PUBLIC

Wairarapa DHB · Hutt Valley DHB · Capital & Coast District Health Board	**AGENDA v.3** Held on Friday 18 December, 2020 **Pilmuir House Boardroom, Hutt Hospital, Lower Hutt** Zoom meeting ID: **858-1247-3720** Time: From 1230 to 1500

3DHB COMBINED DISABILITY SUPPORT ADVISORY COMMITTEE

	ITEM	ACTION	PRESENTER	MIN	TIME
1	**PROCEDURAL BUSINESS**			**15**	**1230**
1.1	Karakia		All members		
1.2	Apologies	**RECORD**	Chair		
1.3	Continuous Disclosure – Interest Register	**ACCEPT**	Chair		
1.4	Confirmation of Draft Minutes	**APPROVE**	Chair		
1.5	Matters Arising	**NOTE**	Chair		
1.6	DRAFT Work plan	**APPROVE**	2DHB Director Strategy, Planning and Performance – Rachel Haggerty		
2	**PRESENTATION**			**30**	**1245**
2.1	Acute Mental Health Integrated Service Response	**PRESENT**	2DHB Director Strategy, Planning and Performance		
	AFTERNOON TEA 15 MIN				
3	**DISCUSS**			**20**	**1330**
3.1	Acute Mental Health Integrated Service Response	**DISCUSS**	2DHB Director, Strategy Planning and Performance - Rachel Haggerty WrDHB Executive Leader, Planning and Performance - Sandra Williams 3DHB General Manager, Mental Health, Addictions and Intellectual Disability Service - Nigel Fairley		
3.2	Mental Health Services and People with Disability 3.2.1 Research Report	**DISCUSS**	3DHB General Manager Disability – Rachel Noble		
3.3	Transport and Accessing Health Services for People with Disability 3.3.1 Report	**DISCUSS**	3DHB General Manager Disability – Rachel Noble		
4	**REPORTING**			**60**	**1430**
4.1	Sub Regional Disability Strategy 2017 - 2022 Update	**DISCUSS**	3DHB General Manager Disability – Rachel Noble		
5	**OTHER**			**10**	**1450**
5.1	General Business	**NOTE**	Chair		
DATE OF NEXT DSAC MEETING: Wednesday 31 March 2021, 1.30pm-4pm					

Karakia

Whakataka te hau ki te uru,

Whakataka te hau ki te tonga.

Kia mākinakina ki uta,

Kia mātaratara ki tai.

E hī ake ana te atākura he tio,

he huka, he hauhū

Tīhei mauri ora!

Translation

Cease the winds from the west

Cease the winds from the south

Let the breeze blow over the land

Let the breeze blow over the ocean

Let the red-tipped dawn come with a sharpened air.

A touch of frost, a promise of a glorious day.

3DHB DSAC Interest Register

14 December 2020

Name	Interest
'Ana Coffey (Chair)	• Father, Director of Office for Disabilities • Brother, employee at Pathways, NGO Project Lead Greater Wellington Collaborative • Shareholder, Rolleston Land Developments Ltd
Prue Lamason	• Councillor, Greater Wellington Regional Council • Chair, Greater Wellington Regional Council Holdings Company • Deputy Chair, Hutt Mana Charitable Trust • Member, Hutt Valley District Health Board • Daughter is a Lead Maternity Carer in the Hutt
Yvette Grace	• General Manager, Rangitāne Tu Mai Rā Treaty Settlement Trust • Member, Hutt Valley District Health Board • Member, Wairarapa District Health Board • Member, Steering group, Wairarapa Economic Development Strategy • Husband is a Family Violence Intervention Coordinator at Wairarapa District Health Board • Sister-in-law is a Nurse at Hutt Hospital • Sister-in-law is a Private Physiotherapist in Upper Hutt
Dr Tristram Ingham	• Board Member, Health Quality and Safety Commission • Director, Foundation for Equity & Research New Zealand • Director, Miramar Enterprises Limited (Property Investment Company) • Member, Independent Monitoring Mechanism to the United Nations on the United Nations Convention on the Rights of Persons with Disabilities • Chair, Te Ao Mārama Māori Disability Advisory Group • Co-Chair, Wellington City Council Accessibility Advisory Group • Chairperson, Executive Committee Central Region MDA • National Executive Chair, National Council of the Muscular Dystrophy Association • Trustee, Neuromuscular Research Foundation Trust • Professional Member, Royal Society of New Zealand • Member, Disabled Persons Organisation Coalition • Member, Scientific Advisory Board – Asthma Foundation of NZ • Member, 3DHB Sub-Regional Disability Advisory Group • Member, Institute of Directors • Member, Health Research Council College of Experts • Member, European Respiratory Society

	• Member, Te Ohu Rata o Aotearoa (Māori medical Practitioners Association) • Senior Research Fellow, University of Otago Wellington • Wife is a Research Fellow at University of Otago Wellington • Co-Chair, My Life My Voice Charitable Trust • Member, Capital & Coast District Health Board • Member, DSAC • Member, FRAC
Sue Kedgley	• Member, Capital & Coast District Health Board • Member, Consumer New Zealand Board • Stepson works in middle management of Fletcher Steel
John Ryall	• Member, Hutt Union and Community Health Service Board • Member, E tū Union
Naomi Shaw	• Director, Charisma Rentals • Councillor, Hutt City Council • Member, Hutt Valley Sports Awards • Development Officer, Wellington Softball Association • Trustee, Hutt City Communities Facility Trust
Vanessa Simpson	• Director, Kanuka Developments Ltd • Relationship & Development Manager, Wellington Free Ambulance • Member, Kapiti Health Advisory Group
Jill Pettis	• Nil
Ryan Soriano	• Community Coordinator for FOCUS, Disability Support Services at Wairarapa DHB • Member, Board Trustee for Saint Patrick School Board, Masterton • Wife Employed as Senior Caregiver at Lansdowne Park Aged Care Facility
Jill Stringer	• Director, Touchwood Services Limited • Husband employed by Rigg-Zschokke Ltd • Trustee on Wellington Welfare Guardianship Trust
Jack Rikihana	• Research Advisory Group – Māori • Kaumātua Advisory Group • Hora te Pai • Noose Monotony Committee • Kapiti Airport • Disability Strategic Advisory Committee
Sue Emirali	• Nil
Bernadette Jones	•
Marama Eddie	• Board member Whaiora Whanui • Sister works for CCDHB

	• Sister works with the Aged Care at the Kandahar Dementia Unit in Masterton • Trustee of Ngati Kahungunu ki Wairarapa Tamaki Nui a Rua Treaty Settlement Trust • Member of Māori Women's Welfare League

3DHB DSAC MEETING **PUBLIC**

3DHB Disability Support Advisory Committee Meeting - PUBLIC

MINUTES

Held on Wednesday 4 November
Main meeting room, Boulcott's Farm Heritage Golf Club, 33 Military Road, Lower Hutt
Zoom link: **976 8527 9736**
Time: 1.30pm – 4pm

Members	Attendance	Membership
Ana Coffey – Chair	Present	CCDHB
Sue Kedgley	Present	CCDHB
Yvette Grace	Present	WrDHB & HVDHB
Tristram Ingham	Present	CCDHB
Prue Lamason	Present	HVDHB
John Ryall	Present	HVDHB
Naomi Shaw	Present	HVDHB
Vanessa Simpson	Apologies	CCDHB
Jill Pettis	Present	WrDHB
Ryan Soriano	Present	WrDHB
Jill Stringer	Present	WrDHB
Sue Emirali	Present	Sub Regional Disability Support Advisory Group Rep.
Marama Taatu	Present	Chair of Kaunihera Whaikaha
Bernadette Jones	Member	Sub Regional Disability Support Advisory Group Rep.
Jack Rikihana	Member	CCDHB Māori Partnership Board Rep.

District Health Board Staff Present		
Dale Oliff	WrDHB[1]	Chief Executive Officer
Fionnagh Dougan	2DHB[1]	Chief Executive Officer
Kadeen Williams	WrDHB	Executive Assistant
Sandra Williams	WrDHB	Executive Leader Planning and Performance
Arawhetu Gray	CCDHB[1]	Director Māori Health Services
Rachel Haggerty	2DHB	Director Strategy Innovation & Performance
Nicola Holden	2DHB	Director of Office of the Chief Executive
Amber Igasia	2DHB	Board Liaison Officer
Rachel Noble	3DHB[1]	General Manager Disability Strategy, Innovation and Performance
David Darling	3DHB	Senior Systems Lead
Leo Goldie-Anderson	3DHB	Disability Projects Lead
Michelle Graham	CCDHB	Disability Education Advisor
Robyn Armour	HVDHB[1]	Disability Advisor
Stewart Sexton	3DHB	Community Liaison

[1] See glossary at end of minutes

Shannon Morris	3DHB	New Zealand Sign Language Projects Lead
Marlin Elkington	3DHB	Māori Disability Advisor
Nigel Fairley	3DHB	General Manager Mental Health Addictions and Intellectual Disability Services
Visitors / Guests		
David Smol, 2DHB Board Chair		

1 PROCEDURAL BUSINESS

1.1 KARAKIA

Tristram Ingham opened the meeting with a karakia following which the Chair welcomed everyone to the meeting.

1.2 APOLOGIES

As noted above.

1.3 CONTINUOUS DISCLOSURE

It was **noted** as current and any changes to be sent to the Board Liaison Officer via email.
Addition of Prue Lamason to the Interest Register, previously omitted.

1.4 MINUTES OF PREVIOUS CONCURRENT MEETING

The Committee **approved** the minutes of the previous 3DHB DSAC Meeting held on 24 June 2020 with the following additions:

- Prue Lamason apologies at previous meeting.
-

Moved	Seconded
‘Ana Coffey	John Ryall

1.5 MATTERS ARISING FROM PREVIOUS MEETINGS

#	Action Requested	Assigned	Action Taken	Status
2.1	1. Load reports into the resource centre; Tangati wha, UN Conventions on rights of persons with Disability, Team presentation and Accessibility Charter, Living Life Well 2. Include link “Ripeka Video Story”	Board Secretary	Email sent, documents loaded on Diligent and links to external docs in email. Video linked below. https://vimeo.com/171010427	Closed
3.1	Greater Wellington Region Collaborative (GWRC) name to be reissued due to confusion with other names	N/A	While it was discussed by the members it is not within the purview of the Committee to request changes of other organisations names.	Closed

4	Extra administration discussion and work to be completed to address work plan, schedules and resources meeting etiquette to be developed for ensuring all members are incorporated	Board Secretary	Work plan on Sep agenda. Meeting etiquette in progress of development.	Open

1.6 DSAC WORK PLAN 2020

The work plan was received and feedback is to be sent to the Board Liaison Officer. Following feedback was provided in the meeting:

- The members would like an opportunity for more strategic discussions in the work plan. This includes information on potential strategic risk.
- A future discussion on how MHAIDS is held to account as a 3DHB service and potentially topics of rehabilitation.
- A question was asked about whether it was enough to be receiving information on Mental Health and Disability every six months and management noted having one topic at each meeting will allow for more in-depth focus at each meeting.
- Māori Partnerships are included. Management noted there is engagement with Māori partnership groups to the Sub-Regional Disability Advisory Group.
- Members also noted they wanted a more comprehensive approach to the meetings, with Board packs to include more papers ahead of time.
- What's planned in the annual plan to connect with future work plans?

2 PRESENTATION

2.1 LIVING LIFE WELL: MENTAL HEALTH AND WELLBEING STRATEGY UPDATE

Presenter: 2DHB Director Strategy, Planning and Performance
General Manager Commissioning Mental Health and Addictions

Presentation was made on the Living Life Well Strategy, the slides are included below.
NOTES:

- Question raised about the plan and how far are we through it? What are the barriers preventing the completion of the plan? Is there anything that can be done at the Board level to remove some of those barriers?

Living Life Well Strategy

2.2 THE ACUTE CARE CONTINUUM

Presenter: 2DHB Director Strategy, Planning and Performance
General Manager Commissioning Mental Health and Addictions
Clinical Director Mental Health, Addictions and Intellectual Disability Services

Presentation was made on the Acute Care Continuum, the slides are included below. Clarification was requested on the definition of AOD, which was defined as Alcohol and Other Drugs.
NOTES:

- A question was raised about crisis support services offered in CCDHB and management noted while investment initially started in the Hutt Valley, the model is 3DHB and future investment will be assessed across the three DHBs, even looking at mobile support services.
- Concern was raised about mental distress and health amongst the disability community and the information was requested on the interface of mental health and disability.

ACTION: A future update on the work on Crisis Support Services to DSAC.
ACTION: Request for more information on mental health and disability.

Acute Care Continuum

2.3 MHAIDS HIGH DEMAND

Presenter: 2DHB Director Strategy, Planning and Performance
General Manager Commissioning Mental Health and Addictions
Clinical Director Mental Health, Addictions and Intellectual Disability Services

NOTES:

- The Committee members wanted to thank everyone who has worked to pull the presentations together as they were very informative.

MHAIDS High Demand

3 ENDORSE

3.1 SIGNING THE ACCESSIBILITY CHARTER

Presenter: 2DHB Director Strategy, Planning and Performance

Disability Support Advisory Committee endorsed, for Board approval:

(a) The signing of the Accessibility Charter.

Disability Support Advisory Committee noted:

(b) The Accessibility Charter and the approach to implementation being a targeted approach tackling specific areas that have a wider scope of impact and will be affordable.

Moved	Seconded
Tristram Ingham	Prue Lamason

4 DISCUSSION

4.1 SUMMARY AND UPDATE OF ACTIVITIES SUPPORTED BY THE SUB-REGIONAL DISABILITY STRATEGY JULY 2020 – SEPTEMBER 2020

Presenter: 2DHB Director Strategy, Planning and Performance

The Disability Support Advisory Committee noted:

(a) Progress in key activities related to the implementation of the Disability Strategy implementation.

4.2 2DHB DISABILITY RESPONSE TO THE HEALTH SYSTEM REVIEW

Presenter: 2DHB Director Strategy, Planning and Performance

The Disability Support Advisory Committee endorsed, for Board approval:

(a) The approach the Sub-Regional Disability Advisory Group is taking to provide feedback directly to the Review Transition Committee regarding the identified gaps in the review.

The Disability Support Advisory Committee noted:

(b) The concerns raised by Sub-Regional Disability Advisory Group (SRDAG) regarding the Health and Disability System Review.

(c) The Subregional Disability Advisory group would like to make high level recommendations for the transformation work arising from the review.

Moved	Seconded
'Ana Coffey	Jill Stringer

5 OTHER

5.1 GENERAL BUSINESS

The Committee thanked Nicola Holden for her work and acknowledged this as her last meeting.

6 NEXT MEETING

Friday, 18 December 2020. Pilmuir House Boardroom, Hutt Hospital, Lower Hutt.

CONFIRMED that these minutes constitute a true and correct record of the proceedings of the meeting.

DATED this day of 2020

'Ana Coffey
DSAC CHAIR

GLOSSARY OF TERMS	
WrDHB	Wairarapa DHB
HVDHB	Hutt Valley DHB
CCDHB	Capital & Coast DHB
2DHB	Hutt Valley DHB and Capital & Coast DHB
3DHB	Wairarapa DHB, Hutt Valley DHB and Capital & Coast DHB
DHB	District Health Board
DSAC	Disability Support Advisory Committee
SRDAG	Sub-Regional Disability Advisory Group
MHAIDS	Mental Health, Addiction and Intellectual Disability Services
AOD	Alcohol and Other Drugs

DSAC ACTION LOG

Action Number	Date of meeting	Due Date	Date Completed	Status	Assigned	Agenda Item #	Agenda Item title	Description of Action to be taken	How Action to be completed
DSAC2020-04	23-Sep-20	18-Dec-20	18-Dec-20	Complete	Board Secretary	1.6	Workplan	Reach out to DSAC in October for further feedback on workplan. Incorporate more detail.	Brought to meeting 18.12.2020
DSAC2020-05	23-Sep-20	18-Dec-20	18-Dec-20	Complete	Director Strategy, Planning and Performance	2.2	Acute Care Continuum	Update on the Acute Mental Health Integrated Service Response	Brought to meeting 18.12.2020
DSAC2020-06	23-Sep-20	18-Dec-20	18-Dec-20	Complete	Director Strategy, Planning and Performance	2.2	Acute Care Continuum	Request for more information on the interface between mental health and disability.	Brought to meeting 18.12.2020
DSAC2020-07	23-Sep-20								
DSAC2020-08									

Work Plan

Year	2021	2021	2021	2021	2021	2021	2021
Month	January	February	March	April	May	June	July
Board Focus:	Annual Plan Planning Workshop (5)	No Meeting	Destravis - Integration Work (3)	Provider Arm Financial and Non Financial (1)	Equity and Integration, Multi-Year Plan (6)	Annual Plan (5) Equity and Integration (6)	Community Based Initiatives (2)
HSC Focus:	No Meeting	Provider Arm Non Financial (1)	Annual Plan (5) Equity and Integration (6)	No Meeting	Draft Regional Services Plan Community Based Initiatives (2)	No Meeting	
DSAC Focus:	No Meeting	No Meeting	Annual Plan (5) Equity and Integration (6) MHAIDS	No Meeting	Draft Regional Services Plan Community Based Initiatives (2) DISABILITY	No Meeting	No Meeting

Work Plan

Year	2021	2021	2021	2021	2021	2021	2021
Month	January	February	March	April	May	June	July
DATE	No Meeting	No Meeting	31	No Meeting	26	No Meeting	No Meeting
Strategy							
Sub Regional Disability Strategy 2017 - 2022 Update					Sub Regional Disability Strategy 2017 - 2022 Update		
Sub Regional Living Life Well - a strategy for mental health and addiction 2019 - 2025			Sub Regional Living Life Well - a strategy for mental health and addiction 2019 - 2025				
Integrated Performance Reporting							
3DHB Disability Integrated Performance					3DHB Disability Integrated Performance		
3DHB Mental Health and Addictions Integrated Performance			3DHB Mental Health and Addictions Integrated Performance				
3DHB Mental Health and Addictions Outcome Framework			3DHB Mental Health and Addictions Outcome Framework				
Health System Investment and Prioritisation							
Mental Health & Addiction Investment Plan			Mental Health & Addiction Investment Plan Priorities 2021				
Disability Investment Plan Priorities							
System and Service Planning							
Minister's Letter of Expectations			Minister's Letter of Expectations				
Draft Annual Plans 2020/21 (Mental Health, Addiction and Disability Sections)			Draft Annual Plans 2020/21 (Mental Health, Addiction and Disability Sections)				
Provider Performance - Efficiency, Outputs and Safety							
Mental Health System Peformance (MHAIDS + SIP)			Mental Health System Peformance (MHAIDS + SIP)				

2021	2021	2021	2021	2021
August	September	October	November	December
		Annual Plan (5) Equity and Integration (6)	**Destravis - Integration Work (3)**	**Equity and Integration - Multi-Year Plan (6)**
No Meeting		No Meeting	**Annual Plan (5) Equity and Integration (6)**	No Meeting
No Meeting	**MHAIDS**	No Meeting	**Annual Plan (5) Equity and Integration (6) DISABILITY**	No Meeting

2021	2021	2021	2021	2021
August	September	October	November	December
No Meeting	29	No Meeting	24	No Meeting
			Sub Regional Disability Strategy 2017 - 2022 Update	
	Sub Regional Living Life Well - a strategy for mental health and addiction 2019 - 2025			
			3DHB Disability Integrated Performance	
	3DHB Mental Health and Addictions Integrated Performance			
	3DHB Mental Health and Addictions Outcome Framework			
			Disability Investment Plan Priorities for 2022	
			Draft Annual Plans 2020/21 (Mental Health, Addiction and Disability Sections)	
	Mental Health System Peformance (MHAIDS + SIP)			

Board Discussion – Public

December 2020

Acute Mental Health Integrated Service Response

Action Required

3DHB Disability Support Advisory Committee note:

(a) Services providing acute and intensive psychiatric and mental health care are under pressure, with a consistent picture of high and increasing demand for services.

