
**DISABILITY SUPPORT SERVICES
CONSUMER CONSORTIUM MEETING**

Tuesday 19th, Wednesday 20th and Thursday 21st April 2011

Full Minutes

**Brentwood Hotel
16 Kemp Street
Kilbirnie
WELLINGTON**

Facilitator/Member: Lee Rutene, Ngati Kapo o Aotearoa

Coordinator: Anne Bell, Ministry of Health

Administration: Debbie Webster, NZFDIC

Raewyn Fowlie, NZFDIC

Natasha Veltman, NZFDIC

Presenters: Anne O'Connell, Group Manager Disability Support Services

Rowan Smith, Technical Advisor, Dept of Internal Affairs

Rhonda King, Group Manager, National Health Board

Feala Afoa, Manager of Pacific Development

Brennan Gracie, Te Pou

Frances Anderson, Te Pou

Suzanne Win, Behaviour Support Project
Contractor

Frances Hughes, Behaviour Support Project
Contractor

Karen Smith, Development Manager Family and
Community

Anne Bell, Community and Living Options,
National Health Board.

Consortium Members: John Greally, Autism New Zealand
Simona Mataiti, PIASS Trust
Lena Berger, Rescare New Zealand
Neville Strong, NZ Down Syndrome Association
Venessa Rice, Parent to Parent
Carolyn Weston, Association of Blind Citizens NZ
Chris Orr, RNZFB
Wendy Brenkley, Carers New Zealand
Harvey Brunt, Cerebral Palsy Society of NZ
Allison Franklin, 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

Robert Martin, People First
Heather Dawson, Hearing Association
Jill Waldron, Muscular Dystrophy Assoc.
Patrick Thompson, Mana Turi o Aotearoa
Wendy Duff, Autism New Zealand
Lolomania Filiai, PIASS Trust
Ngaire Wycliffe, Brain Injury Association
Glennis Wilson, Brain Injury Association

Apologies:

Gayle Cullwick, NZ Down Syndrome Association
Marsha Marshall, Ministry of Health

In Attendance:

Kaeti Rigarlsford, People First

Support persons:

Cheryl Cox
Tina Mataiti
Melissa Blackmore
Lingisou Teulilo

Sign Language Interpreters: Stephanie Awheto, Harri Harrison, Alan Wendt

Day One of the Consumer Consortium started at 9:10 am

Welcome and introductions

Anne Bell welcomed the members to the April 2011 Consumer Consortium. In particular a warm welcome to Allison Franklin as a new member representing Cerebral Palsy Society.

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

Action Points from previous minutes

The Action Points were reviewed from the November 2010 Consortium. All action points completed or ongoing.

There was a query around the proposed Texting Service the Ministry of Health was to trial. Julz Britnell had presented on this project at a previous Consortium and the members had not heard any more about it. Anne to check with Julz Britnell and come back to Members

Disability Support Services Update – Anne O’Connell, Jac Lynch, Roger Jolley

Anne O’Connell gave an update on Disability Support Services response following the Christchurch earthquake, including lessons to be learned for future responses. Jac Lynch presented on the work she is involved in looking at what the gaps and supports that are needed for any possible future catastrophes. She circulated a draft survey for individual consumers to the members, on emergency planning, and asked for feedback. The survey is a planning tool, to learn from what happened and to better plan ahead. It would be aimed for a national response and then to be fed into the DHB’s.

Comments received back from the Consortium members included:

- Allison Franklin of Cerebral Palsy Society developed a booklet through DPA for Civil Defense and offered a copy to the Ministry.
- It might be worthwhile asking the question around the support people and what hours they are with the disabled person.
- Consider family and neighbors of the disabled person.

Roger Jolley gave an update to the Consortium Members on the progress of the Maori Disability Plan.

The actions from the last Consortium was to have set up a National Leadership Group to begin work on the process and the content of the Maori Disability Plan. The Leadership Group is made up of Karen Pointon, Rainus Baker, Maaka Tibble, Sylvia Ratahi, Ruth Jones and David Tamatea.

The Leadership group has met once in April and have two more meetings planned for May and June. A draft plan is being prepared for external consultation which will happen through a series of three hui across the country. Disabled Maori who used DSS funded services will be invited to view the draft plan and give their feedback on the draft. This information will be collated and brought back to the Leadership Group and then to the Ministry. Minister Turia has asked for regular updates on the progress of this piece of work. Previous data from consumer hui and the consortium has also been taken into consideration.

Ministry of Health Redevelopment of Website – Rowan Smith, Alan Potter, Sharon Hill, Wendy Kemp

The Ministry of Health has recently launched a new corporate website at www.health.govt.nz . They have tried to ensure that the website complies with the Government Web Standards of which there are four quadrants, as supplied from the Web Content Accessibility Guidelines:

1. Legal and policy
2. Content and design
3. Strategy and Operations
4. Technical Standards

The team working on this project are aware that some people with disabilities may still not be able to access all the information on the site. The plan is to migrate all the content currently on www.moh.govt.nz into this new website as a second phase; they want to know how they can improve accessibility to the content. The desire is to make the website accessible to all users.

