

Disability Services Consumer Consortium Meeting 4 – 6 October 2010 Summary of Key Points

Summary of key points from Day One.

Anne O'Connell – DS Strategic Plan

- Anne introduced the 2010 – 2015 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.

Summary of key points from Day Two

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 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.

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.

Patrick Thompson, Karen Pointon and Lee Rutene meeting with Roger Jolley

- The Maori represented at Consortium meet with Roger Jolley Manager of Maori Development at the Ministry of Health,
- Seeking action from last Hui.
- Wanting clarification on how Maori are consulted on for the new Maori Disability Plan.
- Asked Roger to set up a Maori Caucus.