010 plan which was developed with the disability community through various forums and strategic planning groups. The 2008 – 2010 plan identified 4 key priorities which informed our development over this period. Further consumer consultation has led to 4 new strategies to support the vision and continue to move towards an outcomes-based approach to the planning and funding of disability services. This means that services are funded in a way that allows more flexibility in what is provided, encourages cross-agency collaboration in providing these services and shifts the ‘ownership’ of the services more towards the consumer.

The plan was influenced by the Government response to the Social Services Select Committee's inquiry into the quality and care and service provision for people with disabilities.

The four Strategies to Achieve the Vision

Strategy One: Give disabled people and their families more control, choice and flexibility. A new model for disability supports is the linchpin initiative. It will integrate approaches we already have underway to ensure good budget management within an environment where there's more devolved decision making by disabled people and their families.

Strategy Two: Modernise and streamline supports. Fundamentally, the new model will enable many clients to access support that better meets their individual needs, and that wraps around them. This will begin with home and Community Services. In the medium term there are clients whose needs may only be partially addressed. The significant group of clients where this is likely to be the case is people with higher needs – such as those in residential services, or likely to enter residential services. In preparation for the recommendations and changes the new model will bring for these clients, Disability Support Services has begun work in this area.

Strategy Three: Manage risks to the sustainability of the support system. The Ministry continues to focus on managing the whole support system – making strategic decisions about the directions of support provision and development, through what we fund at the margins, and what services we develop. Now Disability Support Services has better data to support decision making, and to be able to model likely effects. DSS will also continue to manage a number of other risks, and to manage the budget.

Strategy Four: Give disabled people equitable and quality services by realizing Whanau Ora and Maori outcomes. The rate of disability is greater for Maori than for non – Maori, and the uptake of disability support services is lower. The strategy aims to address the service gaps and improve delivery of services across all MOH funded service types. Purchase and procurement of new services, and existing services will include outcomes based descriptions in the contract specification. Medium term outcomes will be reflected in annual planning priorities. Long term activities include Whanau Ora through targeted improvement to Maori health.

Disability Support Services has prepared a Business Plan for 2010/11 which outlines our detailed planning for the next 12 – 18 months. DSS will continue to work with consumers and providers of disability support services in developing this new programme of work through forums and focus groups.

Details of consultation and meetings can be found on the Ministry of Health Website:

<http://www.moh.govt.nz/moh.nsf/indexmh/disability>

Anne asked the Consortium members for their feedback on draft plan and suggestions for improvement. She also provided the following questions and asked for responses from the members:

1. Does this draft Strategic Plan give you a clear idea about the direction of Disability Support Services group?
2. And do you agree with this direction?
3. If not, why not and what would you like to see?

Anne spoke briefly on her trip to Ireland earlier in the year when she attended the International Initiative for Disability Leadership (IIDL) an exchange and network meeting. The disability exchange is under mental health, with leaders in that field from across the world gather to talk about experiences and new initiatives, combining with people that have similar interests in the sector and meet with providers that do similar things. While there Anne spoke with policy makers looking at how Ireland has been dealing with provision of supports with limited budget. Since then there has been the implementation of a steering group which Anne is a part of. She will keep the members updated as more information comes to hand.

Pacific Updates - Feala Afoa

Feala Afoa introduced himself as the Development Manager Pacific at the Ministry of Health. His presentation to the Consortium is an opportunity to showcase the work that has been completed so far under Faiva Ora – National Pasifika Disability Plan which is due to be launched on the 18th October 2010 by Minister Turia at Parliament Buildings.

The launch of Faiva Ora will be a large event for Pacific peoples. The launch will include key resources that have been developed by Le Va, including the Pacific disabled people's information packs. The information currently available is not accessible to many Pacific people; these new resources aim to inform raise awareness of what support services are available for Pacific people to access. Also to be launched is a booklet that profiles Pacific people working in the disability support sector, encouraging Pacific people to consider this field as a career option, as opposed to just carer support work. Another key launch is the national Pacific leadership group. This has been established to support Faiva Ora; this group is comprised of Pacific disabled people, family carers, and disabled people working in the disability workforce.

Feala has three questions for the Consortium members to respond to. The members broke into three groups to discuss these questions and came back and gave their responses, they are as follows:

Question One: How can we best circulate the Pacific resources to be launched?

Group One: TV/ Media, community groups and forums, through Pacific disability services and in all Pacific languages (not just three but the other four Pacific languages).

Group Two: through churches, newsletters i.e. DPA, Parent 2 Parent, in hard copy and on the web, attitude radio, Pacific radio and libraries.

Group three: on MoH website, brochures sent to organizations, Carers Magazine, PHO's, hospitals and GP's clinics in accessible format.

Question two: are there providers who are part of this forum that want support in engaging and communicating with Pacific disabled peoples and Pacific communities in your areas to access services?

Group one: did not respond to this question

Group two: individualizing support, Autism NZ felt they did need support, and from people of the same culture.

Group three: yes we would need support and how would we access it once we identified who in our organisations would need the help.

Question three: We have established a National Pasifika Disability Leadership Group: we want Pacific disabled peoples who are deaf to be part of this group. We want guidance on how to connect with deaf providers and Pacific disabled peoples with hearing impairment.

Group one: Work with Deaf Aotearoa, create a partnership between Deaf Aotearoa and a Pacific organisation. Consider different ways to best to communicate with deaf people i.e. txt and face to face. There is a large Pacific deaf community in Porirua. To support dialogue need interpreters that can work in Pacific languages.

Consumer Leadership Development Grant - Brennan Gracie (Te Pou)

Feala Afoa introduced Robyn Shearer CEO of Te Pou, Brennan Gracie and Frances Anderson. The micro phone was passed around for the Consortium members introduce themselves.

Te Pou is non Government organization, working in partnership with the Ministry to administer three funding grants:

1. Training Grants (available to assist employers with costs arising from their employee's participation in a Ministry of Health approved national certificate or diploma)
2. Leadership Development Grants (available to assist employers with costs arising from their employee's participation in a Ministry of Health approved leadership development programme).
3. Consumer Leadership Development Grant (provides funding for development opportunities for people with disabilities, their carers, whanau, aiga and the organisations sponsoring them).

All applications for Consumer Leadership Development Grants will be assessed against the following:

Overview

The Consumer Leadership Development Grants enable consumers and organisations to jointly identify the activities which provide the most significant leadership outcomes for consumers.

Participants

Course or training participants must be eligible to receive Ministry of Health funded disability support services, and be either employed or sponsored by a disability support service funded by the Ministry of Health in a role where they have significant interaction with people with disabilities, or have employer or sponsoring organization approval and support to participate in the course of learning. Demonstrate that they are interested in becoming emerging leaders in their peer group.

