

**CAPITAL AND COAST DISTRICT HEALTH BOARD
DISABILITY SUPPORT ADVISORY COMMITTEE (DSAC)
COMMUNITY FORUM & WORKSHOP
HELD IN THE LINDEN SOCIAL CENTRE
10 COLLINS AVENUE, LINDEN
ON WEDNESDAY 12 NOVEMBER 2008 AT 10.00AM**

PRESENT:

Chair, DSAC

Dr Judith Aitken Board / DSAC

Board Member

Ruth Gottlieb Board

DSAC Members:

Helene Ritchie Board / DSAC Margaret Guthrie DSAC

Margaret Faulkner Board / DSAC Nathan Bond DSAC

Hilary Stace DSAC Tavita Filemoni DSAC

Judy Small DSAC

Facilitator

Matthew Frost President, DPA Wellington

Coordinator

Maurice Priestley Inclusion and Disability Advisor

NZ Sign Language Interpreters

Alan Wendt Rosie Henley

Health and Support Service Personnel and Members of the Public

Vandy Pollard	Advocacy Network Services Trust	Taima Fagaloa	Porirua Healthlinks Trust
David Darling	Capital Support	Annette Bridgen	Regional Health Advisor ,
Vicki Kennedy	Capital Support		Work and Income
Alison Hannah	CCDHB	Anna Bishop	RNZFB
Jenny White	CCDHB	Charlotte Bergman	RSA
Marian Tobin	CCDHB	Susan Millington	Ward 6, AT&R
Sandra Williams	CCDHB	Sinead Roe	WCC
Shereen Moloney	CCDHB	Vicki St Clair	Wellington City Mission
Wayne Skipage	CCDHB		Wellington Institute of Technology (WelTec)
Stella Thorp	Child Development Team	Rebecca Burns	Work and Income
Ian Brown	Crown Monitor		
Christine Bongiovanni	Disability Information & Equipment Centre	Nimue Cavanagh	
Derral Barnes	Hearing Association Wellington	Catherine Gregory	
	Hunt Healthcare Ltd	Gayle Cullwick	
Karen Bolton	Mary Potter Hospice - Porirua	Helen Bichan	
Chris Murphy	MASH Trust	Rhonda Heather	
	NZCare Group	Tania Reti	
Ian Cowie		Tricia Caughley	
Donna Mitchell			

APOLOGIES

Virginia Hope	Board		
Selwyn Katene	Board / DSAC	Jules Taniwha	SECPHO
Liz Melish	DSAC		
Wendy Proffitt	IHC advocate	Rosanne	Te Korowai-Whariki
Stuart Parkinson	PCC	Johnston	

WELCOME

Dr Aitken welcomed everyone and thanked them for attending. This forum is a valuable part of capturing people's thoughts on the issues. Dr Aitken encouraged participation and advised that their input would be used to help inform the C & C DHB's work in this particular area.

Both Dr Aitken and Maurice Priestley expressed appreciation to Matthew Frost for his availability to facilitate the meeting. Matthew's involvement with DPA Wellington and CCS Disability Action and his understanding of the issues raised with the Social Services Select Committee during the Inquiry into the quality of care and service provision for people with disabilities would provide a good base for the workshop.

PRESENTATION FROM MATTHEW FROST

The Select Committee Inquiry

- What Could It Mean for CCDHB?

1. Some Recent Context...

1. Election 2008
'Times they are a changing...'
2. National / ACT / United Future Coalition Government. (with possible support from Maori Party) = 70 seats in Parliament.
3. Labour / Green/Progressive = 52 seats.
4. Position of Disability Issues unclear under new Government.

2. Background to the Inquiry

1. 2005-2006: Spectrum Care and Focus 2000 accused of ill treatment and mismanagement.
2. Paul Hutchison (National Disability Issues Spokesperson) calls for Inquiry.
3. Resistance from Government, but majority of Social Services Select Committee agrees in May 2006.
4. Wide Terms of Reference
5. Current Service Provision.
6. Standards of Care.
7. Advocacy, Complaints and Accountability.
8. Training
9. New Zealand Disability Strategy and its place in Disabled People's wellbeing.
10. 150 submissions heard over two years.
11. Final Report Released in September 2008.

3. Policy Context

1. Significant Developments.
2. 5 year review of Disability Strategy
3. Work on review of Long Term Disability Supports (both conducted by Office for Disability Issues)
4. Signing and Ratification of United Nations Convention on Rights of Persons with Disabilities
5. Award to New Zealand of the Franklin Roosevelt Prize for Disability Issues

4. Recommendations

22 recommendations.

Most significant:

- An "appropriately funded lead agency" (or Disability Commission within 6 years)
- Appointment of an "independent disability commissioner"
- A move towards a 'Local Area Coordination' (LAC) model of disability information

provision (unclear if going wider)

- More choice for disabled people about funding (individualised funding)
- Expand advocacy and ensure that audits of service focus on “quality of life and opportunities.”

