

DISABILITY ACTION PLAN

2005-2007

Implementation of the New Zealand Disability Strategy
by Counties Manukau DHB



Counties Manukau DHB's Shared Vision is:

To work in partnership with our communities to improve the health status of all, with particular emphasis on Maori and Pacific peoples and other communities with health disparities

- We will do this by leading the development of an improved system of healthcare that is more accessible and better integrated
- We will dedicate ourselves to serving our patients and communities by ensuring the delivery of both quality focussed and cost effective healthcare, in the right place, right time and right setting
- Counties Manukau DHB will be a leader in the delivery of successful secondary and tertiary health care, and supporting primary and community care

Values

Care and Respect	Treating people with respect and dignity: valuing individual and cultural differences and diversity
Teamwork	Achieving success by working together and valuing each other's skills and contributions
Professionalism	Acting with integrity and embracing the highest ethical standards
Innovation	Constantly seeking and striving for new ideas and solutions
Responsibility	Using and developing our capabilities to achieve outstanding results and taking accountability for our individual and collective actions
Partnership	Working alongside and encouraging others in health and related sectors to ensure a common focus on, and strategies for achieving health gain and independence for our population

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Foreword

Counties Manukau District Health Board's (CMDHB) focus is to maintain and enhance health and disability services provided to our population in order improve health outcomes. This CMDHB Disability Action Plan describes how we will promote the vision of the *New Zealand Disability Strategy (NZDS)* by eliminating barriers for disabled people and promoting a more inclusive community in Counties Manukau.

In the development of this Action Plan we have talked with people with disabilities, and with people who provide disability services. Their feedback has highlighted the need for us to consider:

- Attitudes towards people with disabilities;
- Access to facilities and information;
- Advocacy for, and participation of people with disabilities, so they can influence how services/facilities are developed; and
- Support for families caring for people with disabilities.

The Disability Strategy Action Plan outlines how CMDHB will meet our responsibility to implement the NZDS. The Action Plan encompasses policy, procedures and practices across all facets of the DHB, including areas such as environmental access, service development, recruitment, employment and clinical services.

Stephen McKernan
Chief Executive

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1. Introduction

Counties Manukau District Health Board (CMDHB) is responsible for the funding of health services, and for the provision of hospital and related services for the people of Counties Manukau (Manukau City, and Franklin and Papakura Districts) as set out in the DHB District Strategic Plan under the New Zealand Public Health & Disability Act 2000.

The *New Zealand Disability Strategy: Making a World of Difference – Whakanui Oranga* (2001) identifies the key objectives and actions that need to be addressed by policy makers, service funders, planners and providers in order to achieve the vision of the strategy. This Action Plan describes the actions CMDHB will take in order to meet the objectives of the Strategy.

The Action Plan is also based on the CMDHB District Strategic Plan (2005), and uses its outcomes framework to provide a structure to present actions and relate these to the wider DHB outcomes. It incorporates consultation undertaken with local disabled people and with providers of health and disability support services in Counties Manukau.

2. Purpose

The purpose of the Disability Strategy Action Plan is to outline the way in which Counties Manukau District Health Board (CMDHB) plans to support people with impairments in Counties Manukau.

The founding document for this Action Plan is the *New Zealand Disability Strategy Making a World of Difference – Whakanui Oranga (2001 (NZDS))*. The aim of the strategy is to eliminate barriers for disabled people and to promote a more inclusive society.

“One in five New Zealanders has a long term impairment. Many are unable to reach their potential or participate fully in the community because of barriers they face doing things that most New Zealanders take for granted. The barriers range from the purely physical, such as access to facilities, to the attitudinal, due to poor awareness of disability issues.” (Hon Lianne Dalziel, Minister for Disability Issues, April 2001).

The vision of this Strategy is a “fully inclusive society”. New Zealand will be considered an inclusive society when people with impairments are able to say that the society within which they live “*highly values our lives and continually enhances our full participation*” (MOH. The New Zealand Disability Strategy, April 2001, p 5). CMDHB will measure this by assessing how staff and consumers with disabilities are provided for, in terms of environmental access, support, employment and inclusion, with particular reference to CMDHB policies and practices.

CMDHB, along with all public sector agencies, has a responsibility to implement the NZDS. The Action Plan provides information on policy, procedures and practices across all facets of the DHB including areas such as environmental access, service development, recruitment, employment and clinical services.

3. Strategic Context

CMDHB's *Disability Services Advisory Committee (DiSAC)* is responsible for the implementation of the NZDS within the organisation. This is one of three DHB Board committees which have been established in accordance with legislation. DiSAC was established in 2001 and has developed identified priorities for its work plan. These include development and implementation of an Action Plan, consultation and collaboration with key stakeholders, and participation in northern region planning for disabled people.

The three main objectives of the DiSAC are:

- to oversee the development and implementation of the CMDHB Disability Strategy Action Plan
- to provide a forum for consultation with and by the disability sector (consumer and community representatives)
- to provide an avenue for regional disability planning and consultation.