They acknowledged that it is possible to tick all the boxes around the Web Standards and the site is still not accessible to all users. The web is a diverse place but this is why we have underlying common standards to allow all people to access the web. One of the issues is to find out what the common issues are across government – video, accessible documents and colour also being an issue for some people.

The old Ministry of Health site has been around from 1999 and has a legacy with many issues and limitations such as search, navigation, video, custom elements which means difficult to tweak any parts of that website and over time has turned into a large collection of PDF's.

What they are going to do about this?

Objectives are:

- Better planning
- Credible and sustainable presence
- Trustworthy source of information
- Enable innovative ways to deliver information
- Improve sector networks

New Site www.health.govt.nz

- Build on powerful, flexible platform
- Big improvements to the search function
- Much clearer navigation
- Platform for richer content
- Customisable – easier to change and tweak

What are we doing?

- Launch health.govt.nz
 - “Corporate site” as a pilot 19 March 2011. The new site links back to the old site.
- Further develop health.govt.nz to serve the health sector.
- Presently in the planning stages

How you can help us today?

- Give us feedback on www.moh.govt.nz
- Give us feedback on www.health.govt.nz
- Let us know about your experiences

The Consortium members broke into discussion groups and came back with the following feedback:

Group one:

- Colours and font size – best black on white, larger font with the capacity for the user to increase the font size and consistent sizing with font. Narrator on the site.
- Deaf/blind are not able to use websites – hard copy will always be important.

- Fine motor issues – large buttons, no drop down menus as they are hard to manage.
- Current site – liked top navigation bar had big buttons.
- Sign Language Interpreter videos including sub titles, capacity to zoom, good standards for volume, spoken information with pure audio or video.
- Website in other languages – resourcing to do this would be a challenge.
- Work and Income website easy to navigate and use.
- Consider children and young adults – keep it bright and easy read.

Group Two:

- Contrast – as much as possible for visually impaired, stay away from blue gray colours.
- Consider other languages – Maori and Pacific.
- Consider having an ongoing dialogue with some disability organisations that might have technical people who could be called upon for input.
- Use easy read language to make it accessible to all people.
- Captioning and audio sometimes not easy to follow not as easy as signed video.
- Not all parts of the disability sector have access to the internet, elderly use Telephone Information Service. This service has pre recorded information that is accessed by a person's telephone. It would be helpful if information from the Ministry of Health website could be contained on this service. It is currently for blind people through the RNZFB.

Group Three:

- Colour yellow background – not blue on blue. Have site that you can change contrast and font. Experts from the disability field need to be spoken to when developing this site.
- Do not use complicated tables and charts as they are not accessible to vision impaired people, text of the information stored in the chart or graph is needed.
- Use plain language and text.
- Use of icons on screen to make it easier to recognise subject matter (alongside of text or picture on its own).
- List health topics on side of screen.
- Need different formats for different people
- One positive is the DIAS page has a really good font.
- The IRD website is easy to access as is the Health and Disability, ACC and Community Net from Internal Affairs.

Further feedback to: webteam@moh.govt.nz

Concept Paper: Evaluation framework for disability residential services – Rhondda King

Outcome – Focused: Evaluation framework for disability residential services.

Background

- Social Services Select Committee's 'Inquiry into the Quality of Care and Service Provision for People with Disabilities'
- Evaluations and audits of disability services focus on the quality of life and opportunities for people with disabilities rather than on compliance with minimum standards for audit purposes.
- People with disabilities and their families are given a key role in the monitoring process to ensure quality of life is measured and valued.
- Evaluation reports of services are readily available to the public taking care to preserve the privacy of individual residents or service users and their families.
- Providers within the residential disability services have also expressed their concern about the number of different types of audits they receive and the relevance of these to improving quality of life outcomes for people in line with the developments in the disability field.
- The developmental evaluations undertaken by the Ministry of Health are consistent with the United Nations Convention on the Rights of Persons with Disabilities.

Framework Components

- Organisational self assessment
- External evaluation with a developmental approach
- MOH review of external evaluation report for certification purposes
- Monitoring of provider to improve service quality
- Support to achieve

Model

Service Provider:

Organisational self-assessment of the contribution to quality of life outcomes and the key processes involved with Service Users and their support networks participating in the assessment.

Determination of how well the service provider is doing and development of an action plan to support planned improvement activities over the next three years.

Evaluator:

- External evaluation by DAA evaluator – review of material completed by service provider.
- External evaluation by DAA evaluator – on-site visit focusing on interviews and observation to validate service provider findings.
- External evaluation by DAA evaluator – summary of findings and completion of report.

Ministry:

Certification process resulting in:

- 3 year certificate and conditions including monitoring and support frequency.
- Confirmation of service provider action plan.

