

**Summary of the Disability  
Support Advisory Committee's  
Community Forum  
12 March 2008**

**Capital & Coast District Health Board**

**28 April 2008**

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# 1. Executive Summary

Capital & Coast District Health Board (C&C DHB) developed *Promoting Participation – Kotahi Tātou* as a document to guide the delivery, management and governance of health and disability services, and ensure services align with the principles of the New Zealand Disability Strategy.

The C&C DHB Disability Support Advisory Committee (DSAC) invited community members to attend a Forum on 12 March 2008. Participants were asked to share their experiences of C&C DHB funded health services, and to provide guidance on the future direction of *Promoting Participation*.

Overall, participants commended the committed and passionate individual C&C DHB staff who have an excellent understanding of the New Zealand Disability Strategy, and a willingness to deliver appropriate and quality service to disabled people. However, participants' experiences indicate more work is required to achieve *Promoting Participation's* vision of equitable access and use of general health service. The latter is to be expected, given the relatively short time period in which *Promoting Participation* and the New Zealand Disability Strategy have existed.

Based on participants' experiences of general health services funded by C&C DHB, the following are participants' future priority areas for *Promoting Participation* over the next four years:

- v Disability competency training for staff with a particular focus on improving the discharge process.
- v Physical access with a focus on accessibility of buildings and the accessible transport.
- v Communication in making visible hidden disabilities such as hearing impairments, and using technology to ensure effective communication and access to information.
- v Ongoing active participation of disabled people in C&C DHB's policy direction and decision-making to achieve the vision of *Promoting Participation*.

While not currently explicit in *Promoting Participation*, participants expressed a need for enhanced interagency communication,

**coordination and collaboration to ensure disabled people have access to appropriate supports and funding to meet their short-term and long-term needs.**

## 2. Introduction

### 2.1 Background

Developed in 2004, *Promoting Participation – Kotahi Tātou* guides funding and delivery of health and disability services in C&C DHB. It sets objectives and priorities for implementing the New Zealand Disability Strategy at every level within C&C DHB.

*Promoting Participation's* vision is:

*“People can equitably access, use, and work in C&C DHB funded health & disability support services”*

*Promoting Participation* outlines organisation-wide action to identify and eliminate barriers to participation by disabled people<sup>1</sup> across five priority areas:

- v Disability competence training.
- v Physical access.
- v Communication and access to information.
- v Employment opportunities.
- v Community/ consumer engagement.

*Promoting Participation* had an initial lifespan of three years – 2004 to 2007. It is timely therefore to reflect on *Promoting Participation* and consider the ongoing relevance of its objectives and priorities, which guide C&C DHB to identify and eliminate barriers to participation by disabled people.

To facilitate this reflection, the Disability Support Advisory Committee (DSAC) invited members of the community and healthcare professionals to attend a forum to provide input and guidance on the future directions of *Promoting Participation*.

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<sup>1</sup> Reflecting the New Zealand Disability Strategy, the term disabled people has been used throughout this report.

## 2.2 Forum purpose and structure

The *Refocusing Promoting Participation – Kotahi Tātou Forum* was held in Wellington on 12 March 2008.

The overall purpose of the Forum was to understand the experiences of disabled people participating in the health services funded and managed by the C&C DHB. Through understanding disabled people's experiences, the future objectives and priorities of *Promoting Participation* will be jointly determined.

In designing the Forum, DSAC sought to address criticisms of previous Forums, which were perceived as presenting C&C DHB's perspective to the detriment of the voice of disabled people. In this context, the objectives of the Forum were to:

- v Listen to participants' stories and experiences of the health services funded by C&C DHB to understand what has improved and to identify ongoing barriers.
- v Identify future directions for *Promoting Participation* in seeking to remove access barriers and improve communication with disabled people.

Appendix one contains the Forum's agenda.

Appendix two presents the story telling technique.

## 2.3 Attendance

In total, 38 participants attended the Forum:

- v 21 participants represented a wide range of disabilities and facets of the community including consumers, Alzheimer's Society, Barrier Free NZ, Capital Support, Wellington Hearing Association, L'Arche Kapiti, Phobic Trust, Porirua Union and Community Health Service, RSA, the Disabled Persons Assembly (DPA) Wellington.
- v 10 participants were from C&C DHB.

- v Seven were members of the DSAC committee.

The Forum was facilitated by Liz Smith and Sally Duckworth from Litmus.

Appendix three contains the attendance list.

## 2.4 Report purpose

This report documents participants' discussions and feedback. This information will be primarily used to inform the future direction of *Promoting Participation* in relation to its objectives and priorities.

It is also intended the stories of disabled people's experiences of the C&C DHB will allow others to understand the realities of disabled people in seeking to participate in general health services.