CMDHB has to respond to the NZDS on three levels, each of which have specific requirements for ensuring an inclusive and barrier free environment. These three levels are:

- Planning & funding of health services – CMDHB's role in this regard is to ensure planning of health services takes account of the needs of people with disabilities, and that NGOs who deliver services funded by CMDHB have policies and practices that support the NZDS. (It must be noted that CMDHB is not a funder of disability support services; that role has been retained by the Ministry of Health)
- Provider of health services – disabled people and their families have the right to health care provision that is culturally competent, responsive and inclusive. As a provider, CMDHB has a responsibility to listen to its communities and to deliver health services that meet their needs.
- Employer of people with disabilities - as an employer, CMDHB is responsible for providing employment and workplace policies and practices which support equitable working conditions for all employees, including those with disabilities. CMDHB is also responsible for ensuring that education and information about the needs of members of our community with disability is provided to all staff.

Collaboration

One requirement of the NZDS is to work collaboratively with other national, regional and local agencies and service providers in our area. Key partnerships have been established with Manukau City Council, and Franklin and Papakura District Councils. Of particular importance is collaboration with the other two metro-Auckland DHBs (Waitemata and Auckland), and the Ministry of Health, in identifying priority needs of people with disabilities, and planning to meet these needs.

Regional collaboration and consultation has occurred in particular with Waitemata DHB (WDHB). WDHB has completed a project examining the role of their DHB as an employer of people with disabilities. In particular, their implementation plan has

focused on workplace support and environmental support. The findings of this WDHB project have been used to provide a framework for the CMDHB Action Plan. The main aims of this Action Plan are to address the key themes identified: attitudes, access, environment and supports in terms of removing barriers for consumers and employees with disabilities.

Counties Manukau Population Profile

Counties Manukau has one of the fastest growing areas in New Zealand. It is a diverse population with complex health needs and service requirements. Key features of the CMDHB population are:

- § A high proportion of Maori
- § A high proportion of Pacific people
- § A high proportion of Asian people
- § A high number of young people
- § The fast growth of the population
- § The high proportion of low socio-economic status
- § The high proportion of the community with a disability.

The Counties Manukau Population Health Indicators (2005) includes information about disability in Counties Manukau. The data was obtained using benefit numbers reported by Work and Income (Ministry of Social Development). It shows that the number of children per 100,000 population receiving the child disability allowance was less in the Auckland region than for all NZ; this also holds for adults accessing the disability allowance. This is acknowledged as likely to be an underestimate of those with a disability within Counties Manukau, and to reflect the access difficulties our population experiences.

Summary of the New Zealand Disability Strategy

There are 15 objectives of the NZDS. For the purposes of developing the CMDHB Disability Strategy Action Plan the objectives have been grouped into three key themes:

Access and Education

- 1 Encourage and educate for a non-disabling society
- 2 Ensure rights for disabled people
- 3 Provide the best education for disabled people
- 4 Provide opportunities in employment and economic development for disabled people
- 5 Foster leadership by disabled people

DHB Responsiveness and Support

- 6 Foster an aware and responsive public service
- 7 Create long term support systems centred on the individual
- 8 Support quality living in the community for disabled people
- 9 Support lifestyle choices, recreation and culture for disabled people
- 10 Collect and use relevant information about disabled people and disability issues

Community engagement and participation

- 11 Promote participation of disabled Maori
- 12 Promote participation of disabled Pacific peoples

- 13 Enable disabled children and youth to lead full and active lives
- 14 Promote participation of disabled women in order to improve their quality of life
- 15 Value families, whanau and people providing ongoing support.

The NZDS sits alongside international documentation and practice, such as the World Health Organisation's - ***International Classification of Functioning Disability and Health (ICF)***. The aim of this document is to improve participation in society of people with disabilities by stimulating better care and services. This is central to improving quality of life and facilitating the autonomy of people with disabilities.¹

The foundations of the ICF model are:

- Human Functioning - not *merely disability*
- Universal Model - not *a minority model*
- Integrative Model - not *merely medical or social*
- Interactive Model - not *linear progressive*
- Parity - not *aetiological causality*
- Context - inclusive - not *person alone*
- Cultural applicability - not *Western concepts*
- Operational - not *theory driven alone*
- Life span coverage - not *adult driven*

The NZDS views disability as the process that occurs when one group of people create barriers by designing services and facilities that do not take into account the impairments of other people. These may be physical, sensory, neurological, psychiatric, intellectual or other impairments.

Improving Quality

The other document informing this Action Plan is ***Improving Quality: A systems approach for the New Zealand health and disability sector*** (MOH, 2003). The vision of this document is that "improvements in quality are necessary to support a vision of people in the New Zealand health and disability sector receiving people-centred, safe and high-quality services that continually improve and that are culturally competent. 'People-centred' means involving people and being receptive and responsive to their needs and values. It includes both individuals and population groups receiving services".²

Links to Other CMDHB Plans

In addition to the New Zealand Disability Strategy, the development of the CMDHB Disability Action Plan has been guided by the aims and principles of other key health strategy documents that inform the actions of the DHB. These are outlined in detail in the CMDHB District Strategic Plan (2005) and the CMDHB District Annual Plan.

