Counties Manukau District Health Board
Disability Support Advisory Committee Meeting Agenda

Wednesday, 16 November 2016 at 1.30 – 4.00pm, Manukau Boardroom, CM Health Board Office, 19 Lambie Drive, Manukau

Time	Item
1.30pm	1. **Welcome**
1.30 – 1.40pm	2. **Governance** 2.1 Attendance & Apologies 2.2 Disclosure of Interests/Specific Interests 2.3 Confirmation of Previous Minutes (24 August 2016) 2.4 Action Items Register
1.40 – 2.30pm	3. **Presentation** 3.1 Localities Presentation (Penny Magud)
	Afternoon Tea Break
2.45 – 3.15pm 3.15 – 3.30pm 3.30 – 3.45pm 3.45 – 4.00pm	4. **Reports** 4.1 Clinician Literacy Update (Kim Wiseman) 4.2 Responses to Action Items (Martin Chadwick) 4.3 Disability Data Evidence Working Group (Martin Chadwick) 4.4 Disability Survey Update – Statistics NZ (Martin Chadwick)

Next Meeting: 15 March 2017
Manukau Boardroom, CM Health Board Office, 19 Lambie Drive, Manukau

COUNTIES MANUKAU HEALTH – DISAC ATTENDANCE SCHEDULE 2016

Name	Jan	Feb	9 Mar	Apr	May	1 June	July	24 Aug	Sept	Oct	16 Nov	Dec
Lee Mathias (Board Chair)	No Meeting	No Meeting	✓	No Meeting	No Meeting	✓	No Meeting	✓	No Meeting	No Meeting	X	No Meeting
Colleen Brown (DiSAC Chair)			✓			✓		✓			X	
Sandra Alofivae			X			X		X				
David Collings			X			✓		✓				
Dianne Glenn			✓			✓		✓				
Reece Autagavaia			✓			X		✓			X	
Mr Sefita Hao'uli			✓			✓		X				
Ms Wendy Bremner			✓			✓		X				
Mr Ezekiel Robson			✓			✓		✓				
Mr John Wong			✓			✓		✓				
Anae Arthur Anae*			X			✓		*			*	

* resigned effective 20.7.16

COMMITTEE MEMBERS' DISCLOSURE OF INTERESTS 16 November 2016

Member	Disclosure of Interest
Dr Lee Mathias, Chair	• Chair Health Promotion Agency • Chairman, Unitec • Deputy Chair, Auckland District Health Board • Acting Chair, New Zealand Health Innovation Hub • Director, healthAlliance NZ Ltd • Director, New Zealand Health Partners Ltd • External Advisor, National Health Committee • Director, Pictor Limited • Director, John Seabrook Holdings Limited • MD, Lee Mathias Limited • Trustee, Lee Mathias Family Trust • Trustee, Awamoana Family Trust • Trustee, Mathias Martin Family Trust •
Colleen Brown	• Chair, Disability Connect (Auckland Metropolitan Area) • Member of Advisory Committee for Disability Programme Manukau Institute of Technology • Member NZ Down Syndrome Association • Husband, Determination Referee for Department of Building and Housing • Chair IIMuch Trust • Director, Charlie Starling Production Ltd • Member, Auckland Council Disability Advisory Panel • Member, NZ Disability Strategy Reference Group
Sandra Alofivae	• Member, Fonua Ola Board • Director, Housing New Zealand • Member, Ministerial Advisory Council for Pacific Island Affairs • Member, Social Housing Reference Group • Independent Chair, Social Investment Board
David Collings	• Chair, Howick Local Board of Auckland Council • Member Auckland Council Southern Initiative
George Ngatai	• Chair Safer Aotearoa Family Violence Prevention Network • Director Transitioning Out Aotearoa • Director BDO Marketing • Board Member, Manurewa Marae

	• Conservation Volunteers New Zealand • Maori Gout Action Group • Nga Ngaru Rautahi o Aotearoa Board • Transitioning Out Aotearoa (provides services & back office support to Huakina Development Trust and provides GP services to their people). • Chair of Restorative Practices NZ.
Dianne Glenn	• Member – NZ Institute of Directors • Member – District Licensing Committee of Auckland Council • Life Member – Business and Professional Women Franklin • Member – UN Women Aotearoa/NZ • President – Friends of Auckland Botanic Gardens and Chair of the Friends Trust • Life Member – Ambury Park Centre for Riding Therapy Inc. • Vice President, National Council of Women of New Zealand • Member, Auckland Disabled Women's Group • Member, Pacific Women's Watch (NZ) • Justice of the Peace
Reece Autagavaia	• Member, Pacific Lawyers' Association • Member, Labour Party • Member, Auckland Council Pacific People's Advisory Panel • Member, Tangata o le Moana Steering Group • Employed by Tamaki Legal • Board Member, Governance Board, Fatugatiti Aoga Amata Preschool • Trustee, Epiphany Pacific Trust
Sefita Hao'uli	• Trustee Te Papapa Pre-school Trust Board • Member Tonga Business Association & Tonga Business Council • Member ASH Board • Board member, Pacific Education Centre • Chair, Advisory Group on Tatupu Project with Ministry of Pacific Peoples Advisory roles: • Tongan Community Suicide Prevention Project (MoH) • Tala Pasifika (NZ Heart Foundation Pacific Tobacco Control) Consultant: • Government of Tonga: Manage RSE scheme in NZ • NZ Translation Centre: Translates government and health provider documents. • Member, Ministerial Advisory Council for Pacific Island Affairs.

Wendy Bremner	• CEO Age Concern Counties Manukau Inc • Member of Health Promotion Advisory Group (7 Age Concerns funded by MOH) • Member Interagency Suicide Prevention Group
Ezekiel Robson	• Department of Internal Affairs Community Organisation Grants Scheme Papakura/Franklin Local Distribution Committee • Be.Institute/Be.Accessible 'Be.Leadership 2011' Alumni • Member, CM Health Patient & Whaanau Centred Care Consumer Council
John Wong	• Director, Asian Family Services at The Problem Gambling Foundation of New Zealand (PGF), also part of the PGF national management team • Member, National Minimising Gambling Harm Advisory Group • Chairman and Trustee, Chinese Positive Ageing Charitable • Chairman, Chinese Social Workers Interest Group of the Aotearoa New Zealand Association of Social Workers • Chairman, Eastern Locality Asian Health Group • Founding member and council member, Asian Network Incorporation (TANI) • Board member, Auckland District Police Asian Advisory Board • Member, Auckland and Waitemata DHBs Suicide Prevention Advisory Group • Board member, Manukau Institute of Technology (MIT) Chinese Community Advisory Group • Member, CADS Asian Counselling Service Reference Group • Member, Waitemata DHB Asian Mental Health & Addiction Governance Group • Member, Older People Advisory Group (ACC) • Member, University of Auckland Social Work Advisory Group • Member, Community Advisory Group of Health Care New Zealand • Member, Auckland Regional Public Health Service – Asian Public Health External Reference Group • Member of the Advisory Committee for the School of Social Sciences &Public Policy at AUT University

DISABILITY SUPPORT ADVISORY COMMITTEE MEMBERS' REGISTER OF DISCLOSURE OF SPECIFIC INTERESTS

Specific disclosures (to be regarded as having a specific interest in the following transactions) as at 16 November 2016

Director having interest	Interest in	Particulars of interest	Disclosure date	Board Action

Minutes of Counties Manukau District Health Board
Disability Support Advisory Committee

Held on Wednesday 24 August 2016 1.30 – 4.00pm, Manukau Boardroom, CM Health Board Office, 19 Lambie Drive, Manukau.

Present: Dr Lee Mathias, Ms Colleen Brown (DiSAC Chair), Mr David Collings, Ms Dianne Glenn, Mr Reece Autagavaia, Mr Ezekiel Robson, Mr John Wong and Ms Rebecca Ellis (acting Secretariat).

Apologies: Ms Sandra Alofivae, Mr Sefita Hao'uli, Ms Wendy Bremner, Mr Martin Chadwick and Ms Colleen Brown (for leaving early).

In Attendance: Mr Simon Kerr (Professional Lead, Physiotherapy) in attendance for Mr Martin Chadwick.

1. **Welcome**
   The Chair welcomed everyone to the meeting.

2. **Governance**
   2.1 Attendance & Apologies

   Noted

   2.2 Disclosure of Interest/Specific Interests

   The Disclosures of Interest were noted with no amendments.

   Mr Robson advised that his Specific Interests noted on page 6 can now be removed.

   2.3 Confirmation of Regional Public Minutes – 1 June 2016

   Mr Collings advised he was not present at this meeting.

   Mr Robson questioned the minutes as to whether they achieved what was required and whether they were correct, particularly with regard to the Resolution passed under Item 4.1 as he understood that this was a regional discussion and was not captured correctly and also the Resolution passed under Item 4.4 as it did not make sense.

   With regard to the Resolution passed under Item 4.1, Ms Brown advised that this was in reference to what the region was undertaking as there is a concern with regard to health literacy across the community and the consistent collection of data. Ms Brown advised she was waiting on a response from Sandra Coney with regard to clinical issues.

Item 4.2 Collection of Data for Patients with Disabilities - Ms Brown to contact Mr Chadwick/Doone Winnard to ascertain whether there was attendance from Counties Manukau Health at the Disability Workshops that had been recently held.

With regard to the Resolution passed under Item 4.4, Ms Glenn noted that it was in reference to Be.Accessible.

Dr Mathias advised that there were two versions of the minutes and both were slightly different however, she is satisfied that they correctly reflected what was discussed.

Mr Robson advised he had concerns regarding the next DiSAC meeting as this would be post the election and pre new members taking office. He is conscious only four meetings occur per year. Ms Brown advised that the agenda would be somewhat expanded for the next meeting and that she would discuss this with the Executive prior to that meeting agenda being confirmed.

Resolution

That the Regional Minutes of the Disability Support Advisory Committee meeting held on Wednesday 1 June 2016 were taken as read and confirmed as a true and accurate record noting the changes outlined in the discussion above.

Moved: Dr Lee Mathis **Seconded:** Ms Colleen Brown **Carried: Unanimously (Mr Robson abstained)**

2.4 Action Items Register Public

Item 2.5 Manawhenua community representative for this committee – Mr Robson questioned the approach. Ms Brown advised that the interviews would be completed following proper procedure with an interview panel. All applicants would be required to be treated with the same process. Interviews will occur after the elections.

Item 3.2 (page 17) – change second bullet point *'monitoring the maturation of the Localities and community boards'* to *'monitoring the maturation of the Local Boards and Community Boards..".*

3. **Reports**

3.1 Te Roopu Waiora

Ms Tania Kingi, CEO Te Roopu Waiora, gave the Committee an update on a training pilot entitled Te Tohu Whakwaiora being provided through Te Roopu Waiora.

Ms Kingi acknowledged CM Health in relation to the work being undertaken with the disability programme and community plan. The report tabled today has come out of the findings of that programme.

Te Roopuu Waiora has initiated a training pilot entitled Te Tohu Whakwaiora with the aim of the programme being to discuss issues and solutions surrounding Maaori people and develop

cultural competencies. The pilot will be implemented by Te Roopuu Waiora during the period August 2016 through to January 2017 and will be communicated through CM Health via the GM Maaori Health and Manawhenua.

(Ms Brown departed at 3.30pm. Apulu Reece Autagavaia continued to chair the meeting).

The Committee requested a review be undertaken in relation to the use of interpreters through CM Health services and the need for further education on cultural competencies and workforce education through the community. Mr Kerr to report back to the Committee at the 16 November meeting.

The Deputy Chair thanked the presenters for attending the meeting today and apologised on behalf of the Committee for not having an interpreter present at this meeting.

3.2 Inpatient Experience Survey No. 6

Dr David Hughes, Clinical Director for Patient Safety & Quality Assurance attended and took the Committee through the information in the Survey which focussed on patient experience with a disability focus.

The graph on page 23 of the report was reviewed. Dr Hughes advised that the numbers are much smaller but the margin of error is greater and worth reviewing further. The survey is completed externally and was first undertaken in ADHB and that the format of that report is clear and concise. Our report is of a similar nature.

In response to a question about whether there were any budgetary costs associated with the report, Dr Hughes advised that costs were approximately $38k per annum which is due to the time spent capturing the data and the costs of putting the report together. Capturing the data and collating into an electronic form is one of the largest steps in collating the report.

Dr Hughes noted that the Primary Care survey is about to be rolled out regarding experience of care for inpatients and outpatients. The information from this survey would be available soon.

The Committee advised they were interested to review an outpatient survey report once patients are discharged, with a view on how they rate our hospital, staff and its services. Dr Hughes advised he would look at putting together a quarterly dashboard report/post discharge report for the Committee (date tbc).

Mr Wong questioned the number of responses that had been received. Dr Hughes advised that over 60% of people had responded – 10% Maaori, 10% Pacific Islanders, 10% Asian with the rest European. Statistics to the survey will be available next quarter.