(b) There are significant points of stress in the system including over utilisation of inpatient beds, high volume in crisis response services, poor engagement with NGO services resulting in underutilisation of support care, and fragmentation of the acute response system.

(c) The acute care continuum model of care defines core services which require investment and development to create an improved and better coordinated acute care system response.

(d) Investment approved by the Board in November 2019 has been progressed, following COVID-19 delays, with a core tranche of contracted service improvements in train pending Health System Committee chair authorisation.

(e) Further 3DHB investment including potential additional inpatient capacity will be considered through the redesign and development of Te Whare Ahuru, the Hutt Valley DHB inpatient unit, and establishment of a Kaupapa Māori crisis respite service.

(f) A forum of leaders of clinical and NGO acute care tasked with the responsibility for coordination of acute service response and eliminating fragmentation has been established. This collective forum is a core part of implementation of the model of care.

Strategic Alignment	CCDHB Health System Plan 2030 Subregion Living Life Well A strategy for mental health and addiction 2019-2025. Taurite Ora Māori Health Strategy 2019-2030
Authors	Catherine Inder, Principal Advisor, Strategy, Planning and Performance Chris Nolan, Acting General Manager Commissioning, Mental Health & Addictions
Endorsed by	Fionnagh Dougan, Chief Executive, 2DHBs
Presented by	Rachel Haggerty, Director, Strategy Planning and Performance, 2DHBs Sandra Williams, Executive Leader, Planning and Performance, WrDHB Nigel Fairley, General Manager, Mental Health, Addictions and Intellectual Disability Service, 3DHBs
Purpose	To provide information on demand pressures on our 3DHB crisis and acute system of mental health care, the background to these, our whole of system approach to improving acute care continuum services and progress to date.
Contributors	Kate Stewart, Project Manager, Mental Health & Addictions Sam McLean, Principal Analyst & Team Leader, Analytics Nathan Brown, Senior Health Insights Analyst, Analytics
Consultation	N/A

Executive Summary

Mental health and addiction services are under pressure with increasing demand across our communities. Our adult specialist clinical services from crisis resolution, to inpatient services, experience high numbers of referrals, and admissions, with an increase in the level of acuity and complexity of need. Our services are stretched and people wait to be seen in our Emergency Departments, and our inpatient units are busy and crowded. This is not a unique situation the picture is nationally consistent.

Our community alternatives to inpatient care, crisis support and mobile services are not adequately resourced. The crisis resolution services, community support and inpatient services are not integrated and there is no collective approach to provision of care. The range of presenting issues and increase in acuity requires system development, multi-service investment and a focus on improved coordination of acute services.

The acute care continuum investment plan is in the implementation phase and includes a new inpatient acute and intensive care facility in the Hutt Valley. Our ongoing investment is for the creation of sustainable and appropriately resourced crisis respite services, mobile seven days per week and after hours support services and a collective approach to integrate clinical specialist and NGO inpatient and community services. This multi-service investment and collective approach to service delivery represents a systems approach to design and implementation which will provide transformed and more effective service-delivery models.

Strategic Considerations

Service	The Acute Care Continuum is critical to supporting Tangata Whaiora to be well and reduce avoidable admissions to acute inpatient units.
People	The resourcing schedule is part of the operating budget for 2019/20.
Financial	The resourcing schedule is part of the operating budget for 2019/20.
Governance	The Governance of this work is supported by Strategy, Planning & performance and MHAIDS.

Engagement/Consultation

Patient/Family	The Lived Experience Advisory Group provides support to this service development.
Clinician/Staff	A wide range of clinicians are engaged in the development of the specific models of care and service delivery.
Community	Engagement with our community providers via the Collective Forum that has supported the community developments.

Identified Risks

Risk ID	Risk Description	Risk Owner	Current Control Description	Current Risk Rating	Projected Risk Rating
	Inpatient overcrowding	General Manager, and Medical Director MHAIDS	Completion of risk assessments and clinical team planning Use of casual pool and focus on recruitment Inpatient unit social work roles focus on communication with whanau Ensure appropriate clinical leadership	2	3
	Strong association with increase in incidents aggression and self-harm			3	3
	Potential inadequate staffing resource for the level of acuity and patient numbers			2	3
	Potential impact on discharge planning with reduced time for communication and care planning for discharge plans.			2	3
	Potential impact on clinical decision making due to pressure on clinicians			2	3

Attachments

1. Appendix A - Investment and Improvement of the Acute Care Continuum Services Summary
2. Appendix B - Acute Care Continuum: The Model of Care and The Model of Care Principles
3. Appendix C - Acute Care Continuum Model of Service Delivery

Purpose and background

1. The Board paper *New investment to address Mental Health Acute Care Continuum service*s dated 7 August 2019 sought the Board's support to release funding to address service gaps in the acute care continuum in the Hutt Valley. The more recent Board paper *3DHB Acute Care Continuum Project Update* dated 8 June 2020 provided an update and included 3DHB (Wairarapa, Hutt Valley and Capital & Coast) planned investment in the continuum. On 20 September 2020, an update on progress designing and implementing the acute care continuum
2. This more in-depth paper looks at who accesses the acute care continuum in our 3DHBs and the spectrum of their needs. It describes how people in crisis/needing acute care are accessing services and moving through the system, including 2020 data showing that these services remain under significant pressure. It also explores the key services that make up the acute care continuum, their current issues, and the significant service reconfigurations and investment underway aimed at building a deeply collaborative system of care.

The people who need acute and crisis care

3. Across our 3DHBs there are almost 3000 individuals referred to crisis resolution and acute referral services annually. These are people who are in deep distress and causing their families and whānau, health practitioners and others they are interacting with, real concerns for their immediate safety and future wellbeing.
4. People presenting with acute and intensive care needs require speedy interventions. Timely care will enable many Tangata Whaiora (people with mental health support needs) to be supported at home or to stabilise with a short stay in either acute respite care or an inpatient unit. In our DHBs approximately 10% of Tangata Whaiora are admitted to acute inpatient care and 9% are placed in crisis respite (30% of clients following an inpatient admission). A significant cohort, approximately 20%, with enduring mental health issues, require support services following an acute episode to limit dependence-creating inpatient stays and support stability.
5. Tangata Whaiora stay in acute inpatient units on average about two weeks. There are up to 1200 admissions into the two inpatient units in Wellington and the Hutt Valley per year and they are very busy. Coupled with this activity, at times there is severe overcrowding consequent on these facilities operating on average at above 90% occupancy in our acute unit beds and up to 140% occupancy in the intensive psychiatric care beds. Overcrowding in acute mental health units is well researched and is strongly associated with increases in the incidence of aggression. An underlying and less well researched issue is gender-based vulnerability consequent on restricted choices – female Tangata Whaiora often report feeling unsafe when inpatient units are busy. When there is overcrowding in the intensive psychiatric areas, care for Tangata Whaiora is restricted to avoid at-risk interactions, and seclusion is used more often when there is emerging risk to others due to the confined space for care.
6. Chapter Two of *He Ara Oranga The Report of the Government Inquiry into Mental Health and Addiction* is titled 'What we heard – the voices of the people.' Here are some of the things that Tangata Whaiora had to say about their experiences of crisis and acute care:

   > People recounted being told their situation was not serious enough to meet the threshold for specialist services, a message they interpreted as 'go away and only come back if your condition becomes life-threatening'. Having summoned the courage to ask for help, they felt ignored, minimised and not heard – denied an appropriate service or left in limbo awaiting space in a detox programme or respite care. People spoke of the

cruelty of encouraging individuals, family and friends to seek help from mental health services that are unavailable or severely rationed…

Even when the need for services was acknowledged, people often had to wait a long time. Tāngata whaiora and families reported a constant struggle to gain access to specialist services or to cobble together packages of assistance that were incomplete, inadequate or subject to change. Submitters spoke of deficiency: of beds, staff, specialist care, timely assessments, quick intervention, rehab services, kindness, culturally appropriate care, communication, an integrated care continuum, funding, referral options, and crisis response.[1]

There are profound inequities in our DHBs, and nationally

7. Across the 3DHBs almost 20,000 people accessed specialist mental health and addiction services last year. Overall, Māori are over-represented in their access to specialist mental health services across the 3DHBs and Pacific are over-represented in Wairarapa and Capital & Coast DHBs compared to non-Māori, non-Pacific.

	Number of People				Proportion of Population			
	Maori	Pacific	Other	Total	Maori	Pacific	Other	Total
CCDHB	2,661	777	8,236	10,897	7.2%	3.5%	2.9%	3.4%
HVDHB	1,858	369	4,494	6,352	7.0%	3.1%	3.6%	4.2%
WDHB	738	50	1665	2403	9.1%	5.3%	4.3%	5.2%
3DHB	5,257	1,196	14,395	19,652	7.0%	3.4%	3.5%	3.7%

8. Of Tangata Whaiora accessing specialist mental health services across the 3DHBs, 68% are adults (20-64 years). Māori and Pacific adults are over-represented in their access to specialist mental health services across the 3DHBs compared to non-Māori, non-Pacific.

	Number of People				Proportion of Population			
	Maori	Pacific	Other	Total	Maori	Pacific	Other	Total
CCDHB	2,661	777	8,236	10,897	7.2%	3.5%	2.9%	3.4%
HVDHB	1,858	369	4,494	6,352	7.0%	3.1%	3.6%	4.2%
WDHB	738	50	1665	2403	9.1%	5.3%	4.3%	5.2%
3DHB	5,257	1,196	14,395	19,652	7.0%	3.4%	3.5%	3.7%

9. In 2020, 20 to 22% of more than 26,000 referrals to our specialist mental health services were either acute at the time of referral or, for Crisis Resolution Services (approximately 5,500 referrals). Respectively, 27% and 6% of referrals to Crisis Resolution Services were for Māori and Pacific people despite making up 14% and 7% of the 3DHB population

	Number of People				Number of referrals			
	Maori	Pacific	Other	Total	Maori	Pacific	Other	Total
3DHB	756	209	2,020	2,985	1,410	340	3,507	5,257

10. We recognise that our priority populations – Māori and Pacific peoples, people with disabilities, and our rainbow communities – are over-represented in those accessing crisis resolution and acute referrals. We acknowledge that many Tangata Whaiora will identify

[1] Government Inquiry into Mental Health and Addiction. 2018. *He Ara Oranga The Report of the Government Inquiry into Mental Health and Addiction.* Accessed on 7 December 2020 at: https://mentalhealth.inquiry.govt.nz/assets/Summary-reports/He-Ara-Oranga.pdf. Pages 54-55.

with more than one of these communities compounding the challenges to access and trust mainstream services.

11. Māori experience the highest levels of mental illness and/or addiction of any ethnic group in New Zealand. We acknowledge that these poor health outcomes only tell a partial story – there are many positive aspects of Māori wellbeing not canvassed in this paper.
    - Māori aged 20–64 years are almost two and a half times more likely to access specialist mental health services compared to Non-Māori, Non-Pacific.
    - Māori are more than three times more likely to be subject to a Community Treatment Order under Section 29 of the Mental Health Act compared to Non-Māori, Non-Pacific
    - Māori are more likely to in seclusion during an inpatient admission. The seclusion data suggests that Māori are being secluded unnecessarily.
    - Self-harm rates in Māori youth and Māori suicide (all ages) are higher than those of non-Māori in the same age groups.
    - One in three Māori will experience mental illness and/or addiction issues in a given year compared with one in five in the general population (NZ-wide data).[2]
    - Māori are more likely than non-Māori to have later access to services (NZ-wide data).
12. Pacific peoples also experience mental illness and/or addiction at higher rates than others with 25% experiencing mental illness and/or addiction in a given year compared to 21% overall. Medium to high levels of psychological distress in a four week period were significantly higher in young Pacific peoples aged 15-24 (38%) and adults aged 45-64 (35%) than overall.
13. Disability includes mental health as well as physical, intellectual, sensory and other disabilities. Māori and Pacific people's disability prevalence rates are higher than the general population (32% and 26 % respectively compared to 24%). International research demonstrates notable health inequalities experienced by disabled people, especially in the areas of mental health and wellbeing. Key findings from 2019 research we commissioned relevant to this paper are:
    - The system focus on acute cases means many disabled people don't receive the support they need.
    - Disabled people's mental health needs often go undetected and untreated by health professionals.
    - Service delivery for disabled people with mental health care needs is fragmented.
    - Accessible mental health care facilities are limited.[3]

Access and flow across our acute system of care

14. Our DHBs' mental health and addiction strategy *Living Life Well 2019–2020* aims to transform the MHA system to one that can intervene earlier, both in the life course and when issues arise. Meeting needs earlier will create a positive feedback loop where reduced demand on our specialist MHA services will enable us to focus resources on improving

[2] Capital & Coast DHB. 2019. Taurite Ora Māori Health Strategy 2019-2030. Page 42.
[3] Morrison, Dr Carey-Ann. *Research Report Mental Health Services for Disabled People*. February 2020. Page 5.

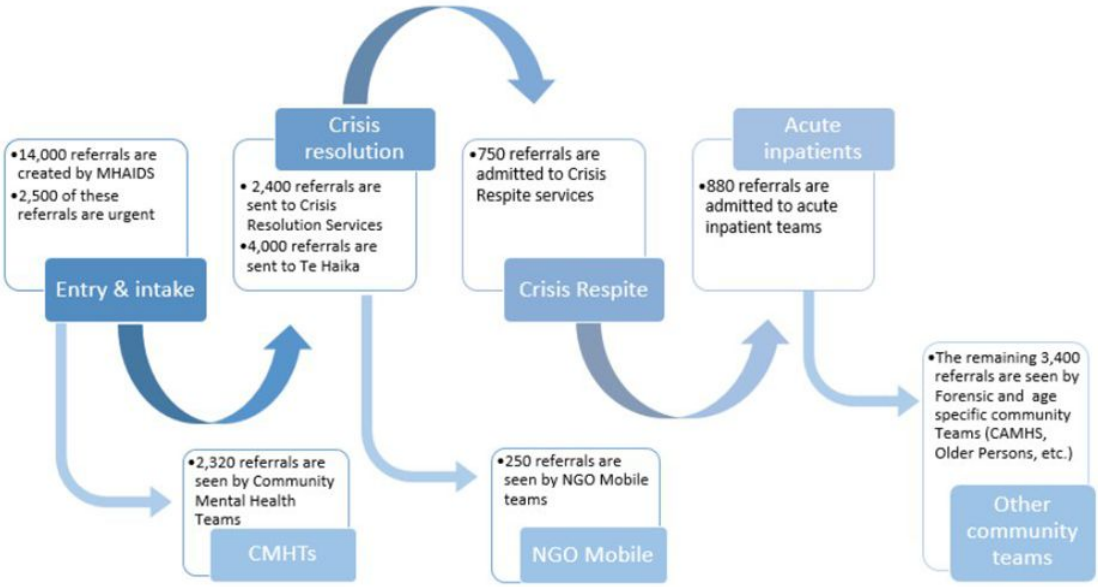
access for first-time Tangata Whaiora and increase efforts towards prevention, early intervention and population wellbeing.

15. Our DHBs are investing in early intervention services across the continuum, but due to sustained under-investment in MHA services, there are significant funding and service gaps in crisis and acute care services that we are addressing.

16. Tangata Whaiora are waiting for assessment, admission to both inpatient and community services and placements with support. There is insufficient community capacity for Tangata Whaiora with acute care needs who require step-up or step-down placements both before, and for those people admitted to an inpatient unit after, transfer of care.

Current trends in our communities

17. The diagram below shows how 3DHB acute care patients moved through the current system of care for the 2020 calendar year up to and including October.



18. The current data picture is complicated as demonstrated by the following "snapshots" of patient flow through the system. The overall picture is of changes in help-seeking behaviours, an increase in urgent presentations, notwithstanding the dip that occurred as a consequence of COVID-19, and indications that MHA services across the spectrum are struggling to meet the demands.

    - During COVID-19 we saw distress in our communities through increased calls to the 1737 and the COVID helpline. These higher rates of distress have been sustained through to October 2020. There were significant increases in calls to 1737 for Non-Māori, Non-Pacific. However the same change in activity was not observed for Māori or Pacific.
    - Across the 3DHBs, approximately 16,000 additional people are on the Jobseeker Work Ready benefit and not coming off. Our Māori and Pacific are likely to be over-represented in this cohort as nationally, 41% of people on the Jobseeker Work Ready benefit are Māori and 10% are Pacific.
    - Primary mental health services have reported an 18% increase in the number of clients seen (160 people), challenging their ability to manage demand. The

increasing number of clients seen by primary care for mental health reasons was present prior to lockdown and has accelerated in recent months with an additional 2,000 people seen compared to the same time last year. Notably, the number of Māori and Pacific people seen by primary mental health services has been growing since the start of 2019.

- In 2020, there has been an overall increase in the need for urgent referrals for Māori (an increase of 8%; 46 additional people) and Pacific peoples (an increase of 31%; 39 additional people); and for Non-Māori, Non-Pacific there has been a 10% increase and 137 people. In total, there has been an additional 296 urgent referrals compared to 2019.
- The number of people self-referring to specialist mental health services has decreased from 2019. However, post-lockdown we are observing more referrals from GPs compared to 2019 and 2018.
- There have been 1400 fewer referrals to Te Haika in 2020 than 2019. However, the number of urgent referrals is increasing at a faster rate post-lockdown compared to 2019 (+275) and calls are taking longer to resolve.
- In 2019 and 2020, those presenting as acute/urgent created 27.3% more referrals and 109.7% more activities, indicative of their need for more specialised care.
- Even with less overall volumes, our specialist mental health services are experiencing increased acute need. The proportion of urgent referrals has increased from 13.9% in 2019 to 17.8% in 2020. This includes 9.4% more urgent referrals from Upper Hutt and 8.9% from Porirua

There are significant points of stress in a poorly connected system of care

19. The Acute Care Continuum project (the Acute Care Continuum project) is a HVDHB-led 3DHB project that reviewed existing demand, identifying system-wide issues. The project is regaining momentum following the slowdown necessitated by COVID-19 and will progressively provide our DHBs with the means to effectively manage the flex in demand for acute and crisis care.
20. The Acute Care Continuum project identified these key system-wide challenges:

    Crisis response – an afterhours services is an essential part of an acute care response because mental health issues often build during the day to crisis point at night. There are historical gaps in our DHBs after-hours coordination service that can facilitate access, depending on need, to an inpatient unit, a crisis respite facility, or community-based recovery support and accommodation.

    Te Whare o Matairangi (CCDHB) and Te Whare Ahuru (HVDHB) – work together to provide a 3DHB inpatient acute and intensive psychiatric care service for the subregion. These inpatient services are over-utilised and often deliver care beyond their funded and operational capacity:

    - bed occupancy in both units is on average over 90%
    - Te Whare Ahuru's bed occupancy is over 100% for up to 4 months of the year
    - the intensive care beds in both units operate at over 100% occupancy all of the time, with up to 140% occupancy for at least six months of the year.

    If normal use is above 90% or close to 100%, there is no flexibility to provide acute inpatient care without impacting existing patients. This means in practice that inpatient units go over numbers or there are early discharges.

While, NASC services actively coordinate inpatient discharges to make room for Tangata Whaiora in crisis, NGO capability and the lack of step-down options are barriers to placement.

NGO Crisis Respite services – these services provide options for people in crisis who do not require inpatient psychiatric care, and are a step-down care option for Tangata Whaiora who can be discharged from inpatient care before return home.