Courses

Courses or training that is proposed must focus on at least one of the following areas:

- self determination and authority
- inclusion
- leadership
- quality

Proposed courses or training must be delivered in New Zealand. Proposed courses or training must be started and completed in the 2011 calendar year.

Applications

- Applications must describe what specific skills or knowledge will be obtained as a result of the course or training, and how the learning will be applied.
- Applications must be made by an organisation funded by Ministry of Health Disability Support Services, on behalf of one or more consumers.
- Organisations applying must demonstrate how they will promote opportunities for disabled people within their governance and the paid workforce.

- Every application must be signed by a senior representative of the organisation who has delegated authority to enter into a contractual relationship with Te Pou on behalf of that organisation.
- Applications for courses or training that are already funded (by other agencies) will not be considered.
- No one trainee or participant will be funded in excess of \$5,000 (GST inclusive) in one year.
- No one organisation application will be funded in excess of \$95,000 (GST inclusive) in one year

Considerations

The criteria above have not been assigned weightings. When determining which applications will be funded, the evaluation panel will carefully consider which - if any - criteria should be accorded greater weight, and how non-complying applications will be treated. Consideration of these matters may involve consultation with the Ministry of Health if the evaluation panel consider this necessary.

Brennan expressed Te Pou's desire to know how best to promote and communicate the Consumer Leadership Development Grant to consumers and organizations.

The members broke into three groups for discussion:

Question One: Feedback about wording of the Consumer Leadership Development grant criteria document.

Group two: felt it was clear and understandable, although it would have been helpful to see an actual application form.

Group three: how to word the document, confused about the narrow definition around who could apply? (This feedback was given to Brennan Gracie who sat in on this group.)

Question Two: Advice on how best to promote and circulate information about the grant to the sector.

Group two: through organisations, newsletters i.e. DPA, Parent 2 Parent, in hard copy and on the web.

Group three: Needed promotion, free to air community notices, organization magazines etc.

More information on Te Pou can be sourced from their website on:

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

Maori Updates - Roger Jolley

Alison welcomed Roger Jolley Manager of Maori Development for the Ministry of Health. This session will provide an outline of the Maori Disability Strategy and Action Plan, and Maori consumer participation in the DSS issues. Suggested reading was the Taskforce Report on Whanau Centered Initiatives presented to Minister Turia earlier this year. This report can be found on the following link:

<http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/initiatives/whanau-ora/index.html>

Strategy four of Draft DSS Strategic Plan is to give disabled people equitable and quality services by realizing Whanau Ora and Maori outcomes.

Questions to the Consortium members and points for consideration:

- How should we be engaging with the Maori disability sector? The Consortium has limited access to a Maori voice and is a valued forum to seek information and provide the Ministry with a consumer opinion.
- What barriers need to be removed and support needs to be put in place to enable inclusion and participation?
- If you think there should be more inclusion into the DSS Strategic Plan, please make comment. Email Roger at Roger.Jolley@moh.govt.nz

The Honourable Minister Tariana Turia

Lee Rutene welcomed Minister Tariana Turia to the Consumer Consortium. This was followed by a Waiata from the Consortium members. The Members introduced themselves and their organisations to the Minister.

Minister Turia acknowledged the members and the wide range of organisations represented at the Consumer Consortium. She followed with her speech:

I wanted to start off by simply acknowledging all of you; your amazing commitment; your resilience; and the investment you each make in the wellbeing of the people whom you care for. And I think the list is important to remind us all, just how complex and diverse the work is, that we are all involved in, one way or another.

I have to admit that when I first looked at the list, all I saw were the people – people whom I respect, people whom I have met with over the years either in my capacity as Minister for Disability Issues, or Member of Parliament; people whom care.

Today then is a wonderful opportunity to bring together those people and the organisations they represent; their support persons, interpreters; advisors from the Ministry of Health and other guests.

The Key focus for the Consortium is driven by people with a disability and their families. This is exactly how it should be.

Your brief, as a member of the Consortium, is to bring together the strength of your experience to focus on the information and advice most pertinent to the people who access disability funded services.

I have always had some difficulty with labels such as client; consumer; end user – categories which appear to place the focus on the goods or services being acquired, rather than the actual people who benefit from them.

To me, what has always been uppermost in my mind is hearing the voice of disabled people and their families. It is because of this, that I have introduced as a regular part of our meetings as the Ministerial Committee on Disability Issues, to listen to the sector. To take a pertinent example, earlier this year we met with the group working to make Auckland accessible for the 2011 Rugby world Cup. The Committee was heartened by their enthusiastic efforts to ensure accessibility is a more visible goal for all.

And just this morning, I attended the inaugural Access Tourism conference in Auckland, where we heard that there is so much more that must be done to build an environment which is accessible to all. I have asked the group from the Accessible Rugby World Cup to come back to the Ministerial Committee later this month, to really see how we can lift our game to ensure accessibility is a target in everyone's planning. The priority I place on the people's voice is very much supported by the focus on what will make the difference.

Tomorrow, Jenny Moor and John Wilkinson from the Ministry, will spend some time talking about the **new model** we have been developing to support disabled people. You will be aware that the request for proposals for an independent support organisation to assist in implementing the demonstration project closed on 19 August.

John Greally from Autism New Zealand and Bronwyn Hayward on behalf of Disabled Persons Assembly have provided a very strong contribution to the programme of work, and I am very keen for you all to continue to be heard, in terms of the model in general, and the lessons we can take from setting up the first demonstration site. Alongside the new model, I am really delighted to announce that as of 30 August 2010, there were 453 people using **Individualised Funding** – a massive increase from 260 a year ago. Karen Smith will be talking more about this tomorrow morning, but I want to acknowledge the important leadership that home and community

support services are providing, in becoming contracted hosts for Individualised Funding.

At this point, providers who have completed the process include Dunedin Home Support, Whaioranga Trust in Tauranga; Vision West from West Auckland; Florence Nightingale in Blenheim and a national provider, Manawanui in Charge. I am interested in your thoughts about how Individualised Funding is working, and how we can improve the coordination and access to information for disabled people and their families.

I know that some of you have thought the NASC providers are not always informing you of the different options. To try to address this, we have a consumer information booklet going to print next month; we're trying to ensure the website and magazines such as *Family Care* have regular updates; and we're doing all we can to spread the word to providers and Needs Assessment Service Coordinators. But I'm always open to hearing what we could do better.

Other sessions on your agenda include an update on the first **National Pasifika Disability Action Plan**; Favia Ora; and the establishment of the first National Pasifika Disability Leadership group. It is fantastic to also witness the progress that has occurred with the Lu'i Ola Strategic Framework – meaning simply, Together I am Able. And isn't that the truth! Together we are able to make the difference – and together, we must continue to keep our eyes firmly fixed on that goal.