Mr Robson noted that the responses in relation to Food & Dietary Needs has raised a red flag at 51%. Dr Hughes advised that the survey did require some further work however, on reviewing the overall result from all responses, it showed that this was not actually a bad result.

Mr Robson further commented with regard to the accessibility of patients being able to eat or drink is one issue being faced and would like to ascertain how WDHB address the issue of accessibility. Dr Hughes to contact Samantha Dalwood – Disability Advisor for WDHB regarding his concern.

Resolution:
That the Disability Support Advisory Committee:

Receive the Patient Experience Report with a focus on Disability.

Moved: Mr Ezekiel Robson **Seconded:** Mr Reece Autagavaia **Carried:** Unanimously

3.3 Regional Data Collection Pertaining to the Disability Community

At the Regional DiSAC meeting it was noted that there is an ability to use population level data to extrapolate and make assumtions around the level of disability within our resident community. What was further noted was that current systems and processes do not easily enable the collection of data around disability issues.

This lack of data around the disability community highlights the issue that should an individual present to our facilities for either a disability related, or an unrelated complaint, the fact that they are living with a disability is not necessarily captured within current systems and processes. As such it is unlikely that it will be coded as such which is critical from a data capture standpoint. This then makes it near impossible to draw any correlation between common procedures and the outcome difference (if any) between someone living with, or not living with a disability. This in turn limits the ability to make informed decisions around how to align services to take into account the needs of the disability community.

This is an issue that is not unique to CM Health, and the Regioanl DiSAC confirmed this issue exists across the region. As we have a large portion of the population that move across DHB boundaries, to approach this in an ad hoc fashion would be less that helpful. There is an opportunity arising out of the Regional DiSAC to take a regional approach as to how this could be addressed.

The Committee questioned the final bullet point in the Recommendations on the paper tabled at today's meeting which read: "*It requests CM Health management to scope the resource needed by CM Health to contribute to such a working group".* It was felt this was unclear.

Resolution

That the Disability Support Advisory Committee **recommend** to the Board that:

- It notes that the Auckland metro DiSAC Committees will:
    - Actively engage with the disability data and evidence working group.
    - Seek to understand how the need for better disability population data will be reflected in the review of the Disability Strategy.
- It notes that DiSAC recognises that while there is the ability to collect and extrapolate population level data pertaining to health needs of the disability community, there is not the same ability to collect and interpret this data at a granular level.
- It notes that any efforts to improve data collection around the disability community needs to be accomplished at a regional level for greatest applicability.
- A small regional working group be established to:
    - Establish guidelines relating to the collection of data to support the DHBs to be good employers of people with disabilities.
    - Quantify the meaningful data that would benefit from being collected pertaining to the disability community.
    - Investigate processes for the collection of the identified data about staff with disabilities.
    - Ensure the same method of data collection be employed across the three regional DHBs.
    - Determine what information is currently being collected.
    - Clarify what gaps exist between 1 and 2.
    - Propose solutions to the prospective DHB Boards to improve the capture of the data pertaining to the disability community.
- It requests CM Health Management to scope the resource needed by CM Health to contribute to such a working group, including the number of people required and if any external parties/groups are required to be involved.

Moved: Ms Dianne Glenn **Seconded:** Mr John Wong **Carried:** Unanimously

4. **General Business**:

4.1 E-mail regarding Disability Strategy

Mr Robson queried the e-mail regarding the Disability Strategy as he felt it was an open ended question. Dr Mathias requested that the Executive's advise what they are doing about the Disability Strategy as this requires action to this Committee.

The meeting closed at 3.26pm. The next meeting of the Disability Support Advisory Committee will be held on **Wednesday, 16 November 2016** in the Manukau Boardroom, CM Health Board Office, 19 Lambie Drive, Manukau.

The Minutes of the meeting of the Counties Manukau District Health Board Disability Support Advisory Committee held on **Wednesday, 24 August 2016** are approved.

Signed as a true and correct record on **Wednesday, 16 November 2016.**

Moved : /Seconded:

Chair _____ 16 November 2016
Colleen Brown Date

Deputy Chair _____ 16 November 2016
Apulu Reece Autagavaia Date

Items once ticked complete and included on the Register for the next meeting, can then be removed the following month.

Disability Support Advisory Committee Meeting – Action Items Register – 16 November 2016

DATE	ITEM	ACTION	DUE DATE	RESPONSIBILITY	COMMENTS/UPDATES	COMPLETE ✓
3.6.2015	2.5	Manawhenua community representative for this Committee.	On Hold	Mr Chadwick	3.6.2015 - deferred to Board Chair for follow-up with Manawhenua. 18.11.2015 – Dr Mathias confirmed that Manawhenua have identified a disabled Maaori representative and that this needs to be followed up with them. 5.8.16 – Board Secretary advised appointment *on hold* due to the local elections taking place in October.	
3.6.2015	5.	Mr Hao'uli suggested that a Pacific community representative with a disability focus be appointed to the Committee and he would step down.	On Hold	Ms Brown	This position has been approved by the Board chair. Ms Brown to now finalise how to appoint to the position. 18.11.2015 – Ms Brown to follow up with Mr Sefita Hao'uli on his suggestion that he step down to allow a Pacific representative with a disability focus to be appointed. 5.8.16 – Board Secretary advised appointment *on hold* due to the local elections taking place in October.	
26.8.2015	3.1	Disability Strategy – Community Dialogue GM Localities to return to DiSAC in one year for an update. For discussion: • Who has the resources to plan, fund & undertake a current state & gap analysis of community groups and services per locality from a disability perspective; • Who can resource disability stakeholder engagement per locality for sustainable service design and development.	16 November	Mr Chadwick	Refer Item 3.1 on today's agenda.	✓

Items once ticked complete and included on the Register for the next meeting, can then be removed the following month.

DATE	ITEM	ACTION	DUE DATE	RESPONSIBILITY	COMMENTS/UPDATES	COMPLETE ✓
18.11.2015	3.1	Clinician Capability – Work-plan findings and actions to be reported back.	16 November	Ms Wiseman	Refer Item 4.1 on today's agenda.	✓
9.3.2016	2.4	Maaori Health Quarterly report against current work programme in relation to engagement with Maaori on disability issues.	15.3.2017		Item deferred pending new GM Maaori Health being appointed.	
9.3.2016	3.2	DiSAC 2016 Focus Investigate if any outreach programmes are currently operating in schools to raise awareness around disability (ie) TAC/Kaleidoscope and look at how we can understand and influence what they do.	16 November	Mr Chadwick	Refer Item 4.2 on today's agenda.	✓
		Clinician Literacy – look into what Te Roopu Waiora are currently doing in relation to training Maaori with disabilities to go into hospitals to assist Maaori patients have a better interaction with doctors, nurses etc.	24 August	Mr Chadwick	This item was discussed at the 24.8.16 DiSAC meeting and can now be removed from the Action Item Register.	✓
9.3.2016	4.1	General Business Look into what the district health board's process is in situations where a disabled person, who is medically dependent on an uninterrupted power supply, has their power disconnected by a lines company who had not been made aware of their dependency by the power provider.	16 November	Mr Chadwick	Refer Item 4.2 on today's agenda	✓
1.6.2016 (Regional DiSAC meeting)	4.2	Collection of Data for Patients with Disabilities Akld metro DHBs to form a small working group to: • actively engage with the disability data and evidence working group. • to understand how the need for better	16 November	Mr Chadwick	Refer Item 4.3 on today's agenda.	✓

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DATE	ITEM	ACTION	DUE DATE	RESPONSIBILITY	COMMENTS/UPDATES	COMPLETE ✓
		disability population data will be reflected in the review of the disability strategy.				
24.8.2016	3.1	Undertake a review in relation to the use of interpreters through CM Health services and the need for further education on cultural competencies and workforce education through the community.	15.3.2017	Mr Kerr	16.11.16 – there has been a lot of work in this space around scope & technology. This would be a good item to present on and has been deferred to the 15 March 2017 meeting.	
24.8.2016	3.2	Inpatient Experience Survey The Committee advised they were interested to review an outpatient survey report once patients are discharged, with a view on how they rate our hospital, staff and its services. Dr Hughes to put together a quarterly dashboard report/post discharge report. Accessibility of patients being able to eat or drink is one issue being faced and the Committee would like to ascertain how WDHB address the issue of accessibility. Dr Hughes to contact Samantha Dalwood – Disability Advisor for WDHB regarding this.	29.11.2017 Date TBC	Mr Chadwick Dr David Hughes	16.11.16 – suggest this is deferred to 29 November 2017 meeting so there can be the ability to report back on progress made.	
24.8.2016	4.1	General Business The Executive to advise what they are doing about the Disability Strategy as this requires action to this Committee.	16 November	Mr Chadwick	Refer Item 4.2 on today's agenda.	✓

Items once ticked complete and included on the Register for the next meeting, can then be removed the following month.

Resolutions						
9.3.2016	3.2	DiSAC 2016 Focus **Resolution** **Endorsed** a focus on the local DiSAC for 2016 on: • Monitoring progress on the initiatives underway around clinician literacy. • Monitoring the maturation of the Local and Community Boards to be able to ensure the voice of the disability community is heard. • Learning from social media campaigns that have been undertaken by CM Health (ie) SnapChat smoking cessation initiative, positive peer pressure to reduce smoking around the hospital, and to determine if there are any lessons that can be applied to raising awareness around the disability community. • Continuing to engage with Health Point and Health Navigator to ensure there is adequate representation of material pertaining to the disability community. • Celebrating disabled employees. **Moved:** Ms Colleen Brown/**Seconded:** Dr Lee Mathias/**Carried:** Unanimously	15.3.2017	Mr Chadwick	16.11.16 – suggest this is reviewed at the 15 March 2017 meeting so DiSAC has a level of satisfaction that there has been progress in these areas and do we choose to keep the same focus or adjust/adapt.	
24.8.2016		**Resolution** That the Disability Support Advisory Committee **recommend** to the Board that: • It notes that the Auckland metro DiSAC Committees will: o Actively engage with the disability data and evidence working group.			1.9.2016 – Resolution passed to the Board Secretary. 16.11.2016 - The Board passed this Resolution on 7 September 2016. Actions are now sitting with Mr Chadwick.	✓

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		○ Seek to understand how the need for better disability population data will be reflected in the review of the Disability Strategy. • It notes that DiSAC recognises that while there is the ability to collect and extrapolate population level data pertaining to health needs of the disability community, there is not the same ability to collect and interpret this data at a granular level. • It notes that any efforts to improve data collection around the disability community needs to be accomplished at a regional level for greatest applicability. • A small regional working group be established to: ○ Establish guidelines relating to the collection of data to support the DHBs to be good employers of people with disabilities. ○ Quantify the meaningful data that would benefit from being collected pertaining to the disability community. ○ Investigate processes for the collection of the identified data about staff with disabilities. ○ Ensure the same method of data collection be employed across the three regional DHBs. ○ Determine what information is currently being collected. ○ Clarify what gaps exist between 1 and 2.				

Items once ticked complete and included on the Register for the next meeting, can then be removed the following month.

		o Propose solutions to the prospective DHB Boards to improve the capture of the data pertaining to the disability community. • It requests CM Health Management to scope the resource needed by CM Health to contribute to such a working group, including the number of people required and if any external parties/groups are required to be involved. **Moved:** Ms Dianne Glenn/**Seconded:** Mr John Wong/**Carried:** Unanimously				

Counties Manukau District Health Board
Disability Advisory Committee
Clinician Literacy Update

Recommendation

It is recommended that the Disability Advisory Committee:

Receive the Clinician Literacy update of activities.

Agree the continuing work plan for 2017.

Prepared and submitted by: Kim Wiseman, Building Capability Lead, Ko Awatea

Purpose

The purpose of this paper is to provide an update on activities to date and outline proposed next steps with regard to the disability support plan for Building Capability.

Background

In June 2015 a problem statement was developed (in partnership with members of the Disability Advisory Committee) to help shape the capability requirements and hence the workforce development for CM Health. This statement then informed the aim which was that:

Any person with a disability or a disability support person will have the confidence that any care delivered will be done in a knowledgeable and respectful way with a focus on inclusion on all aspects of care delivery and in a way which is accessible to the client/patient

Since the last update there has been considerable activity aimed at building clinician capability in a number of broad areas. We anticipate that this will have a positive impact on the experiences of our disabled community when accessing our services. Previously we had no information regarding specific experience data related to patients/clients who identified themselves as disabled. This has changed since the last update with the publication of the CM Health report number 6 on inpatient experience (July 2016). We are now in the position to undertake further targeted work which will enable us to understand in more detail where specifically we are falling short for our disabled community.