Ministry and Service Providers:

Ministry of Health – Monitoring and support events against the action plan.

Feedback requested:

- Questions – what do you think of the model? How could service users be more central to this process? What skills, knowledge, and experience should evaluators have to come into this process?
- Comments
- Feedback

Feedback Received:

- Evaluators need a very good understanding of the sector and experience of residential services. A home should be lived in. Don't go into homes when people aren't there.

- Are providers given any training or guidance on the self assessment? Quality of life is a very subjective concept, how do you measure how good a life a persons having? The outcome should be for the happy life, happiness comes from within.
- I have worked with a residential hostel for children who are deaf; often residents don't have any involvement in the audit process. Not just in the residential home but also their environment. Communication between staff and residents is very important, particularly for deaf residents. If there is a high turn over of staff that is a reason to look to see what might be going on. And professional development for staff is important, so they can understand the world view of the disabled person.
- I found the paper comprehensive and liked that it was people based and not compliance based. It should be mandatory that audits happen every three years. I think there should also be casual walk in type audits – like the health department does with restaurants. Evaluators should have a mind set of assessment and an understanding of disability. If Audits are people based, you will not be seen as the police.
- Evaluators need very good communication skills; they will need training in communicating with all sorts of people. I also think the spot evaluations will be a very good thing. Quality of life should be strictly the main issue.
- For families who have children transitioning into shared houses. There may be these clusters of small homes with 3-5 people living in them and no process for auditing them.
- I think it is important to have self advocate meetings with residents. There are things that can be done to make sure that each person's voice is heard.
- Staff working in Residential Homes need to have a strong commitment to the people living in the home. Staff should provided with the tools and knowledge to work in the service, they need to work to a good framework.
- The Cerebral Palsy Society has a number of members with verbal issues in residential care; the service provider can become stuck in the middle between consumers and families.
- When talking about quality of life for Maori, we talk about the four corner stones of life, which would be a good way to approach this when talking with Maori consumers.

Disability Workforce Development Grants – Feala Afoa, Brennan Gracie and Frances Anderson

Feala Afoa introduced Brennan Gracie and Frances Anderson from Te Pou. Brennan thanked the members for inviting Te Pou back to this Consortium and for previous feedback from the November 2010 Consortium around criteria.

The criteria for the Consumer Leadership Development Grants were circulated to the Consortium Members. Both the Consumer Leadership Grant and the Leadership Development Grants are currently open. For further information on either grant please contact Te Pou at disability@tepou.co.nz or by phone 09 373 2125.

Brennan, Frances and Feala updated the Consortium on the Consumer Leadership Development Grants and how they have been used and invited discussion on the latest Consumer Leadership Development Grant criteria.

Three Questions for feedback:

1. Any comments/feedback around process of application for grants – use of language, website accessibility, any barriers?
2. What implications and workforce development needs might be effected by the proposed new models (IF and LAC etc). What effect might these changes have on the Leadership Development Grants?
3. Issues around applying for travel and accommodation costs through the Consumer Leadership grants. Should travel and accommodation be funded?

The Consortium members broke into three groups to further discuss the questions posed by Te Pou; the following feedback was compiled by Te Pou from the discussion groups. It combines both the large group discussion and the three smaller group discussions.

Issues

Travel and Accommodation

- Must remain as a legitimate cost –‘don’t become a leader in your own back yard’ –need to mix with others outside your own area to broaden experiences –can take leadership back to own locality.
- Young people who are the leaders of tomorrow need investment and don’t have resources to fund themselves.
- NZ can teach world about consumer leadership.

- If you don't fund travel and accommodation then the training will need to go to more areas – which may not be more cost effective.
- Could sponsoring organisations be asked to pay? And perhaps consumers could make contribution.
- Seems some internal contradiction within MOH where LAC is about getting out to rural areas but in this fund travel and accommodation would mean rural areas excluded.
- Training may not be available in your own area.
- Seems we are being tainted with the brush of extravagant public servants or politicians which is unfair. Many are beneficiaries and cannot self-fund.
- May not be able to drive ourselves.
Don't have same transport choices (recent problems with Jetstar for example)
- Also need to pace involvement to accommodate impairments – for example may need to travel to training the day prior to its occurrence to be able to fully participate.
- Recognise government funding not endless but travel and accommodation essential to this fund.
- Need to meet with others nationally to share ideas –perhaps have a national gathering

Sponsorship by Organisations funded by Ministry of Health, Disability Support Services.

- Some consumer groups receive funding from MOH DSS funded organisations but these arrangements are changing and it may not be the right time to be sharing financial details via a sponsored organisation.
- 'By consumer for consumer' training is often the best don't necessarily want training provided by 'providers'
- Some groups are large, longstanding and accountable –so would like to be able to apply in own right.
- Want to maintain independence –seems to contradict the principles of the new MOH model –consumer centred
- Question – If you use IF –does that constitute a contract?
- What if you seek sponsorship through and MOH DSS organisation but they don't agree to sponsor.

