
**DISABILITY SERVICES NATIONAL
CONSUMER CONSORTIUM MEETING**

Thursday and Friday 30 – 31 July 2009

Summary Minutes

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

Facilitator/Member: Anne Wilkinson, Parent to Parent
Mathilda Schorer, CCS Disability Action

Coordinator: Alison Hearn, Ministry of Health

Administration: Debbie Webster, NZFDIC
Tanya Wishart, NZFDIC

Presenters Day One: Pam Henry – ASD Guidelines Implementation
Karen Hunter – ASD Guidelines Implementation
Mark Powell – Manager Service Access
Anne Simpson – NASC Association
Jan White – NASC Association
Henry Harrison – NASC Association
Alison Hearn – Strategy & Contracting Support

Presenters Day Two: Anne O’Connell – Group Manager DSS
Sue Primrose – ESS Programme Manager

Rob Gill – Development Manager Workforce

Julz Britnell – Senior Communication Advisor

Feala Afoa – Development Manager – Pacific

Organization Presentations:

People First

PIASS Trust

Consortium Members:

Hilary Stace, Autism New Zealand

Jennifer Birch, Autism New Zealand

Kevin Anderson, Brain Injury Association

Lolomanaia Filiai, PIASS Trust

Simona Mataiti, PIASS Trust

Lena Berger, Rescare New Zealand

Chris Orr, Royal NZ Foundation of the Blind

Anne Wilkinson, Parent to Parent

Venessa Rice, Parent to Parent

Carolyn Weston, Association of Blind Citizens NZ

Jan Moss, Carers New Zealand

Harvey Brunt, Cerebral Palsy Society of NZ

Mathilda Schorer, CCS Disability Action

Jacqui Carlson, CCS Disability Action

Kim Robinson, Deaf Aotearoa NZ

Trish Anderson, IHC Advocacy

Lee Rutene, Ngati Kapo o Aotearoa

Merv Cox, Deafblind New Zealand Inc

Karen Pointon, Deaf Aotearoa NZ

Rainus Baker, People First

Zandra Vaccarino, NZ Down Syndrome Assoc.

Gillian Smailes, Hearing Association

Support persons: Tony Weston

Kaeti Rigarlsford

Cheryl Cox

Lavinia Filiai

Tina Mataiti

Melissa Blackmore

Interpreters: Advanced Interpreting Management Services

Apologies: Todd Fernie, Ngaire Wycliffe. Day two: Zandra Vaccarino, Kim Robinson

Key for abbreviations used in minutes

Q = Question P = Point Made R = response

Meeting started at 9:10am

Welcome

Anne Wilkinson welcomed the group, in particular the new members and went over house keeping matters.

Participant introductions

Alison Hearn introduced herself and her new role on the Consortium. The microphone was passed around for members to introduce themselves. A special welcome to new member Venessa Rice from Parent to Parent. Also to Zandra Vaccarino from NZ Down Syndrome Association, who is replacing Gail Cullwick at this meeting.

Agenda

The agenda was reviewed by Anne Wilkinson

Action Points from previous minutes

- Terms of Reference in plain language - Anne Bell investigated and it is not able to be done. It is intended that support people are to assist if anyone has difficulty interpreting the document.
- IHC request on health checks - Anne Bell will ask Amanda Hinkley for an update to be e-mailed out to members.
- Behaviour Support – this project was on hold and is now going to run by the Family and Community team under Marsha Marshall. An update will be provided at the next Consortium.
- Directorate Update – Alison is having the organizational chart of the new structure in Word format so it will be accessible to all members. This will be sent out to the members before the next Consortium.
- Mental Health - Anne Bell to follow up with Roz Sorenson re: the DHB in Blenheim. Anne noted there are no planned public consultations for this piece of work.
- Residential Services Booklet in accessible formats – Alison will have Valerie Smith contact Carolyn re feedback on the booklet.
- All other action points completed.

Discussion on interface with Government Ministers – Alison Hearn

There was discussion regarding a request from the consortium members that there might be a regular spot at this meeting for different political parties to send along spokespeople from that party's disability sector to hear the consumer's voice.

P. We need further discussion on this; perhaps people from the select committee would be good to hear from?

P. I would like to feel that the consortium is more pro active in disability issues, if we could invite Minister Tariana Turia to attend our meeting. So she could see and hear our issues. And speak to us and listen to us. We are a strong voice, I would like to see this group not just give advice but to get something back.

P. I think Minister Tariana Turia is quite different in her ideas than Ruth Dyson; it would be good to have her come listen to our group. She has quite different approach to Disability Services.

P. If we were to go in this direction we would need to change the terms of reference and the Association of Blind Citizens would want a draft of those terms of reference to go out to its organization.