The Outcomes Framework in the DHB's Strategic Plan provides a guide for service and business planning across the various divisions of the DHB, and is used in this way in this Action Plan.

¹ International classification of functioning, Disability and Health, WHO, 2001

² Ministry of Health. Improving Quality (IQ): A systems approach for the New Zealand health and disability sector, September 2003, pg vii

4. Feedback from the Community

Three key components to implementing the NZDS are:

1. Including people with disabilities in consultation about issues which affect them
2. Making information available to people with disabilities in accessible formats
3. Provide an avenue for people to raise concerns.

CMDHB has begun to address these three areas through the consultation process associated with development of this Plan, that has included community workshops, verbal and written feedback, and internal communications with staff and management. This feedback will be ongoing as implementation of the Action Plan occurs and as progress is tracked. (For detail of the community feedback, see Appendixes 1, 2 and 3.)

The DiSAC will ensure that the implementation of this Action Plan addresses the core components of the NZDS strategy and the concerns of the community. The Manukau City Council Disability Steering Group has also agreed to be a reference group for this Action Plan and their regular feedback will be sought.

Other progress to date includes:

- Initial steps have begun in establishing relationships with disability service providers in Counties Manukau
- Regional cooperation in the development of action plans in order to advance the objectives of the NZDS has occurred with Auckland and Waitemata DHBs
- Initial scoping of Action Plan initiatives has occurred highlighting the issues of access for patients and staff to CMDHB facilities and services, and the need for training for CMDHB managers in the employment of people with disabilities
- Consultation with consumer groups addressing attitudes and environmental issues is ongoing
- An initial access audit of areas of the Middlemore Hospital site has been undertaken. This will be extended to encompass all CMDHB facilities, and incorporate access standards in future facilities planning.

5. The Outcomes Framework

CMDHB is using an outcomes framework to focus planning and to provide the basis for a performance framework to monitor progress. There are six long term outcomes identified in the draft CMDHB District Strategic Plan (2005):

1. Improve community wellbeing
2. Improve child and youth health
3. Reduce the incidence and impact of priority conditions
4. Reduce inequalities of health status
5. Improve health sector responsiveness to individual and family/whanau need
6. Improve the capacity of the health sector to deliver quality services.

Five of these six long term outcomes provide the framework for this Action Plan (with #3 not being relevant to this Plan).

The Action Plan has been divided into three parts that reflect the different roles the DHB has in regard to the NZDS.

1. Planner & funder
2. Provider of health services
3. Employer

NB: A number of the initiatives and actions included in an outcome area could also be included in other outcome areas, but have only been listed once to avoid duplication.

The Outcomes Framework

VISION

To work in partnership with our communities to improve the health status of all, with particular emphasis on Maori and Pacific peoples and other communities with health disparities.

<p>OUTCOME 1 Improve Community Wellbeing CMDHB aims to:</p> <ul style="list-style-type: none"> • <i>Develop healthy communities by working intersectorally</i> • <i>Improve access to information to enable the community to make informed choices about health care and healthy behaviours including information about the health sector, the role of key organisations and how to access services</i> 	<p>OUTCOME 2: Improve Child and Youth Health CMDHB aims to:</p> <ul style="list-style-type: none"> • <i>Improve health outcomes for infants and pre-school children</i> • <i>Decrease the incidence and impact of risk taking actions by young people</i> 	<p>OUTCOME 4: Reduce Health Inequalities CMDHB aims to:</p> <ul style="list-style-type: none"> • <i>Address systemic origins of inequalities</i> • <i>Implement initiatives to reduce inequalities</i> • <i>Improve the capacity of all providers to deliver services</i> • <i>Improve ethnicity data collection</i> 	<p>OUTCOME 5: Improve Health Sector Responsiveness to Individual and Family/Whanau need CMDHB aims to:</p> <ul style="list-style-type: none"> • <i>Increase access to hospital and specialist services</i> • <i>Improve access to and management of elective services</i> • <i>Increase primary care utilisation</i> • <i>Improve the continuum of care for services provided to older people</i> • <i>Reduce the number of people admitted to hospital who could have been cared for in the community</i> 	<p>Outcome 6: Improve the Capacity of the Health Sector to Deliver Quality Services CMDHB aims to:</p> <ul style="list-style-type: none"> • <i>Ensure that the health sector workforce meets the community's needs</i> • <i>Improve health professionals' communication skills in their interactions with patients and their families/whanau</i> • <i>Ensure that services and facilities are planned to meet the future needs of the community</i> • <i>Support information exchange amongst health professionals</i>
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Planning & Funding Role