Another area that I will be looking forward to your thoughts is the creation of the **Maori Disability Strategy and Action Plan**. I am really keen to hear from this Consortium about who they believe the Ministry should be talking to, to ensure the voices of the tangata whenua are fully engaged throughout this work.

Finally, I want to remind us of the significance of the United Nations Convention on the Rights of Persons with Disabilities, and in particular, Article 33 which requires countries to set up structures to monitor the implementation of the Convention. The office of Disability Issues is working full steam ahead, on preparing our first report, due in March 2011. As part of the work supporting Article 33, we have been working with a coalition of six disabled people's organisations – DPA, Association of Blind Citizens, People First, Deaf Aotearoa, Ngati Kapo and Nga Hau e Wha who are bringing the experiences of people with mental illness to the discussion. This work – and the new roles for the Human Rights Commission and the Ombudsman as independent agencies in promoting, protecting and monitoring the Convention – are fundamental to our future pathway forward.

Our Ministerial Committee on Disability Issues has asked the Chief Executives Group to develop a disability action plan to focus on making progress – and the emphasis I am asking them to take is very much on hearing the voice of disabled people and their families. I want to ensure that anything we do has the mandate of the people – rather than simply for activities sake. So for instance, when we look at respite care for parents of children with Autism – what we have been told from parents is that they want a menu for families to mix and match with what suits them best – such as Individualised Funding options alongside in-home or shared care.

I've been really inspired by the ideas I picked up from the Community Living Project in Adelaide, and have been excited to see how well concepts such as the Circle of Friends resonates with many of our disabled people and their families here at home. I have asked the Ministry of Health to look more into this concept as I think it offers another way forward, in building on the natural support network that families and friends already provide.

There's so much more to talk about that I would never be able to do justice to. But what I do want to say is that my over-riding passion is to ensure all families and whanau can be supported to the best that they can be; to be self managing; to do for themselves.

My focus is on investing in hope – the hope and the knowledge that we will honour our roles and responsibilities to each other; and that we will do all that we can to make the difference in disabled persons lives that they are determined to achieve.

I wish you well at this very important hui. Tena tatou katoa.

Patrick Thompson closed the session with Minister Turia with Karakia.

Disability Support Services Updates – Alison Hearn

Alison updated the members on some of the changes in Disability Services. Geraldine Woods, who was the Deputy Director General for Disability Services, has left to go to the Department of Labour. The Consumer Consortium is now under the National Services Purchasing, National Health Board. Alison introduced Kelvin Moffat to the Consortium. Kelvin has been seconded into Geraldine's position, in an acting role. Kelvin spoke briefly about his role in the National Health Board. He spoke about the biggest opportunity we all have over the next few years is to make the new model to work for the people who need it, including the Individualised Funding model. It is important that what is delivered is not just another layer of the same thing but something that is fundamentally working for those that need it. Kelvin indicated his interest in attending the Consumer Consortium in the future.

Summary of key points from Day One.

Anne O'Connell – DS Strategic Plan

- Anne introduced the 2010 – 2014 Strategic Plan and the four planks for the Strategy.
- The first plank is choice/control/flexibility in the new model, individualized funding and budget management.
- The second plank is to modernize and streamline support including review of 24hour support services (residential).
- The third plank is to manage risks and sustainability in finances, standardization and consistency, prioritization.
- The fourth plank is equity and Whanau Ora.
- Anne also updated the members on her attendance at the Inteth Disability (mental health) Conference in Ireland and that she is now involved in steering group.

Feala Afoa – Pacific Updates

- Launch of the National Pasifika Plan (Faiva Ora) by Minister Turia on 18th October.
- Part of the Plan is to include the launch of resource for Pacific peoples on Disability Support Services, and resource on career choices in the disability sector for Pacific people and a leadership group for Pacific peoples.
- Le Va (an arm of Te Pou) is implementing the plan.

Brennan Gracie – Consumer Leadership Development Grant

- Implementing the Grants for the Ministry, to the workforce front line, the providers to help build leaders and for consumers to help build leaders.
- Feedback from groups very helpful especially connecting with the various disability communities.

Roger Jolley –Maori Updates

- Task Force report on Whanau Ora is available. There are five parts to the framework (aspirations, principles, outcome goals, sustainability, Whanau Ora Trust development)
- Discussion around the connection between Whanau Ora and the LAC type service model. LAC model works with people to establish support needs. Whanau Ora coordinator is the same plus looks at whole family/whanau. The new service model demonstration project will help determine if a person with disability uses Whanau Ora or LAC model or both.
- There is a need for a lot of government support across government agencies.

- Whanau Ora Trust is tasked with implementing the plan. The DSS Strategic Plan has an objective for Maori. There is a need to align/integrate Whanau Ora into Service Specs in Ministry of Health contracts.
- 2006 Maori Disability Survey still needs to be actioned in the plan as is support for Deaf Maori.
- Maori Disability Plan is being written needs to go to Ministers and Caucus then will be brought to the Consortium for consultation.

Minister Tariana Turia

- Disabled people and their families part of the Ministerial Committee.
- The Minister thanked the Consumer Consortium for input into the new model.
- It was noted that 453 people are currently using Individualized Funding, an increase of 200 from the previous year. And extra providers are being contracted. Efforts are being made to improve communication to consumers.
- Great to see work on Pacific National Plan and Lu'i Ola.
- Look forward to Maori Disability Strategy and hearing from Consortium.
- Reminded of the UN Convention article 33 and working with PWD on the implementation of Article 33.
- Ministerial Committee working on Disability Action Plan.
- The Minister encouraged members to look more into the Circle of Friends concept.
- TPIC and Ministry of Social Development to talk on Whanau Ora at next Consortium meeting.

Kelvin Moffat – National Health Board

- Kelvin is the Acting Director of National Services Purchasing (the old HDNS replacing Geraldine Woods)
- One of the most important roles is initiating the new model and the choice and control of individualized funding.

Day One Meeting concluded at 3:00pm

DSS Consumer Consortium

Day Two

Tuesday 5th October 2010

The Brentwood Hotel

Wellington.

Meeting started at 9am

Apologies: Ngaire Wycliffe

Facilitator: Jill Waldron

Individualised Funding: Karen Smith

Alison gave some background to Individualised Funding and introduced Karen Smith, development manager for IF in the Family and Community Support Team for Disability Support Services. Karen presented the following with a power point:

Who we are

Disability Support Services Group, National Services Purchasing, National Business Unit.

Definitions

People/person: disable people/consumer who may choose IF

IF Host: an organisation contracted by the MoH to provide IF services as defined by the IF Service Specification.