R. *You need to be clear on what you are here for, in the terms of reference, you are here for advice to the Ministry. Perhaps what you are discussing here is under a Peak Body Consumer Group, separate to what the Consumer Consortium is to do.*

P. The issue of the Peak Body is a separate issue; we are a group that represents people who receive funding from the Ministry of Health. Change the terms of reference so that other organizations can be invited as the members decide for each meeting. I think it would be good to have the Minister or associate Minister to come to our meeting to have an open discussion with us, who represent the consumers. I would propose that we invite Minister Tariana Turia to the next meeting.

P. A word of warning, we are doing an important work here and going off into other areas would distract from what we are doing here.

P. At the RNZFB, we think we should be able to take any opportunity to speak and that the voice of consumers should be heard and also the voice of service providers. We believe it is very important to talk around the table with the final decision makers and those that influence those decisions. Also the ministerial group that has been put together on disability services issues. Also there are other key people like the transport minister to talk to about disability issues and transportation. The opportunity to dialogue with those decision makers is very important and should be taken.

P. I support all these comments; we need to drive this issue as it is important. It is also important to be accessible and inclusive.

P. Yes we are here to advise the Ministry but it is also important to spread the message that disability encroaches on the whole of life and so to be able to speak with other ministers would be good.

P. Should it be through this consortium or should our individual organizations create a group to go to the Ministers? We need to come to the Ministers with solutions to our problems and ask for the assistance to create those solutions. There is also the Disability Advisory Council who advises the Ministers.

R. *The principal of what you are saying is great, you need to be very clear on what this group is doing and what you are set up for if you want to have audience with Ministers which this group would be good for but perhaps in a different arena. There have been many groups that have been very proactive in seeing Minister Turiana Turia and she is very open to listening. This group is powerful but your individual groups have more power if they each go to her.*

P. I think it is important that we contact, then meet and greet the Minister. As she is new it would be good to invite her to our meeting.

P. I agree with that comment, we have to be careful of not lobbying, but invite the Minister for a meet and greet at our next meeting.

R. *If the next meeting is in Wellington it would be entirely appropriate to have the Minister come and meet and greet and speak and listen to you.*

P. I don't believe a lot of the people in the Ministry of Health really understand what disability is.

P. I have been listening to all of this and my view is when you look close at this group, what are we here for? The terms of reference gives us the power to advise the Ministry I don't think it is our job to be meeting with the MP's. If we want to meet with MP's we need to go through the Council of Disability Issues or our organizations. I don't think we have time here to do that, I think it would confuse our role if we took that on.

P. I'm suggesting we have half an hour on the agenda that we have Ministers that are not necessarily within Disability Services to discuss our issues. I think with the huge government cuts, we have to take every opportunity we have to communicate with them.

P. I'm here from my organization to ask the Ministry of Health what they can do for Maori with disability, what is the Ministry doing for the different cultures in this country e.g. Maori and Pacific Island groups?

This discussion was put on hold for further discussion to continue the next day.

ASD Guideline Implementation – Pam Henry

The Ministries of Health and Education agreed a set of priorities for the next three years of NZ Autism Spectrum Disorder Guideline Implementation. They made this decision after discussions with the ASD Implementation Advisory Group, the ASD Inter-sectoral Advisory Group, and a group of senior officials from a wide range of government departments.

Implementation Priorities areas are:

- Assessment and diagnosis
- Support to strengthen families
- Interventions
- Respite
- Coordination

Assessment and Diagnosis - There are five projects currently underway in this topic area, they are:

1. Development of a handbook for recognizers and referrer of ASD education and health disability practitioners involved in performing assessments and making diagnoses.
2. Development of training materials for specialists in the assessment treatment and management of ASD.
3. Review/Revision of core Needs Assessment and Service Coordination (NASC) Standards, Protocols, Guidelines and Practice Resources.
4. ASD Specific Guideline for NASC's
5. Development of NASC Resources

Support to Strengthen Families – The five projects underway in this area are:

1. Improving information and advisory services
2. Parent Education
3. 'Tips for autism'
4. SPELL evaluation
5. Bright Sparks – programme Enhancements

Interventions – The three projects underway in this area are:

1. Family/Whanau community outreach services
2. ASD – specific communication and behaviour support services
3. Assessment of the feasibility of having ASD-specific behaviour support services.

Respite – The two projects underway in this topic area are:

1. Extending disability respite services
2. Describing ASD-specific respite services

Coordination - The three projects underway in this area are:

1. Business case for the DHB Developmental Coordination
2. NASC ASD Coordination

3. Review of interagency protocols (equipment and therapy) between the Ministry of Education and the Ministry of Health for school aged children.

Associated activity led by the Ministry of Education

In addition to the work that is led by the Ministry of Education in the fields of parent education and teacher support, the Ministry is also leading the following projects in the support of the NZ ASD Guideline:

1. Living Guideline – whose goal is to ensure that the NZ ASD Guideline remains up-to-date and relevant as evidence changes. This process will not add new topics to the NZ ASD Guideline, but keep the current topics up to date. It will focus on areas where the evidence since 2004 has changed enough to warrant changing a NZ ASD Guideline recommendation.