Te Pou Processes (including Website, Grant applications, language)

- Eligibility as per previous consortium believe there are potential leaders missing out because they are financially independent and don't receive MOH funded services.
- Seen initiatives over the years that provide initial training but is crucial to have follow up and an opportunity to put the new skills into practice. See the criteria includes being able to implement so would like to see assurance that sponsoring organisations willing to provide some opportunities.

- How can consumers influence the kind of training funded.
- How do we find out what is available?
- Use plain language to be user friendly for intellectually impaired.

New Model

- Insufficient knowledge about this at present but hope criteria will be adapted to reflect this.
- Work together –integrate across social services and govt agencies.
- Power of the NASC.
- Prioritise Rural areas.

Responses and Update

- Some sponsoring organisations may be able to support in this way but some have limited funding themselves so may only be able to offer the umbrella support but not financial.
- Te Pou clarified that there are individual cap of \$5000.00 and organisational cap of \$50,000, so not talking about extra funding but what cost the funding can be used for.
- MOH outlined reasons for the current criteria of applications being made via and MOH DSS funded organisation. –Provides a measure of accountability and appropriate to direct the investment to the services that it funds. (other funders such as MSD also ring fence to the services they fund).
- Clarified at the meeting that the application needs to be made by an MOH DSS funded organisation, but the training programme can be run by consumers.
- MOH indicated it is working with Te Pou and the DSS Workforce Reference group to consider the needs of the workforce delivering services under IF contracts and the IF hosts will likely umbrella training for those individuals.
- Bring to the attention of Te Pou or Feala Afoa next to the Ministry of Health.
- MOH indicated the funding is intended primarily for grass roots, for those who cannot self-fund and to ensure strong advocacy with regard to services received. Te Pou also clarified that receiving non means tested services such as Disability Information and Advisory Services, for example would meet the criteria. Application Forms asks what opportunities the organisation will provide for those being sponsored
- Te Pou very interested to receive feedback regarding training you regard as the most valuable. Te Pou considering putting together a directory of relevant training available. Can't guarantee that all listed training would receive grant funding.

Day One concluded at 3:30pm

DSS Consumer Consortium

Day Two

Wednesday 20th April 2011

The Brentwood Hotel, Wellington.

Meeting started at 9:00am

Apologies: Merv Cox for lateness, Christine Morrison left the meeting at 1pm

Behaviour Support – Suzanne Win and Frances Hughes

Suzanne Win and Frances Hughes introduced themselves to the Consortium members as contractors to the Ministry of Health for this piece of work on Behaviour Support. The following power point was presented and followed by a question and answer time.

Objectives for today

- Familiarize Consumer Consortium with the Behaviour Support project.
- Get further Consumer input
- Have already spoken with Autism NZ CEO and President Parent to Parent.

Background

Previous work has been going on since 2007 and has included:

- Review by EQS
- Internal review Disability Support
- Literature Review
- Discussion Paper

Object of this project

This project has the purpose of:

- Establishing a consistent and effective behaviour support service
- A well understood continuum of service for the client group
- Underpinned by equity of access and value for money

Behaviour Support Services

- Contracted Providers (10 across NZ) who provide a consultation service for people with intellectual disability who have challenging behaviour.
- Providers are a range of District Health Board and Non Government Organisations
- Standard contract with MoH
- Differing approaches and systems

Principles to underpin the work

- Consistent access (nationally)
- Responsive and flexible (early intervention)
- Culturally responsive/whanau sensitive
- Sustainable and affordable
- Integrated and continuum approach
- Evidence based practice
- Clinical leadership/governance
- Transparency
- Evolutionary
- Retention of current skills and capacity

What it should look like

- To meet current and future needs
- To ensure equitable access
- To ensure clinical approach

Next steps (April/May)

- Ongoing work on models, workforce development issues, costs and procurement planning
- Ongoing testing with MoH for veracity and direction

Next steps (May/June)

Finalise draft report including

- Service configurations, benefits and risks
- Costs of proposed models
- Procurement approach
- Preliminary recommendations
- Complete option(s) and report. Submit to MoH

Questions

- What would you want to see in an ideal behaviour support service responsive to individuals and families
- What might it look like?

Responses:

- I would like to see that people are able to have ABA (Applied Behaviour Analysis). We also need a facility where families are able to

take their family member to with the right trained staff to enable the person to be able to go back to their family with right support in place.