5. An explanation...

- LAC will become an increasingly important concept in disability service provision
- LAC and Individualised funding NOT one and the same
- Elements of LAC
 - Co- Governance
 - Based in local area and on quality and closeness of relationships
 - Key goal: Leading a good life
 - Not impairment specific. Combines advocacy and service provision based on individuals requirements
- Matt happy to explain more if needed

Conversation Starters

- *Board to be commended for being proactive around Inquiry? Or other things to sort first?*
- *Emphasis on quality (or lack of!) of relationships and systems within report How is CCDHB doing on this?*
- *What service provision issues exist for the Board and DSAC?*
- *How do we as Disabled people see the Board's relationship with the NZDS and 'New Lead Agency?'*
- *What do we think LAC could mean for the Board and DSAC?*
- *How can this Inquiry (and the conversations today) improve the implementation of 'Promoting Participation' and the Board's Strategic Plan?*
- *Please feel free to explore other related questions!!*

The participants then broke into groups and spent the next 45 minutes discussing the issues, and making notes for the Feedback session at 11.45am.

The Feedback Session

Four groups reported back to the Forum. Information was recorded on paper and tape for further review.

The Notes are attached as Appendix 1.

Steps Forward

Matthew thanked all the participants for their contributions to the Workshop. There was a diversity in knowledge and experience in the group which is to be celebrated.

The Feedback will be used to inform DSAC and the Board and to help formulate the process going forward. The challenge for all is to make it work. Systemic change is required. A good mix of these issues are immediate.

There will be a Government response to the Select Committee report within 90 days, so it will come out early next year.

Dr Aitken advised that the material will be written up (by Christmas) and will be circulated to you all somehow. (Participants' contact details have been recorded.) The March DSAC meeting recommendations will go to the Board's first meeting in April 2009. From there a paper will be prepared by the Department (MOH) for tabling in Parliament.

Dr Aitken thanked the participants, Matthew Frost, C&C DHB Staff and the Interpreters and closed the meeting, reminding all that the aim was “A Good life – everybody has a life worth living”.

The Forum closed at 12.15pm.

APPENDIX 1

Feedback from DSAC Community Forum
Linden Social Centre, Linden, Wellington
10.00am to 12 noon, 12 November 2008

GROUP 1

- **Rehabilitation Coordination**
 - Maintenance
 - Wrap around services
 - * Service coordinators
 - Need for long term rehabilitation
 - * When needed by person not specified by the service providers etc.
- **Dependent on person to recognize their situation or crisis intervention only**
- **GP's have huge impact**
 - They can create a barrier to further assistance or intervention by saying "no" to other services
- **How can we avoid injuries etc becoming disabilities?**
- **Discharge planning requirement -**
 - needs to be started earlier in the process prior to leaving the hospital - not on the day of discharge - where is this person going to? Is the environment safe? Will there be help there?
 - Follow up care and prevention care
- **Specialist people in DHB for point of admission or discharge -**
 - someone who can follow the person through their process - to ensure their needs are met, arranged for, taken care of
- **Utilising MDT's**
- **Encouraging inter-sectoral work**
 - Inter-sectoral relationships a key - (MSD, MOH and disability services etc)
- **Communication issues (people with disabilities and service providers)**
 - Knowledge of how to access
- **Being more pro-active sooner through lead agencies**
- **LAC a good starting point**
 - Good principles
 - * How would it work in big metropolitan cities
- **Promotion of leading a good life**
- **Have routine check-ins to avoid crisis arising**
- **Needs assessments are paramount**
 - * Having that face- to face contact
- **Knowledge of other services (LAC to provide??)**
 - * Having excellent knowledge of area
 - * Strong link between LAC and Lead Agency

GROUP 2 (Hilary's Group)

- **NASC accountability for funding**
 - Put individual with a disability first, (Dignity of risk)
 - then providers
- **Funding is needs focused / deficit, not on potential**
- **Network to start with people with disability and move outwards**

- **Inadequate funding for under 65s**
 - **Need assessment form to be reviewed**
 - **Transport costs to be included**
 - * **Glaring gaps**
- **Peak body group currently being proposed - IHC; CCS?**
 - **Confusion about Lead Agency... co-governance is critically important**
 - **Open relationship with DHB**
 - **Whole of life focus, not health focus**
- **Select Committee recommendations don't apply to DHB level**
 - **How can DHB affect MOH policy? Who advocates?**
 - **More input from front line workers UP thetree ***
 - **More consumer involvement on CCDHB committees.**
 - * **Includes families**
 - * **= co-governance**
- **NASC to be more transparent, tell people what money supports their package.**
- **Improve local coordination -**
 - * **Linking with eg local Min Social Development and Min of Education**
 - * **LAC - coordination, monitoring and accountability?**
- **Need discussion of Lead Agency function**
 - **What power**
 - **What funding**
 - **Who decides?**
- **MOH Failure**
 - **to lead**
 - **to ensure accountability**
- **Do Ministries talk to each other? Education, Health and Social Development?**
- **DIGNITY OF RISK is compatible with UN Declaration**
- **Transition of health care services**
- **Inadequate health care funding and coordination of services through out person's life. [Child Development Team stops at 16 - should be extended till a person leaves school.]**
- **Disability Commission should be external to HDC**
- **Separate Minister of Disability INSIDE Cabinet**