2. Education ASD Action Plan – whose goal is to develop a coordinated national plan for professional learning and development, including establishing a network of 'Go To' people who will take a leading role in providing evidence-based support and current information.

3. Early Intervention ASD Project – whose goals are exploring the use of the Social Communication, Emotional Regulation and Transactional Support (SCERTS) framework in early intervention in NZ. Specifically, during Phase Two (2009 – 2010), the goals are:

- Improved outcomes for more children, families and whanau
- SCERTS effectively adapted and operating in the NZ context
- More staff with a wider range of skills in providing effective interventions for children with ASD, their families, whanau and education teams
- Further refining an effective model for providing professional learning and development and sustaining effective practices.

New Membership Discussion – Alison Hearn

Alison received a registration of interest from Multiple Sclerosis to join the Consumer Consortium. She suggested the members might like to consider and discuss the following issues:

- The size and the role of the group
- The current funding for the consortium is based of the current numbers; if they increased there may not be enough to cover the meetings.
- Consider the Terms of Reference
- Should there be a cap placed on the number of organizations represented?

- Should a waiting list be employed?
- Fairness across the sector when considering which groups should be involved.

Alison commented that when she applies to the Senior Management Team for future funding, she needs to be able to show what value the Consortium has brought to the Ministry and the Consumers it represents. How the Consortium has inputted into policy and decisions. They will also want to see how the Consortium members have disseminated information back to their organizations. It was suggested that the Consortium might require more structure in gathering and collating that information.

Alison will send out a template to the members to complete.

There is no new initiative money coming in to the Consortium. The group has the funds it has been allocated but no extra. The work of the Consumer Consortium is valuable and should be continued, but the Minister will want to know how the Consumer benefits from the work of this Consortium.

Action Points from this session:

- NZFDIC to assess costs for a maximum number of members.
- To obtain final response from non-attending organizations and remove from membership if required.
- Evaluation form – members to report on how they disseminate information to their organizations; advise on what group/panel work they participate in as a Consortium member; advise on any meetings their organizations have that might be relevant to having a Ministry person attend.

NASC Update – Mark Powell, Anne Simpson, Jan White, Henry Harrison

Local Area Coordination Model Investigation:

Officials from the Disability Support Services Group and Disability Policy have visited Western Australia and Queensland as part of the Ministry’s investigation of Local Area Coordination (LAC) type processes. The Government’s direction to officials to carry out this investigation is contained in the Government’s Response to the Report of the Social Services Select committee on its “Inquiry into the Quality of Care and Services Provision for Disabled People”.

Both Western Australia and Queensland offer Local Area Coordination services that are based on underlying principles that were originally

developed in Western Australia. In each case, Local Area Coordination involved working with individuals, families and communities to make a practical difference to disabled people's everyday lives. It is based on developing ongoing and in-depth relationships with disabled people (and their families) with a view to them identifying what represents a good life for them, and working with family and community resources to make that happen.

Unfortunately, neither John Wilkinson nor Jenny Moor who made these visits will be able to attend this particular meeting. They are therefore asking that the Consortium advise a group with whom they could meet to receive the views of the Consortium members as part of the ongoing investigation.

NASC Qualifications:

The graduate diploma at University of Auckland is underway, it has had a national winter school early July and its advisory group will shortly meet for the first time. Members of the Consumer Consortium have been involved and will be on the advisory group. Rob Gill will join the group so he and your members can share updates and consider together the role of the advisory group and the Consortiums contribution to it.

Henry Harrison – Presentation of the NASC Document Review

Ministry of Health contracted NASCA to undertake a review of NASC documents in the ASD programme.

History of the framework

- 1994 – 95 the initial framework design (rights and responsibilities, funding and payment, principals, standards and guidelines, framework)
- 1999 – National Review of NASC (NASC review project) Health Funding Authority (funding and organizational principals, updated standards and guidelines, agency standards, competencies for NASC's)
- 2000 onwards – defining NASC practice in the context of the NZ Disability Strategy. (policy and procedure guidelines, operational processes)

Each period builds on the earlier work, leading to improvements in consistency and quality of NASC delivery. Each period has a differing emphasis. All contribute to improving service quality over time.

The documents being reviewed are:

- Standards for Needs Assessment for People with Disabilities (MoH June 1994)
- Service Coordination for People with Disabilities, Guidelines for Regional Health Authorities (MoH February 1995)
- Principles for Needs Assessment and Service Coordination Agencies (Health Funding Authority 1999)

- Standards and Competencies for Needs Assessment (Health Funding Authority 1999)
- Standards and Competencies for Service Coordination (Health Funding Authority 1999)
- Support Needs Assessment and Service Coordination Policy, Procedure and Information Reporting Guidelines (MoH 2002)
- NASC Managers' Manual (MoH May 2005)

The Review Includes:

The Funding Pathway

The sequence is as follows:

- Government Funds
- Policy determining eligibility
- Ministry of Health funding to NASCs.