In preparing this report, Litmus undertook a thematic content analysis of participants' feedback as recorded at the Forum.

The report is structured as follows:

- v Disabled people's stories of their experiences of participating in C&C DHB general health services.
- v Key issues in participating in general health services framed against *Promoting Participation's* five priority areas.
- v Participants suggested prioritised areas indicating their preferred future direction for *Promoting Participation*.
- v Participants' feedback on the Forum.
- v Recommendations for C&C DHB.

## **3. Disabled People's Experiences of C&C DHB**

### **3.1 Introducing story telling**

**This section presents the experiences of disabled people and staff in their words.**

**Story telling was used to enable participants to share their experiences of general health services funded and managed by the C&C DHB. These documented experiences offer a rich insight into the realities of disabled people's lives and a sense of whether services are getting better, staying the same, or getting worse.**

**The six stories presented offer a range of perspectives including disabled people, families, whānau and other people who provide support to disabled people and C&C DHB health professionals. The stories are presented as they were told with some minor editing.**

**Participants have reviewed and given their consent for their stories to be presented in this report.**

### **3.2 Story on physical access**

**My story is about houses that are provided for crisis respite, planned respite and transitional houses provided by an organisation called Easy Access Housing.**

**It is almost impossible to get into the houses, and once you are in none of them are accessible. If you can get in the front door, then you have the problem that you can't get into the shower easily. For me, that just means they are totally inaccessible.**

**The easy access housing where I currently am, I have to get over a bath to get in a shower. I was told if they had known that I had a physical disability as well as a mental disability, that they would not have taken me in.**

**All I am asking is to make it possible to get into the shower there, I don't want them to have to do massive reconstruction – just a couple of hand**



holds and a board across the bath so I can sit down and swing my legs in, so I can then stand up to have a shower. They tell me if they have to do that it is not independent living, and they expect people to live independently in their houses. I was taken aback.

I talked to Capital Support and they are prepared to provide me with an hour a week of house support. They said, I want far more than everyone else for housework a week. They want to decide what they want to do, not me, and it has to suit their time.

One of the solutions, I came up with was that before they actually take over houses, there is discussion with the Department of Building and Housing or Housing New Zealand that it is what they need and that they are accessible.

I would like to see monitoring of those housing services to ensure that they are accessible. How can you put the Disability Strategy into place if that's not the case? It is a major problem for all sorts of other services purchased by DHBs and government departments that they are often not accessible. It's not safe, it means people can't get there, and you are locked out of services.

I broke my arm last year, and I have a physical disability. I was left sitting in a toilet in a bathroom for an hour on three occasions because I have low blood pressure and I couldn't stand by myself. That was because a nurse had an attitude problem about my disability and said my physical disability was a manifest of that. It feels awful.

### **3.3 Story on accessible journeys**

My bugbear is the shuttle service between Kenepuru and Wellington hospitals. It seems to be set up more for staff than clients. It's meant to be for clients. But I have seen people with disabilities get off the shuttle because staff have booked and the clients haven't, because they didn't know about the booking or the booking got lost. They have waited long periods of time.

It has been used as a free service for people who don't have disabilities or aren't connected with the hospital. From a rehabilitation point of view, there are services you can only access in Wellington e.g. woodwork that we use for people who have had a brain injury, stroke or

returning to work. For people who live in Kenepuru, they can't access these services, if they can't get on the bus independently, even if they can get to the hospital and get booked on the shuttle, which is quite frustrating as a therapist.

There are also services in Kenepuru - like a body weight supported treadmill - which is a proven intervention to help people who have had a stroke to help with weight bearing and mobility. It is sitting out in Kenepuru but can't be used by people from Wellington in a wheelchair unless a therapist can get them in a DHB car. Relying on taxis, trains and buses isn't viable because of how Wellington is set up. It is financially taxing and costs a fortune which financially disadvantages people. It is frustrating as a therapist not being able to utilise services for people who need it.

### **3.4 Story on taking a disability perspective**

I have four different hidden disabilities, and I often end up in hospital as an outpatient at various different places. Mental health services are trying to fix people's disabilities but you can't fix them. For people like me, we are actually being made to feel responsible for our disability. I am trying to figure out how to change that. We need these services to know that it's not going to change.

In terms of employment, I have intersectoral action with Work and Income, Ministry of Health and three DHBs trying to fix the problem to get me into full time work because they are going to fix people who are on an Invalids Benefit. The health sector is making people responsible for changing. I mean that's how it comes across - really underhanded.

They are not actually providing a palliative service and people with disabilities are not going to go away. At the moment, I don't have access to planned respite under Mental Health, I don't meet the criteria to be treated under the secondary or tertiary mental health services. I don't qualify. If you are in primary care, you need service coordination, with your GP.