- Reduce waitlists.
- The abuse in institutions still has ongoing issues; there are not enough councilors in this country that can work along side people with Intellectual Disability. These are the most vulnerable people. Need to look at what led to the behaviour issues, what came before the behaviour. Need to look at the person the individual to support them to be the best they can be.
- We would like service and support outcomes from these Behaviour Services.
- Some vision impaired people also have intellectual disability so they need this information in an accessible format for them, like plain language Braille. I wonder if a multi disciplinary team approach would be the best approach.
- For workforce, if you are a family with a child with behaviour issues it is hard to retain staff – we need a trained workforce who knows how to deal with difficult behaviour. And for intervention in the teen age years and for teacher aides in schools.
- Within the diverse deaf community we have people who have multiple needs. What we find is that communication is at the heart of the issue. Having a clear sense of a persons communication needs can go a long way towards helping them. In the deaf community it is having access to Sign Language Interpreter services. There is a need for education to providers, clinical staff etc on how to communicate with different people and how they are treated. I would hope that the best communication strategies are put in place to enable people to advance.
- The principles you presented are a good base, and in there you mention clinical staff and professionals but no mention of the disabled people themselves, what about the families who often know best and have the best skills.
- We must see the humanity of all people and get away from our own selfishness and everyone needs a place and to feel loved. You can only do that on an individual basis. The training has to start with the family, no family that produces a child knows what they are doing to begin with, particularly with a child with a disability, right at the very beginning those parents need to be receiving training that needs to be understood by the Ministry. In terms of trying to deliver across the country and have national consistency, your model can have the principals but when it comes to delivery under lay cultural and other guidelines
- A whanau based model worked very well for me personally. I would like to see a more cultural and whanau approach.

Individualised Funding – Karen Smith

Who we are

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

- Karen Smith, Development Manager (IF), Family and Community Support Team, DSS.

What is IF?

- A service that allows people greater flexibility, choice and control over supports that enables them to 'live everyday lives'.
- A way of paying for disability support services where disabled people directly manage the hours they are allocated for Home & Community Support Services

IF is administered through a contracted IF Host.

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

What can be purchased using IF?

IF covers Home Management and Personal Care under Home Community Support Services.

IF can be used to purchase support services provided by support workers, (employees or contracted personnel or organizations), and costs relating to the employment of support workers.

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
- Behaviour Support

These will continue to be funded separately

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

IF is administered through a contracted IF Host. 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

- The provision of IF set-up and coaching. This includes helping disabled people to set up their service and supporting them to understand and manage their responsibilities.
- The provision of an invoicing mechanism allowing disabled people to authorize IF Host to make payments to and invoice the Ministry for support hours used.
- Monitoring and reporting to the Ministry
- Establishment of networks to enable peer support, information sharing and sharing of resources such as staff and staff training

Examples of what IF Hosts may offer in other levels are:

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 of Associations. It may also include other overhead services such as accounting, admin and legal support.

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 the IF Host
- Participate in implementing the Individual Service Plan
- Keep records and report on fortnightly usage of allocation

Who are the contracted IF Host Providers?

Access Homehealth Ltd, Healthcare NZ Ltd, Manawanui in Charge, Presbyterian Support Northern, Lifewise Homecare Services, Vision West, Te Korowai Hauora O Hauraki, Whaioranga Trust, Disability Resource Centre Trust, Presbyterian Support Central, Florence Nightingale Agency, Dunedin Home Support.

Costs

- A fee is paid to the Host Provider.
- Payment is calculated as a percentage of the total cost of support delivered and is determined by the size of the support package allocated by the NASC
- Level 1 services are at a rate set by the Ministry
- Level 2 & 3 services can be determined by the IF Host.

Examples of IF in Practice

- Caregivers are able to assist and attend community activities and events and be paid for it
- Some family members are able to be employed
- Caregivers

Considerations for People

IF offers increased flexibility and control over, who, when and where support services are delivered.

But it is important to point out that there are considerations and responsibilities for people who use IF, which include:

- Records on support services used and how will need to be kept (& retained) in sufficient detail
- Know policy about recruiting family members who live in the home

- Offer a safe and healthy working environment
- Responsibilities associated with employment and managing staff
- Compliance with relevant legislation on employment and tax

Examples of IF in Practice

- Being able to attend a sports/community event and have your support worker funded to support you
- Determining who comes in to provide your support, and when they come
- Determining and negotiating wages for support workers
- The choice to employ your own support workers, including some family members

So far:

- 84% of those surveyed on IF say they are making progress towards goals
- 94% consider the way in which their care was delivered is flexible
- 98% are satisfied with IF as a means to manage disability support services.

The nature of positive feedback received includes:

- better access to communities of choice
- supports are more flexible
- access to mainstream education
- more age-appropriate community participation.

How IF works

- Person contacts NASC to discuss IF as an option.
- Needs Assessment completed and IF discussed as an option.
- Person chooses IF Host from list and NASC makes referral
- Person and proposed IF Host discuss options.
- Person and IF Host agree to level of support needed OR Person and IF Host work together to develop ISP.
- Implementation of ISP and engagement of support staff begins.
- Support Services are delivered.
- Support Services verified by person and IF Host notified.
- IF Host invoices Ministry of Health
- IF Host receives funds and makes payments for supports delivered.