The Disability Policy and Strategy arm and the Funding arm work together on the NASC Framework, NASC Service Specification and Budget Management, Disability Service Specifications, Contracts with Service Providers and Provider payment.

Both teams work to ensure services to Consumers.

New Zealand – Rights verses Standards

This compares New Zealand's Standards based approach to a consumer rights based approach, to clarify the differences the comparable principles are:

- Eligibility verses entitlement

These are codified in:

- Standards verses rights

The outcome is the:

- Baseline level of service quality verses receiving a service.

UN Convention 2006 – The functions of needs assessment and service coordination influence the degree to which people with impairments can access *“on an equal basis with others,” “facilities and services open or provided to the public.”*

Reviewing the Standards and Guidelines

1. Update out of contextual material - remove cross references to old documents; remove referral to extinct organizations; update policy and work programmes references.
2. Consolidate material – base on 1994/95 documents; combine with more recent material; use as commentary where it enlarges original.

It is a tidy up; using the base of the 1994/95 widely consulted supported, and when reviewed, have found to still be appropriate.

Evaluate them against:

1. The New Zealand ASD guideline
2. International comparatives in similar jurisdictions i.e. standards for the assessment of need (Republic of Ireland); Local Area Coordination (WA, Australia); CMSA National Standard of Practice for Case Management (Australia); Case Management Standards and Certification Procedures (Vermont, USA)

We have looked at the changes in the New Zealand context over the past fifteen years, no conflicts with ASD Guidelines evident. Primary change is the role of the environment in disability, and the role of NASCs in capacity building, particularly in the community of the person with a disability. LACs also contribute to building inclusive communities through partnership and collaboration with individuals and families, local organizations and the broader community.

Identify any gaps:

1. Are new Standards required?
2. Are new Guidelines required?
3. What is needed to clarify existing standards and guidelines?

The review will if required, recommend and implementation process, but not complete introduction as part of this review.

At the end of this session Alison distributed copies of the new 'Residential Support Services Booklet', which has been published. This work was presented by Valerie Smith at the March Consortium. There are more copies available from the Ministry of Health. The booklet has not been released officially as the Ministry of Health is undertaking a plain language version. This is an advance release.

Forums/Hui/Fono Summary Report – Alison Hearn

The Consumer Forums are public meetings held by Disability Support Services of the Ministry of Health. These meetings provided an opportunity for disabled people, their families to tell the Ministry what supports and services are working for them, what is not working and what the Ministry could do to change this.

During March and April this year Disability Support Services held twenty meetings around the country. There were mainstream Forums, Hui on Marae and Fono for Pacific communities.

These meetings provided us with a chance to hear first hand the issues facing disabled people and to share a vision and key priorities over the coming year for Ministry of Health funded Disability Support Services.

The Forums covered four main themes:

- General update on services and projects
- What is working – what isn't working – ideas for improvement
- Issues and concerns of consumers attending the meetings
- Discussion on the strategic priorities for Disability Support Services.

Over 550 people attended the forums, fono and hui. This year the forums were held in the main centres again and were spread to some smaller centres not visited in the last round. Consumers were given a pack of information about the services funding by Disability Support Services, updates on projects and Disability Support Services strategic priorities on arrival. Ministry staff were also able to provide information about Disability Support Services in general, what actions and changes Disability Support Services are taking in response to previous forums feedback, and to answer questions raised at the meetings. The provision of accessible documents was appreciated by consumers. The DVD "With support I can", produced by Disability Support Services last year, was also distributed and well received.

Two key priorities came out of Forums, Hui and Fono:

- Improving our systems to allow choice and flexibility of services
- Respecting and honouring the family/carers/whanau/aiga and involving the disabled person and the planning of services.

Meeting concluded at 4:30pm

DAY TWO – Friday 31 July 2009 Hotel Grand Chancellor

Meeting started at 9:05am

Mathilda Schorer welcomed the group and went over housekeeping matters. An apology was received from Kim Robinson.

Consortium Meeting – Mathilda Schorer facilitating

The main points for discussion were Consortium membership and feedback/evaluation to the Ministry and Consortium members.

A summary of what we have discussed.

Membership:

- Reducing from two to one representative from all organisations on the Consortium might not work depending on the needs of the people from those organisations.
- In the Terms of Reference there are three organisations who have not responded to the invitation to attend so could be replaced with another organisation.
- The membership, numbers and size should be established by the Ministry of Health.
- We should have a better representation of ethnic groups for inclusion.
- Having South Island and North Island meetings – to cut costs.
- The Ministry of Health supplying the members with the number of requests they have had from other organisations that would like to be included. And then feedback from the Federation on what impact including those groups would have on the budget.

Feedback:

- Each member to email Federation / Ministry directly with how they are disseminating information to their groups and feedback on panel or group work they are involved in.
- Half hour session to summarise the key points at the end of each day. And to have that minuted and given to members soon after the meeting.
- Evaluation form for members.