The other issue that I get involved in is supporting people from time to time. At the moment, we are working with someone in an Easy Access house. They want their floors to be mopped and carpets vacuumed

twice a day. Capital Support will only give this person two hours support a week because that is what would normally happen in a home.

The Easy Access housing hold the contract with the DHB, this particular house was supposed to be modified for people with disabilities. The Board is not actually monitoring its contracts. This person has been told they are not going to do the modifications. There are a lot of people who are trained in mental health support who have this idea that you need to be super super clean in terms of doing housework rather than actually getting out into the community and participating in things.

### **3.5 Story on cost barriers**

My story regards older adults who are more likely to have a sensory disability, such as vision and/ or hearing loss. Access to services within public system is distinctly limited and takes time. The process of being sent from one part of the system to another becomes particularly cumbersome, especially if subsidisation for the necessary aids, e.g. hearing aids or glasses, is required.

At a recent meeting of Age Concern, there was the case of one old man, just on National Superannuation, needing a hearing aid. After the cumbersome process of being passed from one person to another, and it all taking time, he found that \$1,500 was required, before he could get the aid, so he turned it down. So his disability was not helped and therefore he withdrew.

There are parallel stories concerning oral health when older fillings deteriorate, when one comes from a generation that tends to have a mouth of amalgam fillings. They don't last forever, so the options are do you have extraction and nothing else, or do you have a crown which at least costs \$1,000? Too many are choosing extraction leading to decreased ability to chew food and subsequent dietary restriction. One sees mouths minus teeth too often. I see Māori and Pacific elders with these holes - a mouth without teeth.

### 3.6 Story on identifying hidden disabilities

I am sharing stories mainly of people who are in hospital and can't hear what they are being asked by the medical professionals. These people are often diagnosed as having dementia just because they can't hear. They might have had an operation, or can't put their hearing aid in, therefore these people are often dismissed or treated with disrespect. They aren't cared for in a way they should be as they aren't responding because they can't hear.

It's about taking the time and for somebody else to take responsibility. I know they are busy but doctors or nurses could use a hearing device to assist the hard of hearing.

If you have a penicillin allergy it goes on the front of your file and comes up on Medtech. It is just about going back to basics, having the team aware of the disability - hard of hearing or deaf, and have it straight away on the front of the file.

They won't respond and they will look at you blankly. That is a hidden disability. It's awareness really.

### 3.7 Story on need for disability competency training

My name is XXX and I am using sign language, so you are hearing an interpreter's voice at the moment. My comment is that if a deaf person arrives at the hospital then some of the staff, maybe the receptionist, or perhaps doctors, nurses, many of them don't know how to communicate via sign language. So I'm just wondering about access there.

I would like to ensure that there is some form of system within the hospital to ensure interpreters are booked, that there is contact through the Deaf Association, especially for emergency cases. There is the New Zealand relay service that can be used for access, which is an 0800 number accessed 24/7 for deaf patients' communication needs. There is also a fax number for deaf people to contact the hospital and various departments.

Other staff like ambulance staff need to have knowledge and awareness if they come across a deaf person. They may also need to know where

**to go to organise interpreter services, because there are huge issues around communication.**

**If some of the staff want to learn how to sign themselves, I am actually a sign language tutor as well. I have four years experience teaching sign language.**

**The hospital needs to ensure there is adequate lighting when dealing with these people because that is an important help with being able to see. They need to update signage to include things like where there is TTYs within various areas of the hospital, and they need to have more symbols that show where various departments or services are. A lot of the time it is difficult to navigate around the hospital.**

## 4. Key Themes

### 4.1 Introduction

This section presents a thematic analysis of all the feedback from the Forum.

*Promoting Participation's* priority areas and their associated objectives have been used as the framework against which the significant points from the Forum have been analysed. At the start of each section, the objectives of each priority area are detailed.

Across participants, there was commonality in the issues shared, and also a diversity of emphasis. The latter reflects the diversity and differing needs of disabled people.

### 4.2 Disability competency training

***Objective: A workforce responsive to the needs of people with disabilities.***

- v ***Increase the overall level of understanding, and knowledge of the New Zealand Disability Strategy and disability issues amongst C&C DHB employees and Board members.***
- v ***Improve the level of disability competency amongst clinical and other service delivery personnel so that people with disabilities receive health and disability services that are appropriate and meet their needs.***

Participants commended the committed and passionate individual C&C DHB staff who have an excellent understanding of the New Zealand Disability Strategy, and a willingness to deliver appropriate and quality service to disabled people.

Through participants' experiences, however, it is evident that focus needs to continue on improving disability competence amongst C&C DHB staff, and also in the structure and delivery of services and their supporting systems.