OUTCOME 1	OUTCOME 2	OUTCOME 4	OUTCOME 5	OUTCOME 6
<p>CMDHB Planning & Funding Role – Key Actions</p> <ol style="list-style-type: none"> 1. Participate in the development of regional information systems of services available to disabled people. E.g. Webhealth, Disability resource centre. 2. Encourage NGOs to demonstrate inclusion policies and practices, and report progress to CMDHB 3. Develop opportunities for disabled people to be included in policy, planning and review 4. Strengthen links with local authority for service planning 	<p>CMDHB Planning and Funding Role – Key Actions</p> <ol style="list-style-type: none"> 1. Strengthen links and relationships across Education, Social Services and Health sectors and establish consultation framework for child and youth issues 2. Advocate to the Ministry of Health for the development of skilled carers 	<p>CMDHB Planning and Funding Role – Key Actions</p> <ol style="list-style-type: none"> 1. Establish effective intersectoral communication links with Manukau City Council, and Franklin and Papakura District Councils and relevant government agencies. Foster their links with DiSAC 2. Develop reporting framework for the collection and analysis of data and share this with NGOs and local authorities 3. Facilitate active contributions from disabled people to planning / development of services that are likely to affect them. 	<p>CMDHB Planning and Funding Role – Key Actions</p> <ol style="list-style-type: none"> 1. Encourage NGOs to conduct access audits and develop action plans 2. Develop structures for regular feedback from consumers/disability representatives to service providers and the DHB as funder 3. CMDHB to support PHO capabilities to deliver services to disabled people 	

Provider Role

OUTCOME 1	OUTCOME 2	OUTCOME 4	OUTCOME 5	OUTCOME 6
<p>CMDHB Provider Role – Key Actions</p> <ol style="list-style-type: none"> 1. Develop information systems that are accessible to people with disabilities e.g. Webhealth 2. Demonstrate inclusive policies and practice when planning and reviewing services, e.g. provide opportunities for disabled people to participate in planning and evaluation of services 	<p>CMDHB Provider Role – Key Actions</p> <p><i>Actions for Children with disabilities are incorporated within the CMDHB District Strategic Child Health Plan</i></p> <ol style="list-style-type: none"> 1. Improve access to healthcare and rehabilitative services for Disabled youth by identifying and addressing barriers faced. 2. Identify and promote effective ways of making health services more youth focused in atmosphere and service provision 	<p>CMDHB Provider Role – Key Actions</p> <ol style="list-style-type: none"> 1. Promote disabled leaders as role models and leaders to all New Zealanders. 2. Link NZDS actions to Maori health strategic initiatives 3. Link NZDS actions to Pacific health strategic initiatives 4. Set up a consumer reference group or groups that will include Maori, Pacific and youth representatives. Feedback to DISAC 5. Collect and disseminate accurate information on disability 	<p>CMDHB Provider Role – Key Actions</p> <ol style="list-style-type: none"> 1. Commission access audits by credentialed assessor – actions to be addressed within Facilities Modernisation Project 2. Ensure facilities management staff receive training in designing for accessibility 3. Facilitate the inclusion of a disability advisor as consultant on the design of facilities (medium to major alterations) 4. Develop disabled parking policy and facilities 	<p>CMDHB Provider Role – Key Actions</p> <ol style="list-style-type: none"> 1. Review operational processes to ensure disabled peoples’ rights are upheld e.g. admission to discharge planning 2. Improve CMDHB staff disability awareness by providing anti-discrimination and disability awareness training 3. Develop resources to support clinical staff to act as advocates when working with disabled people and interact with other government, regional and local authorities 4. Develop audit tools to measure whether CMDHB services are culturally appropriate and accessible for disabled people and their families.

Employer Role

OUTCOME 1	OUTCOME 2	OUTCOME 4	OUTCOME 5	OUTCOME 6
<p>CMDHB Employer Role – Key Actions</p> <p>1. Provide opportunities for CMDHB Human Resources staff and managers to access information and training with regard to the recruitment and retention of people with disabilities</p>			<p>CMDHB Employer Role – Key Actions</p> <p>1. Ensure all current work areas are accessible to people with disabilities</p>	
<p>2. Ensure disabled staff in CMDHB understand their rights, recognise discrimination and are able to be self advocates</p> <p>3. Complete job analysis to identify positions for targeted promotion to disabled people</p>			<p>2. Develop disabled staff parking policy and provide parking and/or transport assistance for disabled staff</p> <p>3. Investigate the implications of ensuring that an automatic car is available for staff who need one</p> <p>4. Scope the need for a range of computer access and/or software that can be provided to staff with disabilities</p>	

References:

International classification of functioning, Disability and Health, WHO, 2001

Ministry of Health. Improving Quality (IQ): A systems approach for the New Zealand health and disability sector, September 2003, pg vii

Ministry for Disability Issues. The New Zealand Disability Strategy – Making a World of Difference *Whakanui Oranga*. April 2001

Tomorrow's Manukau – Manukau Apopo – *A Vision for Manukau into the future 2001-2010*. December 2001.