Directorate / DSS Update – Anne O’Connell

Anne introduced herself to the Consortium and gave some of her background which included a wide range of nursing practice; teaching nursing for ten years at the Wellington Polytechnic; and most recently working at ACC in the health/service purchasing area for the past ten years. She has been at the Ministry of Health for three months. Anne’s vision is looking at the role of team she leads, and the job that they are there to do. She is not looking to create something different again, but rather to work with the strategy they have, and the work plan from the select committee, which includes addressing the problems they have with flexibility and choice and looking at new ways of buying services for people. Anne has a lot of experience of what works and doesn’t work with services, and measuring outputs. There is a large challenge for the team who will be working within new budget restraints. Anne acknowledged there is lot of people at this Consortium she needs to meet, and to better understand the issues that are raised here, and is happy to visit organizations to meet their representatives.

Environmental Support Services Update – Sue Primrose

Sue introduced herself to the Consortium and explained that she wanted to run a short workshop about Environmental Support Services, with the members, to get feedback on the Equipment and Modification Services prioritization project that is now underway. She first gave some background information before the workshop.

What is Prioritization?

The legislation the Ministry of Health works within recognizes that the amount of money available for health and disability services is limited. This means that decisions on what services to fund, and how much funding or support the Ministry of Health can assist people with, must be made. There is nothing new about the prioritization idea, simply what can we buy for the amount of money we have?

What happens now?

Prioritisation for Equipment and Modification Services happens already in a number of ways and some of the main ways are:

1. **Eligibility criteria** – you can't get any equipment that costs less than \$37.00 or a housing modification that costs less than \$200.00. This is because decisions were made that people should help themselves and pay for low cost pieces of equipment or modifications.
2. **Income and asset testing** – most people who apply for a housing modification that costs more than \$7,900.00 or to buy a vehicle must have a 'means test'. This test is to work out how much money a person can get from the Ministry of Health, and what they might need to pay themselves. The amount of money they earn (their income) and any big items they own, like a house (their assets), are considered. The reason housing modifications and vehicles are means tested is because of their high cost and people can benefit from them in a number of ways. For example, if a bathroom is improved through Equipment and Modification Services the person may get a better price if they sell the house but they do not have to give any money back to the Ministry. There is no income and asset testing for children less than 16 years.
3. **Priority guidelines** – all applications are given a priority and this is used to decide how long it will be before a service is provided. People who need a piece of equipment or modification to meet essential safety needs have first priority.
4. **Budget Setting** – the amount of money in the budget can determine how much can be purchased by the Ministry of Health.

The current ways 1 – 4 (called the "prioritization framework") is outdated. For example the decision to not pay for equipment that costs less than \$37.00 or a housing modification less than \$200.00 was made by the Government before 1994. Since then the amount of money people earn has gone up and it may be time to increase the amount the government can expect people to fund themselves.

What we want to happen in the future:

Decisions on what to fund should be based on a set of principles. These should be based on what New Zealanders agree is important for Equipment and Modification Services, including what and how much it should provide and to whom.

The Ministry currently has a set of principles and these are:

- Make an effective contribution towards helping people with disabilities to live in their own homes and communities.
- Get good value for money and help disabled people live independently and safely in their homes without relying heavily on their families or carers, or move into residential care.
- Make consistent, fair and equitable decisions
- Recognise that people's needs may change over time and this may influence the types of support they need in the future.

Feedback and Group Work

The meaning of prioritization was discussed i.e. -

“How we make decisions about what Health and Disability Services or inventions for the benefit of New Zealanders within the resources available.”

It's about starting with a principle based approach. From a system wide point of view how should it happen so it is fair and equitable? That we have transparent, open and easy to communicate system so that all people know. How to get the best value for money and also so that it is equitable for all people. We have been looking at what happens in New Zealand and other countries with other services.

There are two parts of the framework that need to be replaced to make it fair and equitable. They are a set of principals and a set of criteria.

Principles for comment:

- Fair, consistent, and equitable
- Ability to benefit
- Effectiveness of what you are getting
- Value for money
- Early investment

Criteria for comment:

- What is most important to you?

Example: Personal safety; carers personal safety, ability to interact with others; ability to undertake roles of life i.e. being a parent, an employee etc; social relationships; leisure.

Questions:

- Are these the right sort of things to be talking about?
- If not, what is?
- What order should your criteria (reasons) be in?

Sue then handed out the principles, criteria and questions to the members, who broke into three groups for discussion, and gave the following feedback:

Group one:

- Principles: person centred is missing from the principles – a lot of discussion around this.
- Criteria: safety needs to be paramount, the consumer and family having input, equipment being included in the bigger picture of the whole assessment and looking at that as a part of not a separate thing.