Staff attending the Forum acknowledged the challenges for disabled people in participating in general health services and in wider society:

*“When you are in the disability field your awareness of disability is heightened. A disability is not necessarily an impediment to their joy of life. Quite often they are treated as something different – they are disabled people. They are either moddycoddled or ignored. If they don’t fit into “normal” they get ostracised.”*

Detailed below are the areas participants discussed which directly or indirectly relate to disability competency.

### Discharge processes

Participants were especially critical of the discharge processes used by C&C DHB, in particular managing the short-term and long-term needs of disabled people. Key issues identified included:

- v Readiness of the patient, with some describing patients as being *“pushed out”*.
- v Ensuring the discharge process is clear and appropriate for people with hidden disabilities (i.e. hearing and vision impairments).
- v A lack of communication, coordination and funding of the support agencies required by disabled people when discharged from hospital, particularly for those with complex needs, and those needing coordination of both short-term and long-term solutions.

*“The tension comes between what is the short-term need and how long it is required to be in place and what is the ongoing long-term need. The ongoing long-term need is funded through regular home supports that may be in place or might be under a residential contract. But often when services are in place, there are those who go into hospital and we don’t even know about it. We don’t even know about the discharge process. Whoever is dealing with the discharge process, I don’t believe they are always speaking to the people who are providing the support or maybe other agencies or sectors. The discharge processes are piecemeal and adhoc and not planned well and of course the issues around who pays for what comes*

*up. I am unable to put supports around short-term needs and that is something that comes under the DHBs around the discharge process.”*

## Hospital appointments

Hospital appointments are a source of much frustration, in particular:

- v Scheduling appointments that conflict with other commitments such as caring for children, travelling times coinciding with peak hour traffic, and limited car parking.
- v Delayed appointments due to over scheduling or extended wait times resulting in having no food or drink and paying more on parking fees.

*“We had an appointment in audiology, and turned up there and sat with another couple who had come in from Paraparaumu. The gentleman couldn’t drive so his wife was there too. We were both sitting there waiting, but not only were we both there for the same appointment, but no one had told the person who was testing that she actually had appointments. The first barrier was finding the person who had to do the specific testing. I let them go first and went to have a cup of coffee. The appointment was at 1.30pm and we finally got out of there at 3.30 – 4pm.”*

Staff attending the Forum affirmed disabled people’s frustrations with appointments, in particular the associated travel costs. However, they also mentioned that people not showing up for appointments creates inefficiencies.

*“Every time there is a Do Not Attend, and that child still needs to be seen, it means there is another person on the waiting list who is shifted.”*

## Admissions process

Some participants felt that disabled people’s “*special needs were not acknowledged*” during the admission process.

The attitudes of younger staff, in particular, were seen as affecting service delivery, as they do not empathise with the specific needs of disabled people. Rather than considering it a lack of understanding,



participants attributed it to lack of experience and life skills of younger staff.

*“Young people don’t have the life skills, which is no fault of their own. But they also have the power to approve or decline your access to a service.”*

### Availability and competency in use of hoists

Participants were complimentary of staff competent in the use of hoists, and the departments where they are available. The dental clinic was noted as being particularly accommodating with staff *“not fazed by people in wheelchairs and have no problems obtaining and using hoists.”* In contrast, the Radiology Department stood out as not having hoists readily available or staff trained in their use.

### Role of carers

Participants feel there is both misunderstanding over the role of carers within the health system, and limited recognition of their value.

Participants commented on the need to justify themselves and their effects to gain recognition for their role.

### Age and disability

Participants raised a number of issues in relation to services that are age appropriate and accessible across ages, specifically:

- v Lack of age appropriate services including respite and rehabilitation for those aged 15 to 30. Young people are being discharged to adult services that do not meet their distinct needs, and to their General Practitioners who may not have disability expertise.
- v Consent processes for young people with intellectual disabilities. A parent of a young person with a disability felt they should consent for their son to have an MRI. However, they were told that as their son was 17, he must give his own consent.
- v Lack of access to services for those under 65 years who have a disability as a result of a degenerative disease, such as dementia.

- v Perceived stigma of disability stopping some older people who have a disability as a result of a degenerative disease, (e.g. stroke) from accessing support services.

### Informal solutions

Participants acknowledged that many health professionals have found unofficial ways to *“plug the gaps”*. These informal support systems are evolving because there is no formal way of giving feedback, and obtaining the services needed by disabled people.

*“The way to sustain access is you have to have a link with someone to get what you need. You can’t just say you have a need. You have to find someone who will listen and then has an understanding.”*

## 4.3 Physical access

***Objective: Barrier free access to the built environment***

- v ***Provide an accessible journey for all visitors to the service and its physical environment.***
- v ***Ensure the needs of people are met as they enter and use health and disability services.***

Physical access was a key priority for many participants at the workshop. They described experiences of physical access issues with getting to and around hospitals, accessible toilet facilities, adaptations to property, mobility taxis and the C&C DHB shuttle.