Manukau City Council. Manukau Disability Policy Action Plan 2004/05

Ministry of Social Development. Positive Aging in New Zealand: Diversity, participation and change – Status Report. October 2001

Ministry of Health: The New Zealand Health Strategy. December 2000

SPARC. No Exceptions Strategy. March 2004

Ministry of Health. The Pacific Health and Disability Action Plan. February 2002

Leanne Catchpole – Implementing the New Zealand Disability Strategy in Waitemata DHB. March 2004

Counties Manukau DHB – District Strategic Plan Draft 2005

Counties Manukau DHB – District Annual Plan – 04/05 & 05/06

Counties Manukau Health Indicators 2005 3rd edition

Ministry of Health. He Korowai Oranga – Maori Health Strategy. November 2002

Appendix one:

**CMDHB
Disability Strategy Implementation Action Plan
Maori and Pacific Consultation
Meeting Notes 29 July 2005**

Meeting was attended by CMDHB Disability Strategy Project Coordinator and Representatives from Te Roopu Waiora Trust; Ngati Kapo Aotearoa; Ngati Kapo Tamaki Makaurau; PIASS Trust (for Pacific Peoples)

Main points for action

- Need strong leadership from DiSAC - intra-sectoral collaboration and action in the DHB & governance of the Implementation plan
- Integration of funding for advocacy
- CMDHB communication and consultation model needs to be in partnership with Maori and Pacific communities; resourced for translation into other languages and culturally aware of the media medium that is accessed by these communities
- One glove does not fit all – need to look at using resources to de-stigmatise disability

Summary of discussion

- Pacific Health strategy implementation at CMDHB has good intentions but there is a resistance to tangible changes. Funding is ring fenced and disability is a low priority.
- Disability is competing with Personal Health issues which are the current high priority and disability is the poor cousin.
- CMDHB has an obligation to monitor the implementation of all the action plans against the various strategies – therefore disability funding/actions need to be reported on by Pacific Health Division.
- Translation from Ministry of Health to DHB to service provision and the community is poor. Need for better translation of practice AND advocacy back to the Ministry that Pacific disability issues are being addressed.
- There is a lack of integration of services in PHOs – need to be able to feel that all needs can be met by the PHO. Not to be told to take disability issues elsewhere.
- CMDHB has a leadership role with the PHOs.
- CMDHB must acknowledge the differences in Pacific cultures.

- Funding allocation is all wrong for disability. 65+ - some of our people won't even make it to that.
- Family systems have traditionally absorbed the cost of a family member with a disability. This has many risks associated with it – cost, possibility of abuse, limited ability to negotiate change
- How will CMDHB demonstrate to the community that we can have confidence that what is being reported on is accurate? Is the Pacific Health Division reporting to the DiSAC and the Board on disability issues?

- For Maori there is limited ownership of the Disability Strategy as less than 10% of the submissions to the consultation round were Maori.
- Disability services are a low priority against other needs such as poverty, housing, violence, food – these issues are the main area of need for the Maori community.
- Lack of integration amongst services is a huge problem – often the Maori health and disability service providers need to support people to get through the system so they can access what they need.
- Partnership model with the whanau to walk with them through the departments – this will need to be resourced.
- Maori are isolated because of a lack of disability competence on top of lack of cultural competence.
- Advocacy role is extremely important on both a personal advocacy level and a system advocacy level.
- Maori disabled often disengage because the organisations are not responsive.
- CMDHB needs to be aware that Maori are a community and allocation of resources needs to acknowledge and accept this. There are traditional community such as iwi, hapu and then there are contemporary community such as Kohanga Reo/Kura Kaupapa, Maori rugby and also gangs. Maori disabled are not using the mainstream organisation such as RNZFB and Deaf Foundation – there are splinter groups that are utilised.
- CMDHB needs to seek partnership with existing contemporary and traditional communities – to consult and to ensure better access to information for the Maori communities.
- PHO – need to monitor how these services are responsive to disability. There are many anecdotes around their failure to address disability or charging people extra.

Appendix two:

Summary of the key issues raised at the CMDHB Disability Strategy Implementation Plan community consultation workshops.

The community consultation workshops were co-facilitated by CMDHB Disability Strategy Project Coordinator and representatives from Ripple Trust. The workshops were attended by representatives of APET Enterprises; IDEA (IHC); 16+ Respite; Lifeboys Trust; Focus 2000; RNZFB; Halberg Trust; Community Service managers; NZ Police; Auckland Down Syndrome Association; Autism NZ; CMDHB staff across the Divisions; DiSAC members; Parents, children and carers.