If you were thinking about IF

- What are some of the advantages you see vs traditional service provision?
- What services would you expect from an IF Host organisation to best support you to manage and control your own supports?

- What other support services would you like to see included as part of the scheme?

Responses:

Q. How do you get training for the staff you employ?

R. *A person can go through the Host provider, all of the Host providers (with the exception of Manawanui in Charge) are also Home and Community Support Providers – you can choose any one of those providers to purchase training from.*

Q. Can you use a provider outside of your geographical area?

R. *There are some providers that are geographically restricted but there are also three national providers you could chose from.*

P. The advantages are that it is individualised and personalised and the Ministry has shown an enormous trust in people. Some comments from Down Syndrome Association are:

- that the paper work and forms are a nightmare and scare people
- Is it possible to have numbered forms and in plain language.
- Could you establish a grant of say \$500 like a start up fund to enable people to pay bills?
- It's infancy in delivery but look at the Host Providers to see if there is a simple most effective template of presenting or delivering IF.
- Respite and Carer Support be good to be included.
- Could the Ministry staff, as a professional development, walk a day with a person who uses IF?

Community Living Options – Anne Bell, Ross Livingstone and Valerie Smith

Anne Bell introduced her colleagues and did a demonstration of the how the Ministry of Health is developing a new way of supporting people. Last year at the Consortium Elliot Lloyd-Jones talked about the Review of Residential Services. This work is now called the Community Living Options Programme.

The new way will mean an extra choice for people who have support needs that mean, under the present system, they live in a residential service.

The four areas that are the key ingredients and questions around these areas are:

Support

- If people with high needs are not going to live in a residential service what do they need to have a good life?

Accommodation

- What stops people choosing where they live?
- What stops people choosing who they live with?
- What changes are needed?

Funding

- What do you think about how the way the Ministry of Health funds services?
- What changes are needed?

Accountability

- How can the Ministry of Health be sure that services they fund help people have the support they want?
- How can the Ministry of Health be sure that people get their fair share of support from their service provider?
- How can the Ministry of Health be sure that the services they fund are good value for money?
- How can the Ministry of Health be sure that any services that they pay for are provided?

Responses:

- One of the supports that are needed is day services. That should be a core component of this work.
- The changes that are needed are more flexibility such as IF and an acceptance that people with disabilities wish to be in charge of their own lives. The term house hold management should go back to domestic assistance. I manage my own home I employ someone to clean it. To say someone is coming into my home to do house hold management is very disempowering.
- Another thing needed is transparency. It always seems we need to be 'accessing' something, non disabled people do not have to 'access' the community. We have closed the institutions but not the institutional attitudes.
- Accommodation needs to be of a universal design and is barrier free, hand rails and ramps can be put into buildings.
- Housing NZ is going to be using Universal Design for new houses they build. Perhaps the two government departments could get together on this.

- With the community type model and looking at providers, there is a need to look at the areas where people live. Those areas are not that accessible. They need to be in areas where there is good public transport – this needs to be taken into consideration.
- There is a need those day services in conjunction with other supports other wise people sit at home being bored.
- How do we maintain consistent reliable support – where do we get that from? That training in the community needs to be followed up, how do we manage that for people in community living?

The things that have been identified so far:

- Accommodation: We think that the funding for accommodation (food, power, TV, rent) should be separated from the support funding. Do you think it is a good idea to have it separated – consensus was that it was a good idea
- Supports: We need different supports – emotional support, spiritual support, practical support, and vocational/day activity support. Don't use old phrases such as home support, or personal support. Inclusion Support.
- Funding: The funding labels will come from the support labels.
- Accountability: needs systems to ensure that what we pay is delivered outcomes achieved, value for money and the consumer gets their fare share of the disability dollar.

Day Two concluded at 3:30pm

DSS Consumer Consortium

Day Three

Thursday 21st April 2011

The Brentwood Hotel, Wellington.

The New Model for supporting people with disability – Jenny Moor and Rowanne Janes

Introducing the New Model for supporting disabled people

Who we are

- Jenny Moor – Development Manager. Disability Support Services, Ministry of Health (Programme Leader)
- Anne O’Connell – Group Manager. Disability Support Services, Ministry of Health (Programme Sponsor)
- and other Ministry staff involved in aspects of the work
- Ruth Gerzon & Lawrence Chok – Inclusion Aotearoa

Why do we need a new way?

- Disabled people want a good life and more choice and control over support they receive.

The Background

- In 2006 MPs set up a Select Committee to talk to disabled people, families and service providers.
- Ministry of Health meetings with consumers highlight need for – flexibility, support for families, workforce and access to information – DSS strategic plan and work programme formed from this.
- The Committee’s report is given to Parliament.
- Ministry of Health research good practices here and overseas, including Local Area Coordination.
- New Model for supporting disabled people developed

What is different about the new model?

Old Way

- Someone else makes decisions about what support you get and when you get it.