Participants noted the legislated physical accessibility requirements for disabled people, and suggested C&C DHB communicate this to all service providers.

### Transport to and around C&CDHB hospitals

Participants highlighted difficulties faced with accessing services and treatment at C&C DHB’s two hospitals – Wellington and Kenepuru. The shuttles between the hospitals were acknowledged as providing an indispensable service and a positive measure to increase disabled people’s access to services.

**However, the shuttles are not mobility shuttles and have no wheel chair access. Consequently, some participants find them difficult to use. It was noted that shuttle's intermediate step can be pulled out to help people get up, but if a person has any issues with standing or turning it is difficult to get into the van with its low ceilings.**

**Use of the shuttles by physically-able people is resulting in a lack of seats for disabled people. Participants also commented that often physically-abled people take the front seats resulting in a disabled person struggling to get in the back.**

**Rehabilitation staff also commented they find it difficult to send disabled and elderly people home knowing they will have difficulty negotiating the shuttle's steps (see Section 3.3).**

**Participants suggested the following improvements to C&C DHB's shuttles:**

- v **Having a bigger mobility shuttle able to accommodate people in wheelchairs.**
- v **Developing clear guidelines on use including who can use the service and how use can be maximised by disabled people.**
- v **Providing a second person who can help people get on and off the shuttle.**
- v **Putting in copper hand holds to help disabled people get into the shuttle.**
- v **Increasing the number of scheduled trips.**
- v **Operating on weekends or public holidays.**

### **Access within C&C DHB and service providers' facilities**

**Participants noted the steep access to the Outpatients Clinic at Wellington Hospital, and the lack of accessible facilities, including disability toilets, at satellite units. Participants felt the number of disability toilets should be increased across all C&C DHB sites.**

**For people with hearing and vision impairments finding their way around hospitals is a challenging exercise. Participants commented on the lack of appropriate mechanisms to support people with hearing and vision impairments. Further feedback on signage and communication mechanisms is in Section 4.4, and for related participant stories are in Sections 3.6 and 3.7.**

### **Access costs**

**Many participants discussed access costs related to parking, taxis and other travel costs. The lack of free and appropriate car parking for disabled people was seen as a significant barrier to accessing services.**

**Participants also reflected that parking costs were often exacerbated if the scheduled appointment time ran over. For some participants, this could be up to two to three hours. Staff were aware some families, particularly those who have many appointments, do not turn up as they cannot afford the car parking.**

## Access to funding

Equity of access to services can be further compounded by a lack of awareness or access to available funding sources. Participants commented on not knowing their entitlements to allowances and benefits for disabled people. Participants believed disability allowances need to be more widely advertised by Work and Income.

## Accessible housing

As detailed in Section 3.2, challenges continue with ensuring housing is both accessible and adapted to suit the specific needs of a disabled person.

## 4.4 Communication and access to information

***Objective: People can communicate freely. Information is useful, easily understandable and accessible.***

- v
***Ensure that people who cannot use usual formats such as written letters or telephones can send and receive confidential information to/ from our Hospital and Health Services.***
- v
***Improve the accessibility of public information produced by C&C DHB through the publication in alternative formats (audio, plain language, large print, pictorial etc) and accessible electronic facilities.***

Participants discussed a number of issues effecting disabled people's ability to communicate and access information.

### ***Hidden disabilities***

Participants discussed that patients with hidden disabilities often suffer further inequities due to limited awareness of their communication requirements. Some patients have been perceived as having dementia when they have a hearing impairment (see Section 3.6). For disabled people with literacy issues the provision of written information further disadvantages them. Other hidden disabilities discussed included intellectual impairments, mental health issues, and learning disorders.

To make these disabilities more visible to staff, it was suggested that patient's disabilities are noted on the top of their file, similar to the notification of a penicillin allergy. The latter would ensure staff are aware of the patient's disability and enabling appropriate communications.

### *Technology to support communication*

To assist the communication requirements of the hearing impaired, some participants suggested having:

- v A roster of sign interpreters.
- v A TTY system which is attached to the phone line and goes to the operator like typewriter. People type in the message which goes to the operator and they type in a message and it comes back to you via [www.nzrelay.co.nz](http://www.nzrelay.co.nz).
- v Touch screen computers to share and access information about where to go.
- v Establishment of a central disability friendly help desk/ information centre where disabled people could identify their disability to staff and ensure appropriate communication.
- v Improvements to signage and symbols around the hospital to assist all patients with hidden disabilities.