The key issues identified are as follows:

Accessing help

Problems:

- ✓ Fragmented services
- ✓ Schooling
 - Lack of information from the “top”
- ✓ ORRS funding criteria are too narrow and unreachable
- ✓ Access to transitional funding for students is minimal and often equipment does not get to move on with the student once they leave school!
- ✓ Short term view in terms of access to equipment and housing modifications
- ✓ Focus on the negative – system is deficit designed rather than needs based
- ✓ GSE/Health – service criteria battles – people in the grey get lost
- ✓ Access to Taikura \$ restricted because of limited access to assessment services
- ✓ Integration of high health needs children with Education sector very difficult for families to navigate
- ✓ Access to information – many families leave hospital services without knowing how to access services and support

Solutions:

- ✓ Need a database of helpers
- ✓ Career support – financial parity
- ✓ Workforce development
- ✓ Need to unite disabled groups to work together
- ✓ A one stop shop for families – assessment, intervention and equipment
- ✓ Access to module training for disabled adults and support staff on health/exercise/wellbeing as part of primary care delivery
- ✓ Follow up support after leaving hospital based services
- ✓ Counselling services need to be more available for parents/whanau around ‘disability grief’
- ✓ Educate disability community on what the DHB provides in a format that is easily understood and in a number of languages
- ✓ Look at links between NASC and DHB – grey area that remains untouched and under serviced – people in the middle are greatly affected by lack of responsibility and lack of clarity

Physical Access

Problems:

- ✓ Kerbs – wheelchair access
- ✓ Crossing points
- ✓ Library access
- ✓ Fire evacuation procedures not clear in many facilities
- ✓ Poor signage and lack of information pamphlets to let people know where to park etc
- ✓ Wheelchairs supplied to children – huge list of issues that impact on their ability to access recreational and educational choices
- ✓ Wait lists are too huge - people's needs change while waiting
- ✓ Parking facilities for rehab – stamina a huge issue, people often buggered before get to the rehab session

Solutions:

- ✓ TLAs need policies around roading for the disabled community – is it adequate or is it lip service?
- ✓ More advocacy for disabled people in council policies and DHB policies etc
- ✓ Allocation of \$ to allow disabled policies to be “enabled”
- ✓ Facilities planned properly for disabled people
- ✓ Councils to include detailed policies around developments i.e. shopping centres – wheelchair access etc
- ✓ Facilities management training re – building codes, law access requirements and best practice guidelines
- ✓ Provide an avenue for reporting of issues – develop a watch dog of service
- ✓ Integrate wheelchair services in one place

Vocational and Employment Options

Problems:

- ✓ Limited access to meaningful vocational/employment
- ✓ New legislation may put off employers
- ✓ Attitude barriers
- ✓ Appears to be limited % of people with a disability employed by DHB

Solutions:

- ✓ Unlimited resources! – provide 1:1 job support, minimum wage, training for an individual that is related to managing their disability in the workplace.
- ✓ Celebrate and reward employers who can demonstrate systems that provide opportunities
- ✓ Media blitz to get public attitude change
- ✓ Ensure access to all levels of education – pre-school, school, tertiary and ensure that students graduate with skills for the workforce such as literacy, social skills and motor skills
- ✓ Attitude training with employers to remove system/process barriers for initial employment and ongoing support
- ✓ Create systems that support employment e.g. awareness of funding, how to break down instructions and provide communication support for non-verbal or illiterate people
- ✓ Health career days – advertise to students with disabilities
- ✓ Link services child-youth-adult
- ✓ Secure equal opportunities by having % of positions secured within DHB for people with a disability

DHB Responsiveness

Problems:

- ✓ Access to in-house training for external organisations (shared training for the workforce will reduce costs and support partnership with community)
- ✓ Where do people go for advice regarding sexuality/relationships? Who provides support?
- ✓ Staff attitudes and awareness of disability
- ✓ Limited services to rural population
- ✓ Focus on throughput rather than quality – numbers based service not wellbeing and ‘wrap around’ services
- ✓ More complex needs children access our DHB services than anywhere else and this impacts on service prioritisation – only see disability rather than developmental delay/coordination that could really make a difference to how children develop and manage their learning environment
- ✓ Understanding the disability versus personal health funding split
- ✓ Model clash – medical versus bio psychosocial model and attitudes/awareness of nursing and medical staff
- ✓ Limited information or support to enable people with disabilities to be included in primary health care initiatives – e.g. diabetes and health programmes
- ✓ Collection of information and statistics for this population are limited – need to incorporate into data and report it

Solutions:

- ✓ Think of long term solutions
- ✓ Educate/up skill DHB staff re: organisations in the community – what are they offering and providing?
- ✓ Extend services to meet rural needs
- ✓ Develop staff awareness of people with intellectual disability
- ✓ Listen to families and support service providers around the disability community or individuals health needs
- ✓ DHB to sponsor Art Awards – Art to be displayed along corridors within hospital setting = visual support of inclusion
- ✓ DHB to appoint people with a range of disabilities and use advocates supporting their participation on committees
- ✓ Create long term support systems that recognise group versus individual needs
- ✓ Lobby Ministry for better funding of services with better measurement tools for effective interventions instead of numbers based
- ✓ Focus on disability impact training for staff that is regular/comprehensive at orientation/induction and updated intervals
- ✓ Create an environment that values staff that work with the disability community – conditions that are competitive
- ✓ Audit services – to develop a blueprint for services for disability community
- ✓ Have a quality cycle – action that are reported on with \$ to ensure actions/change occurs
- ✓ Be real about the issues facing South Auckland – develop a model of service delivery that improves access from Maori/Pacific ethnic groups – use cultural support services and community cultural links
- ✓ Links to training institutes to encourage awareness of bio psychosocial model – we want to think of the whole person not a list of problems