Activity Update

Values

Following the initial activities of the launch of the values in October 2015 the focus has been on embedding the principles. To this end the values have become a “golden thread” which is weaved through virtually every course or interaction that the Building Capabilities team are involved in. This means that we start with Welcome Day so that all new staff members from across disciplines and specialities are introduced to them. That means that we have reinforced the values with in excess of 800 new members of staff. There is also an interactive session on the Code of Rights during Welcome Day. We have also run three more in depth values sessions for new managers who were not in the

organisation during the development of the values so that they can model the behaviour that we are expecting.

As part of the patient safety training (PST) which is an annual update for all registered nurses we have included the values this means that we have reached over 1500+ nurses and midwives during the past 12 months in both the hospital and community settings.

Refresh of AI^{2}DET

The refresh of the AI^{2}DET tool has enabled the incorporation of the principles of health literacy. This tool was originally a communication tool for staff and whilst it was well liked there was an opportunity to renew the pictures to reflect our community. The 'E' has also changed from explanation to Enquire and Effective Communication both of which have a synergy with the identified aim of this work stream. There were a number of options that were tested with staff in July 2016 and the refreshed tool is being launched as part of patient safety week 31 October – 4 November. It is intended that this will be one of the golden threads for 2017 PST and we are planning to incorporate scenarios that will enable the nurses and midwives to relate these aspects to helping people with disabilities to receive care in a way that the individual finds most acceptable.

CALM communication and SPEC courses

We continue to run regular CALM communication courses in the general specialities and SPEC within mental health. SPEC has helped mental health services to reduce the number of seclusions that patients experience. The course has also been held up as the national standard and so it is being shared across the whole of New Zealand.

Health Literacy Education

We now have 617 people across the whole DHB who have received the health literacy learning module. As already outlined we have commenced the process of embedding this in to a variety of offerings as a core skill for the organisation.

CALD 8

We have access to working with CALD families - Disability Awareness which is advertised via SouthNET. Uptake to date has been particularly poor with only one course taking place and another being cancelled during 2016. This means that only eight people have attended. A taster session was arranged for a lunchtime session to promote all the CALD courses but again this was poorly attended. This offering will be reviewed in light of the outcomes from the patient experience workshops.

Data, Information and Knowledge

The focus of number 6 patient experience report has been beneficial to furthering our understanding of some of the issues that people with disabilities have. It is important to note that half the respondents identified themselves as having a disability but there satisfaction with their experience was four points lower than people who did not identify as having a disability and this was statistically significant for interaction with doctors, nurses and midwives.

Whilst we have the broad basis of information the next step is to gain some in depth insight in to the experience of interactions with CM Health staff from people who have a disability and disability support people. In order to facilitate this we have arranged a focus group on the 30 November. The focus for the event is to help us gain an understanding of what we are doing well and what we need to do differently in order to realise equity of experience for all of our patients and whanau.

In early 2017 we will run staff focus groups to explore the issues from their perspective and where current gaps exist in their capability. We will also be leveraging our inter professional student work programme to help explore this issue from their perspective especially as allied health do not demonstrate the difference in experience that doctors, nurses and midwives do.

We have also undertaken a literature search with has provided us with some examples of what others (both nationally and internationally) have undertaken to improve knowledge, skills and capabilities in this field. This information will be utilised to resolve the specific challenge that we identify in CM Health.

International Day of Persons with Disabilities

On 3 December 2015 we utilised a multifaceted approach to promote awareness of disability. This included running lunchtime workshops in Ko Awatea with Toi Ora a live art trust who work with people in support of their mental health and wellbeing. We also presented promotional material to staff, patients and whanau and took treats to areas where a significant number of patients with disabilities are for example the spinal unit and ARHOP.

We are in the process of planning a repeat event for 3 December 2016 but are currently awaiting for some guidance from the commission about contents for the day.

Summary

During in 2016 we have ensured that strong foundations are in place on which we can now build the finer details. We have ensured we are building the capability of our staff in terms of patient experience, communication, values and health literacy. We have now progressed to commence the deep dives in to the specific experiences of people with disabilities. The information and knowledge that we gain from patients, whaanau and support people will shape the intervention that we take with the staff focus groups. It will be important that whatever capability gaps are identified that the solution delivers the improvement in experience and realises the equity of experience that we are all hopeful of.

Work plan for identification of capability gaps and appropriate interventions to realise equity of experience for people with disability

Area	Action	Timeframe
Patient and Whaanau experience	• In partnership with the Patient and Whaanau Care Advisor Interviews with patients and whaanau to understand their experiences of our health system, to include primary and acute services where appropriate	30/11/16
	• Produce thematic analysis	23/12/16
Staff experience	• Interviews with staff to understand their experiences of providing care to people with disabilities, specifically any examples of where they felt unable to provide a high level of care.	Week beginning 23/01/17
	• Produce thematic analysis	30/01/17

Students experience	• Interview undergraduate students to identify their experiences of caring for people with a disability as well as an overview of undergraduate training in this area • Produce thematic analysis	Week beginning 23/01/17 30/01/17
Findings	• Compare the data and thematic analysis from all interviews to identify where we are falling short in terms of patient experience and the capability of our current and future workforce	07/02/17
Development plan	• Design a capability plan and activities with members of the disability community to address the learning needs identified	End February 17
Dissemination	• Write up / publish findings and actions	End March 17

Counties Manukau District Health Board
Disability Support Advisory Committee
Response to Action Items

Recommendation

It is recommended that the Disability Support Advisory Committee:

Receive the Response to Action Items report.

Prepared and submitted by: Martin Chadwick, Director Allied Health

DiSAC Meeting 9.3.2016 – Item 3.2
Investigate if any outreach programmes are currently operating in schools to raise awareness around disability (ie) TAC/Kaleidoscope and look at how we can understand and influence what they do.

Kaleidoscope is a Not-For-Profit organization that was formed by Professor Alan Clark who was a dedicated and passionate medical professional, who had a spinal cord injury. Kaleidoscope is an early intervention and restorative vocational rehabilitation program that provides detailed career advice and planning, educational support and works to reduce the fear of work and remove barriers. Services delivered are specialist work support, both to acute patients and community clients.

Guiding principles are:

- Everyone can have a great job
- Its healthy to be working
- The sooner the better
- There are thousands of work opportunities
- Personal networks are the key
- The process for getting a job is the same as before
- You can do it yourself – Whatever it takes!
- Your life experiences give you unique qualifications

As such Kaleidoscope is a separate entity from CMH, with a particular focus on vocational re-training for individuals who have had a spinal cord injury. It is not believed that they currently carry out any education in High Schools.

The Association for Spinal Concerns (TASC) was originally founded in 1991 by a group of high level spinal injured people as a support group, which has gradually evolved into the present organization. Since 2008 TASC became a registered charity and has now built up a vast network of volunteers who with their various experiences are able to offer moral support, advice and information to the new patients in the Spinal Unit. TASC covers the same geographical area as the Auckland Spinal Rehabilitation Unit, which is from New Plymouth, Taupo, across to the Eastern Bay of Plenty, up to Cape Reinga.

TASC's aims are to - provide peer support for people living with a SCI/their family and whanau - Foster friendships through regional gatherings and social outings - Provide knowledge and information through the TASC newsletters and Facebook page. There is no current strategy in place with TASC to reach out to High Schools.

While the Spinal Unit staff are actively involved in both entities, the primary outreach vehicle is The Right Track, which is an education programme devised as a proactive approach to driver behaviour. It is intended to educate, motivate, challenge, inspire and inform young people through a range of experiences that will

impact upon them and their families and help them make better decisions and choices in the future.

The programme targets young people, adults and recidivist offenders within the Justice System who have been apprehended for Driving Offences. The offender is referred to The Right Track via an Alternative Action Plan, Police Diversion, as a result of a Family Group Conference, by the judiciary through the court system or Community Magistrate, through the Probation Service or by Self-Referral. It is based on participation in a 42-hour programme over a period of four weeks during which the learners are required to attend seven sessions staged on Midweek evenings (two hours) and Saturdays (full day).

Another outreach that is specific to the Allied Health Directorate is The Workforce Expo which is held as a part of the Allied Health Celebration week. It is an opportunity for secondary school students to learn about the wide range of allied health professions that exist in health care. Often this is the first time that students will learn that there are other careers in health that might appeal to them, rather than simply medicine and nursing. The plethora of professions across Counties Manukau's allied health directorate actively engage with these events; interacting and demonstrating aspects of their work to students attending. This is a very hands on event which exposes the students to much of the rehabilitation equipment that is used as a part of rehabilitation, and working with the disability community.

DiSAC Meeting 9.3.2016 – Item 4.1

Look into what the district health board's process is in situations where a disabled person, who is medically dependent on an uninterrupted power supply, has their power disconnected by a lines company who had not been made aware of their dependency by the power provider.

This falls under the umbrella of "Medically Dependent Consumers of Electricity (MDC)". It is the DHB's responsibility to complete the qualification of an individual as an MDC, and to notify the Electricity Retailers. A guideline on "Arrangements to Assist Medically Dependent Consumers" has been developed in consultation with the Ministry of Health, DHBs, the Royal New Zealand College of General Practitioners, other health providers, electricity retailers and social agencies. The Guideline does not imply a guaranteed supply of electricity. As noted in the guideline temporary electricity outages do occur from time to time. It is expected that:

(i) MDCs note that retailers cannot guarantee the supply of electricity at all times. Therefore MDCs need to take responsibility for ensuring that they have an emergency response plan in place to respond to any electricity outage

(ii) such a plan will be particular to the MDCs affected, and may range from ensuring that a stand-by battery is always fully charged, to relocating to a friend's or family member's premises which has electricity at that point in time, or even calling an ambulance to be taken to hospital

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DiSAC Meeting 24.8.2016 – Item 4.1

Executive to advise what they are doing about the Disability Strategy as this requires action to this Committee.

Mr Chadwick to provide a verbal update at this meeting.

Guideline on arrangements to assist medically dependent consumers

Version 2.1

Version control

Version	Date amended	Comments
1.0	2005	
2.0	July 2007	
3.0	January 2008	
4.0	February 2009	Updated version published for consultation, 23 February 2009.
5.0	May 2009	Updated due to consultation process
1.0	July 2009	New Guideline about medically dependent consumers created as a result of consultation with retailers, social agencies, distributors, the health sector and government agencies.
1.1	October 2009	Version released for consultation.
2.0	November 2009	Updated version created after consultation process.
2.1	1 November 2010	Updated for transition to Electricity Authority.

Glossary of abbreviations and terms

Account holder	The person who has a contract with or applies to have a contract with a retailer for the supply of electricity to a domestic premises.
CEME	Critical electrical medical equipment. Any equipment supplied or prescribed by a health practitioner with an appropriate scope of practice, which requires mains electricity to provide critical medical support to a person. It may also include other electrical equipment needed to support the treatment regime (e.g. a microwave to heat fluids for renal dialysis). Appendix B contains a non-exhaustive list of CEME.
Authority	Electricity Authority.
Critical medical support	Support which, in the opinion of a health practitioner with an appropriate scope of practice[1], is required to prevent loss of life or serious harm.
DHB	District Health Board.
Notice of disconnection	A notice of disconnection generally provides at least seven days' notice of the retailer's intent to disconnect electricity from a domestic premises.
Domestic consumer	Any person who purchases or uses electricity in respect of any domestic premises. For the avoidance of doubt, this includes (a) the account holder; and (a) any resident of a dwelling, whether or not they are named on the electricity invoice issued by the retailer Note: it is assumed that communication is generally between the retailer and the account holder.
Domestic premises	Any premises used or intended for occupation by any person principally as a place of residence.
GP	General practitioner.
GPS	*Government Policy Statement on Electricity Governance* (May 2009).
Guideline	*Guideline on arrangements to assist medically dependent consumers*.

[1] As that term is defined in section 5 of the Health Practitioners Competence Assurance Act 2003.

HP	Health practitioner (includes DHBs, private hospitals and GPs). A person who is, or is deemed to be, registered with an authority as a practitioner of a particular health profession under the Health Practitioners Competence Assurance Act 2003.
MDC	Medically dependent consumer. A domestic consumer who is dependent on mains electricity for critical medical support[2], such that loss of electricity may result in loss of life or serious harm. For the avoidance of doubt, medical dependence on electricity could be for use of medical or other electrical equipment needed to support the treatment regime (e.g. a microwave to heat fluids for renal dialysis or equipment such as that listed in Appendix B). This Guideline uses the term 'MDC' to include potential MDC, verified and reverified MDC.
Notice of Potential MDC Status	Notice of Potential Medically Dependent Consumer Status (in Appendix A) is the key means by which retailers identify potential MDCs and obtain details of an MDC's CEME-prescribing/supplying DHB, private hospital or GP.
Retailers	Electricity retailers and distributors who directly charge their consumers.
VC Guideline	*Guideline on arrangements to assist vulnerable consumers*.