## 4.5 Employment opportunities

***Objective: Working conditions and environments are appropriate and welcoming.***

- v ***Have the number of disabled people employed reflect the percentage of people with disabilities in the general working age population.***
- v ***Reduce barriers for employees with disabilities by ensuring working environments and conditions are appropriate.***

Employment opportunities were not discussed to any great extent by participants.

## 4.6 Community and consumer engagement

***Objective: People with disabilities can participate at all levels.***

- ✓ ***Ensure people from all parts of the community have the opportunity to participate in public consultation processes.***
- ✓ ***Build strong relationships and partnerships with the disability community.***
- ✓ ***Lead the community by example in the promotion of disability issues and advocating for the removal of barriers in all sectors.***

In relation to C&C DHB's community and consumer engagement, participants made the following comments:

- ✓ **Need for more youth input in the development of C&C DHB policies and processes. It was mentioned that a young disabled person is a member of C&C DHB's Youth Advisory Board. However, some participants felt there should be more inclusion and communication with younger members of the disabled community to provide feedback on issues relating to them.**
- ✓ **Proactive community engagement. Some participants queried the amount of engagement C&C DHB has with the community and whether their feedback is being used. However, other participants note that while they are being actively listened to and heard, action is not occurring. These participants suggested the development of a five-year strategic plan.**

## 4.7 Other issues discussed

The following are other issues discussed at the Forum:

- ✓ **Access for service with phobias/anxieties. Participants noted that there are limited supports available for people with phobias or anxieties within the health system. There are supports available for these people within the NGO sector, but there needs to be communication between C&C DHB and these NGOs.**
- ✓ **Need for better inter-agency coordination and collaboration. Participants commented on the difficulties faced in transferring**

**between ACC and services funded by C&C DHB. These transfers were describes as taking a large amount of time and effort. Similarly, a lack of inter-agency coordination between government departments and C&C DHB put pressure and strain on disabled people trying to negotiate between the agencies.**

- v **Improve inter-agency communication. Representatives of community organisations noted the need for clearer guidelines and more communication between their agencies and C&C DHB about issues for disabled people in the community.**
- v **Inequality between ACC funded conditions and non-ACC. Participants commented that people with medical conditions (e.g. cystic fibrosis) are ineligible to access Capital Support/ Care Coordination and consequently lack support.**



## 5. Future Directions

Towards the end of the Forum, participants were asked to prioritise where they felt C&C DHB needed to place the focus of *Promoting Participation* over the next four years. Not surprisingly, participants prioritised the areas where there is perceived to be ongoing challenges of equity and access for disabled people in seeking to participate in C&C DHB funded health services.

Based on participants' experiences of general health services funded by C&C DHB, the following are participants' future priority areas for *Promoting Participation* over the next four years:

- v Disability competency training for staff with a particular focus on improving the discharge process.
- v Physical access with a focus on accessibility of buildings and the accessible transport.
- v Communication in making visible hidden disabilities such as hearing impairments, and using technology to ensure effective communication and access to information.
- v Ongoing active participation of disabled people in C&C DHB's policy direction and decision-making to achieve the vision of *Promoting Participation*.

While not currently explicit in *Promoting Participation*, participants expressed a need for enhanced interagency communication, coordination and collaboration to ensure disabled people have access to appropriate supports and funding to meet their short-term and long-term needs.

## 6. Feedback on the Forum

At the end of the Forum, participants were asked to complete an evaluation form on their perceptions of the Forum, and to identify areas of improvement for future DSAC forums.

In total, 12 completed evaluation forms were returned. Overall, written feedback on the Forum was mainly positive, and offered insights for future enhancements.

- v Eight participants rated the forum overall as very good or good, and two rated it average.
- v 10 participants rated being able to obtain a good understanding of *Promoting Participation* as very good or good, and two rated it average or poor.
- v Nine participants rated being able to share their story on accessing, using and participating in health services funded by C&C DHB as very good or good, and two rated it average or very poor.
- v 11 participants rated being able to provide input into setting new targets for *Promoting Participation* as very good or good, and one rated it very poor.
- v Seven participants rated the organisation and planning as very good or good, and two rated it average.

Feedback on the evaluation forms highlighted the Forum was particularly valued by participants in being able to discuss and hear others experiences and to suggest solutions. In the words of the participants:

*“Hearing other people’s stories.”*

*“The opportunity to discuss issues of interest with other interested parties.”*

*“Meeting colleagues with disabilities.”*

*“Having the opportunity to engage with other community members and members of the DSAC committee.”*

*“Opportunity to be heard. Making connections with two other helpful non-government agencies.”*

***“The ability to suggest solutions.”***

***“The range of disabilities spoken about. The barriers ongoing.”***

***“Presence of Committee members to hear the comments first hand.”***

Participants also offered suggestions for improvement relating to group structure and content, wider advertising, venue issues and distribution of supporting information.