Our NGO Crisis Respite services have been underutilised by 20 to 25% of beds largely because these services have been largely staffed by support workers and clinicians working in other services on the acute care continuum have not wanted to discharge still unwell Tangata Whaiora into these facilities. Other issues including their geographic locations combined with their access criteria (e.g. male or female only) have made them unsustainable and has also contributed to their isolation from other services and hampered their endeavours to anticipate demand and coordinate care.

NGO Mobile Support – supports people in their own homes. The service is narrowly focused (e.g. medication monitoring) and resourced for a limited number of Tāngata Whaiora and as a consequence this service can only offer limited support to other relevant MHA clinical and support services.

Day Activity – The day activity service is comprised of two programmes, one facility based where people attend a programme and the other, mobile support during the week including a more limited weekend presence. Both programmes are underutilised due to inadequate resourcing and a challenging facility and environment. Problems include insufficient focus on follow-up care, access barriers including transport, and poor integration with other relevant MHA services.

Our plan to transform the acute care continuum

21. The Acute Care Continuum project recognised that any effective solution to these multiple service issues would require investment in a whole of system response. The model of care multi-year investment within HVDHB for 2019/20 was confirmed by the Board in August 2019. The model of care defines a set of core service components that make up the 'acute care continuum' and recommends improving and investing in the core service components and a focus on improving the overall coordination of the acute care continuum.

Investment in the core service components

22. The core services for investment and improvement are Te Haika - single point of entry, inpatient units, Crisis Response, Crisis Respite, Day Activity and Transition services. Appendix A sets out the high-level service investment and improvement plan in relation to these services. The methodology is adaptable to a 'locality approach' as the core service components and the coordinating forum can be readily replicated. Diagrams of the Acute Care Continuum model of care, the Acute Care Continuum project principles, and the model of service illustrating this approach are attached as Appendix B.

Improving overall coordination

23. The Collective Forum is a coordinating enabler for the system of care. The members are engaged and collaborative services collectively responsive to the full range of acute needs presenting at any point in the acute system and represent the full MHA spectrum (tertiary, secondary and community and primary care sectors).

24. The Collective Forum is responsible for delivering a flexible, fully responsive acute system of care through supporting engagement amongst providers to build trust and collectively problem solving challenges to system change and coordinating project activities, recognising

that providers are at different stages of development and need to understand each other's challenges and to coproduce solutions.

Whole of system benefits

25. The planned improvement and investment in the core service components and the Collective Forum together will contribute to these whole of system benefits:

    - full utilisation of NGO respite capacity will enable a response to significantly more crisis respite referrals (alternative care for over 100 individual Tangata Whaiora across our 2DHBs) both as an alternative to acute inpatient care and to expedite a smooth and effective transition to the community post-inpatient care
    - a smaller number of clients will have a reduced inpatient length of stay and a reduced readmission rate
    - additional reduced wait times at the Emergency Department. Up to 60% of clients presenting at ED are known to MHA services.
    - improved access and utilisation of mobile after-hours support services will improve support to crisis resolution services and enable community mental health teams to intervene earlier and resolve crises closer to a person's home.

Progress to date

26. Our DHBs have achieved the following key milestones:

    ACC Collective Forum – the first meeting was held late 2019, the next meeting was interrupted by COVID-19 and was held in June 2020. The latest collective forum was held 10 December this year and progressed agreements about improving the day activity and crisis respite programmes. The Collective Forum has provided oversight for the following collaborative activities:

    - identified the individual work streams to support the Acute Care Continuum model implementation
    - co-designed a proposed acute alternative day activity service model, inclusive of increased mobile in-home support capacity
    - reconfigured the NGO crisis beds and the staffing necessary to support increased NGO crisis respite capacity and capability
    - developed a clinical pathway for older persons crisis respite
    - developed an implementation reporting and a monitoring framework.

    Strategy Planning and Performance – have developed and agreed the service model changes and service reconfigurations with the lead NGO acute respite care providers and draft contracts are now in train. The team has also increased staff in the HVDHB NGO housing project and integrated it with the combined 2DHB teams.

27. Our 3DHBs are adapting the Acute Care Continuum service model to fit their strengths and service gaps:

    Hutt Valley DHB – is partnering with CCDHB and WrDHB to develop plans for services for their 2020/21 budget and investing in services in accordance with the August 2019 Board decisions:

    - three key NGO providers have draft contracts that will be finalised December 2020 enabling reconfiguration to match the Acute Care Continuum model of care and

discussions are underway with another aged-care provider for age-appropriate crisis respite care

- the 2022-23 investment plan includes a Kaupapa Māori crisis respite service
- final approvals for the new inpatient unit will be sought in February 2021.

Wairarapa DHB – is implementing recommendations from its review of MHA services within an affordability envelope. It has established its own Collective Forum to implement the continuum approach to coordinating acute care and has a plan to redevelop the Crisis Respite service elements such as mobile support.

Capital & Coast DHB – is improving Crisis Respite services with a move to a six bed service and with plans to invest in the conversion of a fourth facility. Additional crisis respite developments to respond to locality-based pressures are subject to investment bids.

Conclusion

28. Our 3DHBs are addressing the historical significant funding and service gaps in crisis and acute care services. We are taking a whole of system approach and have developed a model of care and an implementation plan that includes investment in a new acute modern inpatient unit in HVDHB and increased acute respite capacity and capability.
29. These and other changes will help to transform our mental health and addiction system of care enabling us to intervene earlier with people who need mental health and addiction care and support, and to prevent the onset of mental illness by intervening earlier in the life course.

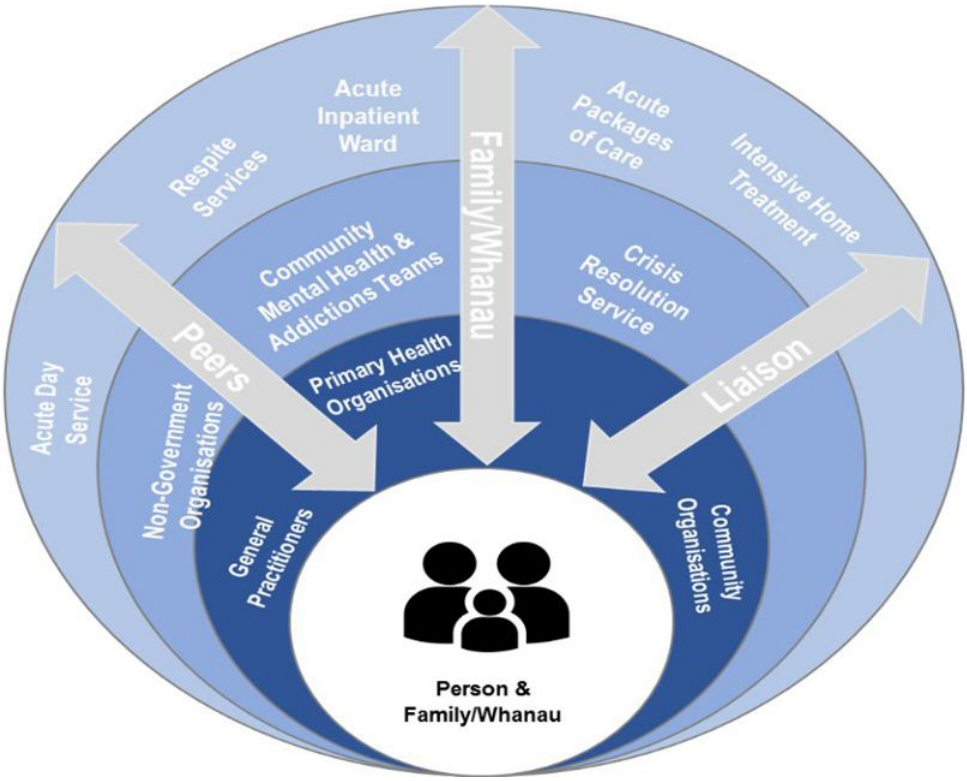
Appendix A

Investment and Improvement of the Acute Care Continuum Services - Summary

1. **Te Haika Crisis Response – strengthening locality-based acute response coordination through:**
    - implementing the recommendations of the Te Haika external review
    - supporting improved coordination and crisis resolution with an extension to afterhours services
    - working with clinical services to increase locality-based intake to overcome lengthy assessment delays in the emergency department or inpatient admissions
    - implementing sustainable and stable afterhours duty coordination of inpatient and crisis respite beds.
2. **HVDHB inpatient unit** – the project to build a new acute and intensive care inpatient will address the need for increased inpatient acute and especially IPC capacity within a better designed properly therapeutic environment.
3. **Crisis Respite** – creating a sustainable respite service as an alternative to inpatient care in HVDHB with three leading NGO services by:
    - increasing critical mass of sustainable services (two six bed/placement services in Hutt with one existing and moving to two in CCHDB) and extending the length of stay
    - providing respite services for older people in locality-based age appropriate environments (rest-home care)
    - increasing service capacity to 'double staffing' levels including peer support
    - employing a clinical role in each facility to provide leadership and service support
    - developing Kaupapa Maori 2DHB crisis respite options.
4. **Mobile After-Hours services** – increasing the capacity and capability of after-hours in-home mobile support services provided by NGOs:
    - 7 day per week service to 10pm at night
    - additional mobile support team staff, including clinical staff, increasing the ability to support Tangata Whaiora with more complex needs
    - closer linkages with the crisis resolution team to enable follow-up when that team's resources are diverted to more urgent situations.
5. **Day Activity** – development and implementation of a revised acute alternative day activity service model to better meet the needs of Tangata Whaiora. This model will move from the current 'weekly day placement service' to a locality base supported by a mobile seven day per week and after hours (up to 10pm) intensive care service.
6. **Sub-acute transitional places** – supporting the rehabilitation of longer term Tangata Whaiora, resourced at similar levels to the Crisis Respite service (see paragraph 3. above), including:
    - 7 day per week service to 10pm at night
    - co-design of a revised service model and the development of a fit-for-purpose facility
    - additional clinical staff and in-home mobile support capacity.
7. **Community Mental Health Teams/NASC** – improved efficiency and flexibility in Package of Care (POC) approval and utilisation processes:
    - funding NGOs to provide POC services
    - more flexible approaches to the application of POC funding
    - monitoring POC utilisation via the Collective Forum.
8. **Housing** – improving access to accommodation with an increase of 1 FTE to address housing and support access for Tangata Whaiora with high and complex needs and other Tangata Whaiora with transitional needs.

Appendix B

Acute Care Continuum: The Model of Care



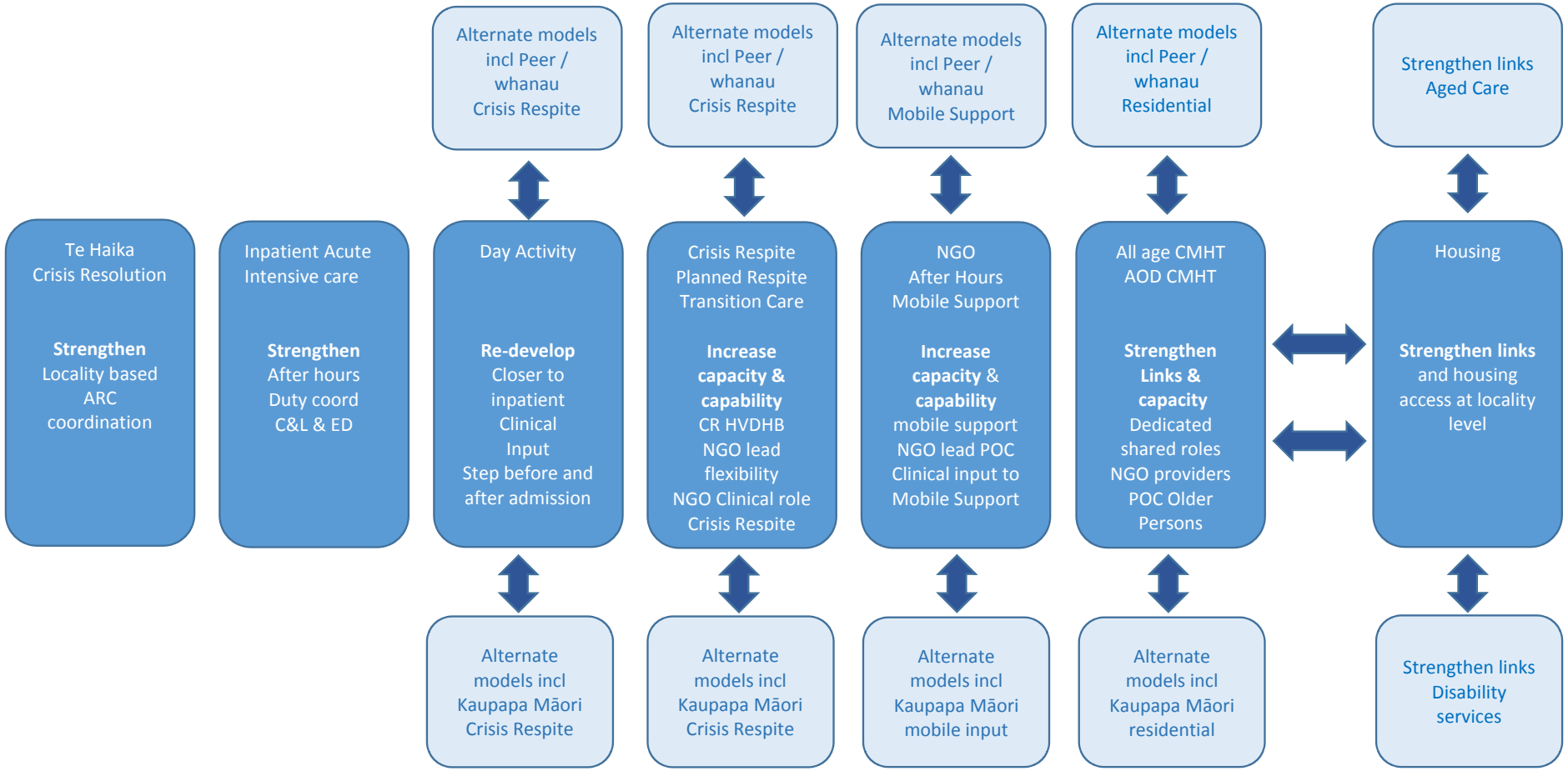
Acute Care Continuum: Model of Care Principles

The Model of Care Diagram is supported by a set of principles which determine how services are expected to meet the needs of individuals and family / whānau.

- *People will lead their recovery*
- *Active involvement of family and whānau is promoted*
- *A collaborative approach without barriers*
- *People are supported in a culturally safe and sensitive environments*
- *Quality of service demonstrates excellence*
- *Tikanga Māori is evidenced throughout*

APPENDIX C: Acute Care Continuum Model of Service Delivery

The Acute Care Continuum model of care is comprised of core service components or models of service that make up an Acute Care Continuum. Adoption of the model of care, defining the components of service and ensuring there is coordination across the continuum will create a 'system' of care which can be collectively responsive to the full range of acute needs presenting at any point in the continuum.



Board Discussion – Public

December 2020

Mental Health Services for Disabled People

Action Required

The Disability Services Advisory Committee note:

(a) The 3DHB Disability Group commissioned a report on mental health services for disabled people.

(b) This report identified a combination of barriers, namely cost, limited availability of services, inaccessible environments and communication, and inadequate skills and knowledge of health workers, prevent disabled people from accessing appropriate mental health care.

(c) Capital Coast and Hutt Valley DHBs will be developing a Disability-Equity Mental Health service model that ensures that disabled people have their mental health needs met alongside any comorbidity they may have.

Strategic Alignment	Sub-Regional Disability Strategy 2017-2022 Enabling Partnerships: collaboration for effective access to health services: Subregion Living Life Well 'A strategy for mental health and addiction' 2019-2025.
Author	David Darling, Senior Development Lead, Disability, Strategy, Planning and Performance.
Endorsed by	Rachel Haggerty, Executive Director, Strategy, Planning and Performance
Presented by	Rachel Noble, General Manager, Disability 3DHB.
Purpose	This paper presents a report on the need for an equitable inclusive mental health service delivery model that includes disabled people at all points of the system.
Contributors	Rachel Noble, General Manager, Disability, Strategy, Planning and Performance.
Consultation	The Sub-Regional Disability Advisory Group

Executive Summary

The attached Report was commissioned to understand mental health services for disabled people.

Research shows that the detection and treatment of mental health conditions is often not well managed for disabled people. Often mental health conditions are either not diagnosed at all or not diagnosed in a timely manner, because the focus was on the person's disability.

For people with multiple and intersecting minority identities, for example disability and race barriers inequities to services are exacerbated. The purpose of this work is to identify how a service model can be applied within the health setting including primary and secondary services that is not determined solely by diagnosis. The People who require assistance from more than one specialty need to have reasonable and equitable access to all services at any one time, and not experience marginalisation due to presenting with comorbidities.

The provision of timely, joined up effective health services is an essential part of ensuring the disability community can achieve optimal outcomes in their wellbeing through engagement with the persons DHB Mental Health service.

Strategic Considerations

Service	Mental Health services and their contracted partners need to provide an equitable service framework, one that is designed to assist all people who require their support irrelevant of comorbidities, therefore achieving equitable health outcomes for the disability community. Ableism training that focuses on the structural dimensions of a disabling world is being developed by the disability team, this is premised on the World of Difference Program developed by Otago University.
People	All staff and community partners need to understand what equitable services provision means for them and understand what it means when disabled people require mental health services. Disabled people accessing mental health services can expect to find services more approachable, responsive, accessible, equitable and appropriate.
Financial	All investment (workforce, organisation, service provision) needs to be considered through an equity lens. Resources will be prioritised to systematically address the need for responsive equitable service delivery.
Governance	The system-wide transformation necessary to achieve health equity by 2030 requires that the Board provide governance for the developing equity based Mental Health service model.

Engagement/Consultation

Patient/Family	Disabled people and their whānau have been active contributors to the review and it is essential that they are involved in any further developmental activities, as without their input assumptions will be made and the result will not be inclusive as intended.
Clinician/Staff	Clinicians contributed to this review.
Community	The disability community provides leadership through the Subregional Disability Advisory Group.

Identified Risks

Risk ID	Risk Description	Risk Owner	Current Control Description	Current Risk Rating	Projected Risk Rating
TBC	There is financial risk of the cost of service delivery.	Director SPP	Incorporate planning for these services into future financial years	Med	Low

Attachment/s

3.2.1 Research report-Mental Health services for Disabled People- February 2020.

1. Mental Health and inequitable outcomes for disabled people

Research shows that the detection and treatment of mental health conditions is often not well managed for disabled people. Mental health conditions are either not diagnosed at all or not diagnosed in a timely manner, because the focus was on the person's disability.

For people with multiple and intersecting minority identities, for example disability and ethnic identity these inequities are exacerbated. The aim of the initiative is to identify how a service model can be applied within the health setting including primary and secondary services that is not determined solely by diagnosis. People who require assistance from more than one specialty need to have reasonable and equitable access to all services at any one time, and not experience marginalisation due to presenting with comorbidities.

Research has highlighted a lack of clinical knowledge as one of the most significant barriers to accessing mental health services, particularly for people with a learning disability. The shortage of speciality psychiatrists and mental health clinicians is also well identified. Limited training about disability can impact upon health professional's ability to work in ways that are respectful and responsive to people's disability needs. This includes language and the ways in which disability, impairment and mental health is talked about, for example ablest and/or discriminatory language, as well as the ways in which physical and mental health needs intersect.

In New Zealand, undergraduate and postgraduate clinical staff in primary care and in hospital services receive limited disability training and education. Key informant interviews with health professionals highlighted the gap in training and education. While some training in specific areas, primarily autism spectrum disorder, is available through joint ventures between a local tertiary education institution and the 3DHB learning development centre, there are limited professional training opportunities available for staff to learn more broadly about disability rights, including the UNCRPD and the New Zealand Disability Strategy.