[2] Support which, in the opinion of a health practitioner with an appropriate scope of practice, is required to prevent loss of life or serious harm. This is usually provided by critical electrical medical equipment (CEME), which is any equipment supplied or prescribed by a health practitioner with an appropriate scope of practice, which requires mains electricity to provide critical medical support to a person, and includes other electrical equipment needed to support the treatment regime (e.g. a microwave to heat fluids for renal dialysis).

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Introduction

1. This Guideline articulates the Electricity Authority's (Authority) expectations of electricity retailers[3] in respect of medically dependent consumers (MDCs). It represents a minimum standard that the Authority expects retailers to meet. However, retailers may choose to design alternative methods for assisting MDCs, so long as retailers meet or exceed the minimum standards.

2. The Guideline:

   (a) defines a MDC;

   (b) is designed to ensure that all MDCs receive the most appropriate consideration of their needs and any support that they are legally entitled to;

   (c) suggests actions designed to assist retailers and MDCs in avoiding or at least minimising:

      (i) non-payment by MDCs[4];

      (ii) the accumulation of debt by MDCs; and

      (iii) the accumulation of credit risk by retailers;

   (d) is intended to assist retailers in ensuring that no MDCs are disconnected for reasons of non-payment for electricity;

   (e) outlines the process for a domestic consumer to become registered with his or her retailer as a MDC; and

   (f) is complemented by:

      (i) a protocol that facilitates the sharing of information between retailers and social agencies[5], and has objectives which support this Guideline; and

      (ii) the *Guideline on arrangements to assist vulnerable consumers* (VC Guideline).

3. The Guideline is not intended to protect those persons:

   (a) who through bad faith do not intend to pay their electricity bill; and/or

   (b) who could be considered fraudulent users of domestic electricity.

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[3] This Guideline also covers distributors that direct bill their customers. However, for simplicity the term 'retailer' is used throughout the document.

[4] Note that the account holder is the person responsible for payment of any invoice.

[5] Protocol between electricity retailers and social agencies developed in 2005 available on the Authority's website at: http://www.ea.govt.nz/our-work/advisory-working-groups/retail-social-agency-protocol-working-group

4. The Guideline does not imply a guaranteed supply of electricity to MDCs. From time to time temporary electricity outages may occur and MDCs should ensure backup plans are in place to handle such temporary outages (see paragraph 10(d)).

Background

5. In the context of this Guideline, the Authority considers electricity to be an essential service for domestic consumers – it is a necessity for individuals and household groups to maintain health and wellbeing, and to sustain a reasonable standard of living.

Medically Dependent Consumers

6. A subset of domestic consumers is that group of people who rely on mains electricity for critical medical support[6]. The Authority defines these domestic consumers as "medically dependent consumers" (MDC), per the following definition:

> A domestic consumer who is dependent on mains electricity for critical medical support, such that loss of electricity may result in loss of life or serious harm. For the avoidance of doubt, medical dependence on electricity could be for use of medical or other electrical equipment needed to support the treatment regime (e.g. a microwave to heat fluids for renal dialysis or equipment such as that listed in Appendix B).

Policy objectives

7. This Guideline gives effect to the *Government Policy Statement on Electricity Governance* (GPS)[7], in particular the objective that:

> "any consumer who is dependent on electricity for critical medical support will not be disconnected for reasons of non-payment"[8].

8. A key concept underpinning this Guideline is that early intervention (i.e. when an electricity account first goes into arrears) is an important strategy for minimising debt accumulation by domestic consumers:

   (a) if a domestic consumer anticipates difficulties paying his or her electricity bills, then that domestic consumer should be given the opportunity to notify his or her electricity retailer and discuss any alternatives to standard monthly payments.

   (b) similarly, if a retailer believes that domestic consumers are experiencing difficulty paying their electricity bills, that retailer should discuss payment alternatives with

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6 Support which, in the opinion of a health practitioner with an appropriate scope of practice, is required to prevent loss of life or serious harm. This is usually provided by critical electrical medical equipment (CEME), which is any equipment supplied or prescribed by a health practitioner with an appropriate scope of practice, which requires mains electricity to provide critical medical support to a person, and may also include other electrical equipment needed to support the treatment regime (e.g. a microwave to heat fluids for renal dialysis).

7 "Arrangements for the benefit of low income consumers and vulnerable domestic consumers" (paragraphs 44 and 45 of the GPS, May 2009).

8 "Arrangements for the benefit of low income consumers and vulnerable domestic consumers" (paragraph 44 of the GPS, May 2009).

those consumers and, if appropriate, provide contact details of social and budgetary agencies that may be able to assist.

9. It is also important to recognise that retailers have a right to be paid.

Expectations

10. The Authority's expectations with respect to this Guideline are as follows:

General

(a) privacy and confidentiality of domestic consumers will be respected;

MDCs

(b) it is the domestic consumer's responsibility to disclose private or personal information that may be relevant to any disconnection decision by a retailer. This includes information on a person having been assessed by a DHB, private hospital or GP to be a potential MDC (as defined in this Guideline), or information on any change to a domestic consumer's MDC status over time;

(c) domestic consumers are responsible for their actions. Retailers, health practitioners (HPs) and Work and Income are not responsible for, nor required to monitor, consumer/patient/client choices;

(d) the Guideline **does not** imply a guaranteed supply of electricity. **Temporary electricity outages do occur from time to time.** It is expected that:

(i) MDCs note that retailers cannot guarantee the supply of electricity at all times. Therefore MDCs need to take responsibility for ensuring that they have an emergency response plan in place to respond to any electricity outage;

(ii) such a plan will be particular to the MDCs affected, and may range from ensuring that a stand-by battery is always fully charged, to relocating to a friend's or family member's premises which has electricity at that point in time, or even calling an ambulance to be taken to hospital;

Retailers

(e) retailers should exercise all reasonable due care and diligence and be as fully informed as possible when making the decision as to whether a domestic consumer is a MDC and therefore not subject to disconnection for reasons of non-payment;

(f) retailers should record sufficient information about their consumers' MDC status to ensure that any MDCs are not disconnected for reasons of non-payment for electricity;

Health Practitioners (HPs)

(g) "only people well enough or with sufficient support to effectively communicate with their retailer will be discharged from hospital with CEME"[9];

(h) the initial medical opinion as to whether a domestic consumer is a potential MDC is made by a DHB, private hospital or GP. Subsequent opinion verifying a domestic consumer's ongoing MDC status, as outlined in this Guideline, is given by a HP with an appropriate scope of practice[10];

(i) HPs, in accordance with appropriate clinical practice, are responsible for providing knowledge, training and support to a MDC supplied with or prescribed CEME about:

(i) the use of the CEME;

(ii) what to do in an emergency, including when the supply of electricity may be interrupted for any reason; and

Work and Income

(j) the role of Work and Income is to ensure that people receive all the government financial assistance that is available to them. Work and Income's role is not that of a credit agency, nor does it have any responsibility for, or to pay off, consumer debt.

11. These expectations are complementary to any provisions set out in the Model Contract for Domestic Consumers[11].

[9] Ministry of Health Letter to the Electricity Commission; 18 February 2008.

[10] As that term is defined in section 5 of the Health Practitioners Competence Assurance Act 2003.

[11] The Authority notes that its proposals around the contracting arrangements between retailers and domestic consumers are currently under review.

Identifying and recording medical dependency

Process outline

12. A domestic consumer's health may fluctuate over time. DHB representatives have advised that it may not be clear at the point at which a domestic consumer is prescribed CEME by their DHB, private hospital or GP, whether the disconnection of electricity at some future point in time may result in loss of life or serious harm, and thus whether the domestic consumer is medically dependent. Therefore, when a DHB, private hospital or GP issues a domestic consumer with CEME, that domestic consumer should also be given documentation by their DHB, private hospital or GP to give to their retailer that identifies them as 'potentially' medically dependent. This is the Notice of Potential Medically Dependent Consumer Status (Notice of Potential MDC Status), see Appendix A.

13. When an account holder gets into arrears with their electricity bill it is important for the retailer to know whether the disconnection of electricity may result in loss of life or serious harm for a domestic consumer resident at the premises i.e. whether a domestic consumer is medically dependent.

14. Thus, when the retailer would ordinarily send a notice of disconnection, the retailer may choose to go through a process to verify whether or not there is a MDC at the domestic premises. The verification process includes working with a HP with an appropriate scope of practice. This recognises that the MDC's ongoing care may be provided by a different HP than the DHB, private hospital or GP which supplied or prescribed their CEME.

15. In addition to verification when a retailer would ordinarily send a notice of disconnection, retailers may wish to verify/reverify domestic consumers' MDC status at regular intervals. In the Authority's view, this should occur no more frequently than once every 12 months.

16. The process for gaining potential MDC status has been developed with the following principles in mind:

    (a) only a DHB, private hospital or GP can fill in the Notice of Potential MDC Status;

    (b) MDC verification or reverification would be primarily just for the much smaller group of MDCs accumulating debt; and

    (c) for verification or reverification, a letter from a HP with an appropriate scope of practice confirming the domestic consumer's ongoing MDC status is acceptable.

Advising the consumer about the MDC process

17. To provide domestic consumers an opportunity to notify the retailer that they qualify as a MDC, retailers should communicate details about what a MDC is and how the domestic consumer can notify the retailer that they have potential MDC status, where practicable, by;

    (a) providing details on their website;

    (b) informing all new domestic consumers when they first contract with the retailer for electricity supply;

    (c) informing all domestic consumers in writing at least once annually[12]; and

    (d) informing domestic consumers in any late payment notice that has a reference to potential disconnection.

Advising retailers about medical dependency

18. When a domestic consumer is prescribed or supplied CEME, he or she will be provided with the Notice of Potential MDC Status by their DHB, private hospital or GP[13].

19. After receiving the Notice of Potential MDC Status, the domestic consumer should notify their retailer of their MDC status (e.g. by telephone). The domestic consumer should then give the Notice of Potential MDC Status to his or her retailer (e.g. by post)[14].

20. It is the domestic consumer's responsibility to keep his or her electricity retailer informed when there is no longer a MDC resident at the property.

21. When switching retailers, it is the domestic consumer's responsibility to inform the new retailer of their MDC status. It is likely that the domestic consumer will also have to provide the new retailer with the Notice of Potential MDC Status. This relies on the domestic consumer retaining the Notice of Potential MDC Status in order to provide it to any prospective new retailer they may choose to switch to.

22. For the avoidance of doubt, the Authority does not expect domestic consumers to obtain a new Notice of Potential MDC Status from a DHB, private hospital or GP every time they switch retailer.

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[12] This could be combined with other material sent out by the retailer, e.g. a newsletter.

[13] This is the key means by which retailers identify potential MDCs and obtain details of a MDC's CEME-prescribing/supplying DHB, private hospital or GP.

[14] It is up to the retailer to decide if they want the original or a copy. If a retailer does ask for the original, it should be returned to the MDC.

Verification

23. After a retailer has received the domestic consumer's Notice of Potential MDC Status, the retailer may choose to verify or reverify their MDC status:

    (a) when the retailer would ordinarily send a notice of disconnection; or

    (b) no more frequently than once every 12 months.

24. The verification or reverification process entails a retailer requiring a domestic consumer to provide suitable evidence (e.g. a letter) from a HP with an appropriate scope of practice that confirms that they are medically dependent.

Costs

25. It is expected that a domestic consumer will pay for all costs associated with gaining potential MDC status[15].

26. However, where a retailer wishes to verify or reverify a domestic consumer's MDC status, the retailer should reimburse the domestic consumer for the reasonable costs incurred if the verification or reverification confirms the domestic consumer's MDC status.

[15] A retailer may choose to pay if it wishes to.

Advice to all medically dependent consumers

Work and Income

27. Retailers should follow any protocols they have agreed with social agencies.

28. Where a domestic consumer that has been identified as a MDC is in payment default, the retailer should (after first trying to negotiate alternative payment options with the MDC and then obtaining their consent to do so) refer the MDC to Work and Income (consistent with the *Protocol between electricity retailers and social agencies*). Work and Income will seek to ensure that the MDC is provided with all financial or other assistance to which he/she is entitled.

29. The act of referring a domestic consumer that has been identified as a MDC to Work and Income does not negate the general rule that MDCs will not be disconnected as a result of non-payment for electricity.

30. The scope of the MDC's consent needs to cover:

    (a) the retailer disclosing personal information to Work and Income (such as the MDC's details, account details and repayment options already discussed) and Work and Income collecting that information from the retailer; and

    (b) Work and Income disclosing to the retailer the progress and outcome of the MDC's referral for an assessment of whether the MDC will receive assistance regarding his or her electricity account.

31. It is possible that a domestic consumer that has been identified as a MDC may refuse to give, or fail to give, his or her consent to the retailer to contact Work and Income. This may be because the MDC wishes to contact Work and Income themselves or he/she is clearly not eligible for Work and Income assistance.