v **Group structure and content:**

***“Possibility of reassigning the groups as my group had only one person sharing their story, whilst others had virtually all members sharing their story.”***

***“More discussion time – smaller groups.”***

***“Those specific issues on which input would be helpful.”***

***“More discussion time – smaller groups.”***

v **Wider advertising of Forum:**

***“More direct advertising to community partners.”***

***“Youth health agencies / youth forum involvement – could arrange to have leave from school or input in ways after the meeting? Not sure from the Forum where this will fit in.”***

v **Venue issues:**

***“To have had a hearing loop to go with the microphones.”***

***“Room was quite noisy and separation of interest groups to separate locations would have achieved higher concentration.”***

***“Difficulty refilling parking meter every two hours – perhaps this can be provided.”***

***“As a Disability Forum a more appropriate venue might have been used to ease parking difficulties.”***

***“Parking!!”***

v **Distribution of supporting information:**

***“PowerPoint circulated.”***

***“Possibly attach a copy of the Promoting Participating document to the email circulated.”***

**Other comments from participants included:**

***“Everyone is different. Acknowledge everyone, as far as possible – personalise service.”***

***“A worthwhile exercise and worthy of being repeated every five years.”***

***“Great seminar – need more like it.”***

***“Too long – (architect new hospital).”***

***“It will be good if input is acted on. If it isn’t this has been a waste of time.”***

***“No request made to have cellphones off or on silent.”***

**In contrast, verbal criticism was received at the end of the Forum. One participant expressed, on behalf of some other attendees, their dissatisfaction with the Forum. These participants felt the use of the story telling approach was inappropriate, given *Promoting Participation* had ‘expired’ in 2007. These participants desired a more action focused approach.**

**Overall, this Forum succeeded in achieving C&C DHB’s intent of ensuring the voices of all participants were heard, and that C&C DHB did not impose their perceptions of the future directions for *Promoting Participation*. Going forward, there is a need to ensure participants ongoing participation in setting the future direction for Promoting Participation. Ideally, participants are seeking an active role in overcoming ongoing barriers to participate in general health services at C&C DHB.**

## 7. Recommendations

Based on the feedback from the Forum, Litmus recommends C&C DHB:

1. Acknowledge the ongoing need for *Promoting Participation* as a visionary and guiding document.
2. Give due consideration to the alignment between participants' priority areas for *Promoting Participation* and C&C DHB's strategic direction and internal relativities.
3. Review the employment opportunities for disabled people, and in this context consider the need to revise *Promoting Participation's* objective on employment opportunities. (Note: Given the relatively short time period since the introduction of *Promoting Participation*, the objective should be retained, but may require amendment.)
4. Distribute this summary report to Forum participants and other interested stakeholders with C&C DHB's response in relation to the redrafting of *Promoting Participation*.
5. Seek key stakeholder feedback on the redrafted *Promoting Participation* via email feedback mechanisms and discussions.
6. Reconvene the Forum in September 2008 to update stakeholders on the redrafting of *Promoting Participation*, and to input into prioritising its implementation. Widen the invitation list to the Forum and revise the Forum's format to support more action orientated feedback.

## Appendix 1: DSAC Community Forum Agenda

<i>Tea/coffee on arrival</i>		
<b>Karakia</b>		<b>9.30 am</b>
<b>Welcome</b> <b>Purpose/house-keeping</b> <b>Introduction of C&amp;C DHB</b> <b>Agenda setting</b>	<b>Liz Smith,</b> <b>Litmus</b>	<b>9.35 am</b>
<b>Historical overview; <i>Promoting Participations</i>' link with NZDS</b> <b>Future directions for <i>Promoting Participation</i></b>	<b>Judith Aitken,</b> <b>Chair DSAC,</b> <b>Capital &amp; Coast DHB</b>	<b>9.40 am</b>
<b>Set up for breakout discussions (instructions and questions)</b>	<b>Liz Smith,</b> <b>Litmus</b>	<b>9.50 am</b>
<b>Refocusing <i>Promoting Participation</i> – <i>Kotahi Tātou</i></b> <b>Sharing stories about things that have helped or hindered the way you access, use and participate in, health services funded by the Capital &amp; Coast District Health Board</b> <b>Listening and flip charts</b>	<b>Table discussions</b>	<b>9.50 am</b>
<b>Selecting preferred stories and sharing back</b> <b>Stories digitally recorded</b>	<b>Group work (Liz to facilitate)</b>	<b>10.50 am</b>
<b>Identifying future direction</b> <b>Which objectives should be kept, replaced, or added to in <i>Promoting Participation</i> – <i>Kotahi Tātou</i> for the next four years?</b> <b>Flip charts and sticky dots</b>	<b>Each person identifies (Liz to facilitate)</b>	<b>11.20 am</b>
<b>Summary/next steps</b>	<b>Liz Smith,</b> <b>Litmus</b>	<b>11.45 am</b>
<b>Close</b>	<b>Judith Aitken,</b> <b>Chair DSAC,</b> <b>Capital &amp; Coast DHB</b>	<b>12.00 noon</b>