Group two

- Principles – important to look at the big picture the value of money not always apparent, the bigger picture might reduce costs over the long time; early investment being needed; important for people to advocate for themselves but aware that currently it's the squeaky wheel gets the oil; some cultural groups not speaking up due to culture and language issues and often just take what's offered and not what's right for them.
- Criteria – safety is a not negotiable; can't prioritize the rest as that is an individual decision and comes out of the needs assessment process for other parts of a persons life and so why not for equipment and modifications as well?

Group Three

- Principles – there is no flexibility in the benefit they are broad ideals, not always realistic as your comparing apples with bananas, hard to be fair and equitable as disability is variable between people, sensory disability is always low down on the food chain and is that equitable?
- Criteria – number one should be personal safety and carer safety, we don't believe that carer safety should be funded from this bucket of money; the ability to interact with other people should also include access to information; this was not mentioned but should be included in the criteria, an increase of an individual's independence. Leisure and socialization go together, as they often go hand in hand. Leisure should be acknowledged as important.

Lu'i Ola / National Pacific Plan – Feala Afoa

Feala Afoa came to discuss the draft National Plan – Lu'i Ola and National Pacific Plans.

Strategic direction 2009 and beyond:

Stage One – Development Implementation 2007 – 2009

Stage two – Action Plan – 2009 – 2013

- Priority one: Performance improvement and development July 2009 – June 2010.
- Priority two: New innovations July 2010 – June 2012
- Priority three: Transition July 2012 - June 2013

Stage Three Community Action and Ownership 2013 and beyond

Strategic Direction:

Our vision is for:

‘A community based regionalized strategic group composed of Pacific leaders with disabilities, Pacific community and Pacific service provider representatives’.

Actions to achieve this include:

- Establish a formalised group endorsed by government agencies, disability sector and private sector.
- Coordinate and oversee development and improvement of services across government agencies, community groups and the private corporate sector.
- Develop regional Pacific disability innovations for government agencies, disability support services and businesses.

Current Status of Plan

- Draft document.
- Signed off internally.
- Currently undergoing through a focused external feedback process with selected stakeholders.
- Resubmitted internally for final sign off by end of August 2009.
- Implementation early September 2009.

New Draft LU'I OLA (Auckland) Pacific Action Plan 2009 – 2013

This work has been underway since 2007. There is now a new action plan to take us to 2013:

Vision

To contribute to the achievement of the Disability Support Services vision with a particular focus on improving outcomes for Pacific peoples, their aiga and caregivers.

- A support system that can respond to individual's different needs now and into the future.
- A capable and reliable disability support workforce.
- Strong and supported families and whanau and informal carers.
- Information and advice that is useful for people with disabilities, and helps to improve disability support services.

Phase One

Performance improvement and development:

- Structure and Governance
- Project management

- Current Initiatives
- Assessment of effectiveness (evaluation)

Phase Two 2010/12

New innovations:

- Leadership
- Community action
- Research
- Current Initiatives (roll out)

Phase Three 2012/13

Transition:

- Pacific disabled peoples lead planning and support implementation of transition with support of Lu'i Ola agencies.

Current Status

- Steering Group signed off plan in principle on 29 July 2009.
- Implementation of activities 2009/2010.

Pasifika Disability Action Plan 2009 – 2013

Priority areas of focus and outcomes we expect:

Workforce development:

- Disability support work as a desirable career pathway for Pacific peoples with disabilities, their aiga and also members of Pacific population.
- Cultural competencies for the disability workforce.
- Pacific disability workforce innovations.

Provider Development and Sector Capability:

- Annual provider forums
- Implementation of Lu'i Ola initiatives.

Leadership:

- Pacific Leaders with disabilities.
- Representation of Pacific leaders with disabilities at governance and policy level, service development.

Community Action:

- Engagement models with Pacific community and Pacific peoples with disabilities.
- Annual disability community and provider events.

Information and Communication:

- Specific ethnic specific information with appropriate formats in Pacific languages that is accessible.

Workforce and New qualifications – Rob Gill

Rob presented an update to the members on the workforce action plan.

Workforce Update July 2009

rob_gill@moh.govt.nz

Phone: 09 580 9111

DSS Workforce Action Plan: 2009 – 2014

- Drafted in 2008
- Incorporates advice from the workforce reference group
- Developed with extensive consultation
- Is the basis for DSS workforce development
- Was a deliverable under *Statement of Intent 2008/09*
- Emerged from the current DSS Strategic Plan

The Plan

- Responds to strengths and weaknesses
- Focuses on solutions
- Builds on solutions that are working

Benefits

- Enables planning from now to 2014
- Establishes priorities
- Guides resource allocation
- Focuses on front line workers
- Links to other work e.g. DHBNZ

Aim

To provide career paths for the disability support workforce to improve the status of disability support work by retaining and recruiting skilled workers who will support disabled people according to the spirit and intent of the New Zealand Disability Strategy.