2. Developing accessible mental health services

The provision of timely, joined up effective health services is an essential part of ensuring the disability community can achieve optimal outcomes in their wellbeing through engagement with the persons DHB Mental Health service.

To be successful across the 2DHB region we need to design networks to ensure we have collaborative advantage across the region. This will require systemic development. Essential considerations are:

a. Research based outcomes focusing on internationally proven best practice

b. A Model that will meet the demands of the current population, adapt to change and benefit not only the community, but also the organisations services including secondary services

c. A model that is culturally appropriate for all sectors of the community.

The 3DHB Disability Team will work with mental health services commissioning over the next twelve months to develop a service responses that incorporate the findings and recommendations of this report.

Imagine Better

Research Report

Mental Health Services for Disabled People

February 2020.

Prepared by:
Dr Carey-Ann Morrison
Imagine Better Ltd

Imagine Better wish to thank everyone who participated in the project.

Imagine Better provides resources that help disabled people, their families and whānau, and their allies, take action for a more accessible, fair, and inclusive world. We want to help build a powerful, passionate, growing, well-resourced and effective disability rights and justice movement

Contents

1 Executive Summary

International research demonstrates notable health inequalities experienced by disabled people, especially in the areas of mental health and well-being.

A combination of barriers, namely cost, limited availability of services, inaccessible environments and communication, and inadequate skills and knowledge of health workers, prevent disabled people from accessing appropriate mental health care.

This report details findings from a small study that aims to understand more about the barriers and enablers disabled people experience accessing mental health services through the 3DHB – Wellington, Wairarapa and Hutt Valley. A literature review focusing on the social determinants of mental ill-health, barriers to access, and strategies for improving access was used alongside key informant interviews with health professionals and disabled people.

> Key findings include:
>
> - Disabled people's mental health outcomes are negatively impacted by the social determinants of health.
> - The mental health system is complicated, can be expensive to use, and requires people to strongly advocate for themselves.
> - The system focus on acute cases means many disabled people don't receive the support they need.
> - Disabled people's mental health needs often go undetected and untreated by health professionals.
> - Lack of knowledge about disability impacts negatively upon disabled people's experiences of mental health care.
> - Service delivery for disabled people with mental health care needs is fragmented.
> - Accessible mental health care facilities are limited.
> - Little data and information about disabled people's experiences of mental health care is collected.

To conclude the report we offered several recommendations in line with the findings addressed in the report.

2 | Introduction

Discussions about mental health dominate public discourse and government policy settings. Mental health and wellbeing are priority areas for the New Zealand Government.

In the 2019 budget, the Government invested $1.9 billion into new mental health wellbeing and addiction initiatives.[1] Issues around access and provision of services, lack of funding, and high rates of mental ill-health receive regular attention in the media and by health researchers. What is noticeably absent from much of this discussion is a consideration of the mental health and wellbeing experiences and needs of disabled people.

In October 2019, Imagine Better was commissioned by 3DHB Disability Strategy, Innovation and Performance Management to conduct a small project to understand more about the barriers and enablers disabled people experience accessing mental health services. The 3DHB's Mental Health, Addictions and Intellectual Disability Service (MHAIDS) provides services across Wellington, Porirua, Kapiti, the Hutt Valley and the Wairarapa, as well as some central region and national services.[2]

The project comprised a literature review and key informant interviews with health care professionals and disabled people who have experience accessing MHAIDS, or other mental health services. The project is underpinned by the United Nations Convention on the Rights of Persons with Disability (UNCRPD), with a particular focus on article 25 which states: "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."[3] Human rights frameworks offer a cohesive approach for addressing inequities

1 https://www.budget.govt.nz/budget/2019/wellbeing/mental-health/index.htm
2 For more information about MHAIDS, see http://www.mhaids.health.nz/
3 https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html

because they bring together multiple sectors and stakeholders, while the monitoring and reporting requirements of rights frameworks help to maintain transparency and accountability.

This report provides an overview of local and international literature related to mental health care and disability. Particular consideration is given to the following areas:

1. Social determinants of mental ill-health for disabled people
2. Barriers disabled people experience accessing mental health care
3. Potential strategies to increase access to mental health care

Literature on physical disability, learning disability[4], blind and/or vision impairment, and Deaf and hard-of-hearing people was reviewed. There is significant body of literature on these issues in the area of learning disabilities, and a smaller volume of scholarship in the areas of physical, deaf/hard-of-hearing, blind/vision impairment. The majority of the research comes from a medical model focus rather than from a social model or a human rights framework. It is important to note the very limited New Zealand-based research, and research specifically in relation to Māori disabled and other minority populations. There is currently no New Zealand evidence about the accessibility of mental health services for disabled people.[5] The lack of research into disabled people's experiences of mental health services means these issues are often not considered in the development of funding and policies. Issues relating to disability, mental health and addiction were not explicit in the literature but would be worthy of further investigation.

2.1. Methodology

A small number of key informant interviews were conducted. Key informant interviews are a qualitative method used to gather detailed perspectives on an issue from experienced and well-informed people from within the community. Dr Carey-Ann Morrison, Imagine Better Senior Researcher conducted the key informant interviews with health professionals from MHAIDS. Dr Morrison is an experienced qualitative researcher and is a parent to a young disabled son. Three key informant interviews were held with four health professionals in the following MHAIDS departments:

- MHAIDS Directorate
- MHAIDS Intellectual Disability Services
- MHAIDS Mental Health Needs Assessment

[4] There is significant variation in the terms used to describe learning disability, including intellectual disability, intellectual impairment, and developmental disability. In line with the social model of disability, we use the term learning disability to reflect the preferred terminology of People First https://www.peoplefirst.org.nz/your-rights/language/

[5] Cunningham, A Kvalsvig, D Peterson, S Kuehl, S Gibb, S McKenzie, L Thornley and S Every-Palmer. 2018. Stocktake Report for the Mental Health and Addiction Inquiry. Wellington: University of Otago

Two individual interviews were conducted with health professionals and a third was a joint interview with two health professionals. Alice Mander, Imagine Better Event Coordinator, who has lived experience of disability conducted the disabled person peer interviews. Two people had first-hand experience of using MHAIDS and the third person choose to bypass the public system in order to access private mental health care. Research on disability and mental health care still tends to priortise the perspectives of medical professionals. There is a very little research that seeks the views of disabled people about their experiences of, and views about, mental health care services. Information about the project was distributed through Disabled Person's Organisations as well as through word of mouth. We asked to hear from disabled people with physical, sensory, learning and other impairments and mental illness. Interviews took roughly one hour. Interviews were audio-recorded and then transcribed verbatim. Participants with lived experience of disability were given a koha to thank them for their time.

2.2. Definitions

This project draws upon the social model of disability, which shows that people are disabled by society rather than impairment[6] and the UNCRPD's definition that says disabled people include: "... those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others..."[7]. At this point, we want to emphasise that it is important to remember that the boundary between mental health and disability is often blurred. For some people, mental ill-health is disabling. According to the 2013 Disability Survey, an estimated 242,000 people (or 5% of New Zealanders) are living with a disability caused by psychological and/or psychiatric conditions.[8] For other people, mental ill-health happens alongside other impairments. For the purposes of this report, we are focusing on disabled people with physical, sensory, learning and other disabilities and mental illness although we acknowledge the disabling impact of mental illness for some people.

Due to concerns about the medicalization of disability, there has been a reluctance by many within the disability rights movement to campaign on the issue of health and impairment.[9] The focus has mostly been on using the social model of disability to challenge social barriers and medicalized views of disability. This focus has meant that issues to do with health and healthcare have often been overlooked. We want to stress that acknowledging disabled people's healthcare needs, including mental health, should not result in people being defined by their impairment or health condition. Like everyone else, disabled people have health needs. Discrimination and injustices occur when disability is overmedicalised.

6 Oliver, M. (1996) Understanding disability: from theory to practice. Basingstoke: Macmillan.
7 https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html
8 Based on results from the 2013 Disability Survey, cited in R Cunningham, A Kvalsvig, D Peterson, S Kuehl, S Gibb, S McKenzie, L Thornley and S Every-Palmer. 2018. Stocktake Report for the Mental Health and Addiction Inquiry. Wellington: University of Otago
9 Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities", discussion paper commissioned by the Special rapporteur on the rights of persons with disabilities (2018), pp. 21–26. Available at http://disabilitycentre.lshtm.ac.uk/resources/.; Hall, E. (2000). "'Blood, brain and bones; taking the body seriously in the geography of health and impairment." Area 32(1): 21-29.

We begin this report with an overview of disabled people's experiences of healthcare, looking at the social determinants of health, as well as the barriers disabled people experience to receive appropriate healthcare. Disabled peoples' experiences of mental health care sits within the broader context of healthcare and the issues are important for gaining a fuller understanding of disabled people's experiences. We then move to focus on disabled people with Mental ill-health, and health care services, looking at the social determinants of mental ill-health for disabled people, and the barriers disabled people experience accessing mental health care. Findings from the key informant interviews are incorporated in to this section. We conclude by offering some recommendations to improve access to mental health care.

2.3. Limitations of the report

Resources and timeframe limited the scope of the report. The number of key informant interviews with disabled people and health professionals was small. Disabled people we spoke with were women, between the ages of 20 and 40 years old. Additionally, we have focused specifically on the mental health experiences of disabled adults, although the issue of young disabled people's experiences of mental health care was raised in some of the key informant interviews. As such, this project does not claim to be representative of all disabled people's experiences, but rather aims to provide some insights into how MHAIDS and the wider mental health care system is experienced by some disabled people. Future research would need to be sure to include people from a range of cultural backgrounds, ages, gendered identities, and sexualities, amongst other demographic/ identity characteristics.

3 Disabled people and health outcomes

"Health is a disability rights issue"[10]

Research consistently shows that disabled people have poorer health outcomes than non-disabled people and do not receive appropriate health care.

Globally, disabled people are:

- twice as more likely to find healthcare provider skills and
- facilities inadequate;
- three times more likely to be denied health care;
- four times more likely to be treated badly in the healthcare system.[11]

Findings from the New Zealand Health and Independence Report[12] shows that 50% of disabled people rated their health as fair/poor compared with only 10% of non-disabled people. The health status of people with learning disabilities, in particular, is worse than other New Zealanders across all of the health status indicators.[13]

People with a learning disability can expect to live for 16–24 fewer years than other people.[14] Secondary conditions are common among disabled people. While some of this may be

[10] Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities", discussion paper commissioned by the Special rapporteur on the rights of persons with disabilities (2018), pp. 21–26. Available at http://disabilitycentre.lshtm.ac.uk/resources/.
[11] World Health Organisation, 2011: World Report on Disability, Malta.
[12] Ministry of Health. 2018. Health and Independence Report 2017: Wellington: Ministry of Health.
[13] Ministry of Health. 2011. Health Indicators for New Zealanders with Intellectual Disability. Wellington: Ministry of Health. https://www.health.govt.nz/publication/health-indicators-new-zealanders-intellectual-disability; Milner P., Mirfin-Veitch B. & Conder, J. 2013: On the Margins of Good Health: An analysis of the health status, health knowledge and health literacy of people with a learning disability who completed the Special Olympic HAS Health Promotion Screen. Dunedin: Donald Beasley Institute
[14] Ministry of Health. 2018. Health and Independence Report 2017. Wellington: Ministry of Health

impairment-related, often the social determinants of health and inequities in access to health care are the underlying cause of many of these conditions and/or contribute to making them worse.

Inequities are exacerbated along the lines of gender, age, cultural background, and impairment type. Disabled people are much worse off than non-disabled people across several health and wellbeing indicators, as demonstrated in table 1.

Table 1: Disadvantages experienced by disabled people[15]

Compared to non-disabled people, disabled people have:	
Income	Half the median weekly income
Employment	Half the employment rate; a quarter for those aged 15–24
Education	Half the qualification rate
Housing	Greater likelihood of renting and of damp, weather tightness, and other problems
Health	Less than a third the rate of reporting excellent health
Social connection	Good contact with family and friends but low level of leisure activities
Crime	Twice the likelihood of being a victim of violent crime
Access	Greater likelihood of living in areas of high socioeconomic deprivation with low access to services
Children	Greater likelihood of being in a one-parent home, a low income household, a house that is too small

[15] Health and Disability System Review. 2019. Health and Disability System Review - Interim Report. Hauora Manaaki ki Aotearoa Whānui – Pūrongo mō Tēnei Wā. Wellington: HDSR

3.1. Barriers to healthcare

Disabled people also face barriers to accessing healthcare across the spectrum of health services – promotion, prevention, and treatment. Drum et al argue that "people with disabilities may be the largest underserved subpopulation demonstrating health status disparities that stem from preventable secondary conditions."[16] It has been shown that compared to non-disabled people, both disabled men and women are significantly more likely to report needing healthcare services but not receive them.[17] A Canadian study found that disabled people aged 20-64 had three times the level of unmet healthcare needs as adults without disabilities.[18] In New Zealand, 20% of disabled Māori and 14% of disabled non-Māori report unmet need to access a health professional.[19] Pacific people with disability also have higher levels of unmet need for health care.[20]

Barriers to health service are created by physical environments, poor attitudes of health professionals, lack of knowledge about specific impairments and the health conditions that are associated with them, and systemic factors such as funding or eligibility.[21] Prohibitive cost is a common barrier disabled people face when accessing healthcare. It is well known that disabled people experience higher levels of poverty.[22] In the New Zealand Ministry of Health baseline study that happened in the Midcentral region[23] prior to the implementation of the new disability support system – Mana Whaikaka – participants identified cost as one of the main reasons they did not visit health professionals.[24]

Health care facilities that are inaccessible and poor communication practices within healthcare settings are also common barriers for disabled people. For Deaf and hard-of-hearing people, insufficient provision of sign language interpreters as well as a lack of knowledge by healthcare

16 E Drum, Charles & Krahn, Gloria & Culley, Carla & Hammond, L. 2005. Recognizing and Responding to the Health Disparities of People with Disabilities. Californian Journal of Health Promotion. 3. 29-42. 10.32398/cjhp.v3i3.647.

17 Beatty PW et al. 2003: Access to health care services among people with chronic or disabling conditions: patterns and predictors. Archives of Physical Medicine and Rehabilitation, 84:1417-1425; VanLeit B et al. 2007: Secondary prevention of disabilities in the Cambodian Provinces of Siem Reap and Takeo: perceptions of and use of the health system to address health conditions associated with disability in children. Brussels, Handicap International; Bowers B et al. 2003: Improving primary care for persons with disabilities: the nature of expertise. Disability & Society, 18:443-455; Gulley SP, Altman BM. 2008: Disability in two health care systems: access, quality, satisfaction, and physician contacts among working-age Canadians and Americans with disabilities. Disability and Health Journal, 1:196-208.

18 McColl, M.A., A. Jarzynowska, and S.E.D. Shortt, Unmet health care needs of people with disabilities: population level evidence. Disability & Society, 2010. 25(2): p. 205-218.

19 Statistics New Zealand. 2014. Social and Economic Outcomes for Disabled People: Findings from the 2013 Disability Survey. Wellington: Statistics New Zealand. http://archive.stats.govt.nz/browse_for_stats/health/disabilities/social-economic-outcomes-13.aspx

20 Ministry of Health. 2008. Pacific Peoples' Experience of Disability: A paper for the Pacific Health and Disability Action Plan Review. Wellington: Ministry of Health. https://www.health.govt.nz/publication/pacific-peoples-experience-disability-paper-pacific-health-and-disability-action-plan-review

21 McColl, M. A. H., Shortt, S., Hunter, D., Dorland, J., Godwin, M., Rosser, W., & Shaw, R. (2010). Access and quality of primary care for people with disabilities: A comparison of practice factors. Journal of Disability Policy Studies, 21(3), 131

22 Mitra, S., et al. (2017). "Extra costs of living with a disability: A review and agenda for research." Disability and Health Journal 10(4): 475-484.

23 https://manawhaikaha.co.nz/

24 Morrison, C.A. and Wilson, C.S. (2019). Baseline Study of the Disability Support System in the MidCentral Area: Summary Report. Prepared on behalf of the Ministry of Health, New Zealand. SAMS Evaluate, Innovate, Educate

professionals about the linguistic and cultural differences associated with being Deaf is commonly reported.[25] People with physical disabilities can experience reduced accessibility through lack of ramps, narrow doorways, and inaccessible bathrooms.[26] Many people with physical disabilities do not receive complete medical examinations because equipment such as weight scales, examining tables, and mammography equipment do not accommodate their disability.[27] For people who are blind or have vision impairment, a lack of communication material in braille or large print can prevent them from accessing adequate care.[28] People with learning disability report health professionals often make assumptions about their communication abilities and direct conversations towards their support person rather than to them.[29] A lack of experience interacting with people with learning disability, and inadequate skills and knowledge, often means health professionals are ill-equipped to respond to their needs. The American National Council on Disability, in its 2009 report, noted that "The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care."[30] Moreover, health promotion and prevention activities seldom target disabled people. Population-based health promotion strategies rarely include disabled people in their campaigns, and seldom focus on specific targeted interventions to meet any additional needs.[31]

[25] Witko, K., Boyles, P., Smiler, K., McKee, R. 2017: Deaf New Zealand Sign Language users access to healthcare, NZMJ 1, 130(1466), 53-61. Smeijers AS, Pfau R. 2009: Towards a treatment for treatment: on communication between general practicioners and their Deaf patients. The Sign Language Translator and Interpreter, 3(1), 1-14; Human Rights Commission 2013: A new era in the right to sign – He Houhanga Rongo te Tika Ki Te Reo Turi. Repof the the New Zealand Sign Language Enquiry, Wellington: Human Rights Commission

[26] Pharr, J and Chino, M. 2013: Predicting barriers to primary care for patients with disabilities: A mixed methods study of practice administrators, Disability and Health Journal 6 116-123; Mudrick, N. R., Breslin, M. L., Liang, M., & Yee, S. (2012). Physical accessibility in primary health care settings: Results from California on site reviews. Disability and Health Journal, 5(3), 159

[27] Krahn, Gloria L., Deborah Klein Walker, and Rosaly Correa-De-Araujo. 2015. "Persons with Disabilities as an Unrecognized Health Disparity Population." American Journal of Public Health 105: S198–206. https://doi.org/10.2105/AJPH.2014.302182

[28] Cupples, M, Hart, P M, Johnston, A. Jackson, A.J. 2012 Improving healthcare access for people with visual impairment and blindness, BMJ, 344, e542.; Sibley E, Alexandrou B. Towards an inclusive health service: a research report into the availability of information for blind and partially sighted people. www.rnib.org.uk/aboutus/Research/reports/2009andearlier/Access_Health.pdf

[29] Ward, R., Nichols, A., & Freedman, R. (2010). Uncovering health care inequalities among adults with intellectual and developmental disabilities. Health and Social Work, 35(4), 280-290.

[30] National Council on Disability. The current state of health care for people with disabilities, 2009. Available at: http://www.ncd.gov/publications/2009/

[31] Kuper, H.; Smythe, T.; Duttine, A. 2018: Reflections on Health Promotion and Disability in Low and Middle-Income Countries: Case Study of Parent-Support Programmes for Children with Congenital Zika Syndrome. Int. J. Environ. Res. Public Health, 15, 514

4 Barriers disabled people face accessing mental health services through the 3DHB

As raised by the Special Rapporteur on the right to health, there is an alarming "global burden of obstacles" that hinders the implementation of the right to mental health, including the dominance of a "biomedical model", power imbalances between disabled people and health professionals and the biased use of evidence in mental health.[32]

For people with multiple and intersecting minority identities – for example disability, race and sexuality – barriers and inequities to services are exacerbated.[33] In the key informant interviews, people spoke about a range of physical, attitudinal, legislative and communication barriers that restricts disabled people's access to appropriate mental health care services.