Nominated Agent: someone who can make decisions on behalf of a person using IF such as a family/whanau member or full time caregiver.

Staff member, IF Host: someone who delivers the IF service on behalf of an IF Host.

Support Worker/Employee: provides Household Management or Personal Care supports to a person.

Support Plan (SP): The plan a NASC develops with a person as a result of an assessment.

Individual Service Plan (ISP): Developed between the IF Host and a person

Service Levels: Various levels of IF Host services that are offered to people depending on their interest and need.

Brief History of Individualised Funding (IF)

- Has been available in parts of Great Britain, USA and Australia since early 1990's
- Developed in ad hoc way in some NZ NASC's during late 1990's and early 2000's under discretionary funds
- Early 2000's interest from disability community in greater control over how their supports delivered.

2003 – MoH pilots IF with Manawanui In Charge

2008 – Evaluate pilot and decide to extend IF

2009 – Establish Implementation Reference Group. Access to IF extended to all those allocated HCSS.

2010 – HCSS providers to apply to become IF Host Providers. Write IF Service Specification and Guidelines. Contracting with Providers.

Karen mentioned that there will be twelve IF providers across the country. Currently the national provider is Manawanui In Charge, however four more have just been appointed:

- *Florence Nightingale in Blenheim*
- *Dunedin Home Support*
- *Whaioranga Trust In Tauranga*
- *Vision West (formerly Baptist Home Care) in West Auckland*

Over the next few weeks another 6-7 providers will be appointed.

What is IF?

- A service that allows people greater flexibility, choice and control over supports that enables them 'to live everyday lives'.
- It is also a payment mechanism and hosting arrangement to enable them to do this.

What does IF include?

- It will cover core and flexible Home Management (HM) and Personal Cares (PC) delivered as described in the HCSS Service Specification.
- In an IF context, all hours are flexi
- It will not cover other MoH funded supports such as: day or vocational services; supported living; Respite (through a contracted provider) or carer support; residential support; rehabilitation services; information and advisory

services; equipment and housing modifications; any treatment services; behavioral support.

What's in IF for People?

They say –

- Who comes into their home to help
- When they come, such as at 11:30pm to help them to bed after being at the movies
- What they do, such as showing them how to make biscuits
- How much employees get paid, provided it's at least the minimum wage

They can –

- Have more flexibility, such as having a two week holiday and using those hours later in the year
- Decide what level of support they require from an IF Host to manage IF

Suitability for IF

- IF is discussed with all people allocated Home Management and or/ Personal Care.
- Ultimately it is a person's choice to be referred to an IF Host.
- Comfort with the choice needs to be felt by both the person and the NASC before a referral can be made.

Service Levels

There can be multiple levels of services offered by IF Hosts. All IF Hosts must offer Level 1 to people and can decide if they want to offer additional levels.

Level One

- Set up advice and coaching to manage IF
- Provide an information pack with: forms, information on employment law, Employment Agreements, tax requirements, ACC and Kiwisaver
- Have an invoicing mechanism to allow people to authorize payments, pay wages and for the IF Host to invoice the MoH
- Develop an ISP
- Establish networks to enable people develop peer support and share resources
- Collect information (such as time sheets) to ensure support is delivered
- Monitor and report to the MoH on services delivered and the quality of them

Level Two

- The provision of a payroll service allowing people to authorize IF Hosts to make payments to employees. It may also include management of ACC, TAX and Kiwisaver obligations.

Level Three

- The provision of other functions associated with employing staff and may include; recruitment, staff training, a bureau function and membership.

How does IF work for a person?

As an overview they:

- Receive an assessment and develop a Support Plan with the NASC
- Engage collaboratively with the NASC during the process of jointly agreeing to choose IF as their service delivery option.
- Choose an IF Host
- Develop an Individual Service Plan with IF Host
- Choose which level of support they want from IF Host
- Participate in implementing the Individual Service Plan
- Keep records and report on fortnightly usage of allocation.

Considerations for People

People need to:

- Realistically discuss with the NASC their, or an Agent's, ability to manage a budget and direct how supports will be provided
- Become very aware of their responsibilities under the three levels of hosting
- Work with the IF Host on the best level of support for them – understanding what the fee is for each level
- Implement their ISP with coaching from the IF Host
- Know policy about recruiting family members who live in their home
- Offer a safe and healthy working environment
- Ensure fortnightly reporting detailing how many hours have been used are forwarded to the IF Host
- Retain and make available all records for review by either the IF Host or the MoH.

What can people purchase using IF?

HM and PC under HCSS

Example: Angi requires her Support Worker to maintain a current first aid certificate and has agreed to. Angi wants to go to the movies but doesn't have a friend to take her. She asks her Support Worker.

What could Angi pay for?

Other costs relating to the delivery of support can be purchased. Costs must relate to goals identified in Support Plan and Individual Service Plan, and may include:

- Full or partial cost for Support Worker training
- Movie Ticket for the Support Worker only

It's important to know

- A person's goals will still underpin what funded and unfunded support options are considered.
- An allocation of support hours will not change or reduce as a result of IF.
- Identifying natural supports with a person on IF will still be a component of the NASC process.
- NASC's will see that people understand that funded support is based on need not lifestyle choices.
- A person may decide to use their core and flexible hours in a more fluid way provided their employees are happy with this.
- A person may choose to use their tradable hours as they like within any allocation period.
- Accountability for the appropriate use of IF rests with both the person and the IF Host.
- IF Hosts will need to work beside people in a partnership, as people on IF take more of the control.

For further information:

Website:

IF Project page: <http://www.moh.govt.nz/moh.nsf/indexmh/disability-keyprojects-ifp>

Service Specification: <http://www.moh.govt.nz/moh.nsf/indexmh/disability-contracting-processes#if>

Contact: Karen Smith karen_smith@moh.govt.nz 09 580 9056

Karen posed the following three questions to the members for their feedback:

1. When considering the option of using IF, what are the three key suggestions/improvements/additions you would make to the way the current scheme works, and why?
2. If you could prioritise (most to least) what other services do you think should be made available for purchase using IF, how soon and why?
3. What would you look for or expect from a good IF Host provider, and why? Are these reasons different to how you would select other support service providers (outside of IF)?

Responses:

- The information you have is quite complex what is important that this information gets to the consumer and at a level that is easy to digest. Should not be a top down filter but to the people who need it in their hands.
- You should set up a steering group of people to work with you on this plan.
- Provision of staff and training for that staff. Also we need to include direct disability training and training for our communities around IF. And Safety training for Carers in home too.