Phase One (begins now)

- Build a training framework with career pathways and agreed competencies
- Make training more accessible
- Support informal carers to work safely
- Innovate to promote and reward excellent performance
- Create more financial certainty for providers

Phase Two

Make disability support work more attractive for:

- People who have disabilities
- Maori
- Pacific peoples

Identify and promote the aspects of disability support careers that attract people to work in the sector. Build additional leadership capability in the disability work force – including informal carers.

Phase Three (long term)

- Develop better funding methods so the workforce becomes and remains competent.
- Boost the supply of disability support specialists to provide support to people with disabilities and providers of services.
- Ensure health professionals are trained to provide services to people with disabilities.
- Ensure that workforce databases incorporate data for the DSS workforce.
- Make disability support work more attractive for informal carers.
- Adopt the *National Guidelines for the Promotion of Healthy Working Environments* (HWAC 2006).

The Plan Demonstrates:

- Our intention to be leaders in workforce development
- A commitment to work with the sector
- That priorities will drive resource allocation

The Training and Leadership Fund (new name?)

Aims to foster leadership by disabled people within the disability sector, so that people with disabilities confidently manage their own supports. (Launched as a one-off funding opportunity in 2008 -2009.)

Services in 2008 /09 were provided by:

- Deaf Aotearoa New Zealand
- CCS Disability Action
- Standards Plus & Up2date
- SAMS
- People First Christchurch

Plan to extend the fund for 2009/10 subject to available funding.

Proposals will be invited in 2009:

Watch the GETS (Government Electronic Tender Service) website and listen for news from the Consumer Consortium Secretary.

Proposals will need to:

- Either train or develop people with disabilities to confidently manage their own supports or develop leadership skills in the disability community
- Include solutions to challenges of nationwide access
- Have a start and end date (between 2009 – June 2010)
- Involve disabled people in service design and delivery

Questions to the Consumer Consortium:

- Is there anything else this fund should seek to achieve? Do we need to broaden or narrow the scope?
- Are there priority areas?
- Are there any 'no – go' areas?

Communications and the new texting service – Julz Britnell

Julz presented to the members on a new texting service.

There was feedback from the Forums was that there was no text number, so we are trying to address what consumers have requested.

Disability Support Services has a texting service available for use run by TiXT. We have a domain name called DSD. When someone texts our dedicated number they get an automatic reply based on what they sent. We have sixteen possible automatic replies that we programme in ourselves. One is called a 'wild card' which accepts any words that come in, the other fifteen can be set up with whatever questions/answers we want. We can change them whenever we like depending on what project, meeting, information we want to promote at the time.

How does it work?

Someone texts (dsd dot keyword) to 4664 and they get an automatic reply sent back to them. This reply is pre-programmed by us depending on what the likely questions/comments are. The texts sit in a mailbox hosted by TiXT. When a text arrives in our mailbox a notification is sent by TiXT to our

disability email saying we have a text and then we can login to look at it. This option is useful for anyone who sends a text that is not one of our pre-programmed options. In this case we can formulate a response and send it back via email as a text to the person. Texts are limited to 100 words.

Upside

- It would be useful when advertising things like forums.
- It is another way for people to get information.
- We can change information depending on what we're promoting.
- "Wild card" captures any questions outside the pre-programmed ones.

Downside

- It is not a free service, texts cost twenty cents
- We are limited to 15 questions and answers at a time

Why is it not free?

For it to be free the Ministry of Health needs our own exchange server for texting which we do not currently have, is expensive to buy, requires a telecommunications infrastructure (like telecom/Vodafone etc) and isn't possible for an organization such as ours.

Feedback from members:

- If you put in a keyword you might not get the answer you're are looking for and cause frustration.
- Different languages?
- The cost for the younger generation will not be an issue
- I see if being a subscription service for updates on events and where and how to access information. I see this as the next big thing for access.
- Regarding Pacific Community, communication might be a problem. A benefit for the younger generation, but perhaps not so much with the older generation. Where does the twenty cent charge go to? (it's the TiXT service who get that, as they are charged by Telecom or Vodafone for using their infrastructure)
- Local NASC details

Consumer Organisation Presentations: People First/PIASS Trust

RNZFB has asked if they can present at the next meeting.

People First Presentation

People with learning disability speaking up for ourselves. Nothing about us without us!

People First are in many countries around the World:

- It started in Salem Oregon in America in 1974.
- The name came from people with intellectual disability saying “We are people first!”
- It is in many countries around the world like England, Scotland, Australia, Canada and Germany.

People First in New Zealand:

- People First started in NZ in 1984.
- It was started and supported by IHC for the first 20 years.
- In 1984 at the National People First Conference, members said “we want our own organization and to become independent and to have a national committee and our own national office.”
- In 2003 IHC supported People First to become an independent organization.
- On the 16th October 2003 People First launched the independent organization at Parliament and then we had a party!

Meeting new people:

- People First is a good place to meet new people.
- We talk to other disabled people.
- We talk to people who work with people with a learning disability.
- We talk to people in the government.