## Appendix 2: Story Telling Technique

### Sharing your experiences of Capital & Coast DHB

**Working on your own, reflect on where Capital & Coast DHB is now in providing general health services to disabled people.**

**Using your experiences of services funded and provided by Capital & Coast DHB, please think of a story, you are happy to share, that shows where Capital & Coast DHB is now in providing general health services to disabled people.**

**This story will show how things are getting better, or staying the same, or are getting worse, since the introduction of Promoting Participation Kotahi Tatou in 2004.**

- ♣ Why is this story significant?**
  
- ♣ What needs to change?**

## Appendix 3: Attendance List

<b>Participant</b>	<b>Organisation</b>
<b>Liz O'Hare</b>	<b>Alzheimer's Society</b>
<b>Alexia Pickering</b>	<b>Barrier Free NZ</b>
<b>Greg Sayer</b>	<b>Capital Support</b>
<b>Laurence Bartup</b>	<b>Capital Support</b>
<b>Linda Hall-Thorpe</b>	<b>Capital Support</b>
<b>Rebecca Phillips</b>	<b>Capital Support</b>
<b>Joslyn Tjeerd</b>	<b>Hearing Assn Wellington</b>
<b>Neil Newman</b>	<b>Hutt Valley DPA</b>
<b>Cheryll Graham</b>	<b>HV DHB</b>
<b>Keith Banks</b>	<b>L'Arche Kapiti</b>
<b>Michelle Ness</b>	<b>L'Arche Kapiti</b>
<b>Ray Rodrigo</b>	<b>Phobic Trust</b>
<b>Merani Davis</b>	<b>Porirua Union &amp; Community Health Service</b>
<b>Charlotte Bergman</b>	<b>RSA</b>
<b>Frances Acey</b>	<b>DPA Wellington</b>
<b>Matt Frost</b>	<b>DPA Wellington</b>
<b>Alexandra Smith</b>	<b>Community consumer</b>
<b>Bronwyn Hayward</b>	<b>Community consumer</b>
<b>Rhonda Swenson</b>	<b>Community consumer</b>
<b>Tania Reti</b>	<b>Community consumer</b>
<b>Wendy Randall</b>	<b>Community consumer</b>
<b>Jenna Booth</b>	<b>C&amp;C DHB</b>
<b>Derek Milne</b>	<b>C&amp;C DHB</b>
<b>Paula Brown</b>	<b>C&amp;C DHB</b>
<b>Warren Collins</b>	<b>C&amp;C DHB</b>
<b>Alison Hannah</b>	<b>C&amp;C DHB</b>
<b>Maurice Priestley</b>	<b>C&amp;C DHB</b>
<b>Sandra Williams</b>	<b>C&amp;C DHB</b>



<b>Participant</b>	<b>Organisation</b>
<b>Shirley Raitt</b>	<b>C&amp;C DHB</b>
<b>Helene Ritchie</b>	<b>C&amp;C DHB DSAC</b>
<b>Judith Aitken</b>	<b>C&amp;C DHB DSAC</b>
<b>Margaret Faulkner</b>	<b>C&amp;C DHB DSAC</b>
<b>Selwyn Katene</b>	<b>C&amp;C DHB DSAC</b>
<b>Valerie Bos</b>	<b>C&amp;C DHB DSAC</b>
<b>Liz Melish</b>	<b>C&amp;C DHB DSAC</b>
<b>Margaret Guthrie</b>	<b>C&amp;C DHB DSAC</b>
<b>Sue Doris</b>	<b>Child development team, C&amp;C DHB</b>
<b>Pauline Boland</b>	<b>Community rehabilitation team, C&amp;C DHB</b>

### **Independent Facilitators**

<b>Liz Smith</b>	<b>Director, Litmus</b>
<b>Sally Duckworth</b>	<b>Director, Litmus</b>

## Appendix 4: Participants' Feedback

Table 1: Participants Rating of the Forum

	Very good No.	Good No.	Average No.	Poor No.	Very poor No.
Ability to obtain a good understanding of <i>Promoting Participation – Kotahi Tātou</i>	3	7	1	1	
Ability to share your story on accessing, using and participating in health services funded by Capital & Coast DHB	6	3	1		1
Ability to provide input into setting new targets for <i>Promoting Participation – Kotahi Tātou</i>	3	8			1
Organisation and planning	5	2	3		
<b><u>OVERALL</u></b> rating	4	4	2		