New Way

- With support, you decide what's important to you to have a good life.

Four parts to the model

1. A stronger focus on information and personal assistance
2. Allocation of funding not services.
3. More choice and control for people over the support that are purchased.
4. Stronger accountability arrangements.

Local Area Coordination

- The most visible part of the new model in the demonstration will be Local Area Coordination.

A local area coordinator (LAC) will help you :

- get information
- work out how you want to live
- build relationships with people and organisations in your community or town
- work with the community to encourage them to include disabled people.

What else is the new model about?

- Funding, not services – allocate dollar value rather than type of service, self assessment.
- What you can use the funding for – expanding IF, increasing flexibility.
- Accountability – for everyone – Ministry, providers, service users, focus on quality and having a good life.

What is Individualised Funding?

- Individualised Funding (IF) is a way of paying for support services.
- You can choose: who comes into your home, when they come, what they do, how much they get paid (provided it's at least the minimum wage).

Demonstrating the New Model

- Western Bay of Plenty/Tauranga has been chosen as the first place to test out some elements of the New Model.
- Inclusion Aotearoa are supporting the Ministry of Health with this Demonstration project.

Community Engagement

- We want to work closely with the community to share ideas, and to refine and evaluate the model.
- Inclusion Aotearoa has set up a local working group, who meet regularly to work with the Ministry of Health to decide what will work in the demonstration area
- A National Reference group is being set up as a strategic forum for development of the New Model and its demonstration

For further information:

Inclusion Aotearoa

Web site: <http://inclusionaotearoa.co.nz>

Phone: (07) 3124191

Email: inclusionaotearoa@gmail.co.nz or write to P O Box 3017, Ohope, Whakatane

Ministry of Health Disability Support Services

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

Where we are now

Inclusion Aotearoa was the organization chosen on the ground to assist to engage with the community. Their next step is to employ the Local Area Coordinators, a manager and possibly up to three coordinators. A challenge is to be able to identify in these communities a base for LAC's that will be inclusive and accessible. There is also work progressing towards a funding allocation (through the process of what can be identified as fair share and how that can be used). Also considering it can be used for and not used for – policy decisions to be made around that. John Wilkinson at the Ministry of Health is working on how to test some of the thinking around this, in order for this to work for people.

There has been a call for nominations for the National Reference Group, and the successful nominations will have been advised in past couple of days. Inclusion Aotearoa and the Ministry of Health went through the nominations. Sixteen have been chosen for the Reference group which encompasses a broad based group with a majority of disabled, geographical spread, Maori

and Pacific voice. The Consumer Consortium will continue to be invited to input into this work. Inclusion Aotearoa is the first point of contact.

Evaluation

Rowanne Janes is the leader of work stream four which is the accountability work stream. There is work happening now on an accountability framework, including the consideration of research done overseas. As more work happens on the ground more evaluation will be required and this will be ongoing.

There has been research undertaken, having spoken to key agencies on what's currently happening for people with disabilities. This information is being compiled into a report which will be due in June 2011. This will create a baseline of what is current so when the New Model is rolled out nationally there will be a comparison. This will be an informative piece of work.

The evaluation of the project will take up to two years and is a two stage process of procuring evaluators for the project. And then following the Registration of Interest there will be a Request for Proposal. There is work involved in getting evaluators for the model working closely with disabled people, giving strong recommendations of how the model and its components should take shape, making sure the aims and intent and meeting needs of people with disabilities.

Questions:

- What do we need to keep in mind to select development evaluators?
- What do we need to include in the questions asked during the developmental evaluation?

Responses:

- The evaluators would need very good communication skills to communicate with people with different types of disabilities. And also to be able what report back what the person has said in the persons own words.
- Cultural awareness and sensitivity.
- Attitude and a real empathy of this sector.
- have crucial understanding of disability itself, and recording word for word what the person has said. Use friendly language and even pictures for people to understand. Some people with learning disabilities cannot read or write.
- Consider using disabled people with the right skills as evaluators.
- Talk to the person with the disability not just their family or support person.

Self Assessments

Jane Pembroke is working with Support Net the local NASC in the Bay of Plenty and with the local working group. They are looking at a tool used in Lower Hutt and could be revised for this work. They are also considering what has already been done locally in the way of self assessment tools.

Questions:

For people with lower levels of need to do a self assessment on paper or electronically (considering other languages and need for different formats)

- What do you want us to keep in mind or important to remember?
- What would encourage people to take up the offer of self assessment?

Responses:

- Some of families that are stressed and they don't know what they need, which would make self assessment very hard for them, although those that are further down the track know exactly what they need.
- Generic open ended questions, long hand rather than tick boxes. Validated by whanau and friends as people down play their strengths
- Plain language.
- I would recommend you use DIAS providers, working in groups particularly for Pacific People, this would work best.
- Approach needs to consider peoples feelings and backgrounds, so questions that pull out what is really going on for a person rather than things that can be ticked off.