- I think it is about people with disabilities training staff. Nobody knows our world best than those themselves. The staff need to have right attitude and values, it is open to abuse and we want staff that help nurture and guide for people to live a life of dignity and respect.
- Communication to consumers is important. Don't hold information to just providers and NASC's. Consumers need to know what the ceiling that providers can deduct for each level; offer guidelines for level two and three so consumers know guidelines providers are working under.
- The culture thing is important; I have experienced Carers coming in and tried to control how I live in my house. Training in cultural awareness is important. I like to teach my own Carers.
- Have you considered expanding IF to residential services? The power in residential services lies with the provider. Lack of information and sharing of information to Consumers, I think it would be exciting to see the principals that underlie IF to be transferred to a residential setting.
- I utilize Individualised Funding and have been told many variations of information so consistency with information would be good. I would like to see the policies on people living in the home and working as Carer. Regarding other services purchased I think Day Services would be really helpful.
- Make the information accessible CD, large print, Braille etc. Regarding IF hosts, they should be a separate organisation to the provider host, as I believe there a conflict of interest. Will consumers feel comfortable choosing another service provider that is not their IF Host?

Respite – Natasha Gartner

Natasha Gartner introduced herself and gave some background to her role as Contract Relationship Manager for Respite and Carer Support. The major projects that are being undertaken are first implementing a new flexible respite model, including in home and out of home respite, secondly conducting a central wide review of currently purchased respite services and thirdly a review and revision of Carer Support Guidelines to improve transparency and user friendliness. Respite Services are not purchased consistently throughout the country; some reasons for this are quite complex and related to client specific situations.

The Current situation

- Dedicated out of family respite facility
- Out of family respite beds
- There are positives and negatives to both types of contracted services

Respite:

- Is a topic which families are very passionate about we know this by the numerous numbers of Ministerial letters, family feedback and from Consumer Forums.
- The message has been that families want and need respite services
- New Respite services – in Auckland, Northland, Waikato, Bay of Plenty Wanganui, Hawkes Bay and Wellington.
- Outcome of those services is that the occupancy has been very mixed uptake.

Natasha showed three slides to the members showing percentages on the occupancy of capacity funded respite services tendered in 2008 and 2006/7 and other capacity funded respite services. The overall statement from these slides are that not all capacity funded respite services are well utilized, important to note the ministry has carefully monitored these services they have been audited and evaluated and the feedback has been consistently positive from families and carers, there is no obvious link to quality in the services. The Ministry wants to understand the reasons behind why the capacity funded respite services well utilized. Some of the reasons may be travel and the associated costs, people don't want to overnight, families want other options for respite.

Future Planning:

- Respite review - consultation with families, carers and providers. Want to know what constitutes respite for families?
- Respite trial – plan to run a respite trial in an area that offers flexibility, offering out of home and in home respite. Like to trial a new flexible respite model. Developing service specification. Trial for about two years and intend to start in next few months. Evaluation of this trial will help with the Respite review.

Natasha asked the members to break into groups to discuss and come back with feedback on the following:

1. An understanding of the key issues, ideas and concerns related to respite, for the members representative groups.
2. The member's ideas around some potential solutions to the above key issues.

Responses:

Question One

Group One – understanding of terms is respite care for individual or families.

Group Two – speed of deliver, safety for messages, break for the respite to be interesting not just a holding pattern, reaching out to other cultures, respite is for the Carers.

Group Three – safety regarding knowledge around specific disabilities and cultural competency, adequate buildings for respite, for people that live on their own not just those in families, including those with behaviour issues, in home respite issues if parents and siblings have to leave the home, people assuming badly behaving peers might adopt that behaviour, .parents of a person with a disability getting a break

Question Two

Group One - reintroduce or extend current camps while maintaining flexibility using accessible accommodation sites i.e. CCS home in Queenstown

Group Two – taking a friend to respite care, respite person likes timeout from Carers and normal environment, sense of holiday – hotel experience - contract with school camp sites. Overriding choice and flexibility

Group Three – key person to help with complex packages, IF as a payment option, home to home shared care, in home residential, knowing options in a region, what a respite facility will provide, activities to be – appropriate, enjoyable and stimulating activities.

Carer Support

We get a lot of feedback from families, Carers, individuals saying they are allocated Carer Support but they can't use it for a variety of reasons. The Ministry wants to see Carer Support becoming more user friendly over the next six months. Carer support guidelines will be under review to include consultation with Carers, families, consumers and with the Consumer Consortium. In the future these services should look quite different. Future changes should show – improved flexibility and increased choices.

New Model for Supporting Disabled People – Jenny Moor and John Wilkinson

Jenny updated the Consortium on the new model/framework and the demonstration project that will follow on from the model. Jenny asked for feedback from the members on what they have been hearing about or questions received on the new model from their organizations.

John gave background information on the process to date. He referred to the Select Committee enquiry which started in 2006 and report produced from that enquiry and the recommendations that came out of that. John developed a paper and produced a model after investigation into Local Area Coordination type models from the UK and Australia.

The model has four main elements:

- Introduce local area coordinators to walk alongside the disabled person to help them determine what sort of life they want to lead.
- How do we change the way we use the money that we have. Moving to a system where we allocate funding, rather than services while looking at what you can and can't use the money for.
- Once allocated money how do you go about purchasing? Individualised Funding would be available for most people for most supports – giving

flexibility. If people choose to use Ministry contracted supports – have those supports contracted for on a more flexible/outcomes orientated way.

- Strengthening accountability arrangements – What are the Ministry and disabled people, accountable for? Thinking more broadly.

The Demonstration Project:

- To demonstrate this model in one or two regions, starting in the near future. For example Western Bay of Plenty with a mixture of rural areas.
- Needs to be diverse where there are people/families wanting to access supports. These people could decide if they want to meet with a LAC.
- The new model will have consequences for established NASCs or DIAS providers. There are some service providers who say they are already performing a LAC type role – we need to work with these providers.
- The intention to establish demonstration then to evaluate. Choose an area, introduce model into that area. The first area may not be the best area. But we want to learn the most from when sufficient learning the move to another area, this will take a couple of years. Then take to cabinet to seek national rollout.
- Start with local people and a national strategic level. Phase each level in with IF, bringing in LAC (define roll and recruit). Another RFP soon to speak to people in the first area to establish a base line in that area. Then another RFP to procure evaluators to do a developmental evaluation to be able to make adjustments along the way. Demonstrations will need to run a couple of years but will start the second one while the first is still going.
- LAC
- Self assessment
- Allocation of funding – coming up with an amount
- More IF
- Greater choice = more accountability

John asked for people to brainstorm suggestions on what people should be able to spend money on and what they shouldn't. To consider the allocation of indicative funding based on a persons plan to support their life over and above what the people require everyday. The responses were as follows:

Good ideas: holidays and self respiting, self advocacy training, purchasing that prevents immobility and waiting for transport, transport costs, adaptive equipment – to purchase technology that can't be funded from other different areas (access to information), maintain physical ability – gym fees, sporting subs etc, social contact – anything that allows for this, everything – draw a line in the sand and below the line are the things that are essential and above the line everything else should be available; day services very important; access for deaf people to access SLI and access to Maori land courts etc

Not Good ideas: do not take away home management – look at peoples roles in the home; anything illegal; do not take away flexibility of choice.