32. Once assistance (if any) from Work and Income has been provided, if a MDC debt remains outstanding, retailers must pursue other measures to recover debt than disconnecting the MDC.

Payment alternatives

33. All invoices should have the 'due date' clearly marked.

34. Where a domestic consumer is having difficulty meeting his or her payments, and it is clear to the retailer that the domestic consumer is not on the best tariff for his or her consumption pattern, the retailer should advise the domestic consumer of all appropriate tariff options available, and assist the domestic consumer to move to the domestic consumer's desired tariff.

35. Retailers should ensure that all domestic consumers are informed of the payment options available from the retailer, and the budgeting and other advice and assistance available from social agencies. Retailers should clearly communicate this information to all domestic consumers at least once every 12 months.

36. Retailers should offer domestic consumer who are having difficulty paying their bills a range of alternatives to standard monthly payments. Retailers should offer arrangements to recover debt within a reasonable timeframe that does not create an adverse credit situation for the retailer and minimises hardship for the domestic consumer[16]. Payment options should include prepayment meters, smoothed payments, and redirection of income[17].

Prepayment meters

37. The Human Rights Commission has confirmed to the Authority that a retailer's refusal to provide a prepayment meter to a domestic consumer because they are a MDC would constitute discrimination, and therefore be in breach of the Human Rights Act 1993[18].

38. However, electricity retailers may:

    (a) strongly recommend that prepayment meters not be installed in premises where there is a MDC. Where a MDC requests a prepayment meter, the retailer should ensure that the MDC has been fully informed of the risk of self-disconnection, before the prepayment meter is installed, so that the MDC can make an informed decision; and

    (b) where a retailer is unable to provide a prepayment meter, refer MDCs who request a prepayment meter to another retailer that can supply a prepayment option[19].

Smoothed payments

39. Smoothed payment contracts are contracts where domestic consumers pay an amount that varies little from one payment period to another. The payment is reassessed periodically with respect to actual consumption, but any arrears are recovered over time, not all at once. It is recommended that:

    (a) retailers promote smoothed payment contracts to those domestic consumers on low incomes;

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16 "Arrangements for the benefit of low income consumers and vulnerable domestic consumers" (paragraph 44 of the Government Policy Statement, May 2009).

17 Retailers are not obliged to repeat the offer of repayment arrangements to any domestic customer that has previously reneged on such an arrangement.

18 The relevant clause was amended in the January 2008 Guideline.

19 http://www.ea.govt.nz/industry/market/metering

(b) smoothed payment options be combined with more frequent payment periods (more than once a month) where this would assist the domestic consumer in stopping his or her debt levels from spiralling upwards;

(c) domestic consumers using a smoothed payment option should still be able to access prompt payment discounts where appropriate; and

(d) refunds for substantial overpayment on smoothed payments should be offered as soon as possible, within reason (e.g. there is little point in making a repayment to a domestic consumer just before winter).

Redirection of income

40. Retailers could agree with domestic consumers to adopt income redirection so as to assist with electricity bill payments. It is recommended that:

(a) redirected income payments be smoothed so that domestic consumers have more certainty around their remaining income;

(b) the amount and frequency of redirected income be a matter of agreement between the retailer and the domestic consumer; and

(c) domestic consumers using redirection of income should still be able to access prompt payment discounts where appropriate.

Bonds

41. A bond is an up-front payment of a lump sum as a condition of some electricity agreements for connections to provide security to retailers. In the case of non-payment of a bill, the retailer can use the bond to recover debt.

42. Bonds may cause undue hardship on some domestic consumers and therefore, generally, should not be used unless:

(a) the domestic consumer refuses any other suitable arrangement that would provide credit security to the retailer;

(b) there has been tampering or interfering with equipment;

(c) the domestic consumer refuses to allow access to the premises; or

(d) accessing the premises is a health and safety risk.

43. Where a bond is used, it is recommended that:

    (a) the domestic consumer should be informed of the reason for the bond;

    (b) the amount of the bond should not exceed $150[20];

    (c) the bond should normally be refunded after 12 months of the domestic consumer paying all bills on time. If the 12-month period is extended, a reason should be provided to the domestic consumer; and

    (d) the domestic consumer should be informed of how and when the bond will be refunded.

Alternate contact

44. Domestic consumers should be informed at least once every 12 months that, if they believe that at some time in the future they may have difficulties with their payments or with communicating with their retailer, they may provide one or more 'alternate contacts' who have agreed to assist if a payment issue is pending.

45. The alternate contact could be a family member, friend, or a social agency. The alternate contact's role may, for instance, be to communicate with the domestic consumer to ensure that he or she fully understands the situation, or to provide financial assistance to the domestic consumer[21].

Ongoing monitoring

46. Retailers should report annually to the Authority on the extent to which they have implemented the Guideline, and where the minimum standards in the Guideline have not been complied with, provide reasons why. The Authority will make the information received publicly available on its website.

47. The Authority will monitor the performance of retailers in implementing the Guideline and if the uptake of the Guideline is not satisfactory, will consider recommending regulation.

[20] Paragraph 45 of the GPS states that "The Government considers that, in principle, bonds should not exceed the value of one month's electricity consumption by an average household." The amount of $150 was estimated to be the average household consumption for a month in June 2005.

[21] For the avoidance of doubt, the alternate contact would not have a contractual relationship with the retailer, but would only be used to assist the domestic consumer or to provide an alternative method for the retailer to contact the domestic consumer.

Sources of additional information

48. If you require further assistance, please contact the Authority:

Electricity Authority
P O Box 10041
Wellington
Attention: Director Retail

Telephone: 04 460 8860
Fax: 04 460 8879
Email: retailoperations@ea.govt.nz

Appendix A Notice of Potential Medically Dependent Consumer (MDC) Status[22]

To the Patient

Please pass this form onto your electricity provider.

Hoatu te puka nei ki tō kaiwhakarato hiko.

Fa'amolemole 'ave lenei pepa i le kamupanī 'olo'o sapalai maia lau 'eletise.

Kātaki 'o 'ave 'a e foomu ko 'eni ´ ki he kautaha 'oku mou ma'u 'uhila mei ai ´.

Me ka tika, tukuia atu teia fōmu ki toou ona ūira.

请把本表交给您的电力供应商。

PART A - PATIENT DETAILS

Patient's name: _____

Patient's date of birth: _____

Patient's contact phone number(s):
_____(h) _____(m) _____(w)

Caregiver's contact phone number(s) – *if different from patient's*:
_____(h) _____(m) _____(w)

Full physical address (*PO Box or RD is not acceptable*) where the patient will reside on discharge (Residence):

_____
_____
_____

Name(s) of electricity account holder(s) at residence where the patient will reside on discharge:

_____ _____ _____

Contact phone number(s) of electricity account holder(s):
_____(h) _____(m) _____(w)

Residence's electricity ICP number (*this can be found on the residence's electricity bill – usually up to 15 characters*): _____

Residence's electricity account number (*this can be found on the residence's electricity bill*):
_____

[22] As per the definition within the *Guideline on arrangements to assist medically dependent consumers*.

Consent: - As the recipient of this medical equipment and a potentially medically dependent consumer, I consent to the information on this form and information on the future status of my dependence on the medical equipment to be shared between the health practitioner(s), electricity retailer(s) and/or the electricity account holder for the domestic residence where I will be residing, for the purpose of ensuring that the electricity retailer is informed of my medical dependence on electrical equipment and my status as a medically dependent electricity consumer. The electricity retailer may use this information to identify residences where electricity disconnection, for whatever reason, may have significant consequences.

Patient signature: _____ Date: _____

and/or

Caregiver signature: _____ Date: _____

PART B - CONFIRMATION THAT ELECTRICITY IS REQUIRED

I certify that _____ (patient's name) with NHI number _____ is:

(a) using mains electricity dependent critical electrical medical equipment (CEME); and

(b) at some point in the future may be dependent on the CEME to the extent that disconnection may result in loss of life or serious harm. (If so, the patient is a potentially medically dependent consumer (of electricity)[23].)

I also certify that the patient listed above has been provided knowledge, training and support, in accordance with appropriate clinical practice:

(a) for the use of the CEME; and

(b) what to do in an emergency, including when the supply of electricity may be interrupted for any reason.

Where:

(a) Critical medical support is defined as support which, in the opinion of a DHB, private hospital or GP, is required to prevent loss of life or serious harm; and

(b) CEME is defined as any equipment supplied or prescribed by a DHB, private hospital or GP, which requires mains electricity to provide critical medical support to a person, and includes other electrical equipment needed to support either the CEME or the treatment regime (e.g. a microwave to heat fluids for renal dialysis).

Note: The patient's electricity retailer may seek advice on the patient's status as a MDC if at any point in the future the patient faces disconnection.

Date: _____

Name of DHB/private hospital/GP:

_____

[23] As defined in the Electricity Authority's *Guideline on arrangements to assist medically dependent consumers* (October 2009).

Name of the health practitioner treating the patient (including designation):

_____

Signature of the health practitioner treating the patient:

_____

OR

Name of another health practitioner, signing on behalf of the health practitioner treating the patient (including designation):

_____

Signature:

_____

Contact number and/or email address of signatory:

_____

Disclaimer: The DHB/private hospital/GP/issuer of this Notice of Potential MDC Status on behalf of the patient, takes no responsibility for any debts incurred by the patient in relation to transactions or arrangements entered into by the patient with the electricity retailer.

ADDITIONAL:

Notice of Potential Medically Dependent Consumer Status (Notice of Potential MDC Status)

The Notice of Potential MDC Status has 2 parts:

Part A – to be completed by the patient/caregiver.

The DHBs, private hospitals and GPs can assist retailers by checking that the patient/caregiver:

- has filled in as much of the form as possible as this will assist his/her retailer to identify the correct account. Specifically, providing a residential address (not a PO Box or RD number), and recording the names of any of the household members who may be the account holder, will be particularly useful;
- understands and has signed the consent portion of the form; and
- understands the importance of:
    - completing the Notice of Potential MDC Status; and
    - giving the Notice of Potential MDC Status to the patient's retailer.

Part B – to be completed by a representative of the DHB, private hospital or GP, and signed by the health practitioner treating the patient (or by another health practitioner signing on behalf of the health practitioner treating the patient).

DHBs, private hospitals and GPs should check that the patient/caregiver has been informed of all relevant aspects of using the CEME including:

- what to do in the case of planned or unplanned electricity outages;
- information on the likely costs associated with operating the CEME and, if appropriate, advising the patient/caregiver that financial assistance may be available from Work and Income;
- advising that if electricity loss occurs, there may be loss of power to the telephone if the only phone in the home requires electricity (relevant if the telephone is needed to call an ambulance in the event of a power outage); and
- discussing whether critical mobility aids (for example wheelchair hoists), may require battery backup.

DHBs, private hospitals and GPs should also ensure that patients are well enough or with sufficient support to effectively communicate with their retailer when discharged from the hospital with CEME (as per Ministry of Health Letter to the Electricity Commission; 18 February 2008).

Appendix B Non-exhaustive list of critical electrical medical equipment

- Continuous Positive Airway Pressure (CPAP) machine
- Nasal Continuous Positive Airways pressure machine
- Non-invasive Ventilation (NIV) Bi-level Positive Airway Pressure (BiPAP) machine
- Oxygen concentrator
- Renal dialysis – Automated Peritoneal Dialysis (APD)
- Renal dialysis – Continuous Ambulatory Peritoneal Dialysis (CAPD)
- Renal haemodialysis machine
- Total Parenteral Nutrition
- Ventilator
- Ventricular Assistance Device.

B.1 Please be aware that this is a **NON-EXHAUSTIVE** list of CEME.

Correspondence with Office for Disability Issues regarding Disability Data Evidence Working Group

Recommendation

That the Disability Support Advisory Committee:

1. **Receives the report.**
2. **Notes the correspondence sent to the Office for Disability Issues regarding the Draft Enduring Questions consultation and Disability Data and Evidence Working Group, and response letter received.**

Prepared by: Michelle Webb (Corporate Committee Administrator)
Endorsed by: Marlene Skelton (Corporate Business Manager)

Glossary

DiSAC	Disability Support Advisory Committee

1. Executive Summary

On behalf of the Auckland Metro Disability Support Advisory Committees (DiSACs), correspondence has been sent to the Office for Disability Issues regarding the work of the Disability Data and Evidence Working Group, and the wishes of the Auckland Metro DiSACs to engage with the Working Group throughout the consultation process and ongoing activities relating to the development of a Disability Data and Evidence Plan.

2. Background

At the 1 June 2016 regional meeting of the Auckland Metro DiSACs a discussion took place regarding the collection of data for patients with disabilities and the activities of a working group formed by the Office for Disability Issues to develop a Disability Data and Evidence Plan.

Consultation on the Draft Enduring Questions for the plan was open until 9 September 2016. The Auckland Metro DiSAC groups were eager to make a submission but were unable to respond prior to the closing date.