Equipment and Modification Services – David Guest and Alison Barber

David Guest of Enable and Alison Barber independent contractor to the Ministry of Health presented a series of vignettes for the Consortium members to consider and prioritize in order of greatest need. The vignettes were handed out to the members to consider. The question was asked who out of the vignettes should be considered first when it comes to EMS Prioritisation.

The responses from the Consortium members as follows:

- I always look at where a person is in their life, how much resource they have themselves. I would pick the youngest.

- ACC is cutting the amount people receive for hearing aids. Do you look at the value of the pieces of equipment?
- The question here is that there is high and low priority. How long does the low priority take? There is a need to let people know that they have been accepted and how long they can expect to have to wait.

EMS Prioritisation Power Point Presentation

- Ministry of Health EMS Funding - when demand exceeds budget - Who gets the services first?
- 8 individuals requesting funding with a total cost of \$150,000, \$100,000 is available. Who should get access to that funding?
- Existing priority guidelines (client viewpoint)
 - ineffective
 - lack of information
 - factors important considered low priority unless associated with risk
 - mistrust of consistency and reliability of assessors to represent needs adequately
- How can the system change?
 - Date order (based on time request received)
 - Age based criteria (younger people get funding first, older people wait)
 - Income and asset test (who decides who is rich)
 - More money
- What factors would make the process 'fair' in the minds of disabled people, public, disability providers, funders, decision makers?
- Services focussed on *needs and expectations* of clients and their families.
- The *right* services deliver the maximum benefit to the individual client and their family.
- To *fairly* meet greatest need within available resources.
- Consumer focussed system guided by sound principles that is:
 - Equitable, Transparent, Cost-Effective, Systematic and Consistent.

Development process:

Workshops held with disabled people, therapists, sector representatives, identify key factors for 'need' Prioritization tool development. We all identify with key factors but put a different value or view point on those factors.

Organisations Represented

- Association of Blind Citizens of New Zealand
- Deaf Blind Inc
- Local City Council Disability Advisory groups
- Royal NZ Foundation of the Blind
- Deaf Aotearoa
- Age Concern
- Autism NZ
- CCS Disability Action
- Parents representing themselves as carer's of disabled children or young adults
- Grey Power
- Ngati Kapo Ki Otautahi - Blind Maori (Christchurch)

Disabilities Represented (not linked to organisations)

- Vision Loss
- Hearing Loss
- Intellectual Disability
- Physical Disability
- Cerebral Palsy
- Multiple Sclerosis
- Muscular Dystrophy
- Autism Spectrum Disorder
- Deaf/Blind combined

Three Key Factors

- Impact on Life of the disability
- Reversal – removal of barriers to activity
- Ability to pay

Impact on Life (self assessed)

- Safety to self and others
- Ability to Self manage and maintain Independence
- Ability to fulfill external roles, obligations and responsibilities important to the client
- Primary/important relationships including family
- Ability to participate in activities important to the client
- Deterioration
- Destabilisation of Carer Support (the ability of the carer to manage)

Last two factors are looking at risk, what might happen in the future.

Reversal

- Benefit of solution for the person
- Duration of benefit
- Likelihood of achieving that benefit

Total Score

- Impact on Life – 38.2%
- Reversal – 54.3%
- Ability to pay 7.5%

What next?

- Pilot
- Review
- MOH Decision
- Implementation
- What will change for Disabled People, EMS Assessors and Suppliers

EMS Prioritisation Tool Pilot – Progress

- Pilot aim is to take a sample of the population need for EMS and relate to new priority and current eligibility criteria
- Pilot underway – slow to start but assessor training now complete
- Over 170 prioritisation assessments captured across broad spectrum
- Consumers have the opportunity to comment on the process and tool as they complete the IOL.

Like an iceberg the biggest part of this project is what is under the water not what is showing above the water. Upon looking at the unmet need it may be that that iceberg gets flipped on its head and the much larger portion is what is seen.

Evaluation of Pilot

- Test the accountability of the EMS Prioritisation Tool to consumers and EMS Assessors
- Review the Tool's impact, identifying potential financial and policy implications
- Assess whether the Tool is a 'fairer' process than currently used
- Inform what is required nationally to change the system, including recommendations....
- Recommendations report due July 2011
- Ministry will review recommendations and consider a decision to proceed

Q. Where are the three pilots?

R. They will be in three DHB's Mid central, Southern and Counties Manukau.

Q. What about modifications for people who are in private rental homes where the landlord won't allow modifications?

R. *We can use modifications that are equipment (that don't affect the house), i.e. ramps, etc if it is a bathroom modification we have to get the approval of the landlord if they do not give that approval we don't have any control over that.*

Meeting closed at 3pm

Facilitator next meeting: Karen Pointon (Deaf Aotearoa)

Dates: Monday 10th, Tuesday 11th and Wednesday 12th October 2011.

Venue: The Brentwood Hotel, Wellington