4.1. Social determinants of health and increased rates of mental illness

Disabled people's mental health outcomes are negatively impacted by the social determinants of health:

[32] https://documents-dds ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf?OpenElement
[33] Corbett J. O'Toole & Allison A. Brown (2002) No Reflection in the Mirror, Journal of Lesbian Studies, 7:1, 35-49; William F. Hanjorgiris, Joseph F. Rath & John H. O'Neill (2004) Gay Men Living with Chronic Illness or Disability, Journal of Gay & Lesbian Social Services, 17:2, 25-41, Denman, L. 2007: "Enhancing the Accessibility of Public Mental Health Services in Queensland to Meet the Needs of Deaf People From an Indigenous Australian or Culturally and Linguistically Diverse Background." Australasian Psychiatry. 15:1, 85-89.

> The broader picture is that mental health or wellbeing isn't actually often related to major mental illness. It's related to poverty, housing, employment, all those social determinants, intergenerational offending in families, violence and child abuse, and if as a country we could solve those issues we probably wouldn't be having a conversation about wellbeing and mental health, and disabled people are across all of that, and they are much worse off in outcomes, and people with major mental illness are much worse off in all of those outcomes (**Health Care Professional 1,** 25 November 2019)**.**

Research shows that disabled people are at higher risk of developing mental ill-health than the general population due to persistent structural inequalities across housing, education, and employment, as well as social isolation, deprivation, stigmatization and violence.[34] For example, a series of studies in the United Kingdom demonstrated that specific risk factors make women with learning disability more vulnerable than other women to mental illness.[35] A study on people with deafblindeness shows high levels of psychological distress as well as high levels of unmet need.[36] Studies also show that disabled people have higher rates of suicidal ideation than non-disabled people.[37] During a key informant interview with a health professional, the lack of autonomy and self-determination people with learning disabilities can experience and the link this can have to poor mental health was discussed:

> The main one probably is the lack of control that they may have over their lives and very often we'll go and do an assessment and we'll say, "Why is John living with George? We know they don't like each other." It's like, "Well, we know that as well, but there isn't anywhere else they can go" (**Health Care Professional 2,** 13 November 2019).

For many disabled people, mental distress is a response to having to negotiate on a daily basis a range of barriers that impinge upon their lives.

[34] Conder, J, Mirfin-Veitch B., & Gates, S. 2015: Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability, Journal of Applied Research in Intellectual Disabilities, 28, 572–583; Honey, A., Emerson, E., Llewellyn, G., 2011: The mental health of young people with disabilities: impact of social conditions Soc Psychiat Epidemiol (2011) 46:1–10.

[35] Taggart L., McMillan R. & Lawson A. (2008) Women with and without intellectual disability and psychiatric disorders. An examination of the literature. Journal of Intellectual Disabilities 12, 191–211. Taggart L., McMillan R. & Lawson A. (2009a) Listening to women with intellectual disabilities and mental health problems. Journal of Intellectual Disabilities 13, 321–340. Taggart L., McMillan R. & Lawson A. (2009b) Predictors of hospital admission for women with learning disabilities and psychiatric disorders compared with women maintained in community settings. Advances in Mental Health and Learning Disabilities 3, 30–41. Taggart L., McMillan R. & Lawson A. (2010) Staffs' knowledge and perceptions of working with women with intellectual disabilities and mental health problems. Journal of Intellectual Disability Research 54, 90–100.

[36] Sarah M. Bodsworth, Isabel C.H. Clare, Sara K. Simblett and Deafblind UK 2011: Deafblindness and mental health: Psychological distress and unmet need among adults with dual sensory impairment, British Journal of Visual Impairment 29(6)

[37] Giannini, M J., Bergmark, B. Kreshover, S., Elias, E., Plummer, C., and O'Keefe, E. 2010. "Understanding Suicide and Disability through Three Major Disabling Conditions: Intellectual Disability, Spinal Cord Injury, and Multiple Sclerosis." Disability and Health Journal 3 (2) 74–78; McConnell, David, Hahn, L., Savage, A., Dubé, C., and Park. E., 2016. "Suicidal Ideation Among Adults with Disability in Western Canada: A Brief Report." Community Mental Health Journal 52(5): 519–26; Giannini, M. J, Bergmark, B., Kreshover, S., Elias, E., Plummer, C., and O'Keefe, E., 2010: "Understanding Suicide and Disability through Three Major Disabling Conditions: Intellectual Disability, Spinal Cord Injury, and Multiple Sclerosis." Disability and Health Journal 3(2). 74–78.

4.2. Cost, complexity and self-advocacy

Cost and complexity were identified by participants as significant barriers to accessing mental health services. As one participant explained:

> **Participant 1:**
> I've had quite a few friends who've gone through the public system and really struggled to get the level of care that they need to be well.
>
> **Researcher:**
> Do you think that's sort of exaggerated as an issue when you also have a disability, or other needs?
>
> **Participant 1:**
> Yeah. Absolutely. I think particularly the cost thing because a lot of people with disabilities don't have the income to be able to access it privately; but I think actually just navigating the system is really difficult, and I think you have to really be able to advocate for yourself and really push for the services that you need, and I think having a disability makes that harder in so many ways. Yeah, for sure, that makes that access harder (10 December 2019).

The importance of being able to advocate for yourself came up frequently in the interviews with disabled participants. In a system that is described as complex and resource-limited, people felt that they needed to fight for their right to care.

> **Participant 3:**
> Some people can't articulate their needs are all, and that is something that is a problem because if you can't articulate your needs the system is definitely not going to work, public or private.
>
> **Researcher:**
> Yeah, you need to have the ability to speak up for yourself
>
> **Participant 3:**
> You do... It can be really tricky, and I think it depends on your level of experience, your level of disability and how articulate you can be, and if you can't go into battle for yourself is there anyone else who can... because if you're fighting your own battles all the time, it's hard. It's tiring, and you're more likely to give up (16 December 2019).

One person noted that while her experience of using MHAIDS was mostly positive, she didn't think that was how it was for all disabled people. She explained that in addition to being able to self-advocate, strong family support was necessary in order to receive good care:

- I guess I come from quite a privileged background, I have very good family support. A lot of the people in the inpatient unit with me didn't have that, and I think that they had a much harder time than I did because I had that family support on top of the inpatient support were providing (**Participant 1**, 10 December 2019).

For Deaf and hard-of-hearing people, it is often their family members that are expected to act as interpreters in medical settings, even though they may not be fluent in sign language or able to communicate complex medical information.[38] It was also noted that family support often includes contributing to or covering the cost of mental health care:

> **Researcher:**
> Have there been any main problems accessing the services, in terms of accessibility or cost?
>
> **Participant 3:**
> It is expensive. I'm lucky that my mother will pay, but it's $200 for an hours session, which is I think probably the average cost if you went privately. So it is expensive, especially if you're going semi-regularly. ... So she's willing to shoulder that cost. Otherwise, I probably wouldn't be able to afford it (16 December 2019).

Another person explained:

- The times when I've been on the supported living payment and I've been having therapy, counselling or whatever, it's always been because my parents have helped, as well as getting a disability allowance and stuff like that (**Participant 2**, 12 December 2019).

4.3. Funding focus on acute cases

The policy and funding focus on acute cases was identified as a barrier to disabled people receiving appropriate mental health care:

> **Health Care Professional 2:**
> The biggest one for me is probably about the fact that mental health services are strongly focused - and for good reason, that's what they're funded for – to work with a relatively small percentage of the population.
>
> **Researcher:**
> Is that acute? Is that what it would be described as?

[38] Witko, K., Boyles, P., Smiler, K., McKee, R. 2017: Deaf New Zealand Sign Language users access to healthcare, NZMJ 1, 130(1466), 53-61.

> **Health Care Professional 2:**
> Yeah, that moderate to severe. It can be difficult sometimes for people with an intellectual disability who clinically may only have a mild to moderate mental health issue, but for other reasons [such as] their limited resources or their environment or something like that, and the lack of other options out there means that they might present to mental health services but, of course, they don't quite reach that threshold (13 November 2019).

The Special Rapporteur on the right to health explains that most public policies continue to have a narrow focus on systems and services that emphasise individual pathology and 'treating' conditions whilst failing to address some of the drivers of poor mental health for disabled people.[39] This means that public expenditures on mental health services are mostly directed to acute, in-patient care.[40] In New Zealand, funding is focussed on the most unwell 3% of the population.[41] As a result, many people do not meet the 'threshold' for support. One of the people we spoke to about their experiences of using MHAIDS spoke about the different levels of care she has received:

- The first time I was admitted, because I attempted suicide, I was admitted straight away ... so I think because it was a suicide attempt, it was taken pretty seriously, and it was reasonably easy to be admitted and to access that service. It was more difficult this time round seeing a psychiatrist, I knew from I guess, from my friends trying to access psychiatry services through the DHB, that it was gonna be difficult to get access to a psychiatrist, even though I really needed one (**Participant 1**, 10 December 2019).

He Ara Oranga The Report of the Government Inquiry into Mental Health and Addiction shows that across the country people have to "fight for access to mental health care due to high thresholds of acuity, limited and non-existent services, or complex care requirements beyond current service provision."[42] One participant, with the support of her GP and her family, deliberately chose to bypass the public health system because she knew that she wouldn't meet the threshold for support:

- If we have to go through the DHB, we're going to have to make it seem like something it's not in order for you to actually get seen, and we don't want to make things seem worse than they actually are (**Participant 3**, 16 December 2019).

One participant reflected on her experience of trying to access the community mental health team. She was experiencing side-effects from taking anti-depressants alongside other medication for physical health and wanted to talk through her options but because she wasn't 'acute' she didn't receive an appropriate level of care:

[39] Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/HRC/35/21
[40] WHO, Mental Health Atlas 2014 (Geneva, 2015), p. 31.
[41] Cunningham, A Kvalsvig, D Peterson, S Kuehl, S Gibb, S McKenzie, L Thornley and S Every-Palmer. 2018. Stocktake Report for the Mental Health and Addiction Inquiry. Wellington: University of Otago
[42] 2018 He Ara Oranga Report of the Government Inquiry into Mental Health and Addiction.

> I tried going to the community health service; and it was just really useless. I was having issues with my medication and was very very depressed and also having just bad side effects from my medication. I think I was referred to them from my GP. It just took so long; it so long to get to see them and then I went in and they were like, "Tell us about your mental health," and it was like, "This is really bad, and that's really bad," and all that kind of stuff. Then they just didn't really do anything (**Participant 2**, 10 December 2019).

4.4. Poor detection and management of disabled people's mental illness

Research shows that the detection and treatment of mental health conditions is often not well managed for disabled people. In the evaluation of the Enabling Good Lives Demonstration in Christchurch, it was reported that there were difficulties in meeting the needs of disabled people who also had mental health problems. The report shows that people's mental health conditions were either not diagnosed at all or not diagnosed in a timely manner, because the focus was on the person's disability.[43] For Deaf and hard-of-hearing people, communication difficulties, such as poor interpretation, can lead to hesitation amongst some people to discuss their symptoms, can result in misdiagnosis, or their symptoms are ignored.[44] In a key informant interview, a health professional gave an example of a time when a disabled person's mental health condition wasn't picked up:

> **Health Care Professional 3:**
> We were working with someone who had a hearing impairment and did actually experience auditory hallucinations, but that wasn't picked up for such a long time.
>
> **Researcher:**
> Is that hearing noises?
>
> **Health Care Professional 3:**
> Yeah. Hearing voices, but someone that was deaf. And so he was being treated in a different... he was like, well, that's just behavioural and that's just a behaviourally driven, rather than actually this person could have a mental illness. It was sort of like how could he have been hearing voices if he's deaf? (21 November 2019)

People with learning disability are particularly vulnerable to the experience of 'diagnostic overshadowing', that is, reports of physical ill-health being viewed as disability-related and so not investigated or treated.[45]

[43] Anderson, D., Janes, R., Pope, P., Enabling Good Lives Christchurch Demonstration Phase 2 Evaluation report, MSD, MoH, MoE.
[44] Landsberger, S. A., & Diaz, D. R. (2010). Inpatient psychiatric treatment of deaf adults: Demographic and diagnostic comparisons with hearing inpatients. Psychiatric Services, 61(2), 196–199; O'Hearn, A., & Pollard, R. Q. (2008). Modifying dialectical behaviour therapy for deaf individuals. Cognitive and Behavioral Practice, 15(4), 400–414. Sheppard, K., & Badger, T. (2010). The lived experience of depression among culturally deaf adults. Journal of Psychiatric and Mental Health Nursing, 17(9), 783–789. Steinberg, A. G., Barnett, S., Meador, H. E., Wiggins, E. A., & Zazove, P. (2006). Health care system accessibility: Experiences and perceptions of deaf people. Journal of General Internal Medicine, 21(3), 260–266.
[45] Merikangas KR et al. (2007): The impact of comorbidity of mental and physical conditions on role disability in the US adult household population. Archives of General Psychiatry, 64:1180-1188; Moussavi S et al. 2007: Depression, chronic diseases, and decrements in health: results from the World Health Surveys. Lancet, 370:851-858; Sousa RM et al. 2009 Contribution of chronic diseases to disability in elderly people in countries with low and middle incomes: a 10/66 Dementia Research Group population-based survey. Lancet, 374: 1821-1830. Ministry of Health. 2013. Innovative Methods of Providing Health Services for People with Intellectual Disability: A review of the literature. Wellington: Ministry of Health. www.health.govt.

For Deaf and hard-of-hearing people, communication difficulties, such as poor interpretation, can lead to hesitation amongst some people to discuss their symptoms, can result in misdiagnosis, or their symptoms are ignored.[46] Reflecting on specialist intellectual disability services, a health professional explained:

> Some of the reasons why those people may not be getting into the services is perhaps misunderstanding or a lack of acknowledgement that people with intellectual disability can present with mental health issues. A tendency to say if there is a problem, it can be associated with their intellectual disability rather than they might be presenting with other things like mental illness (**Health Care Professional 2**, 13 November 2019).

Donner et al. found that service users, carers, and service providers all experienced the incidence of diagnostic overshadowing as a barrier: "everything is attributed to the intellectual disability".[47] In 2003, the Government's National Health Committee published their "To Have an Ordinary Life — Kia Whai Oranga Noa", which showed that many adults with learning disability are prescribed out-dated medications or combinations of pharmaceuticals that are not in line with safe prescribing practices.[48] Local and international research concludes that a substantial proportion of people with learning disability are prescribed anti-psychotic medications for behavioural purposes, rather than for the treatment of a diagnosed psychotic illness, and that they can have their drugs substantially reduced or withdrawn, with improved mental and behavioural states. Conder et al found that for the learning disabled women in their research who had experienced major mental illness, they were offered few opportunities for therapies aside from medication.[49] One of the people who participated in the key informant interviews reflected upon resourcing as a reason that staff were quick to use medication when responding to patients' displaying emotional distress:

> When I was an inpatient I found that the staff were really quick to medicate, and that was not just me but with other patients as well; they were very quick to use sedatives. I found that quite difficult. I think, because it felt kind of like we were being shut down quite a lot... there's not always enough kind of resource to manage those incidents kind of personally, rather than through medication (**Participant 1**, 10 December 2019).

[46] Landsberger, S. A., & Diaz, D. R. (2010). Inpatient psychiatric treatment of deaf adults: Demographic and diagnostic comparisons with hearing inpatients. Psychiatric Services, 61(2), 196–199; O'Hearn, A., & Pollard, R. Q. (2008). Modifying dialectical behaviour therapy for deaf individuals. Cognitive and Behavioral Practice, 15(4), 400–414. Sheppard, K., & Badger, T. (2010). The lived experience of depression among culturally deaf adults. Journal of Psychiatric and Mental Health Nursing, 17(9), 783–789. Steinberg, A. G., Barnett, S., Meador, H. E., Wiggins, E. A., & Zazove, P. (2006). Health care system accessibility: Experiences and perceptions of deaf people. Journal of General Internal Medicine, 21(3), 260–266.

[47] Donner, B., Mutter, R., & Scior, K. (2010). Mainstream in-patient mental health care for people with intellectual disabilities: Service user, carer and provider experiences. Journal of Applied Research in Intellectual Disabilities, 23(3), 214–225.

[48] At nearly two decades old, this report remains one of the only New Zealand studies exploring these topics.

[49] Conder, J, Mirfin-Veitch B., & Gates, S. 2015: Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability, Journal of Applied Research in Intellectual Disabilities, 28, 572–583;

4.5. Workforce knowledge and skill

Limited training about disability can impact upon health professional's ability to work in ways that are respectful and responsive to people's disability needs. This includes language and the ways in which disability, impairment and mental health is talked about, for example ableist and/or discriminatory language, as well as the ways in which physical and mental health needs intersect. In New Zealand, undergraduate and postgraduate clinical staff in primary care and in hospital services receive limited disability training and education.[50] Key informant interviews with health professionals highlighted the gap in training and education. While some training in specific areas, primarily autism spectrum disorder, is available through joint ventures between a local tertiary education institution and the 3DHB learning development centre, there are limited professional training opportunities available for staff to learn more broadly about disability rights, including the UNCRPD and the New Zealand Disability Strategy. In a key informant interview, one person commented that she had never encountered a health professional working in mental health that approached disability from a disability-rights lens:

> I've never been to a therapist or a counsellor or anyone who understood disability, or had any kind of framework for talking about it or that I was in anyway aware; that I've been aware of, had any framework for understanding it from a kind of social model, rights-based place. I've never had any mental health support that talked about it from that perspective (**Participant 2**, 10 December 2019).

Because health professionals have such limited understanding of disability outside a medical model perspective, often disabled people must spend significant amounts of time explaining disability issues and 'educating' mental health professionals[51], which raises serious ethical issues as shown in the following comment:

> I felt like I've spent a lot of time explaining disability to people, spent a lot of my counselling therapy sessions explaining disability and that kind of stuff. If I didn't have to work so hard to have people understand, then maybe we could talk about it at a slightly deeper level (**Participant 2**, 10 December 2019).

Article 4.1 of the UNCRPD requires that state parties "promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights."

[50] Mirfin-Veitch, B. & Paris, A. 2013. Primary health and disability: A review of the literature. Auckland: Te Pou o Te Whakaaro Nui
[51] O'Toole, J.C 2000: The View from Below: Developing a Knowledge Base About an Unknown Population. Sexuality and Disability, 18:3, 207-224.

It was agreed by health care professionals that more training would be beneficial. It is worth noting that participation in this project acted as an impetus for some health care professionals to access the New Zealand Disability Strategy and think about how it could inform their practice. In a report highlighting consumers experiences of the closure of specialised regional Deaf Mental Health Service, it was shown that there was a strong desire to see more medical professionals have Deaf awareness training, including learning how to use New Sign Language.[52] It was also noted that sometimes, due to the complex intersection of poverty, addiction, housing and mental health, amongst other issues, people's disability and disability-related needs aren't necessarily seen or acknowledged:

- Disability adds another element into what people need to think about and at the time they possibly don't (**Health Care Professional 1**, 25 November 2019).

One person reflected upon her most recent time in hospital where, for the first time, she was offered mental health support:

- That was the first time I had ever very been offered any mental health support from a doctor, and I have been in the hospital probably 25-30 times over my life... like at this point, I guess it didn't surprise me that doctors hadn't asked me about my mental health. It surprised me that a doctor did ask about my mental health; it was the opposite you know? Other than a GP, it surprised me that anyone in the hospital system asked me about my mental health (**Participant 2**, 10 December 2019).

She spoke about a time when she was in hospital receiving treatment for a significant health issue and the lack of mental health support that was offered upon getting some particularly difficult news:

- I was kind of like, "should I not go on this trip that I've got planned?" I was going to a conference and they were like, "No, you should go because you won't be able to travel again." They were like, "You won't be able to walk on crutches or anything; you'll be in a wheelchair and you'll probably be in a lot of pain." With no offer of mental health support or anything like that. There was no offer of mental health support at all at the time (**Participant 2**, 10 December 2019).