GROUP 3 - (HELEN'S)

- **Legislation to address ability to complain about access to services**
- **Fragmentation of current services**
- **Need for generic tool suitable for use across services (ICE)**
- **Resourcing issues can create barriers to access**
 - **Young people in Aged Rest Homes**
- **Resources are limited so prioritizations of needs in needs assessment process is essential**
- **?Disability Commissioner could action gaps in services**
- **No registration process for caregivers /checks difficult to carry out**
 - **Care givers can move around the rest homes etc without work history following**
 - **Not a transparent (recruitment/appointment of workforce) process**
 - **Remuneration is also an issue**
- **Ratio of skilled/unskilled staff in facilities**

- Agency/ facilities may not always be transparent when dealing with issues (serious) due to fear of repercussions
- Discharge planning needs to commence early in clients admission so that housing modifications/aids can be in place prior to discharge
- All level of supports could be available to others (eg ACC)
- Appropriate consequences for service providers for non-provision

GROUP 4 (HELENE'S)

Expertise:

**Disability Information and Equipment Centre owner
Weltec Disability
Consumer
Board member**

Issues:

1. ACC - timeliness of application
2. Health * provision
3. under 65s respite care **VERY MAJOR NEED**
4. NO choice, No informed choice
5. ACC - referred to Occupational Therapy - takes ages – timeliness of process
6. NASC - people don't fit into boxes - criteria for help
- commonsense not allowed
7. People should get what they need - LAC
8. People don't know what questions to ask or what help [is available] from organisations
9. Advocates / needed local area coordination - navigation needed
10. Coordinators - don't know where to start
 - a. Second hand equipment
 - i. Equipment centre - sells equipment - who provides
 - ii. Provision at cost price
 - iii. Hire out
 - iv. Assessment needed
11. Kapiti - distance to help
12. Coordination of specialists to come to Kapiti
 - a. Cost effective
 - b. Efficient
13. Age appropriate services
14. Respite care - Never anywhere to go - elderly people are mixed with the young
15. Carer Scarcity, Relief carers scarce
16. Carer:
 - a. Pay
 - b. Contracts of service
 - c. Training
17. Education and Qualifications
 - a. National Certificate of Community Support
 - b. WELTEC - Risk Management Plans / Advocacy
 - c. Disability Information provision - career
 - d. National Executive Disability Centres -
 - i. Certificate
 - ii. Diploma
 - iii. Degree
 - iv. In workplaces...

18. Kapiti -

- a. highest over 65 population
- b. high numbers of people with disability

19.2 years -more buildings, more respite

GROUP 4 CONTD...

The 2 minute 2 year Plan - Requirement on the Board

- Respite
- Appropriate new buildings / places [of caring]
- Disabled accommodation / housing
- All audits / publicly released reports, within 6 months
- One Stop Shop -
 - a service centre which coordinates and gives information about services
 - central point
 - care coordination centre needs to be broad
 - use volunteers - ie disabled people who can't get work
- Local area service coordination - run a pilot?
 - To eventually replace NASC
 - Central point to integrate services and voluntary organisations
 - And information
 - Advocates/ coordinator needs
- Age appropriate placements - providers
 - Including young dementia
 - ▣ Degenerative diseases, and neurological illnesses eg
 - Eg multiple sclerosis
 - Motor neurone
 - Parkinson
 - Brian injury
 - Huntingtons -

APPENDIX 2 – Evaluation Responses

Capital & Coast District Health Board Disability Support Advisory Committee (DSAC) Community Forum and Workshop, 12 December 2008

Summary of responses:

3 Evaluation questionnaires were collected after the forum.

	Very good	Good	Average	Poor	Very poor
Information and notification of the Forum	2	1			
Suitability of the venue	3				
Facilitation	3				
Ability to participate	3				
Organisation and planning	3				
OVERALL rating	3				

What did you particularly value?

- Collaboration
- Discussion
- Notion that opinions will be valued
- The opportunity to discuss with a wide range of representatives – opportunity to inform the board
- Ability to link with other agencies and hear their views / experience

What could we have done better?

- Read the report before attending
- Knowing what LAC was
- An indication on prior reading of LAC – new idea – would have liked more info.
- N/A

Other comments?

- Valuable knowledge gained
- Thank you – great 2 hrs – worth coming!