At the request of the Auckland DHB DiSAC Chair on behalf of the Auckland Metro DiSACs, correspondence has been sent to the Office for Disability Issues. The letter informs on the view of the Committees that there needs to be a consistent approach across the Auckland region in the way such data is collected, and that information needs to be collected regarding different impairment and age groups as these can make a positive difference to health outcomes. It also advises that the Auckland Metro DiSACs wish to engage with the Disability Data and Evidence Working Group throughout the consultation process and ongoing activities.

3. Conclusion

The attached letter was sent to the Director of the Office for Disability Issues on 6 October 2016. A response was received on 3 November 2016 and is attached. Officers will continue to pursue a dialogue with the working group and regular updates on the progress towards development of the Disability Data Plan.

AUCKLAND
DISTRICT HEALTH BOARD
Te Toka Tumai

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6 October 2016

Megan McCoy
Director
Office for Disability Issues
PO Box 1556
Wellington
New Zealand

Re: Draft Enduring Questions and Disability Data and Evidence Plan

I write to you on behalf of the Auckland Metro Disability Support Advisory Committees (DiSAC) regarding the work of the Disability Data and Evidence Working Group and recently closed consultation on the Enduring Questions for the Disability Data and Evidence Plan.

The Auckland Metro DiSAC groups were eager to make a submission but were unable to respond prior to the 9 September 2016 closing date. It is the view of the groups that there needs to be a consistent approach across the Auckland region in the way data is collected, and that information needs to be collected regarding different impairment and age groups as these can make a positive difference to health outcomes.

The DiSAC groups wish to engage with the Disability Data and Evidence Working Group to ensure that a regional and connected voice is heard.

The DiSAC groups would also like to be kept current with information on the development of the Disability Data and Evidence Plan, and to actively engage with the working group throughout the consultation process and ongoing activities.

The Committees would be grateful if you could advise how best this can be achieved.

Yours faithfully

Michelle Webb
Corporate Committee Administrator

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA

31 October 2016

Ms Michelle Webb
Corporate Committee Administrator
Chief Executive's Office
Auckland City Hospital
PO Box 92189
Victoria Street West
Auckland 1142
Email: michellewebb@adhb.govt.nz

Dear Ms Webb

Thank you for your letter of 6 October 2016, written on behalf of the Auckland Metro Disability Support Advisory Committees (DiSAC).

The DiSAC's interest in engaging with the Disability Data and Evidence Working Group (DDEWG) to ensure that a regional voice is heard, is appreciated. DiSAC's view on the importance of a regional focus in the collection of data will be conveyed to DDEWG.

There will be an opportunity for DiSAC to contribute to the public consultation on the draft Disability Data and Evidence Plan. It is expected that the public consultation will take place in early 2017. This will be the next phase of work following the earlier consultation on the Enduring Questions.

The members of DiSAC can keep up to date with the activities of DDEWG by accessing their webpage on the Office for Disability Issues website at: http://www.odi.govt.nz/what-we-do/better-evidence/index.html. Information on the consultation will also be shared through our newsletter. Members may like to sign up to this via our website at: https://msdnz.secure.force.com/ManageContactDetails?token.

I hope you find this information helpful.

Yours sincerely

Megan McCoy
Director

The Aurora Centre / 56-66 The Terrace / Wellington 6011
PO Box 1556 / Wellington 6140 / New Zealand
Phone: 64 4 916 3300 / **Fax**: 64 4 918 0099 / **www.msd.govt.nz**

Disability Survey Update – Statistics New Zealand

Recommendation

That the Disability Support Advisory Committee receives the Disability Survey Update – Statistics New Zealand report.

Prepared by: Samantha Dalwood (Disability Advisor, Waitemata DHB)
Endorsed by: Debbie Holdsworth (Director of Funding, Auckland and Waitemata DHBs)

Glossary

DDEWG	Disability Data and Evidence Working Group
ODI	Office for Disability Issues

1. Executive Summary

Further to the Disability Data and Evidence Working Group (DDEWG) is working with the Office for Disability Issues (DOI) and Statistics New Zealand to develop a shared understanding of the data and evidence needs relating to disabled people in New Zealand.

Disabled people and the disability sector are unhappy that the Disability Survey is planned for 2023 and that there was no consultation with them about this.

Statistics New Zealand has agreed that it will ensure that there is consultation with disabled people and the disability sector in future. They are also working with the DDEWG to ensure disabled people are included in other household surveys.

Statistics New Zealand is doing some testing at the moment of a new set of disability questions to see if disability can be included in the 2018 Census. The Government Statistician will make a decision on this in 2017.

2. Background

At the consultation workshop on the proposed enduring questions in Wellington on 17 August 2016, it was agreed that Statistics New Zealand and the ODI would provide an update on what happened with the Disability Survey and what happens next.

In 2012 the Government agreed funding for Statistics New Zealand's forward work programme of official social and population statistics. Given the need to plan for the collection of statistics well in advance; this agreement covered a period of 10 years. The forward work programme covers all of the social statistics produced by Statistics New Zealand including:

- Employment
- Income
- Expenditure
- Wealth
- Family
- Housing
- Maori
- Education
- Wellbeing
- Disability

This included agreeing to alternate the Disability Survey and the Maori Social Survey

Funding allocations were made to match the Government's priorities for information at that time. This funding allowed for only one post-census survey to be run after each 5 yearly population census. It was decided at the time to alternate the Maori Social Survey and Disability Survey, with the Maori Social Survey to follow the 2018 census. Even though the Disability Survey has been carried out since 1996, it has never been part of the on-going forward work programme for Statistics New Zealand. The previous funding allocation, covering the 10 years from 2004 to 2014, allowed for the 2006 and 2013 Disability Surveys. The next Disability Survey is due in 2023.

The consultation process that informed advice to Government at the time could have been better

While there was consultation on the overall programme and priorities that informed the advice from Statistics New Zealand to Government, there was no specific consultation with interested sector groups, such as the disability sector. After the consultation and the decision by the Government, it was communicated to the stakeholders that had been involved in the consultation.

Statistics New Zealand acknowledges that it failed to consult with interested sector groups and to inform them specifically of the outcomes that affected them. This could have been handled better to provide greater transparency.

Statistics New Zealand will ensure there is consultation with the disability sector in future

It is important to Statistics New Zealand that disabled people and the disability sector get to have a say on things that impact on them. In future, Statistics New Zealand will ensure there is appropriate consultation with the disability sector on issues relating to the collection of statistics about disabled people. Statistics New Zealand will also work with the Office for Disability Issues, as the government's focal point on disability issues.

The Disability Data and Evidence Working Group, which is co-chaired by Statistics New Zealand and the Office for Disability Issues, is helping to ensure that decisions on the collection of statistics and evidence about disabled people, is informed by the views of the disability sector. This includes for example, the recent consultation on Enduring Questions (the long-term data needs about disabled people).

There will be more consultation with the disability sector on the development of a Disability Data and Evidence Plan. This will identify what needs to be done to ensure the right information about disabled people is collected to inform decision-making. The next steps on this process are currently being worked through following consultation on the Enduring Questions.

Improvements in the collection of statistics about disabled people are already being made

While national disability surveys provide the most comprehensive source of statistics about the lives of disabled people, there are other sources of information that are needed too. Making sure disabled people are included in other household surveys is important as it helps build a wider picture about the lives of disabled people. It also ensures disabled people are visible and counted.

The Disability Data and Evidence Working Group has already helped Statistics New Zealand to make improvements in the inclusion of disabled people in other household surveys. Disability will be included in the:

- General Social Survey from 2016
- Household Labour Force Survey from mid-2017

Information on disabled people from the census is not published

A lot of people have asked about what questions have been included in the census on disability. Until now, a couple of disability questions have been asked in the census. However these have only been included to help Statistics New Zealand identify who they could ask to complete the Disability Survey; this means they were only included to help provide a sample of the population for follow-up.

The information from these questions is not published because they were designed only to provide the sample for the survey. This means they measure something different to the questions in the Disability survey. To avoid confusion of having different measures available only the Disability survey results are published.

However it might be possible to include information on disability in the next census

Statistics New Zealand is doing some testing at the moment of a new set of disability questions to see if disability can be included in the 2018 Census. (Note: testing is an important part of statistics; it helps make sure the right questions are asked in the right way). The Government Statistician will make a decision on this in 2017.

3. Conclusion

Statistics New Zealand is working with the DDEWG to ensure that there is a shared understanding of the data and evidence needs of disabled people in New Zealand.

It has been agreed that there will be consultation with disabled people and the disability sector in future.

Disabled people are unhappy that the next Disability Survey will not be until 2023. Statistics New Zealand is including disabled people in other household surveys and looking to see if a set of disability questions can be included in the 2018 census.

4. References

http://www.odi.govt.nz/what-we-do/better-evidence/update-on-the-disability-survey.html
http://www.stats.govt.nz/browse_for_stats/health/disabilities.aspx

Office for Disability issues
Te Tari Mō Ngā Take Hauātanga
Administered by the Ministry of Social Development

Statistics New Zealand
TATAURANGA AOTEAROA

Disability Domain Plan

Enduring Questions

On behalf of the Disability Data and Evidence Working Group

28 July 2016

New Zealand Government

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Contact: Evidence_Working_Group@msd.govt.nz

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Introduction

In the 2013 Disability Survey[1], 24 percent of the New Zealand population was estimated to be disabled; a total of 1.1 million people. Currently, there is no shared understanding of the data and evidence needs relating to disabled people in New Zealand.

To help build this understanding, the following questions need to be answered:

- What data and evidence about the lives of disabled people is needed to inform policy, plan services, and monitor progress?
- What are the least intrusive, and most cost effective, ways to ensure that the relevant information is available when required?

It is against this background that the Disability Data and Evidence Working Group. (DDEWG) was established in 2015.

The DDEWG is jointly facilitated by the Office for Disability Issues and Statistics New Zealand and contains representatives from government agencies, independent agencies, disabled peoples' organisations, service providers, and academic institutions.[2] The DDEWG aims to define, clarify and prioritise disability information needs and to recommend strategies to address information gaps.

To achieve its aims the DDEWG has been developing a Disability Domain Plan.

Disability Domain Plan

The purpose of a domain plan is to develop a shared understanding of the strengths, gaps, overlaps and deficiencies in data and evidence relating to a particular subject matter or population group – in this case the relevant group is disabled people.

The plan will help to ensure that the most important information for informing policy and funding decisions is available when decisions are going to affect the lives of disabled people. In addition, monitoring key aspects of the lives of disabled people compared with others helps to ensure that the rights of all people are being upheld.

There are four stages involved in the development of a domain plan:

1. Develop an agreed set of enduring information needs.
2. Carry out a 'stocktake' of the data and evidence currently available.
3. Analyse the stocktake in relation to the information needs to determine gaps or deficiencies in available data.
4. Identify and prioritise initiatives to address the gaps or deficiencies identified.

A domain plan is a statement about information needs and how they might be addressed. It does not guarantee that the data and evidence will be collected or made available as outlined in the plan. This depends on the recommended initiatives being accepted and funded.

[1] http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx
[2] The members of the DDEWG at July 20th 2016 are shown in Appendix 1.

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What are ‘enduring questions’?

Enduring questions are the way in which long-term data and evidence needs are represented in a domain plan. They are open-ended questions organised under a series of topics. Enduring questions focus on aspects of each topic that are likely to remain of interest or concern for the foreseeable future and that can be regularly updated and compared over time. The questions should be interpreted broadly, they are a starting point for discussion about the types of evidence that are useful to inform decision-making and monitor progress.

How were the enduring questions developed?

At a workshop held by the DDEWG in May 2016, members held a brain-storming session and suggested a wide range of topics around which enduring questions could be arranged. Statistics New Zealand collated and analysed the suggested topics and drafted lists of enduring questions under each topic area. Members of the DDEWG then provided further feedback on the draft set of enduring questions.

The result is a set of topics ranging from the labour market to health to attitudes and awareness. In this document each topic is introduced with a brief description and the related enduring questions are listed.

Consultation on the enduring questions

It is important to seek feedback from a wide range of people to help ensure that the enduring information needs are understood and agreed as broadly as possible across the community.

In August 2016, three workshops will target a range of key stakeholders with an interest in information about disabled people. These stakeholders include: government agencies, independent organisations such as the Human Rights Commission and the Office of the Ombudsman, Disabled People’s Organisations, the New Zealand Disability Strategy Revision Reference Group, service providers and universities/research institutes.

An online public consultation, hosted on the Office for Disability Issues website, in August/September 2016 will also enable people to give feedback on the proposed enduring questions.

How will the enduring questions be used?

A stocktake of data held by central government agencies has been completed and a non-government stocktake is underway. A gap analysis will be used to see how well available information sources can meet the needs identified in the enduring questions.