Speaking Up:

- This is about being brave enough to speak up and tell people what you want in your life.

- At local meetings you will get support to talk about things you want in your life.
- You might hear about things that other people are doing and want to try them!

Speaking Up Courses:

- The Christchurch Group has been holding Speaking Up Courses.
- Members from the Christchurch People First group are teaching other people with learning disability to speak up.
- The course is run during the day and people who use community participation services are going to it
- People First is working out how we can offer this course throughout New Zealand.

Having Fun:

- We have fun celebrating our successes at People First.

Tuhonohono Working with Maori:

- People First has our own Cultural Advisor.
- In 2007 the National AGM was held at Omaka Marae in Blenheim.
- The National Committee said they want to hold National Annual General Meeting in the future at Marae.
- People First is working with other disability organizations to make sure that we work well with Maori.

Learning How to become a leader:

- At People First meetings you will get the chance to take part; learn in a safe place; know that it is OK to make mistakes; get the chance to speak up and have your say.

Connecting with your local community:

- When the group gets confident you can talk to people at places like the City Council and your local Politicians office.
- You can put People First pamphlets out and about in your community.
- Talk to other people who might like to join or help out at or with People First.

People First DIAS:

- This service is for people with a learning disability and anyone else who wants to find out information about learning disability.
- Information about where and how you live, getting a job, where to get support and how to get involved in things you want to do.

- Call us between 8:30am and 4:30pm on our free phone number and it won't cost you any money! 0800 20 60 70.

PIASS Trust Presentation

PIASS Trust is Pacific Information Advocacy and Support Services Trust.

PIASS Trust

The National Pacific DIAS service that is:

- Centred around, and directed by, disabled people
- Promotes and actively encourages clients to maximize their independence, autonomy, interdependence
- Acknowledge and values the involvement of volunteers, family/whanau, and employees, in the planning and provision of support.

Organisational Background:

- Operating since 2001, providing services to the wider Auckland Region from its office in South Auckland.
- Governed by Pacific, for Pacific Disabled Peoples.
- Currently the lead NZ Pacific disability provider of Information, support, and advocacy services for Pacific disabled peoples, providing services to in excess of 2000 Pacific people with disabilities.
- Certificated with Quality Health NZ 2007.
- Incorporated with Malologa Trust known as VAKA TAUTUA December 2007.
- Branches in Auckland, Christchurch and Wellington.
- Staff: 3 in Auckland, 2 in Christchurch and 2 in Wellington

Pacific Health and Disability Action Plan (2002)

Key Points:

- Builds on the NZ Disability Strategy.
- Strategic direction to improve the health outcomes and participation of Pacific peoples.
- Reduce inequalities between Pacific and non-Pacific peoples.

Priorities:

- The Plan Highlights 6 priority areas where improvements can be made to health and disability services.

Priorities

1. Pacific child and youth health (0-14 & 15-24 years).
2. Promoting Pacific health lifestyles and wellbeing.
3. Pacific primary health care and preventative services.

4. Pacific provider development and workforce development.
5. Promote participation of disabled Pacific peoples.
6. Pacific health & disability information and research.

Pacific Peoples in New Zealand (2006)

- 265,974 or 6.9% of people in NZ were Pacific, projected to reach 420,000 by 2021.
- Demographic: Samoan (131,103), Cook Island Maori (58,008), Tongan (50,481), Niuean (22,476), Fijian (9,864), Tokelauan (6,819), and Tuvaluan (2,628).
- Approximately two thirds of Pacific peoples live in the Auckland region.

New Zealand Pacific Disability Situation

- One in seven Pacific people has a disability.
- Pacific boys (0-14yrs) are more likely to have a disability than Pacific girls.
- Disease or illness is the most common cause of disability for Pacific peoples.
- Pacific adults with disabilities are less likely to be in the work force than Pacific adults without disabilities.

The Reality

- Over half (53 percent) of all disabled Pacific people are reported as having more than one disability.
- Physical disabilities were the most common type of disability reported by Pacific people.
- Fifty six percent reported having a physical disability (15,600).
- 'Other' disabilities were the most common type, affecting forty two percent.

Where to from here?

- Priority 4 goal 5.5: Support disability workforce development and training for Pacific peoples.
- Priority 4 goal 5.6: Support establishment of new Pacific disability services.
- Priority 5 goal 6.1: Increase access to and quality of disability support services.
- Priority 5 goal 6.2: Encourage Pacific communities to consider disability issues and perspectives.
- Priority 6 goal 7.5: Undertake information collection and research focusing on disability issues for Pacific peoples.

Conclusion

Venue for next meeting: Wellington

Facilitator for next Consortium: Ngaire Wycliffe to be asked.

Next Consortium: October or November, dates to be confirmed

Meeting closed at 4:30pm

**CONSORTIUM ACTION POINTS
July 2009**