Jenny asked the members what questions are out there that people want answers to. We want to hear directly from you so we can put questions and answers on the website.

Further ideas and/or questions can be sent to John at john_wilkinson@moh.govt.nz

- The link to the MOH website for the information and updates on the work on the new model or framework for supporting disabled people

<http://www.moh.govt.nz/moh.nsf/indexmh/disability-keyprojects-model>

- The report on the MOH website (in PDF) to the Ministerial Committee in Sept 2009 on the investigation of LAC type processes

[http://www.moh.govt.nz/moh.nsf/pagesmh/5362/\\$File/local-area-coordination-paper-mar2010.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/5362/$File/local-area-coordination-paper-mar2010.pdf)

Summary of day's key points

Karen Smith – Individualised Funding

- Brief history was given 1990 – 2010. From 2000 more work done.
- New plan for extension and new service specs
- Now contracting with 12 additional contractors
- All providers and NASC's have been trained
- Is for Home Care Support Services
- Does not cover (at present) Day or vocational services, supported individual living, respite, rehab, DIAS, equipment modifications, behavior support, residential.
- Consumers can decide who, what, where, and how – more flexibility and can decide level of support from IF Host
- Gave examples of what can and cannot be purchased. New ground for consumers being the employer and they need to be clear, up front; the support plan outlines the responsibilities of all supports allowed.
- Three aspects to future expansion: increase to host providers again out of Home Care Support Services and expand services – respite in non-contracted facility; additional services within LAC demonstration site and reviewing IF – funding appropriations and impact on NASC.
- Some issues for consumers is the difficulty finding and training staff, can be an employer, contractor or use a provider to get staff.
- Three ways to get staff: become an employer, become a contractor, approach a provider to engage.
- There is concern that providers and NASCs will over ride the consumer voice and we need to watch this.
- Host providers are Home Care Support Service providers. IF is for anyone who is eligible for HCSS.

- There is a clear plan which checks accountability and the model as we go – better to get this right before any expansion.
- There were several suggestions to Karen in response to the questions Karen asked of the group.
- Guide for IF now available for consumers.

Natasha Gartner – Respite

- Natasha currently manages respite at a national level.
- New work includes in home and out of home; respite review; carer support review.
- Currently service not consistent and the model does not suit all.
- MoH has capacity funded model and fee for service funded model.
- New respite services funded in 2008
- Tables presented showed year to date occupancy and latest month occupancy. Shows capacity funded services are not well utilized. It was not a quality issue so MoH are reviewing why they are not used. Therefore they have two projects underway Respite Review (what constitutes respite for families and why are services under-utilized) and the Nelson respite trial (want to trial in home respite as a new flexible model).
- The members broke into groups for discussion and feedback.
- Carer Support – review to make it more user friendly, will review Carer Support Guidelines and will seek further Consortium consultation.
- Wants improved flexibility and improved choice.

New Model – Jenny Moor and John Wilkinson

- John gave a review of the history of where the project came from.
- Model is in four parts: the information and personal assistance; the funding I am allocated for support; what I can use my allocated funding for; the quality (and accountability) of support I use.
- Consumer consultation has been integral to the model and will continue.
- IF will be part of the demonstration project.
- Needs to be more ways to distribute information and in accessible formats.
- Jenny discussed the demonstration project: LAC, self assessment, allocation of funding, more IF, greater choice and accountability.
- The site will have rural consideration, diversity and work with local NASC and providers
- Choose an area, introduce the project. When learned sufficiently will move to another area. To be in place by December for first site.
- Need to be careful how you ask things of consumers. Self evaluation – need a comprehensive look at it all together.
- Self Assessment will be a both/and situation
- Lac will be independent of NASC and providers
- Will be working with Whanau Ora
- Brainstorm on what is ok and what is not OK to spend money on within a support plan in the new model. Challenge for the model is how do you use the resources in an efficient and cost effective way to allow sustainability.
- What does a LAC look like?

- Where should LAC be employed. Do we use NASC also etc. There will be a list of Q&A on the Ministry web site. Word doc to be sent to Admin to forward to members.

Meeting concluded at 3pm

DSS Consumer Consortium

Day Three

Wednesday 6th October 2010

The Brentwood Hotel, Wellington.

Meeting started at 9.05am

Facilitator: Robert Martin

Apologies: Christine Morrison

Residential Review Project – Elliot Lloyd-Jones

This session is about the Review of Residential Services. There is a need to review contracts and agreement documents as they have not been reviewed for some time. Elliot presented the members with four questions and asked for their response:

1. What we should be trying to achieve (in terms of residential services)?
2. What do we need to do to achieve this?
3. What do we need to measure so we know whether or not we have been successful?
4. How best to have ongoing engagement with consumers? How to structure consumer involvement?

The UN Convention on the Rights of Persons with Disabilities says “Persons with disabilities have the opportunity to choose their place of residence and where and

with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

The Ministry of Health needs consumers to help them relate this statement to work looking at Residential Services. The Ministry wants to hear from Consumers how best to achieve this. Suggestions are;

- Family involvement in services is welcomed and encouraged.
- Support Services are person centered and consumer driven
- People have choice and control over support services
- Funding is used in cost effective ways to achieve outcomes.

This will mean that “People live where they want, with the people they want to live with and make decisions to ensure they receive the support they need in the way they want it”.

Are these the results the Ministry should be aiming for? What does the Ministry need to do to achieve this?

The Ministry will:

- Look at residential service contracts.
- Look at how they can give people more choice
- Look at changing the way we pay providers
- Think about new sorts of residential services

What does the Ministry need to measure to know whether or not they have been successful?

Time frames:

- Till end of 2010 is the design Phase and would have completed literature review (contracted out) and looking at potential innovations. A project plan to be completed. What would priorities be and to create work streams and work plan and pulling in all the other bits of work going on in the Ministry.
- Then looking at once work stream established, how best and most efficient way to utilize consumer consultation. Trying to put all the residential work in one bucket.

Other projects under the wider banner of residential services is a paper being prepared on a project with people with disabilities living in residential care, and Supported Living Services and third project is the Contract Board Project that Anne Bell will speak on shortly.

Responses to Elliot's Questions:

What we should be trying to achieve (in terms of residential services)?