The final stage in the completion of the domain plan will be the development of a prioritised list of targeted initiatives to address gaps or deficiencies in available information.

The end-result of the development of a Disability Domain Plan will be a shared understanding of the information needed to support decisions that impact on disabled people. It will provide up-to-date knowledge about the kinds of data and evidence required to ensure the development of sound policy and appropriate services to meet the needs of disabled New Zealanders. Recommendations on how priority data needs could be addressed will be made and knowledge and understanding about disability issues will be improved across the wider disability sector in New Zealand.

Topic 1: Labour Market

Work provides people with opportunities to learn new skills and build social contacts as well as being the principal source of personal income.

The UN Convention on the Rights of People with Disabilities (CRPD) requires that ratifying governments 'recognize the rights of persons with disabilities to work on an equal basis with others', and outlines a number of steps to achieve this objective.[3]

Patterns of labour force participation cover a wide range of characteristics of the interaction between people and work. These include labour force status[4] and employment status[5] as well as the occupation, industry and hours worked for those in employment. Level of satisfaction with one's work situation is also important given the differing need and desire for attachment to the labour force. We need to be able to compare the labour market situation of men and women, as well as different age-groups and ethnic groups within the disabled population.

Barriers to labour force participation may be physical, technological or attitudinal. Some global businesses view having accessible workplaces and employment circumstances as a competitive edge and incorporate accessibility into their organisation's culture.[6]

Article 17 of the CRPD requires that disabled people have 'the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible'[7] to disabled people. Understanding and influencing employers' views on engaging disabled people in their business is an important factor in ensuring greater choice for all people.

Enduring questions on the labour market

1. Do patterns of labour force participation differ between disabled people and others?[8]
2. What are the barriers to equitable access to employment for disabled people?[9]
3. How satisfied are people with their labour force situation and does this differ between disabled people and others?
4. How well do current employment services[10], systems[11] and policies[12] meet the needs of disabled people?
5. How well do current employment services, systems and policies meet the needs of employers and potential employers of disabled people?

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[3] United Nations. (2008) Convention on the Rights of Persons with Disabilities.
[4] Employed, unemployed or not in the labour force
[5] Wage or salary earner, employer, self-employed or unpaid relative assisting.
[6] Global Reporting Initiative. (2015) *Disability in Sustainability Reporting* Available from Disability in Sustainability Reporting. www.globalreporting.org
[7] United Nations. (2008)) Convention on the Rights of Persons with Disabilities page 17
[8] Including patterns of labour force attachment across people's life span.
[9] Including physical and attitudinal barriers
[10] Services provide benefits that aim to meet people's needs. They can be public, private or voluntary, and operate at local, community, regional, or international level. People, associations, organisations, agencies or governments may provide them. The benefits provided by services can be general or specially designed.
[11] Systems are administrative control and organisation of services by governments at local, regional, national, and international levels. Systems are designed to organise, control and monitor services that provide benefits to people.
[12] Policies are rules, regulations, conventions and standards established by governments at the local, regional, national, and international levels, or by other recognised authorities. Policies govern and regulate the systems that organise, control and monitor services.

Topic 2: Education and Training

Access to quality education and training at all levels is an important determinant of life outcomes. There is an enduring need for information on participation and achievement in education and training to indicate how well New Zealand's systems and practices are working for all people.

Under Article 24 of the CRPD access to free education at primary and secondary level in one's own community, with appropriate individualised support and reasonable accommodation[13] is the expectation. In New Zealand accessible pre-school education is also an essential requirement.

Systems and policies set the context within which people are educated and trained in New Zealand. We need to ensure that they are consistent with an inclusive view and designed to optimise outcomes for all.

An understanding of education and training achievement and participation by disabled people broken down by personal and socio-economic characteristics is required. It is important that we can look at differences within the disabled population, for example by characteristics such as age-group and sex.

Enduring questions on education and training

1. How does participation in education and training differ between disabled people and others?
2. How do levels of achievement in education and training differ between disabled people and others?
3. What are the barriers to equitable participation in education and training for disabled people?
4. What are the barriers to equitable achievement in education and training for disabled people?
5. How well do current education and training services, systems and policies meet the needs of disabled people?

[13] Reasonable accommodation is 'Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms' (Article 2 of UNCRPD)

Topic 3: Health

Achieving a high level of positive health outcomes across the population is fundamental to a well-functioning society. To do this we must understand the medical and social determinants of health status and the barriers that people face in attaining good health. Self-assessed health and medical health status are both important indicators and where disparities in health status exist we need to explore what is causing them.

Health services must be accessible to all and provided in a way that addresses both diversity and personal dignity. Recognising that disabled people have the right to enjoy the highest standard of attainable health without discrimination is a requirement under Article 25 of the CRPD.

Analysis of the relationship between health outcomes and socio-economic characteristics helps us to understand how a range of factors can influence health. Data collected on health outcomes should be available in a format that allows for this type of analysis. Disaggregation of health outcomes information by personal characteristics will be required.

Enduring questions on health

1. To what extent does the health status of disabled people differ from that of others?
2. How does life expectancy differ between disabled people and others?
3. What barriers to accessing health products and services are faced by disabled people?
4. How well do current health products and services, systems and policies meet the needs of disabled people?

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Topic 4: Domestic Accommodation

A place to live is a basic need. Our homes provide shelter, security, privacy, and personal space and are also important places for fostering and maintaining relationships. The type and quality of a person's home also has major implications for their health and wellbeing.[14]

Living independently is not just about where you live but also with whom you live and whether the residence is suitable for your needs. Having the ability to choose their place of residence and with whom they live is a right for all people and is specified in Article 19 of the CRPD.

Housing quality includes physical aspects of the building, both interior and exterior, as well as living conditions such as dampness, the ability to heat rooms, and the provision of functioning utilities like water, sewerage and power.

Housing quality is also about with the suitability of the home for the people who live there – both in terms of the size, the facilities available and the affordability. Where guidelines and regulations exist to support housing quality, we need to understand the extent to which these obligations are being met.

Enduring questions on domestic accommodation

1. In what types of private and non-private dwellings do disabled people live and does this pattern differ from the living arrangements of others?[15]
2. With whom do disabled people live and how does this compare with others?[16]
3. Where do disabled people live (location) and does this differ from others?[17]
4. Are disabled people able to choose where and with whom they live?
5. Does the quality of domestic accommodation differ between disabled people and others?
6. Does the domestic accommodation in which disabled people live meet their needs?[18]
7. What are barriers are faced by disabled people in accessing domestic accommodation that meets their needs?
8. How well do current housing products and services, systems and policies meet the needs of disabled people?

[14] Statistics New Zealand (2015) Measuring housing quality: *potential ways to improve data collection on housing quality in New Zealand*. Available from stats.govt.nz *Measuring housing quality*
[15] Includes dwelling type and tenure
[16] Including household composition and family structure
[17] Location at local level is required for planning purposes
[18] Including being affordable

Topic 5: Travel

The ability to travel, including local, national and international journeys, is a fundamental part of modern life and, for most, local trips are an everyday activity. When travel is difficult, or impossible, participation in a wide range of activities will suffer. This is not merely inconvenient; it can lead to social isolation, loneliness and poor health.[19]

Accessible transport is important for ensuring equality of opportunity for all people. The mode (type of transport), time taken (wait time and length of journey) and cost, are all important aspect of a journey. Getting to and from transport facilities must also be considered.

Disabled people face a range of environmental barriers in both short and long-distance travel. For a pedestrian the quality of footpaths, including the gradient and condition of the surface and access to safe road crossings, can significantly affect a journey. Trained transport staff, kneel-buses, and accessible information about transport services[20] will make public transport more accessible for all people.

Private transport is a major form of travel in New Zealand and driving or travelling as a passenger may be made possible if private vehicles are modified. We need to understand the extent to which people are able to access modifications that allow them to use private transport and what barriers might prevent this.

The accessibility of all forms of transport and barriers faced, including for disabled people, is included in the enduring questions for the Transport Domain Plan published in January 2015 by Statistics New Zealand and the Ministry of Transport.[21]

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Enduring questions on travel

1. Are people able to travel in their local area when they need or want to do so?
2. What are the barriers to achieving equitable access to local places for disabled people?
3. Are people able to travel longer distances when they need or want to do so?
4. What are the barriers to equitable access to national and international places for disabled people?[22]
5. Do patterns of short distance travel differ between disabled people and others?
6. Do patterns of long distance travel differ between disabled people and others?
7. How well do current transport services, systems and policies meet the needs of disabled people?

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[19] Hine, Julian. Mitchell, Fiona. (2001) *Better for Everyone? Travel Experiences and Transport Exclusion.* Urban Studies (Routledge), 01/02/2001, Vol. 38 Issue 2, p319-332, 14p.
http://www.barrierfreenz.org.nz/technical/accessibility-principles.html
[20] Waikato Regional Council. (2015) Measuring Accessible Journeys
[21] http://www.transport.govt.nz/research/transport-domain-plan
[22] Including cost

Topic 6: Standard of Living

A person's standard of living includes the level of comfort, material goods and necessities available to them. Standard of living can differ by location and across a person's lifetime. In a market economy standard of living is almost entirely dependent on the monetary income that can be accessed either by the person themselves or through the activities and entitlements of members of their family or household. The incomes of extended family and friends or inherited and accumulated wealth can also influence living standards.

Income is the flow of economic resources a person or household receives; it includes wages, salaries, profit from self-employment, and resources received from investments, property, retirement savings and social transfers. Wealth is a stock of accumulated assets such as properties, vehicles, household goods, as well as pensions and financial assets.[23] Both income and wealth are important factors underlying the standard of living that people can achieve.

With higher levels of income and wealth a person, family or household will be more resilient to shocks to employment or health, or from the effects of a natural disaster. People with higher incomes are able to access safer, healthier and more suitable homes and create more comfortable and desirable living conditions. They are also able to put aside income for retirement. When people are unable to access sufficient income or reserves to provide a minimal standard of living for themselves and their dependents, life chances and outcomes will be reduced.

Enduring questions on standard of living

1. Do levels of income (personal and household) differ between disabled people and others?
2. Do levels of wealth (personal and household) differ between disabled people and others?
3. Do levels of material standard of living differ between disabled people and others?
4. Do disabled people have sufficient income to meet their needs, including the need to save for the future?
5. What are the barriers to achieving an equitable standard of living for disabled people?
6. How well do current systems and policies for income support meet the needs of disabled people?

[23] Statistics New Zealand. (2016) Household Net Worth Statistics. Available from www.stats.govt.nz

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Topic 7: Support Services

Access to a range of support services, including both formal and informal networks, is essential to our wellbeing. Formal systems of social support include services that are provided by central and local government, and by community agencies, both commercial and non-for-profit. It is important to understand the uptake of both disability-specific and mainstream social support services.

As with all services, barriers to accessing support services can include the built environment, the attitudes and awareness of people providing services, the availability of suitable products and technologies, and the legislative and regulatory frameworks within which service systems are embedded.

In addition to formal services people are supported by family and friends. The extent to which these informal networks are able to provide people with support that they need during different phases of their lives is an important determinant of life quality. It is also important to ensure that people who are supporting disabled people are themselves supported in this role[24].

Enduring questions on support services

1. What barriers to accessing support services are faced by disabled people compared with others?
2. To what extent do disabled people use informal support networks compared with formal networks?
3. How well supported are people who provide informal support for disabled people?
4. How well do current support services, systems and policies meet the needs of disabled people?

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[24] See https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/ for information on the New Zealand Carer's Strategy

Topic 8: Community and Social Life

Community groups, both formal and informal, provide opportunities to engage with people who share interests and beliefs. Service and religious organisations, local social clubs and professional associations are examples. Article 19 of the CRPD requires that disabled people have the same right as others to full inclusion and participation in the community.

Informal social networks and connections are an integral part of people's support systems. The relationship between social integration and health is well established.[25] When people face barriers in connecting with members of their social networks they can become isolated. This places them at greater risk of poor mental health and general wellbeing. Social connections are important at all stages of life but are essential during formative years of childhood and youth.

The right of disabled people to take part on an equal basis as others in cultural life; in recreational, leisure and sporting activities and to utilise and develop their own creative, artistic and intellectual potential is protected under Article 30 of the CRPD.

Recreation and leisure activities include among other things, playing and watching sport; visiting art galleries, museums, cinemas or theatres; engaging in arts, crafts and hobbies; and socialising. These activities add meaning to life and help to maintain a sense of identity and autonomy. Cultural clubs and informal gatherings foster and maintain cultural and linguistic identity.

Opportunities for relaxation, self-expression and learning result from engagement in pursuits such as crafts or hobbies, reading for enjoyment, playing musical instruments, and travelling for pleasure. Many leisure activities are social in that they involve clubs or organisations which bring together people with shared interests or are enjoyed within informal groups of friends and family.