Poor staff attitudes were also identified by some health care professionals as a barrier to disabled people receiving mental health care. This is consistent with international research findings.

[52] Best, Z. and Allen, Ly. 2014: The Consequences of Decisions: Deaf Mental Health. Deaf Mental Health Development Group Report. Wellington: Kites Trust

- Part of it was they lacked the knowledge; part of it was that they lacked the willingness. I've even had people say, "I used to work in intellectual disability, but I got out of that world; I'm now in mental health. I don't actually want to see those people anymore." People say things like that ...there are attitudes that need to be challenged (**Health Care Professional 2**, 13 November 2019).

In some instances, lack of training and poor attitudes was talked about as being related:

- There might be staff attitudes. In fact, let's say there will be. There will be some staff that feel this is something that they are not competent or confident, probably confident with, they will be very confident with the mental illness side of things, but probably not know how to connect with the disability side of things, and connect with disability services in the community and all that kind of stuff (**Health Care Professional 1**, 25 November 2019).

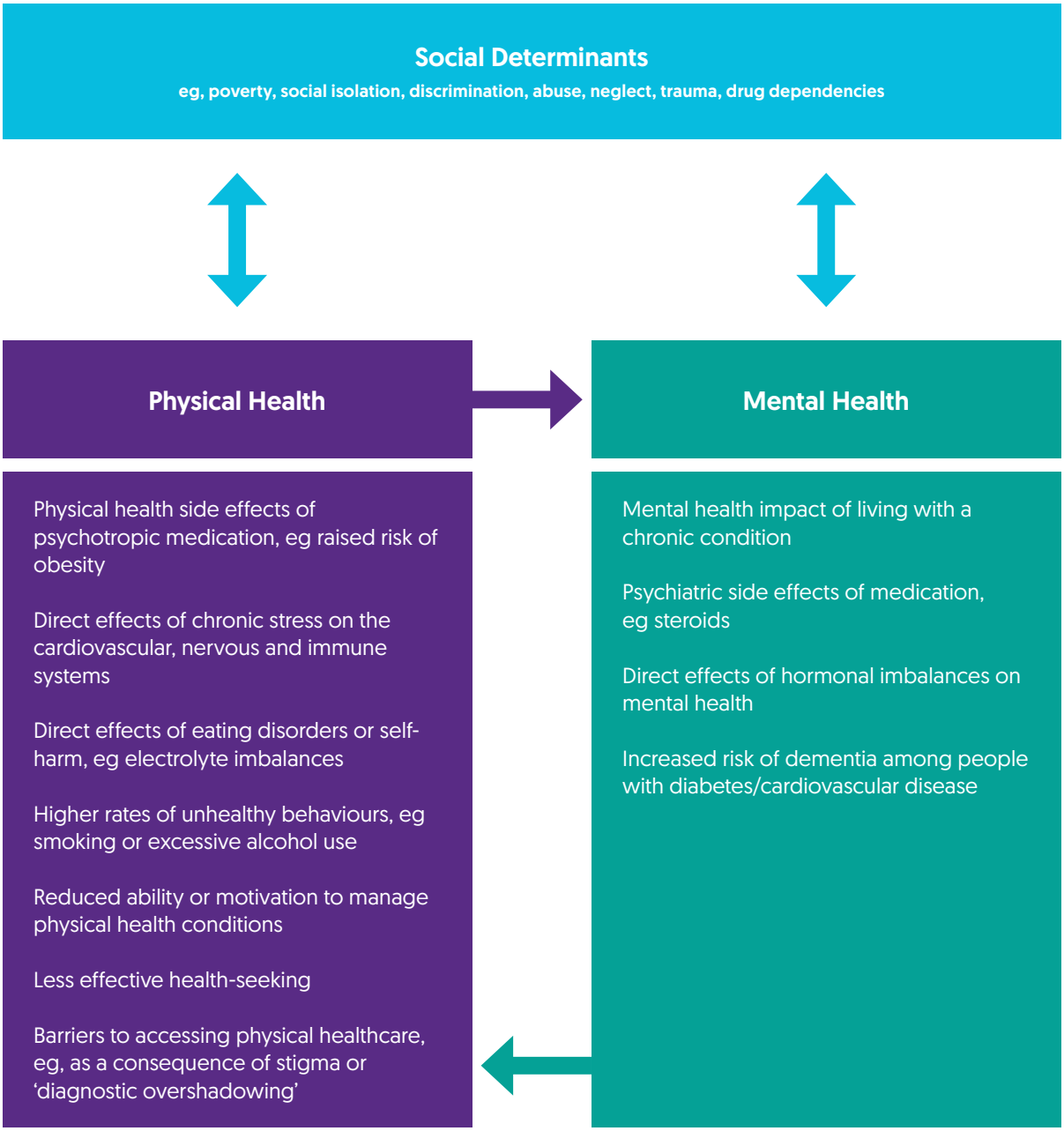
Research highlights a lack of clinical knowledge as one of the most significant barriers to accessing mental health services, particularly for people with a learning disability. The shortage of specialty psychiatrists and mental health clinicians is also a well identified.[53] Mental health clinicians often view themselves as inadequately resourced and trained to meet the needs of people with learning disability.[54] Martins similarly explains that there is a significant gap in clinical knowledge of the mental health of adults with autism, particularly in relation to the impact of other impairment on rates and types of psychiatric disorders, but also in the effective provision of treatment.[55] Key informant interviews with disabled people similarly showed that practitioners often did not demonstrate an understanding of how disability and mental health intersect:

- The whole system should recognise disability and definitely when visiting other specialists, they have not at all been accommodating of my disability - just my physical needs in the room, it's also just the experience of disability and how that impacts on health as a whole. Like I don't think that's very well understood throughout the health system (**Participant 1**, 10 December 2019).

It is now well established that when the mental health needs of people with physical health conditions are not adequately addressed, this increases costs and undermines patient outcomes.[56] Figure 2 below demonstrates the complex relationship between physical health, mental health and social determinants.

53 Werner, S., & Stawski, M. (2012). Mental health: Knowledge, attitudes and training of professionals on dual diagnosis of intellectual disability and psychiatric disorder. Journal of Intellectual Disability Research, 56(3), 291–304.
54 Jess, G., Torr, J., Cooper, S.-A., Lennox, N., Edwards, N., Galea, J., & O'Brien, G. (2008). Specialist versus generic models of psychiatry training and service provision for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 21(2), 183–193.
55 Matthews, M. D. (2016). Autism and Comorbid Psychiatric Disorders: Assessment, Treatment, Services and Supports (Thesis, Doctor of Philosophy). University of Otago.
56 Naylor, Chris, Preety Das, Shilpa Ross, Matthew Honeyman, J Thompson, and H Gilburt. 2016. "Bringing Together Physical and Mental Health: A New Frontier for Integrated Care." London. https://doi.org/10.1177/0141076816665270.

Figure 2: Intersection of mental and physical health with social determinants[57]



[57] Adapted from Prince M, Patel V, Saxena S, Maj M, Maselko J, Phillips MR, Rahman A (2007). 'No health without mental health'. The Lancet, 370:9590, pp 859–77.

4.6. Fragmented service delivery

Another barrier to access that was identified through the key informant interviews was fragmented service delivery within and across health, mental health and disability services. Services working in isolation of each other was noted as impeding disabled people's ability to get and receive good mental health care. Artificial boundaries between services often mean that many people do not receive co-ordinated support for their physical health, mental health and wider social needs, and instead receive fragmented care that treats different aspects of their health and wellbeing in isolation. Key informants talked about departments within the 3DHB failing to work together as well as MHAID working ineffectively with other organisations.

4.6.1. Service delivery within 3DHB

It was noted that sometimes people failed to receive appropriate care in the early stages of their 3DHB experience:

- Sometimes our clients are coming through emergency departments and they need really good assessment, physical assessment before they can be moved on, because there is always a risk that that doesn't happen, people say 'oh this is a mental health thing' and so that is kind of important, that if people come to emergency department, that's where they are brought or that's where they come, they need to get properly assessed (**Health Care Professional 1**, 25 November 2019).

Poor care experiences throughout the hospital system can have an impact on how disabled people experience MHAIDS services:

- It's also interactions and how people with disability get treated through those processes. How that works for them, and the process and system overall. [Poor treatment] in other areas of the hospital can lead to distress and all the outcomes from that (**Health Care Professional 1**, 25 November 2019).

Similarly, it was noted that the transition between child and adult health systems does not necessarily facilitate good mental health wellbeing outcomes for disabled people:

- I'm thinking of something like we get a number of referrals for people with intellectual disability who also have ADHD for example and what we often see is that they are having a paediatrician or a child psychiatrist or someone like that that's been prescribing and overseeing that medication and then when they become an adult, the adult mental health services don't automatically pick that up (**Health Care Professional 2**, 13 November 2019).

Health professionals also raised the issue of disability support services not knowing about mental health.

> I think you could flip it and say actually the disability sector probably needs to do more training around mental health (**Health Care Professional 3**, 21 November 2019)

In a study by Conder et al on how learning disabled women experience their mental health and wellbeing, they found that, for some women, care following discharge from psychiatric hospitals was inadequate. For women living rurally, there were limited mental health services available and many were reliant on support staff who lacked knowledge of mental illness and recovery. The women felt frustrated and worried about the lack of confidence shown by support staff and many had frequent readmission to hospital because early signs of mental distress were not picked up by support staff.[58]

4.6.2. Mental health service and disability support services

It is well-established that mental health services and disability support services are siloed, making it difficult for disabled people with mental ill-health to move between the two.[59] It has been suggested that demarcation between mental health and disability services is one of the most prominent barrier in the provision of good quality mental health services for disabled people.[60] Findings from the Christchurch EGL demonstration evaluation show that some service providers struggled to get mental health assistance for disabled people who were threatening self-harm because service delivery is compartmentalised. They stated "The NASC funds support for disabled people but not mental health problems, which are dealt with by "a whole other system". Health professionals taking part in the key informant interviews similarly reflected upon the boundaries around service delivery:

Health care Professional 3:
Some of the NASCs are very boundried [sic] in their criteria and who can access services.

Researcher:
Do you mean NASCs in the disability sector?

[58] Conder, J.A, Mirfin-Veitch, B. and Gates, S. 2015: Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability Journal of Applied Research in Intellectual Disabilities 28, 572–583

[59] Sullivan, D., Robertson, T., Daffern, M., & Thomas, S. (2013). Building capacity to assist adult dual disability clients' access effective mental health services. In V. G. Senior Practitioner— Disability (Ed.). Melbourne, Australia: Department of Human Services. Cumming. 2011. Integrated care in New Zealand. International Journal of Integrated Care 11 (special 10th anniversary edition), e138. www.ncbi.nlm.nih.gov/pmc/articles/PMC3226018/.

[60] Bennett, C. (2008). Services for a person with a dual disability. Melbourne: Victorian Dual Disability Service. Chaplin, E., O'Hara, J., Holt, G., & Bouras, N. (2009). Mental health services for people with intellectual disability: challenges to care delivery. British Journal of Learning Disabilities, 37(2), 157–164; Davis, E., Barnhill, L. J., & Saeed, S. A. (2008). Treatment models for treating patients with combined mental illness and developmental disability. Psychiatric Quarterly, 79(3), 205–223.

> **Health care Professional 3:**
> Yeah. They're very tight with their criteria and will stick to that and quote that. And I guess mental health is quite flexible in who they see and who they bring into services. Sometimes there's a level of, "Oh, they've got a mental health diagnosis, they're yours," even though their driving needs are disability. So, there's quite a bit of friction sometimes still (Health Care Professional 3, 21 November 2019)

This was related to compartmentalising care delivery based around a particular diagnosis or condition:

- I think in some ways if you have a mental health diagnosis, that's what's being focused on if you're within secondary services and you may well have a disability. I think they do separate them out a bit and say, "We'll focus on this," and then someone else can focus on that, but actually you need to be looking at them as a whole (**Health Care Professional 3**, 21 November 2019)

Competing paradigms between mental health and disability services, particularly for people with intellectual disability, have been identified as confusion over issues of clinical and financial responsibility, and impacting on the quality and accessibility of each of these services.[61] Research shows that the impact of this demarcation is felt by staff working in this area. One study found that staff across both mental health and learning disability services didn't understand the scope and responsibility of each other's services, and that they often felt they needed to be assertive in order to access each other's services.[62]

[61] George, A. P., Pope, D., Watkins, F., & O'Brien, S. J. (2011). How does front-line staff feel about the quality and accessibility of mental health services for adults with learning disabilities? Journal of Evaluation in Clinical Practice, 17(1), 196–198; Patterson, T., Higgins, M., & Dyck, D. G. (1995). A collaborative approach to reduce hospitalization of developmentally disabled clients with mental illness. Psychiatric Services, 46(3), 243–247; Nugent J. 1997: Handbook on Dual Diagnosis: Supporting People with a Developmental Disability and Mental Health Problem. America: Mariah Management.

[62] George, A. P., Pope, D., Watkins, F., & O'Brien, S. J. (2011). How does front-line staff feel about the quality and accessibility of mental health services for adults with learning disabilities? Journal of Evaluation in Clinical Practice, 17(1), 196–198.

4.7. Design and physical accessibility of buildings

Design and physical accessibility of buildings was identified as a barrier to disabled people accessing services. Although it was noted by a health care professional that specialist advice had been sought in the recent renovation of many community-based facilities, it was also suggested that an accessibility audit would be useful to ensure that facilities are accessible. The issue of limited availability of accessible beds in respite services was also talked about:

> **Health Care Professional 3:**
> Most of the houses that we have, have stairs, so we have to really consider who we're referring into those services and what their mobility is like. And we really only have one house, which is a purpose-built house, I think there's eight beds? Six beds. It has your wet floor, rails, wide hallways for allowing wheelchair access. It's the only service that we have out of 144 beds is those six beds. And so it really does impact on who we can actually take into those services.
>
> **Researcher:**
> What would happen to the people that need those services and those accommodations, and if there wasn't a bed available, what would happen?
>
> **Health Care Professional 3:**
> They'd have to wait until there is something available (21 November 2019).

4.8. Data, monitoring and evaluation

During the key informant interviews, health professionals were asked questions about data, monitoring and evaluation. Article 33 of the UNCRPD, states parties should develop independent mechanisms 'to promote, protect and monitor implementation of the present Convention' [UNCRPD Article 33(1), UN 2006a]. This speaks directly to the need to evaluate health services, access and outcomes for disabled people. One of the fundamental barriers to any assessment of the rights of disabled people in New Zealand is the paucity of demographic and analytical data available about them. Overall, it appears that there is a lack of data that is held or reported on about disabled people accessing MHAIDS.

> **Researcher:**
> What about data on disabled people, is that something you collect?
>
> **Health Care Professional 1:**
> We don't collect it specifically.
>
> **Researcher:**
> Would that something you would find useful?

> **Health Care Professional 1:**
> Yep. I mean we could get it out if we were asked how many disabled people were in your service, depending on what the disability is, we could get it, but we don't report on it, it would be quite a good thing to report on actually....It would be quite useful (25 November 2019)

Health care professional 3 also said:

- We wouldn't know how many of the people that we would see that would have a disability as well as a mental health diagnosis, so we probably wouldn't single that out also or capture that in any way (**Health Care Professional 3**, 21 November 2019).

Interview discussions didn't reveal whether or not MHAIDS routinely collects information about how well their services are performing for disabled people, but monitoring mechanisms would enable accountability and quality improvement.

5 Conclusion and recommendations: enabling disabled people to better access 3DHB mental health services

The current mental health system in New Zealand does not deliver equitable outcomes to disabled people.

A combination of barriers, including prohibitive cost, limited availability of services, inaccessible environments and communication, and inadequate skills and knowledge of health workers, prevent disabled people from accessing appropriate health care.

The recommendations in this report are specific to improving access for disabled people using 3DHB services. Many of the issues identified in this project relate to systemic problems within the mental health system, for example, resourcing and cost, and these issues are experienced by all users of the system. The 2018 He Ara Oranga Report of the Government Inquiry into Mental Health and Addiction addresses these issues and provides several recommendations. We endorse all the recommendations. We also support the core thinking contained within the Wellbeing Manifesto: Open access to a full menu of resources and services to sustain and restore wellbeing prepared for PeerZone and ActionStation.[63]

While attention could be directed to disabled people's unique needs in relation to all of the issues identified in He Ara Oranga Report, below we provide six specific recommendations which we think will help improve the delivery of 3DHB services to disabled people.

[63] https://www.wellbeingmanifesto.nz/

5.1. Accessibility audit

We recommend that the 3DHB undertake an accessibility audit of all its MHAIDs facilities and services:

- **Physical buildings and sites.** CCS Disability Action provides accessibility advisory services and are able to complete accessibility audits.[64]
- **DHB communications practices.** Review of all MHAIDS communication practices, including face-to-face interaction between DHB staff and disabled people; print media and correspondence, on site way-finding and other signage; digital print and media, in particular, address the communication support available for people with learning disabilities, such as easy-read, or who do not use oral language to communicate, such as assistive technologies.

5.2. Consumer involvement: "Nothing about us, without us"

Disabled people need to be active contributors at all levels of the 3DHB mental health system, including planning, design, delivery and monitoring. In particular, disabled people need to be at the forefront of any work done by the 3DHB in (re)designing services that are intended to meet the needs of disabled people.

We recommend that the 3DHB work closely with disabled people, including and where appropriate disabled persons organisations, to ensure that the voices of disabled people are part of the co-design and creation of mental health services. Ensuring that disabled people are actively involved in the planning, design, delivery and monitoring of mental health services would help ensure that any new initiatives are driven by the community and responsive to community needs.

5.3. Education and Training

We recommend the 3DHB work with disabled people, including and where appropriate disabled persons organisations and other disability rights and advocacy organisations, to develop training programmes in the following areas:

- **Disability rights.** Rights-based care and support for mental health is an integral part of health care for all New Zealanders.

Training should specifically align with the UNCRPD and the New Zealand Disability Strategy and should include ways in which staff can support the meaningful participation of disabled people on an equal basis with others in mental health care, for example, supported decision-making.

64 https://www.ccsdisabilityaction.org.nz/assets/Uploads/Accessibility-Advisors-National-Electronic.pdf

- **Ableism training.** Training that focuses on the structural dimensions of a disabling world.

Imagine Better can provide customised training on the ways in which the mental health and wider health care system works to disadvantage disabled people. It would help 3DHB staff learn to recognise often seemingly invisible power structures and what they can do to facilitate change within their work practices.

- **Clinical training.** 3DHB staff should have access to ongoing training to develop their understanding of how general medicine, impairment and disability, and mental health intersect.

It is important to note that when speaking about positive experiences of engaging with 3DHB mental health services, participants remarked upon the skills and knowledge of individual staff members. One person said:

> The psychiatrist that I've been seeing has just been excellent. He has a really good understanding of general medicine and the interactions between the psychiatric medications, and the pain medications that I'm on; and how to manage both of those at the same time. And he's really taken into account my health condition at the same time as my mental health; which, I was actually really surprised by how well that was managed, because in general I haven't had an amazing experience with specialists through the DHB's system. I think I've been really lucky to have struck him in terms of this service (**Participant 1**, 10 December 2019).

- **Training for 3DHB staff should be designed and delivered with and by disabled people.** We strongly recommend that any new training initiatives have a large component that is taught and delivered by disabled people and their family members.

Research shows that one-off lecture-style training are less effective in changing negative attitudes towards disability than contact with disabled people themselves.[65] Hearing from those with direct experience of disability and mental illness is likely to make more impact and be more memorable.

- **Training for family and caregivers.** Education about mental illness and early intervention.