- ✓ Support service providers of disability community to develop primary health care services – e.g.
 - § visual charts and calendars used to give LD adults health eating information or
 - § IDEA are providing screening for diabetes or
 - § Green Prescriptions programmes to be promoted by GP's and DHB

Community Participation and Engagement

Problems:

- ✓ Intersectoral communication breakdowns – problems with collaboration
- ✓ Services too fragmented
- ✓ Lack of leadership in communication
- ✓ Lack of accountability – consultation needs to have actions that are reported
- ✓ Maori and Pacific groups don't often attend combined meetings – need hui/fono that address language, cultural protocols and processes
- ✓ Need more holistic/widespread advertising of consultation meetings (use a range of networks – media e.g. radio, ethnic newspapers, TV pacific programmes, churches etc)
- ✓ Lack of funding of youth services and lack of inclusion of young people in consultation
- ✓ Lack of respite support services restricts availability of parents and carers for consultation

Solutions:

- ✓ Multi layered approach to advertising DHB is seeking community input and consultation e.g. women access health information from family GP
- ✓ DHB reference group made up of a number of different groups with good communication networks to who they represent (Youth Forum, Children's Forum also)
- ✓ Support transport and choose family friendly times
- ✓ MoH and NASC need to listen/acknowledge families too
- ✓ Youth Advisory Council – consultation and training of professionals
- ✓ Parent groups – create links and opportunities for them to provide information to the DHB to design responsive services
- ✓ Consumer advisor on interview panels – related to the service staff are working in
- ✓ Advocate for community services provided to the disability community to be well resources and monitored by the Ministry of Health (referrals, audits etc)
- ✓ Support links to local councils – related to access of services – pools, gyms, parks, recreational services, holiday programmes etc
- ✓ Develop a disability card – allows access to services – health and wellbeing facilities and training
- ✓ Develop faster and more efficient access to Interpreter services – include people who can support those who use Augmentative Alternative Communication systems (such as picture charts or voice output devices)
- ✓ Family focused consultation – times that can be possible for working parents
- ✓ Network and advertise the disability networks in the region – e.g. Get Connected and Disability Resource Centre

- ✓ Think about how to get Maori and Pacific people to attend meetings or to provide feedback to DHB – use existing cultural supports and focus on how information on health can be delivered and received

Education/Leadership

- ✓ DHB needs to provide leadership in educating public and government
- ✓ Non disabled people should not access accessible toilets/parking
- ✓ Promote public health of disabled community – toilets and change areas need to be kept clean because of increased risk of infections
- ✓ Health services in schools need to be DHB responsibility not education sectors – DHB needs to advocate for access to recreational activities – e.g. swimming,
- ✓ Overworked and high caseload demands of therapists in schools result in through put not quality interaction that are tailored to individual needs
- ✓ Provide and publish long term strategic plans – report on actions to disability community regularly
- ✓ Include people with disabilities on projects that affect them e.g. facilities such as ramps, toilets from the beginning not as an add on later.
- ✓ Advocacy role – barriers from schools
- ✓ Model collaborative working with the Community

Other:

- ✓ Improve Ministerial links between Health, Education and Social Services
- ✓ Make hoists available at Super Clinics
- ✓ Ensure post operative care and education plans are realistic for the disabled and their carers
- ✓ Access to therapy services for over 20 very limited – their needs are not limited!

Appendix Three:

Summary of the key issues raised in the focus group with young people with disability on the CMDHB Disability Strategy.

1. The health care we as young people receive

Problems:

- There is nowhere to go when we are down and upset
- There is a lack of age appropriate information for us about our health – the information that is provided is not easily understood
- The doctors and other health professionals don't understand how to explain things to us and tend to explain it to our parents instead of us
- Sometimes there is a lack of privacy
- Staff just don't understand what it is like and are just not friendly
- There is a lack of availability of information discussed or available on sensitive issues such as sex, contraception, drugs/alcohol etc
- Hospital is a "horrible place" for young people
- The environments where we are seen are set up for children with toys or adults with nothing for us to do – we do not fit
- It feels like we are always fighting for things we need such as medication, information, getting back on a waiting list
- Everything costs money and we do not have it i.e. prescriptions, GP visits
- Appt times never suit it means missing out on course or school
- We have to see so many people on so many different things