Enduring questions on community and social life

1. Do opportunities for, and methods of, social contact differ between disabled people and others?
2. What are the barriers to social contact for disabled people?
3. Do levels of participation in leisure activities differ between disabled people and others?
4. What are the barriers to participation in leisure activities for disabled people?
5. Do levels of participation in community life differ between disabled people and others?
6. What are the barriers to participation in community life for disabled people?

[25] 'A search of the literature published since the mid-1970s … presented strong evidence that social integration leads to reduced mortality risks, and to a better state of mental health.'
http://www.sciencedirect.com/science/article/pii/S1047279796000956

Topic 9: Civic Engagement and Institutional Trust

Civic engagement is essential for a healthy democratic society. Specifically, in a diverse society, high levels of civic engagement help to ensure that political structures are representative. Through participation in community life citizens can influence local living conditions and shape their community's future.

At its most basic level, civic engagement is the right to express your political voice through voting in local or national elections. Other activities include communicating with your local member of parliament, participation in lobby groups or protests, engaging in public policy formulation, and standing for a governing body.

The disabled community has distinct characteristics and goals that require representation in the civic sphere. It is important to measure levels of civic engagement by disabled people and determine whether they differ from others.

Civic engagement and institutional trust go hand in hand. If people or communities have low levels of confidence or trust in civil and governing institutions they are less likely to engage with them. When groups are not represented at levels of influence in society they risk marginalisation.

Enduring questions on civic engagement and institutional trust

1. Do levels of civic engagement differ between disabled people and others?
2. What are the barriers to ensuring that civic engagement opportunities are inclusive?
3. Do levels of institutional trust differ between disabled people and others?
4. What are the barriers to improving levels of institutional trust for disabled people?

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Topic 10: Crime and Justice

The extent to which people can access various parts of the justice system must be understood in order to ensure that their rights are being met.

Article 13 of the CRPD requires that effective access to justice is ensured including through the provision of appropriate accommodation where necessary. All people must be able to fulfil roles as direct or indirect participants in legal proceedings.

The CPRD also requires that appropriate training is available for relevant people to facilitate an inclusive justice system.

It is important that we can look at differences within the disabled population, for example by characteristics such as age-group and gender.

Enduring questions on crime and justice

1. How do patterns of victimisation and crime differ between disabled people and others?
2. How does the experience of the justice system differ between disabled people and others?
3. What are the barriers to equitable participation in the justice system in any role (e.g. as victim, witness, suspect, offender, juror, etc.)?
4. How well do current justice services, systems and policies meet the needs of disabled people?

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Topic 11: Personal Safety and Civil Protection

The right to liberty and security is fundamental and protected under national and international law. These, and all universal human rights, are to be enjoyed by all people without distinction of any kind.[26]

It is difficult to assess the extent to which people are actually at risk of being treated badly, exploited or abused. Measures generally cover people's perceptions of their safety in different locations, at different times and when alone or in company. Anxiety, fear and avoidance behaviour can occur if a person does not feel safe, with clear consequences for personal wellbeing.

Incidents of degrading treatment, discrimination, bullying and crime victimisation can be monitored to see whether disabled people are disproportionally affected. Articles 14, 15 and 16 of the CRPD outline the obligations of ratifying governments to ensure that this is not the case in their country.

Institutional arrangements for public safety and civil protection are important factors in making us feel safe. Emergency preparedness by responsible agencies must take into account the needs of disabled people as must the members of households in which they live. This includes having an emergency kit and plan at home as well as ensuring that agencies involved in rescue operations or disaster relief are trained and equipped appropriately for all people in their community.

Under Article 11, the CRPD requires that '…all necessary measures are taken to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.'[27]

Enduring questions on personal safety and civil protection

1. To what extent do disabled people feel safe in their homes and communities and does this differ from the experience of others?
2. To what extent are disabled people subject to behaviour that impinges on their right to personal safety and how does this compare with others?
3. What are the barriers to improving personal safety for disabled people?
4. Are public safety and emergency relief agencies able to manage all people in their community?

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[26] United Nations (1948) The Universal Declaration of Human Rights
[27] UNCRPD Article 11

Topic 12: Products and Technology

A wide range of products are specifically designed or adapted to help people with impairments perform tasks that would be difficult or impossible without them. These so called 'assistive devices' are only one part of the picture. Mainstream manufactured goods also play an important role in mitigating the effects of impairments and enabling greater independence. Examples include 'labour saving devices' such as dishwashers and food processors. These may be the difference between preparing your own meals and being reliant on someone to do if for you.

Adopting a 'universal design' approach to products, environments, programmes, and services allows them to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design[28].

Understanding the ways in which people use products and technologies to mitigate the effects of impairments and identifying any barriers to doing this is the essence of the enduring questions below.

Enduring questions on products and technology

1. What products and technology do disabled people use to carry out and participate in the activities they want to do?
2. What products and technology do disabled people need to carry out and participate in the activities they want to do?
3. What barriers are faced by disabled people in accessing the products and technology they need to do the things they want to do?

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[28] UNCRPD Article 2

Topic 13: Attitudes and Awareness

The importance of attitudes and awareness in the lives of disabled people cannot be overstated. Negative attitudes towards disabled people have been consistently identified as a barrier to their being able to access the same opportunities as others.[29] This is a cross-cutting issue. Barriers resulting from attitudes to and awareness of disability arise in all aspects of life.

Social inclusion and exclusion are largely determined by dominant cultural values and perceptions[30]. Changing community attitudes towards disability requires complementary methods, including providing information and extended personal contact.[31] The enduring questions below focus on establishing the extent of the problem in our communities.

Understanding what it means to self-identify as disabled and how this changes over time is also an enduring concern. What are the views of disabled people towards their own situation?

Enduring questions on attitudes and awareness

1. What are the predominant/common attitudes towards disability and disabled people?
2. To what extent are people aware of inequities faced by disabled people?
3. How can peoples' attitudes towards disability and disabled people be influenced?
4. Are current attitudes towards disability and disabled people being influenced appropriately?
5. To what extent do disabled people feel discriminated against compared to others?
6. To what extent are disabled people provided with 'reasonable accommodation'?
7. How many people identify themselves as disabled and how is this understood?
8. How do disabled people see their impairment/disability (negatively, positively, as just a difference and/or as a culture/identity)?

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[29] http://www.msd.govt.nz/about-msd-and-our-work/newsroom/factsheets/budget/2010/improving-attitudes.html
[30] http://www.melbourneinstitute.com/downloads/hilda/Bibliography/Other_Publications/2013/Thompson_etal_community_attitudes_to_disability_op39.pdf
[31] http://www.unicef.org/protection/World_report_on_disability_eng.pdf

Topic 14: Accessibility

Disabled people should have access, on an equal basis with others, to 'the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and rural areas'.[32]

An accessible world is one in which disabled people can live independent lives and participate fully in any aspect of life should they choose to do so. It is a cross-cutting issue and affects all the topics discussed in this document. Its inclusion as a separate topic helps to ensure that we can look across all aspects of people's lives through the accessibility lens.

Enduring questions on accessibility

1. What are the main accessibility issues faced by disabled people?
2. How well do current standards and guidelines, systems and policies achieve desired levels of access for disabled people?
3. What is the cost of not providing access for disabled people across a range of facilities and services?

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[32] UNCRPD Article 9

Topic 15: Self-assessed Wellbeing and Personal Autonomy

Self-assessed wellbeing is the simplest tool to describe the quality of a person's life. Wellbeing is a complex web of interdependent factors including physical health, emotional and mental health; wealth and income; social relationships; employment and educational skills/status; civic engagement; cultural identity and participation; safety and security; and housing.

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Self-assessed wellbeing has three distinct components. The first is the person's evaluation of their life, often described as satisfaction. The second focuses on sense of meaning, purpose and worthwhileness in life. The third is an affect measure, which focuses on the balance between positive and negative experiences of moods, feelings, and emotions.[33] If there is a significant disparity in multiple areas of wellbeing between disabled people and others, self-assessed wellbeing could reveal this in a straightforward manner.

Autonomy, being able to make decisions about one's own life, is independence that comes from choice and control. For example a child may not be able to attend their closest school if it does not reasonably accommodate their needs, or might have to live in a residential facility far from friends and family, in order to be cared for. Disability, functioning, autonomy, and dependency are significant concerns for the disability community.[34] The first general principle of the UNCPRD outlined in Article 3 is 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

Personal resilience is the ability to adapt to change, adversity, trauma, or significant sources of stress. This can occur when an aspect of one's wellbeing (mentioned above) takes a significant hit. This includes the loss of income, relationship difficulties, births, deaths, or natural disasters.

Enduring questions on self-assessed wellbeing and personal autonomy

1. Do levels of self-assessed wellbeing differ between disabled people and others?
2. Why do levels of self-assessed wellbeing differ between disabled people and others?
3. To what extent do people have control over their own lives (personal autonomy) and does this differ between disabled people and others?
4. What are the barriers to personal autonomy for disabled people?
5. Do levels of personal resilience differ between disabled and others?
6. If levels of personal resilience differ between disabled and others, and how can the difference be addressed?

[33] OECD (2015.) *How's Life? 2015 In Figures*. Available from: OECD Measuring wellbeing www.oecd.org

[34] European Union Agency for Fundamental Rights. (2012) Autonomy and inclusion for people with disabilities. Accessible from www.fra.europa.eu

Topic 16: Personal Characteristics

Demographic characteristics are fundamental to understanding any population group. They include the age profile of the group, and the sex and ethnic distributions.

Understanding the demographic profile helps to ensure that any support or intervention to improve disabled people's lives is appropriate for them. For example, older people have different needs from children. It also enables researchers to establish whether there are demographic differences in any observed disadvantage, are support services working well for some groups and not others.

Answering the enduring questions on personal characteristics will allow us to quantify and describe aspects of the disabled population and assess the situation of specified population subgroups such as women[35] and children[36] as required by the CRPD.

Enduring questions on personal characteristics

1. What is the age structure of the disabled population and does it differ from that of others?
2. What is the sex distribution of disabled population and does it differ from that of others?
3. What is the ethnic distribution of disabled people and does it differ from that of others?

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[35] UNCRPD Article 6
[36] UNCRPD Article 7

Topic 17: Disability, Impairment and Limitations

For any data collection about disabled people the threshold criteria for being disabled must be identified and the relevant characteristics for assigning disability status captured in the collection.

In official data collections it is usually information on functional or structural impairments and/or limitations in everyday activity that provide the threshold characteristics. Eligibility criteria for targeted services require that applicants have, for example, a vision impairment or mobility limitation at some predetermined and measurable level. Combinations of impairment types and activity limitations at specified levels are generally used in setting thresholds for who counts as disabled in surveys.

Threshold criteria are also necessary when collecting information on groups within the disabled population. These may be specified in terms of impairment type, level of difficulty with specified activities or extent of participation in specified aspects of life.

Where the extent of impairment or level of limitation a person has are used in defining thresholds for disabled population groups within data collections they must be available for this purpose. These aspects of disability also allow us to better understand people's differing situations and needs. The cause, duration and time of onset of impairments and limitations are important factors in understanding the effects of disability on people's lives.

Enduring questions on disability, impairment and limitations

1. What groups of disabled people are of interest (for policy and funding decisions, research, and monitoring systems) and why?
2. How are the groups of interest to be identified?
3. To what extent are people impaired or limited?
4. What are the causes of impairments and limitations?
5. When was the onset of impairments and limitations?
6. What is the duration of impairments and limitations?
7. What underlying health conditions are associated with impairments or limitations (where relevant)?

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Appendix: Members of the Disability Data and Evidence Working Group **(at July 20th 2016)**

1. Diane Ramsay (General Manager, Labour Market and Households Unit, Statistics New Zealand) co-chair
2. Megan McCoy (Director, Office for Disability Issues) co-chair
3. Dr Catherine Brennan (Advisor, Office for Disability Issues)
4. Litia Tapu (Manager, Wellbeing and Housing Statistics, Statistics New Zealand)
5. Clare Shepherd (Regional Practice and Implementation Manager, Special Education, Ministry of Education)
6. Anne Hawker (Principal Disability Advisor, Ministry of Social Development)
7. Patrick Power (Principal Advisor, Information Management, Ministry of Justice)
8. Christopher Carroll (Senior Policy Analyst, Disability Policy Team, Ministry of Health)
9. Samuel Murray (National Policy Coordinator, CCS Disability Action) representing disability service providers
10. Dr Brigit Mirfin-Veitch (Senior Lecturer, Centre for Postgraduate Nursing, University of Otago/Director, Donald Beasley Institute) representing university researchers
11. Dr Jonathan Godfrey (Senior Lecturer in Statistics, Massey University, Palmerston North) representing Disabled Persons' Organisations
12. Raymond Burr (Senior Communications and Engagement Advisor, ACC Communications and Customer Engagement)
13. Kevin Eames (Advisor, People and Environment, Ministry of Transport)

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