[65] Shakespeare, T & Kleine, I. 2013: Educating Health Professionals about Disability: A Review of Interventions, Health and Social Care Education, 2:2, 20-37

Training could be developed by the 3DHB in collaboration with disabled people, families and whānau, including and where appropriate disabled persons organisations, family network and carer organisations, and disability service providers to help increase families and caregivers' recognition of signs of mental illness to aid in prevention and early intervention.

5.4. Community based support

We endorse the development of community-based mental health services that are integrated with other health and social supports. Disabled people would benefit from being able to access support that is available as close to their homes as possible, for example, it would reduce travel time and cost and make it more accessible, and through proximity to other supports available in the community, such as Work and Income. A community hubs mental health care model in Trieste, Italy has resulted in low levels of compulsory treatment, absence of restraint and seclusion, high levels of re-engagement in community life, and an overall reduction in the costs of mental health services.[66]

We support the strategic direction outlined in the 'Living Life Well: A Strategy for Mental Health and Addiction 2019-2025' which aims to move towards "people-based care" that is "accessible and convenient services delivered close to home"

5.5. Collaboration between local Ministry of Health Disability Support Needs Assessment and Service Coordination (NASC) and 3DHB Mental Health Services

We recommend closer and formal collaboration between local Disability NASCs and the 3DHB mental health services. Working across service boundaries can help make sure services are coordinated and disabled people receive person-centred and holistic support.

It was noted in the key informant interviews with health professionals that there currently exists a positive working relationship between the 3DHB mental health services and local disability NASCs. This was identified as a strength of the 3DHB mental health service delivery. This relationship could be further built upon, for example through:

- Joint education and training initiatives.

Joint training opportunities would help create a shared framework and understanding for working with people who access both services. It would also create opportunities for networking and relationship building, and result in better knowledge about the role and work of each service.[67]

[66] Hefford, M., Ehrenberg, N. and Pacific, L.A., 2010. La via Trieste. Discussion paper #1: Comparing the Trieste approach to delivering mental health services with New Zealand models.
[67] Mohr, C., Curran, J. and Rymill, N., 2002 Interagency training in dual disability. Australasian Psychiatry, 10(4): p. 356-364.

5.6. Data, research and evaluation

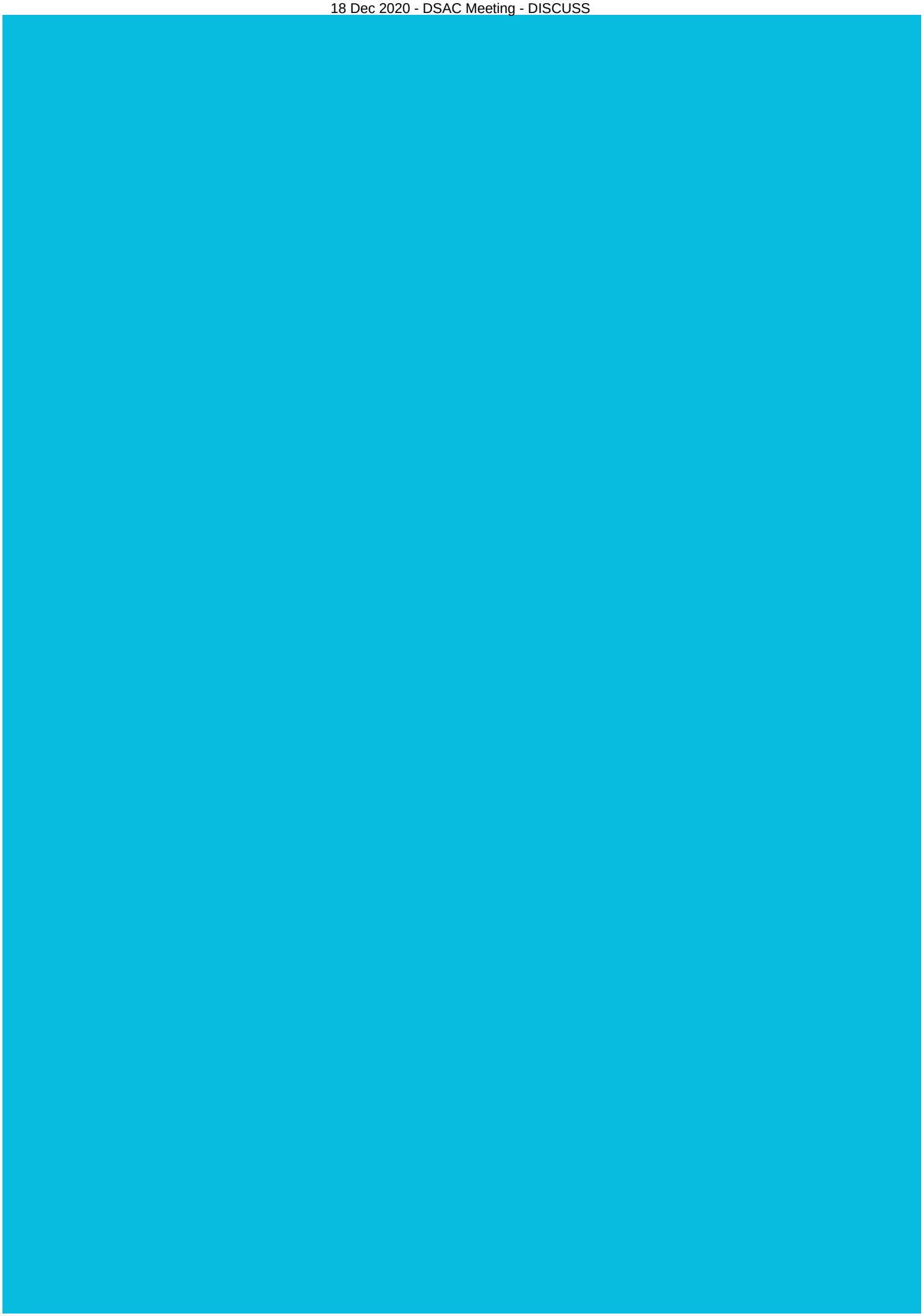
Relevant, accurate and timely information is critical to improving the mental health and wellbeing outcomes of disabled people in Aotearoa New Zealand. Research that aims to gain a better understanding of the health and wellbeing of disabled people is needed. This includes:

- evaluation of effective interventions, assessment tools, models of health care service delivery;
- qualitative research that places disabled people's voices, perspectives and needs as the centre. Most research is conducted through the medical model of disability, is clinical-based and does not prioritise the subjective experiences of disabled people.

We also recommend the ongoing collection and evaluation of people's experiences of interacting with the 3DHB mental health system. Disabled people, particularly people with learning disability, are particularly at risk of poor experiences.[68] Data should be gathered using a variety of quantitative methodologies, including surveys and focus groups to build a nuanced understanding of disabled people's experiences over time.

We support the use of tools, such as Marama, which provide opportunities for people to provide real-time feedback on their experiences, however, we note the importance of ensuring that such tools are accessible to disabled people and that support for using them is available if and when it is required. It is also important that people are informed about any findings or developments as a result of their participation, this might include regular briefings with disabled organisations or newsletters.

[68] Iacono, T., Bigby, C., Unsworth, C. et al. A systematic review of hospital experiences of people with intellectual disability. BMC Health Serv Res 14, 505 (2014) doi:10.1186/s12913-014-0505-5



Imagine Better LTD
PO Box 8377
New Plymouth 4340

info@imaginebetter.co.nz
www.imaginebetter.co.nz

Board Discussion – Public

December 2020

Transport and Equity of Health Access for People with Disability

Action Required

Disability Services Advisory Committee note:

(a) International research demonstrates a clear link between transportation barriers and poor health outcomes. Disabled people, in particular, are disproportionately affected by transport barriers.

(b) These barriers directly impact upon disabled people's access to healthcare services and lead to health inequalities.

(c) Focusing on the relationship between transport barriers and health is important for addressing disabled people's over-representation in poor health outcome statistics.

(d) The Disability Team will work with the Regional Council, District Health Board and the disability community to find solutions to the issues raised by disabled people in relation to accessing public transport to attend health services

Strategic Alignment	3DHB Disability Strategy Focus Area Two: Inclusion and Support The sub-regional DHBs will improve and promote the full inclusion of disabled people and will ensure the best service for disabled people and their families is available on an equitable basis. Improve access to funding, information, services and support.
Author	Rachel Noble, General Manager 3DHB Disability
Endorsed by	Rachel Haggerty, Director Strategy Planning & Performance
Presented by	Rachel Noble, General Manager 3DHB Disability
Purpose	This report details findings from a study that aims to understand more about the ways in which transport acts as a barrier or enabler to and from 3DHB healthcare settings. It recognises that every stage of a journey from start to finish needs to be accessible, this report considers all aspects of a person's transport journey to and from 3DHB healthcare settings, including scheduling and arriving at appointments, as well as planning, boarding, exiting and travelling on their chosen mode of transport.
Contributors	David Darling, Senior Systems Development
Consultation	Sub Regional Disability Advisory Group Transport Co-Design Group: Solmaz Nazari WCC Accessibility Advisory Group Taulolo Fiso Director Community Partnerships, CCDHB Angela Desmarais Researcher DPA Michelle Tindling Parent

Jay Hadfield	Senior Advisor – Sustainability, CCDHB
Pamela McNeill	Sub-Regional Disability Advisory Group, 3DHB
Laura Ellis	Consumer Engagement Manager, CCDHB
Hannah Wignall	Project Manager - Integrated Care, CCHDB
Marlin Elkington	Maori Disability Advisor, CCDHB
Valerie Smith	Sub-Regional Disability Advisory Group, 3DHB
Sue Emirali	Sub-Regional Disability Advisory Group, 3DHB
Maurice Priestly	Sub-Regional Disability Advisory Group, 3DHB
Rachel Noble	General Manager Disability, 3DHB
David Darling	Disability, 3DHB
Carey-Ann Morrison	Researcher Imagine Better / Note taker
Tony Paine	CEO Imagine Better/meeting facilitator

Executive Summary

The attached report outlines in detail the many challenges and barriers that people with disabilities must overcome to access health services. This has a significant impact on equity of access and health outcomes for the disability community.

The working group have identified recommendations for both the health sector and the transport sector. They have also identified solutions that improve transport for people with disabilities.

The 3DHB Disability Team is forming a working group with the Regional Council and other key decision makers and disabled people. Disabled people will be highly represented with 50% of the group having lived experience of disability.

Responsibilities of the Development Group:

- Review information on the current journeys and the complexity of the issues
- Use information to define strategies and ongoing project
- Develop an approach to resolving barriers, with appropriate feasibility assessment
- Develop clear and useful information is available to the disability community
- Develop and refine shared indicators based on selected strategies

Service	The multiple transport-related barriers disabled people encounter when trying to access health care are a significant contributor to poor health outcomes.
People	People with Disability experience barriers to healthcare because of transport barrier.
Financial	The financial implications are not yet known.
Governance	Under the governance of the Subregional Disability Advisory Group

Engagement/Consultation

Patient/Family	Participants in the Co-Design Group

Clinician/Staff	Participants in the Co-Design Group
Community	Participants in the Co-Design Group

Identified Risks

Risk ID	Risk Description	Risk Owner	Current Control Description	Current Risk Rating	Projected Risk Rating
TBC	That the Regional Council and transport agencies are unwilling to engage in developing solutions.	Rachel Haggerty	Strong stakeholder management.	Med	Low

Attachment/s

1. Disabled people's experiences of using passenger transport to access 3DHB healthcare services. Imagine Better

1. Transport and Equity of Access

Accessible transport has been identified by the disability community as a significant issue in accessing health services. Some of this is within the control of health services providers when developing service delivery model but it is acknowledged that it is not always within the DHB scope to provide solutions.

The 3DHB disability team undertook a review of the accessibility of public land transport after being prompted by the experiences of disabled people. The review was completed by Imagine Better. The review considered the accessible journey as this covers all the steps needed for a person to get from their home to their destination and return. All steps in the accessible journey are interlinked and are of equal importance.

The review highlighted the many complexities that resulted in disabled people being marginalised when accessing transport services. These included, attitudinal deficits by providers; poor planning, including the planning undertaken by health services; inadequate funding and lack of accessible information. The review was an open, transparent, non-adversarial investigation of the extent of accessibility with recommendations on how it might best be increased into the future.

Disabled people and their organisations provided a wealth of information and defined many issues that they experienced which created insurmountable barriers for individuals which in turn resulted in health appointments being ignored or missed completely.

We met with key people to review the final review paper and agreed the following key messages:

- The multiple transport-related barriers disabled people encounter when trying to access health care are a significant contributor to poor health outcomes.
- This is a human rights issue. It's important to understand how exclusion, discrimination and ableism create multiple barriers to accessible journeys.
- The 'accessible journey' requires an end-to-end approach that addresses everything from information; appointment processes, timing and reminders; financial issues; support people; accessible buses, taxis and other vehicles; parking; wayfinding and length of appointments / waiting times.
- This is a complex issue. There are lots of actors, gate keepers and decision makers – needs a multi-targeted approach, and a coalition of people working for change – with reach and influence in all parts of the system (health, transport, funding etc) – is required.
- As with many aspects of disability, we do not have good enough data about the costs (personal, financial and on the overall health of communities) of inaccessible health care due to transport issues. It is likely that the value of improvement in health outcomes that fully accessible journeys to health care settings create would far outweigh the costs of fixing transport access issues.

2. Discussion

Significant numbers of disabled people in the Wellington region are having severe and on-going difficulties with using public transport services, including buses, trains, taxis, driving services and the related services and infrastructure. With an ageing population this means the need for accessible public land transport services will only increase.

Developing a clear understanding of the current processes including arranging transport, and the completion of an accessible journey. This will detail availability, affordability, accessibility and acceptability in relation to transport solutions, service information, and environmental infrastructure.

Recommendations arising from the review require refinement, and some may require significant investment, while others can be achieved at relatively modest cost, or within existing budgets. Any development will consider these options and provide a range of returns on the investment made.

The recommendations in the review were directed first to the DHBs as custodians of the information provided by disabled people. But they are also directed to various stakeholders and agencies who contribute to the current accessible transport system in the Wellington region. Any subsequent comprehensive action on the reviews recommendations requires coordination and cooperation, with the participation of disabled people at every level.

Through the review it was voiced that any changes that make public transport more accessible for disabled people also improves access for other marginalised communities who are reliant on public transport.

3. Recommendations

The Report identified key recommendations for the healthcare sector and the transport stakeholders. These recommendations are detailed in the attached report and summarised below:

Healthcare Perspective

Communication of appointment information

"They need to put more information in the letter about what it relates to. If they put an appointment with sleep clinic or appointment for MRI instead of an appointment with Doctor so-and-so. That would save us having to call up and waste Wellington staff's time." – Service provider

"Text message reminders consistently across departments/DHBs" – Multiple

"Needs a disability-specific process that takes into account people's needs and look at the physical environment in terms of what would be the best options for people. That kind of service should be specific for disabled people but it should be designed with disabled people. It's the able bodied who put in all these processes and procedures and we're expected to adhere and conform." – Wheelchair user

"Filling out my forms at home before the appointment would save a lot of time and ensure that privacy." – Blind

Communication of access information

"If I knew about the disability concessions, I would be in a better situation to afford to attend appointments and not cancel" – Parent

"Put a map of the hospital building, the grounds, mobility parking and bus stops in with the appointment letter they send you." – Multiple

"I think it would be really helpful if there was a website or something set up that people were told about when they are diagnosed with a disabling condition where it has all the

contacts of all the people that you need to talk to, the subsidies available and what transport you can get – like the shuttles." – Mobility

"Closer collaboration between hospital travel coordinators" – DHB Staff

Education

"Hospital staff need to know what accessible is – to each group – and know whether each service provider is accessible or not" – Wheelchair user

"Better understanding of social model of disability" – Wheelchair user

Flexibility

"If they could consider that if it's an appointment you don't actually have to be examined for, is it possible to do Telehealth, it would be easier and cheaper all round" – Parent

Funding

"Better organisation and resourcing is required" – Wheelchair user

"Fund specialist services in Wairarapa." – Service provider

"Better funding available for out-of-area appointments" – Mobility

"Funding for a travel support person or for accommodation to stay close to the hospital if you need attention. A support person travels for free on Total Mobility but you've still got to be paid for your time." – Service provider

Hospital infrastructure

"Need somewhere not so surrounded – especially if you've got sensory issues as well. That would be a good thing." – Parent

"It would be good to have a space to park up, it's quite rare." – Wheelchair user

"More mobility parking because not everyone can access public transport." – Wheelchair user

"Provide a charging area for mobility scooters at the hospitals." – Wheelchair user

"The DHB need an integrated shuttle system that goes between Kenepuru to Lower Hutt and does an 'H', so Kāpiti -Wellington-Kenepuru and Kenepuru-Lower Hutt-Wellington-Lower Hutt, Wairarapa" – Mobility

"There is will from the Kāpiti shuttle providers to do more depending on how it is structured. There is room to add another vehicle and do different runs, like two straight through to Wellington and a few to Kenepuru. That would require Capital Coast to purchase wheelchair accessible shuttles - $120k each" – KHAG

Transport system

Accessibility

"Metlink needs a contingency plan for wheelchair users when the train stops and you have to transfer to a bus." – Wheelchair user

"Make the shuttles wheelchair accessible" – Wheelchair user

"Integrate the Snapper card with the trains" – Multiple

"Fix the gaps. We need better infrastructure, better public transport, reliable taxi services, more accessible transport." – Low vision

Availability

"Encourage taxi services to increase operating capacity on weekends or provide people in Wairarapa with transport options if running weekend appointments" – Mobility

"Local taxi services need a kick up their backside. There's no competition so they don't have to fight for anything." – Service provider

Information

"Promote the shuttles" – Parent

"Safely navigating roads as part of the Metlink journey planner" – Blind

"Not many people access Total Mobility scheme because they don't know about it or they think that they don't qualify, there is a need to open the criteria up so there is free transport under the Total Mobility scheme and public transport" – KHAG

Education

"Driver awareness training" – Multiple

Innovation

"… ride sharing app - for people who could afford it least it could be a really low cos, like someone with a community services car, it's a shared vehicle you call on demand, if someone from the public wants to use it, they pay a premium because its more direct – it doesn't go all around the bus routes" – GWRC Staff

Existing solutions that improve accessibility

The following services were referred to by participants as examples of transport models that enabled better access to healthcare settings:

a) Health shuttles

i) St John New Zealand Health Shuttle Service

ii) Horowhenua Community Health Shuttle

iii) Waitemata Distract Health Board Shuttles

a) Ridesharing apps

i) RideShark

ii) Uber, Ola, and Zoomy

b) Navigation apps

i) BlindSquare

c) On-demand and on-request transport services

i) Timaru on-demand public transport service

ii) Wairarapa on-request private transport service

Disabled people's experiences of using passenger transport to access 3DHB healthcare services

Prepared by:

Dr Carey-Ann Morrison
Imagine Better Ltd

and

Angela Desmarais
Disabled Person's Assembly

13 December 2020

Contents

List of Acronyms

3DHB	Coalition of Capital and Coast, Hutt Valley, and Wairarapa District Health Boards
CCDHB	Capital and Coast District Health Board
DPA	Disabled Persons Assembly NZ
DPO	Disabled Persons Organisation
GWRC	Greater Wellington Regional Council
HVDHB	Hutt Valley District Health Board
KHAG	Kāpiti Health Advisory Group
MSD	Ministry of Social Development
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WDHB	Wairarapa District Health Board

1. Executive summary

International research demonstrates a clear link between transportation barriers and poor health outcomes. Disabled people, in particular, are disproportionately affected by transport barriers. These barriers directly impact upon disabled people's access to healthcare services and lead to health inequalities. Focusing on the relationship between transport barriers and health is important for addressing disabled people's over-representation in poor health outcome statistics.