Group One: change name – 24 hr care, high needs people – look at Swedish model (dream)

Group Three: more flexibility choices, opportunity to expand peoples horizons – staff training understanding need of individual, better assessments, rehab opportunities, services available to achieve persons goals, peoples rights must be respected, power to person to speak out and be heard, importance for person to have choice, power and control, better services in rural areas.

Group two: more embracing model – name change (to include contract board) safety cultural appropriateness, age appropriateness of placements, community activities to be included, clients have input to local council for activities.

What do we need to do to achieve this?

Group one: looking at the good stories – risk to be evaluated, more choice for service, IF could come in for some – an option

Group two: choice of community homes, survey present consumers and families

Group Three: contracting process and service specs need to be examined carefully, disabled people be part of audit, to appreciate how person is coping if person auditing have similar disability as person living there, be aware of persons funding when audit to better understand, common sharing of information between all stake holders to create common base of communication, establish a family governance service, governance group could feed into monthly meetings person has.

What do we need to measure so we know whether or not we have been successful?

Group one: stories are vital, do something with the results, audit template with spot check from MoH,

Group two: survey of all concerned,

Group three: people being involved at reference group level, people with good knowledge of sector and consumers, foundation core group to bring in other people to the core group this process works well, consult with people outside Wellington as well

How could this group and consumers be involved in the development of Elliot's work? Is there a structure that could be used to feedback?

Group one: the MoH should involve and resource disabled people to be involved in consultation.

Group two: through the Consumer Consortium names consumers could be put up (8-12) when the Ministry needs input they could call on these people, at a higher ratio than the Ministry.

Group three: important that the Ministry has Consumers involved in reference groups, having a core group would work well and be efficient, selection of who to sit on this group is important.

Contract Board Project – Anne Bell

Contract board is about intellectually disabled people living/boarding with other people/families. The Ministry pays an organization to organize 'board' with families for people with an intellectual disability. This is called Contract Board. Most of the people who have this service are supported by IDEA; there are a few other providers who also do this. There are about 300 people around New Zealand who are in Contract Board. The funding the Ministry gives to the providers helps them train the families so they can support the people appropriately.

Anne explained the time line for this project; the first priority is to sort out the payment mechanism to organizations and then look at whether to continue to offer Contract Board or not (considering the risks and benefits).

Anne presented the following points to the members and invited their response:

- Is Contract Board a good thing or not? .
- A concern the disabled person living in a private home can become invisible to the audit procedures used for people living in Residential Care.
- Are the provider organization's auditing the homes they have fostering disabled people?
- Concern that people's right of choice on how to live might not be there as the families may not allow them to make those choices.
- The service spec says this is for people with an intellectual disability, should it be opened to others?
- The number of people using Contract Board have reduced in the past twelve months from 400 to just fewer than 300, why is this?
- Could Contract Board be Supported Living, by just putting a mechanism in place to enable people to this?

The members broke into groups to do a SWOT analysis of the questions presented, their responses are as follows:

Questions to members:

- What is good about Contract Board services?
- What could be wrong about Contract Board services?
- How could Contract Board be improved?

- Do we still need Contract Board or could people be supported to make their own arrangements with a Supported Living, Home Based Support or Individualised Funding provider for example.
- Any other ideas or suggestions?

Group one: *strength* – options for clients; *weaknesses* – life skills have to offered and training for families; *opportunities* – advocacy; *threats* – no monitoring of the homes, boarding is a temporary thing is that good or bad.

Group Two: *strength* – family offers rehab skills and family community; *Weaknesses*- lack of audit of homes, general awareness of service not well known, lack of mentoring of person in the home, lack of knowledge of other services available to a person; *opportunities* – family matching, cultural matching, flatting opportunity, could be offered to people with other impairments, should advertise this model as it particularly in the rural community as it would be a good alternative; *Threats* – funding, the upcoming revamp of the Disability model, suggestion to paint a big picture - small issues in order to see big picture, things shouldn't be done in isolation (create a diagram to illustrate). Is it time to take a saw to things like NASC?

Group three: *Strengths* – should be offered to wider group of people with disabilities, inform consumer groups about Contract Board so they can let their people know, independence, flexibility and the options to experience real life – disabled people don't need protection from that; *Weaknesses* – funding should be addressed, quality of care, surround Contract Board with a governance group for people to refer to if there are difficulties., *Opportunities* - This concept good for Brain Injury people and those in rural areas; *Threats* - social isolation – need for advocate for people.

Deaf Blind Presentation

Deafblind Inc was established 1987 as the New Zealand Vision and Hearing impaired and then there was name change in 1998 to Deafblind. Deafblind is not Deaf or Blind or Deaf and Blind. It is Deafblind. It comes back to communication, for Deafblind people they communicate through tactile interpreting. Deafblind comes under the umbrella of RNZFB, it is funded through them. In 2006 Deafblind went into a recession, and in 2008 it started up again. So it is a fairly new group. It is run by Deafblind people for Deafblind people.

Helen Keller came to New Zealand 1947. With young children all around her, one of those children is still alive today living in Christchurch. In 2001 the World Helen Keller Conference held in Auckland and attended by Deafblind people from around the world. There are approximately around 1500 Deafblind people in New Zealand; a review was done on Deafblind about 3-4 years ago. It was discovered from this review that one in six deaf people have Ushers syndrome, a unique dual sensory

loss which affects a person's quality of life. RNZFB has Deafblind services for Deafblind people, and also work closely with Deaf Aotearoa.

Merv handed the microphone over to Phil who is a Deafblind man from the Hutt Valley. Phil shared his personal story with the Consortium on how he contracted bacterial meningitis while living and working in Queenstown; he went into coma for three weeks as a result and was in rehabilitation for eight months at Dunedin hospital. Communication was very difficult, until someone introduced Phil to hand signing. He also experienced severe Tinnitus. Phil and his family moved to Wellington to be closer to family, linked with the Laura Fergusson Foundation where Phil goes during the day. Life is incredibly difficult and frustrating for Phil and his family. Communication is an everyday struggle. Braille is opening Phil's world up; he can send and receive emails with a specialized computer. Tactile diagrams help Phil to know his environment. He expressed his frustration with not knowing what is going on around him, and has to work on taking things calmly. Being a driven person he is starting to ask more questions. It is easy to read situations wrong and get bothered which leads to more frustration.