Solutions

- Packs available for us as young people with disability on sensitive subjects such as sex; or the development of a website
- Health professionals should be trained on the issues that arise for us as young people with disability and taught how to better communicate with us
- Teen appropriate places in the hospital and clinics – posters, radios, play station 2, DVD's etc
- A ward in hospital for teenagers only
- Ensure health professionals get parents out of the room for consultations so we can speak to them alone but also have time for the doctors to speak to our parents alone
- Health information provided that is easily understood and in our language
- Assistance is provided in becoming more independent in managing our health care i.e. teach us how to fill a prescription, pick it up, how to cancel an appt, how to get there alone, how to communicate on the phone
- Peer support programmes should be available with more young people working for the services also
- We could have input into services and resources being developed for us like a youth council
- Someone who is aware of our needs as young people to co-ordinate all our care but also all the other things that are important for us in becoming an adult such as ensuring we know how to get a license, we are transitioned into a course etc

- That there are more youth specific services available
- One stop youth shop place where everything we need is sorted; our health, our benefits, learning to cook etc

2. Being accepted by others

Problems

- Being stared at and given strange looks
- Not accepted by some people because we are different
- People not understanding what we go through
- For some young people bullying is an issue especially when younger

Solutions

- Providing opportunities for young people without disability to experience what its like to have a disability i.e. having a game of wheelchair basketball, being blindfolded for a period of time
- There needs to be more opportunities for abled and disabled young people to engage in activities together
- Provide what the young people describe as "mentoring classes" – this where young people with disability share their stories in hope of better understanding from able bodied young people. This is aimed at intermediate and high school age group
- The presence and visibility of more young people with disabilities on television i.e. having a character with a disability playing a Shortland Street role or presenting on TV shows

3. School / Tertiary Education / Vocational Issues

Problems

- Being discriminated against due to disability for work or course opportunities
- Not being able to do what it is that you really wished to do
- At school and course there is a lack of access to equipment which would make things easier i.e. computers
- A lot of school can be missed – always trying to catch up and keep up
- There is not enough teacher aide assistance or reader-writers etc
- School and health services need to understand and work better together. While in hospital or away that help is provided to keep up and then when you return extra support to catch up. This to try and avoid failing, low grades or having to repeat
- Career counsellors telling you what to do rather than what you want to do

Solutions

- Having a lot more support in place at school as needed and to meet our individual needs
- There needs to be far more funding to assist young people with disability at school or course. This money for more reader-writers, teacher aides, people to come to your home or hospital when away and help

- More general support in school to address concerns and problems that arise - someone to talk to
- Training school teachers and school health staff on the issues that arise for us as young people with disability and taught how to better communicate with us
- More assistance in transitioning into courses or work rather than doing this at the last minute. More choice and options explored
- Assistance in negotiating time off, or catching up, working shorter hours, equipment needs etc for employers or course co-ordinators

4. Socialising/Peers

Problems

- Parental 'over protectiveness' – “Just kick me out please”, “let me do more stuff”
- Transport the main barrier having to rely on mum, dad or a taxi
- The cost of a taxi and no other options for transport apart from parents
- Air transport, buses, trains difficult for young people with disabilities to access and use
- Activities can be unsuitable due to access issues for young people to participate
- Steps, unsuitable toilets, no lifts, long distances to cover, curbs, The height of bars too high to order drinks, counters at shops too high, doors not wide enough, shop layouts unsuitable for wheelchair use
- A real lack of social opportunities, sports, extra curricular activities available that can include young people with disability
- Many of the activities available segregate disabled and abled youth

Solutions

- More activities for abled and disabled young people to socialise together outside of school/work
- Opportunities to attend camps for disabled young people but also camps that are mixed
- Making compulsory specifications for door widths and heights of counters. The availability of ramps on buses, someone available to assist. Compulsory to have buildings with disabled toilets, lifts etc. More suitable air transport.
- Allocated free transport via taxi per year to use at their own discretion
- The concept of a buddy on hand be allocated for a period each week where a young person can ask to be driven to the mall and assisted to go shopping, or attend a movie without relying on family or friends
- Health professionals be available to assist mum and dad/caregivers with working through letting us go and helping us become more independent

5. Independence

Problems

Flatting – not allowed to go by parents
 Scary to go out alone, not sure whether we have the skills but we want to

Cost too much with no suitable options especially if alterations are required or assistance needed

Driving Only one person in Auckland who can provide lessons with a modified vehicle– it's expensive
Difficulty with modifying cars
Affording a car for many young people is an issue though a key to us for more independence

Finances WINZ and others often too difficult to negotiate with
Difficulty communicating on the phone, not getting the message across – frustrated
Benefit provides such little money we have no idea how to budget and afford everything we need
Have to go there they don't come to us but we have no transport available

Solutions

- People and programmes to assist us with skills to become more independent, teaching us how to access the appropriate benefits, how to budget, cook, wash etc
- Opportunities for young people with disability to go flatting or live independently
- Young people with disability provided with easier access to driving lessons, the purchasing of a vehicle and then modifying it, assistance with lottery grants etc to seek funding
- A youth advocate available to assist in advocating for appropriate benefits and entitlements etc