The microphone was passed on to Lorraine Lawson from Palmerston North, who shared her story. She was born deaf and went through the regular school system but struggled at school and was not able to hear although she wore aids. She worked for 20 years and then worked at Massey University for 19 years. Lorraine participated in Deaf community for many years. She is also an ex committee member for Deaf Association of New Zealand for five years as well as supporting the Deaf community for many years. She eventually gave up driving due to sight loss, after that participation in deaf community lessened and lost many friends in that community due to this. Her increased blindness was due to Ushers and Lorraine is a Deafblind person. In 1993 she went to first national Deafblind conference in Auckland and met other Deafblind people for the first time and realized they were different to Deaf people, they were different cultures. Lorraine never learnt sign language and felt Deafblind was the right group of people for her to be involved with. Before thinking about cochlear implant her hearing deteriorated and communication became harder, Lorraine decided to go for cochlear implant with encouragement from family and friends. This has proved a great success and is able to communicate well with friends and even strangers and talking on the phone, listening to music and TV. Being able to communicate better she has begun to support the Deafblind community and is on the Deafblind Executive Committee. She has found it very rewarding supporting this community. There are still times where Lorraine needs support from her communication guide and thankful for the support she receives. A support worker helps Lorraine get out into the community, with out this support she would stay at home and playing on computer.

Merv also shared his own story with having Ushers two. He explained the difference between Ushers One (where a person is Deaf and will lose their sight usually during teenage years) and Ushers Two (where a person loses hearing and sight over a period of time). He acknowledged the support and help of the RNZFB. After meeting other Deafblind people he was encouraged and that helped in accepting his disability. Merv also explained the different types of tactile interpreters.

Tactical Interpreters – there is about four different tactile interpreting methods:

- Alphabet in the hand
- Sign language in the hand
- Braille dots in the hands

DSS Overview and 2011 Forums/Hui/Fono – Alison Hearn

Consumer Forums/Hui/Fono happens every other year from one end of the country to the other. There are Forums and Hui and Fono in each Island. Two years ago we went to all the main centres. The purpose of the Forums is to get Consumer feedback on key issues in their lives and for them to input into some of the Ministry development work.

For 2011 we will go to the smaller communities as we hear from them they don't get to see us and they sometimes find it hard to a main centre. The itinerary for 2011 is as follows:

South Island: Forums in Alexandra, Timaru, Blenheim and Nelson and Fono and Hui in Christchurch.

North Island: Forums in Palmerston North, New Plymouth, Pukeho and Albany. Fono in Tokeroa and Hui in Whakatane.

Two Questions:

What would be key issue/topics for Consumer information and feedback?

- Ministry presenters and representative from local NASC at meetings.
- For the Pacific Island community – respite care, carer support, Home support, funding
- The LAC – what is it about?
- Individualized Funding – what is it about? And the changes it could bring to people. How it fits with Whanau Ora.
- Having other agencies – this could create confusion for people, could have contact details to give out for other agencies (local contact name, phone, email)
- Use local radio bulletin boards and local rags
- Rather than cross agency stick with MoH with LAC IF etc there is too much going on in disability. It may be appropriate for the future
- Use DRC's to get info out to local web site

How can the Consortium help to get people to the meetings?

- For Pacific Island community go through the churches and promote them through Pacific language radio programmes and through Vaka Tautua.
- Transport biggest issue – getting people there.
- Organize buses to get people from towns to meetings; people in wheelchairs will have difficulty.
- Information in accessible formats as well. There are costs involved with this.
- Phoning people a week before to remind them
- Send information out to people before
- Get dates out early to put in peoples diaries, use Facebook, Twitter etc to get younger people.
- When information first goes out make it in very plain language so the average person knows it is for them, use the DRC in Whakatane for the Hui
- For Hui have stay over on Marae. Use Consortium Maori members to go to Hui. Use Maori radio and TV for advertising.
- RNZFB can help with getting it out to the blind and blind Maori – Chris Orr work with staff to get info out. Chris committed to get ten people to the forums, needs to be at night because a lot of people work. Timing critical, also food critical.

Summary of key points for Day Three

Elliot Lloyd-Jones – Residential Review Project

- New way of delivering and offering residential support. Four main things for discussion:
 1. What should we be trying to achieve? (UN Convention)
 2. What do we need to do this? (changing the way we do things)
 3. How do we measure if we are successful (choice for the consumer)
 4. Want feedback and consumer involvement at the early stages.

Responses to Elliot's four questions:

- Reminder to build on good stories and good models.
- Information should go to families so they can be part of the measurement.
- Use of family and governance groups for preview and contract board.
- To assist with feedback the Consortium could put up names for advisors or in their special areas of expertise. A core group may be the most efficient and needs to be from across the country.

Anne Bell - Contract Board

- About 300 people using the service (living with another family)
- It is for people with Intellectual Disability.
- Ministry of Health pays the organization and the organization pays the family. The consumer also pays host family some of their benefit.
- The organization matches the disabled person to a family.
- Foster care ceases at 16years and some of these persons are able to continue with their foster family under the Contract Board arrangement.

Things to consider/question:

1. Why only available to persons with Intellectual Disability?
 2. Why is there reducing numbers using this service?
 3. Need to have a way to check the safety of the individual consumers.
 4. How sure are we that the person's choices continue as adults?
- We need to clarify where it sits. Technically Contract Board is not a Residential Service. However the persons Residential Support subsidy is given to the host family for the Board. The provider is to provide all other needs.

Deafblind Inc Presentation – Merv Cox

- Started in 1987 by hearing and vision impaired peoples.
- Now Deafblind under RNZFB umbrella, restarted in 2008.
- One in six have Ushers Syndrome
- Phil Thorn shared his journey to becoming Deafblind, showing wonderful resilience and courage as Bacterial Meningitis caused him to lose his hearing and sight.
- Lorraine Lawson also shared her story of loosing her sight later in life and also suffers hearing loss. She is very active and supportive of the Deafblind community.
- Merv Cox shared his struggle with Ushers Syndrome to accept his blindness and hearing loss. He has found strength from his own consumer group.

2011 Forums/Hui/Fono – Alison Hearn

- Consumer Forums going to the regions next year, not the same places as 2009.
- Alison asked of the members: to help identify the key topics to address at these meetings; to help get consumers to these meetings.

Venue for next meeting: Brentwood Hotel, Wellington

Facilitator for next Consortium: Lee Rutene and NZFDIC

Meeting closed at 3pm

CONSORTIUM ACTION POINTS
To be completed by next meeting

ACTION POINTS	PERSON RESPONSIBLE
Admin to circulate the calendar of Member Organizations events.	Debs
Admin to update the Consortium page on Quick Place on the Ministry website.	Debs
Respite: Send information to Natasha Gartner Natasha_gartner@moh.govt.nz on CCS Home to Home model	Mathilda Schorer
The New Model: Further ideas and/or questions on the policy John is writing can be sent to John Wilkinson at john_wilkinson@moh.govt.nz	All Members
Residential Review Project: To assist with feedback the Consortium could put up names for advisors or in their special areas of expertise. Send to Elliot at Elliot_Lloydjones@moh.govt.nz	All members
Forums: help identify the key topics to address at these meetings and help to get consumers to these meetings.	All members

Email addresses for Actions:

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