This report details findings from a study that aims to understand more about the ways in which transport acts as a barrier or enabler to and from 3DHB healthcare settings. The 3DHB area is made up of three District Health Boards: Capital and Coast, Hutt Valley, and Wairarapa. Recognising that every stage of a journey from start to finish needs to be accessible, this report considers all aspects of a person's transport journey to and from 3DHB healthcare settings, including scheduling and arriving at appointments, as well as planning, boarding, exiting and travelling on their chosen mode of transport.

The project is underpinned by a human rights approach and the social model of disability. It uses a broad definition of disability endorsed by the UNCRPD, who define disability as "an evolving concept [that] results from the interaction between people with an impairment and attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others."[1] It understands transportation barriers as a shortcoming of inaccessible systems and infrastructures.

A literature review was carried out, as well as interviews with disabled people and families in the three DHB regions. Their stories and lived experiences have driven the direction of this study. Interviews with other stakeholders, including District Health Board and Greater Wellington Regional Council staff, and the Kāpiti Health Advisory Group were also conducted.

The report details findings in two key areas:

a. Healthcare system

Enabling factors include:

- accessible hospital buildings and infrastructure;
- clear communication about appointment times provided in appropriate formats;
- approachable and friendly hospital staff;
- accessible transport options such as health shuttles provided by the DHB.

Barriers include:

[1] United Nations. (n.d.). *Convention on the Rights of Persons with Disabilities (CRPD).* Retrieved on 20 August 2020 from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

- limited availability of local healthcare services;
- poor communication of appointment;
- scheduling of appointments at unsuitable times of the day and difficulty rescheduling appointments;
- lack of information about where to go for hospital appointments and hospital maps that are complex and difficult to understand;
- poor communication about travel subsidies and entitlements;
- limited understanding by some staff on transport access issues in relation to hospital appointments;
- variation in cost, availability and accessibility of DHB health shuttles and transport services across the 3DHB locations;
- limited onsite parking options for people with access needs.

b. Transport system

Enabling factors include:

- journey planning tools, such as Metlink app;
- improved driver interactions based on increased awareness of mobility access issues;
- improvements in transport mode accessibility;
- travel subsidies which help with cost of transport to healthcare appointments;
- work by the Greater Wellington Regional Council to improve customer experience and accessibility.

Barriers include:

- limited availability of public transport options, particularly for those living in rural locations;
- no direct transport links to any hospitals in the 3DHB area;
- inaccessible trains and buses, unreliable public transport infrastructure, poorly designed bus stops and stations;
- limited availability and supply of accessible taxi services;
- drivers' lack of awareness of disability issues and discriminatory behaviour.

Another significant finding is in relation to the high personal cost disabled people experience travelling on public transport. This cost is not purely financial. Disabled people often bear the heavy burden of both emotional and physical labour to attend their DHB appointments.

To conclude, we recommend improvements from the perspectives of disabled people and other stakeholders, and present details of other models operating that enable better access to healthcare settings.

2. Introduction

Access to healthcare is a basic human right.[2] Transportation to and from healthcare settings is an important access consideration.[3] An accessible healthcare system considers the extent to which people and communities can easily obtain health services when needed. However, barriers to transport affects people's ability to access healthcare services. Disabled people, in particular, are disproportionately affected by transport barriers and this affects their ability to access healthcare services. Understanding the relationship between transport barriers and health is important for addressing disabled people's over-representation in poor health outcome statistics.[4] The coalition of Capital and Coast, Hutt Valley, and Wairarapa District Health Boards (3DHB) has a commitment to ensure that disabled people have healthcare options that are accessible and available across the region as and when required.[5]

The availability of accessible, affordable and reliable transport is an important enabling factor for the use of healthcare services. This study looks at ways in which transport acts as a barrier or enabler to and from 3DHB health care settings. It draws upon the concept of the 'Accessible Journey', which:

> covers all the steps needed for a person to get from their home to their destination and return. All steps in the accessible journey are interlinked and are of equal importance. If one link is inadequate, the whole journey may be impossible.[6]

This report considers all aspects of a person's transport journey to and from 3DHB healthcare settings, from scheduling appointments to arriving at the healthcare setting, including planning, boarding, exiting and travelling on their chosen mode of transport. It provides a comprehensive picture of how disabled people experience transport to and from 3DHB healthcare settings, including:

- key stakeholders, their role and relationship to each other;
- key access issues and barriers disabled people face traveling to and from 3DHB health care settings;
- local solutions being used and how well they are working.

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[2] Humphreys, J. S., & Smith, K. B. (2009). Healthcare accessibility. *The International Encyclopaedia of Human Geography, 5*, 71-79.
[3] Goodman, N. J., Stapleton, D. C., Livermore, G. A., & O'Day, B. (2007). The health care financing maze for working-age people with disabilities. Social Science Research Network. http://dx.doi.org/10.2139/ssrn.962125.
[4] World Health Organisation. (2011). *World Report on Disability*. World Health Organization.
[5] Bloomfield, A., Chin, D., & Isbister, A. (2016). *Sub-Regional Disability Strategy 2017-2022.* Retrieved from: https://www.ccdhb.org.nz/news-publications/publications-and-consultation-documents/sub-regional-disability-strategy-2017-2022.pdf
[6] Noonan, R., Hunt, R. & McGregor, J. (2005). *The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport.* Retrieved from: https://www.hrc.co.nz/our-work/people-disabilities/past-projects/accessible-journey/

It draws upon stakeholder interviews as well as local and international literature on the impact transport barriers have on health outcomes for disabled people. Interviews with disabled people in the 3DHB area provide examples of lived experience of barriers to accessing transport to healthcare settings. Many of the issues identified in this report have previously been raised in other reports/papers and brought to the attention of CCDHB.[7] This report builds upon the cases for improvement presented in these earlier papers.

While research has been undertaken in Europe, the United Kingdom, the United States, and to a lesser extent in Australia, there has been little exploration of the links between transport accessibility and healthcare services for disabled people in Aotearoa New Zealand. The lack of research into disabled people's experiences of transport and healthcare accessibility means these issues are often not considered in the development of funding and policies. There is no nationwide data on the availability of transport that enables access to healthcare.[8]

2.1. District Health Boards in the 3DHB area

The 3DHB area is made up of Capital and Coast, Hutt Valley, and Wairarapa District Health Boards.

Table 1. *Hospitals in the 3DHB regions*

District Health Boards	Hospitals	Location
Capital and Coast DHB	Wellington City Hospital	Wellington
	Kenepuru Hospital	Porirua
	Kāpiti Health Centre	Paraparaumu
Hutt Valley DHB	Hutt Hospital	Lower Hutt
Wairarapa DHB	Wairarapa Hospital	Masterton

Capital and Coast District Health Board (CCDHB), Hutt Valley District Health Board (HVDHB) and Wairarapa District Health Board (WDHB) are grouped together under the 3DHB coalition. Each DHB runs mostly independently of each other and there is variation in systems and procedures between the three DHBs.

CCDHB operates two public hospitals, Wellington City Hospital in Wellington and Kenepuru Hospital in Porirua, as well as the Kāpiti Health Centre at Paraparaumu. HVDHB operates Hutt Hospital in Lower Hutt and WDHB operates Wairarapa Hospital in Masterton[9], supported by neighbouring hospitals in Wellington, Hutt Valley, and Palmerston North for its tertiary services.

[7] Smith, V., & MacLeod, R. (2015). Transport issues [Unpublished memo]. Sub Regional Disability Advisory Group (SRDAG); Presto, J. (2018, September 21). Kāpiti Transport Update [Unpublished memo]. Capital and Coast DHB.
[8] Collins, A., & Wilson, G. (2008). Māori and informal caregiving: a background paper prepared for the national Health Committee. National Health Committee.
[9] See *Appendix A* for information on 3DHB geographical boundaries

Not all 3DHB services are campus based and there are numerous community health spaces located throughout each region, such as child development teams, blood collection and mental health sites, which presents a range of transport challenges for disabled people.

2.2. Approach

This project promotes a human rights based approach to healthcare services and draws upon the social model of disability, which shows that people are disabled by society rather than impairment.[10] The United Nations Convention on the Rights of Persons with Disability (UNCRPD) defines disabled people as: "[…] those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others […]".[11]

Acknowledging the social model of disability means that transportation barriers are seen as a shortcoming of inaccessible systems and infrastructures to provide essential access to resources[12] as opposed to a problem being inherent in disabled people. Considering this, the project is underpinned by two key documents:

1. The UNCRPD, specifically:

a) Article 20 – Personal Mobility[13]

> "Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost"

b) Article 25 – Health[14]

> "Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"

[10] Oliver, M. (1996). *Understanding disability: from theory to practice*. Macmillan.
[11] United Nations. (2006). *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).* Retrieved from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html
[12] Sze, N. N., & Christensen, K. M. (2017). Access to urban transportation system for individuals with disabilities. *IATSS Research, 41*(2), 66-73.
[13] United Nations. (2006). *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): Article 20.* Retrieved from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-20-personal-mobility.html
[14] United Nations. (2006). *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): Article 25.* Retrieved from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html

2. The New Zealand Disability Strategy, which identifies eight areas which contribute to achieving a non-disabling society in New Zealand, including:

a) Outcome 3 – Health and Wellbeing[15]

"Access to mainstream health services is barrier-free and inclusive"

2.3. Methodology

In March 2020 Imagine Better was approached by 3DHB Disability Strategy team to conduct a study on transport issues for disabled people accessing healthcare services. Due to the onset of COVID-19, the project was put on hold until May 2020.

Interviews took place during May and June 2020 and were all carried out online over Zoom. Disabled Persons Assembly (DPA) was subcontracted by Imagine Better to gather and collate experiences from the disability community across Wellington, Kāpiti Coast, Hutt Valley and Wairarapa.[16] DPA have extensive experience in this area and were able to draw upon existing knowledge and community networks to identify key access issues disabled people face with transport to healthcare settings.[17]

The perspectives and lived experiences of disabled people and families have driven the direction of the project. We aimed to speak to at least 4 disabled people and/or family members in each location, with a range of impairments, to gather a diversity of experience.[18] Participants had varied experiences and came from a range of backgrounds. The majority of people we spoke to had physical or mobility impairments. We also spoke to people who experienced mental ill-health, were blind or low vision, learning disabled or autistic. We were unfortunately unable to recruit any participants who identified as Deaf or hard-of-hearing, which means we are unable to comment specifically on their experiences, however, we do make reference to literature which identifies the specific transport challenges they experience in relation to healthcare.

[15] Ministry of Social Development. (2016). *New Zealand Disability Strategy 2016–2026.* Retrieved from: https://www.odi.govt.nz/nz-disability-strategy/outcome-3-health-and-wellbeing/

[16] As a pan-disability Disabled Persons Organisation (DPO), DPA have a broad understanding of the diverse issues disabled people face in relation to accessing transport and healthcare.

[17] For example, in 2019 a group of DPA members in Wellington identified public transport as a key issue for disabled people in the region. A transport working group was formed to investigate barriers at all stages of a public transport journey for people with a variety of access needs. The working group identified five key priority areas: the inclusion of disabled people in decision-making processes on all transport projects, improved access to information both before and during transit through the implementation of visual and auditory communication tools, increased supply for the Total Mobility scheme, and disability responsiveness training delivered in a way to get transport providers and drivers on board with a model of social change.

[18] See *Appendix B* for participant information

Angela Desmarais from DPA conducted the interviews with disabled people and produced a review of relevant literature. Angela is a disabled researcher with extensive experience in qualitative research and evaluation in the fields of Discourse Analysis and Disability Studies. Dr Carey-Ann Morrison Senior Researcher for Imagine Better, conducted interviews with stakeholders working at local councils, the DHB and other interested groups, such as the Kāpiti Health Advisory Group (KHAG).[19] Carey-Ann is a parent to a young disabled son and is experienced working with disabled people and families and carrying out qualitative research and evaluations.

It is important to note that some of the project was carried out during the nationwide lockdown due to COVID-19. We therefore acknowledge the added barriers to access experienced by disabled people at this time and, where appropriate, have incorporated these experiences into the findings.

2.4. Report outline

The report proceeds as follows. First, current research in transport, health and disability is reviewed. Second, transport options available in the 3DHB area are outlined. Third, findings related to the healthcare system are addressed, focusing on enablers and barriers to access. Fourth, findings related to the transport system are presented, focusing on enablers and barriers to access. In our conversations with disabled people it became clear that there is a huge difference in experiences across these three DHBs, both in healthcare and transport services available. Fifth, we present recommendations for improvement from the perspective of disabled people and other stakeholders. We conclude the report by providing details of other models operating nationally that enable better access to healthcare settings.

[19] See *Appendix C* for stakeholder information

3. Current research in Transport, Health, and Disability

There is a substantial body of international literature showing that, for many people, transportation is a barrier to accessing healthcare. Transportation barriers can have a direct impact on health outcomes, for example, missed healthcare appointments due to unavailability of appropriate transport options and poor scheduling, living outside of urban centres, and travel distance to health care settings. Barriers to transport can also lead to poor health outcomes through transport-related social exclusion. Transportation barriers affect disabled people's ability to fully participate in social, economic, and political activities, which impacts their well-being.[20]

Research shows that disabled people experience inequitable access to both private and public transport. Personal car ownership is unattainable for many disabled people, due to persistent structural inequalities in relation to employment and lower incomes, as well as high car-related expenses, including vehicle modifications.[21] Disabled people who do not have access to a private vehicle are more reliant on passenger transport systems, including the use of subsidized taxi schemes and public transport systems.[22]

Disabled people are more likely than non-disabled people to use a taxi.[23] Subsidized taxi schemes are sometimes available to disabled people to help cover the costs of the fare. However, research conducted in New Zealand,[24] the United Kingdom and the United States[25] shows that disabled people who use subsidized mobility schemes still find them prohibitively expensive, and that they often

[20] Rose, E., Witten, K., & McCreanor, T. (2009). Transport related social exclusion in New Zealand: evidence and challenges. *Kōtuitui: New Zealand Journal of Social Sciences Online, 4*(3), 191-203.
[21] Office for Disability Issues and Statistics New Zealand. (2009). *Disability and travel and transport in New Zealand in 2006: Results from the New Zealand Disability Survey.* Retrieved from: http://archive.stats.govt.nz/~/media/Statistics/browse-categories/health/disabilities/disability-travel-transport-nz-2006/dttnz06.pdf; Woodbury, E. (2012). *Auto-Mobile: Disabled Drivers in New Zealand* [Doctoral dissertation, University of Otago]. Our Archive. Retrieved from: https://ourarchive.otago.ac.nz/bitstream/handle/10523/3715/WoodburyEstherZ2013PhD.pdf?sequence=1
[22] Rose, E., Witten, K., & McCreanor, T. (2009). Transport related social exclusion in New Zealand: evidence and challenges. *Kōtuitui: New Zealand Journal of Social Sciences Online, 4*(3), 191-203; CCS Disability Action. (2018). *Briefing to Hon Phil Twyford Minister for Transport.* Retrieved from: https://www.ccsdisabilityaction.org.nz/assets/resource-files/Briefing-to-the-Minister-of-Transport.pdf
[23] Velho, R. (2019). Transport accessibility for wheelchair users: A qualitative analysis of inclusion and health. *International Journal of Transportation Science and Technology, 8*(2), 103-115.
[24] Noonan, R., Hunt, R. & McGregor, J. (2005). *The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport.* Retrieved from: https://www.hrc.co.nz/our-work/people-disabilities/past-projects/accessible-journey/
[25] Gaete-Reyes, M. (2015). Citizenship and the embodied practice of wheelchair use. *Geoforum, 64,* 351-361; Murray, J. (2017). A systems analysis of Access-A-Ride, New York City's paratransit service, *Journal of Transport and Health, 6,* 177-186.

experience discrimination, for example, one study found that in Deaf people in Namibia said that taxi drivers were often unwilling to transport them, or dropped them off at the wrong destination.[26]

There is evidence that disabled people experience difficulties using all modes of public transport.[27] While some disabled people have difficulty with limited or no public transportation systems, others have trouble with inaccessible infrastructures and systems. For example, in the United Kingdom, research on the use of public transport by disabled people revealed that the journeys of wheelchair users can take 50% longer due to inaccessible stations not enabling the fastest route.[28] Inaccessible systems can cause problems at stations and terminals, as well as while travelling on different modes of transport.[29] Deaf and hard-of-hearing people are unable to access information for passengers about train or bus delays or cancellations because most of it is conveyed via loudspeaker only and is not displayed in written form. They may also have no access to announcements about stops made by loudspeakers on trains or buses, having to rely on prior knowledge of the trip, or asking other passengers or drivers.[30] Inaccessible sidewalks, steep ramps, inadequate lighting, poor drainage, and

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[26] Kaundjua, M. B. (2019). "Barriers affecting access to health information and health care services among the Deaf Community in Namibia." Journal for Studies in Humanities and Social Sciences 8(2): 37-77.

[27] Office for Disability Issues and Statistics New Zealand. (2009). *Disability and travel and transport in New Zealand in 2006: Results from the New Zealand Disability Survey.* Retrieved from: http://archive.stats.govt.nz/~/media/Statistics/browse-categories/health/disabilities/disability-travel-transport-nz-2006/dttnz06.pdf; Noonan, R., Hunt, R. & McGregor, J. (2005). *The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport.* Retrieved from: https://www.hrc.co.nz/our-work/people-disabilities/past-projects/accessible-journey/; Preston, J. M. (2009). Public transport. In, R. Kitchin & N. Thrift (Eds.), *International Encyclopaedia of Human Geography* (pp. 452-459); Rose, E., Witten, K., & McCreanor, T. (2009). Transport related social exclusion in New Zealand: evidence and challenges. *Kōtuitui: New Zealand Journal of Social Sciences Online,* 4(3), 191-203.

[28] Ferrari, L., Berlingerio, M., Calabrese, F., & Reades, J. (2014). Improving the accessibility of urban transportation networks for people with disabilities. *Transportation Research Part C: Emerging Technologies, 45,* 27-40.

[29] Blais, D., & El-Geneidy, A. (2014, January 12-16). Better living through mobility: The relationship between access to transportation, well-being and disability. In *Proceedings of the 93rd Annual Meeting of the Transportation Research Board, Washington, DC*. Retrieved from: http://tram.mcgill.ca/Research/Publications/Development_disability.pdf; Giertz, C., Hobden, K., & LeRoy, B. (2010, June 1-4). Freedom to ride: Measuring the effectiveness of Michigan's Transportation Voucher Program. In *Proceedings of the TRANSED 2010: 12th International Conference on Mobility and Transport for Elderly and Disabled Persons, Hong Kong, China.* Retrieved from: https://pdfs.semanticscholar.org/2b1b/c37609828672cef967c2e3b73c02ba246245.pdf?_ga=2.106103684.688501259.1594937757-724217052.1584563638

[30] Ebling, S; & Glauert, J. (2013). Exploiting the full potential of JASigning to build an avatar signing train announcements. In: Third International Symposium on Sign Language Translation and Avatar Technology, Chicago, IL, USA, 18 October 2013 - 19 October 2013.; Hersh, M., et al. (2010). "Investigating Road Safety Issues and Deaf People in the United Kingdom: An Empirical Study and Recommendations for Good Practice." *Journal of Prevention & Intervention in the Community,* 38(4): 290-305.

short crosswalk time can all prohibit disabled people from accessing bus stops and stations.[31] People with learning disabilities and neurodiverse people report difficulty understanding complex public transport schedules and bus announcements.[32] A Canadian study showed that people with Autism Spectrum Disorder experienced significant challenges using public transport, with 81.6% having instead to rely on the private transport of friends and family.[33] It is acknowledged by healthcare practitioners, family members and people with learning disabilities that transportation is a common reason that people with learning disabilities are unable to attend healthcare appointments.[34] A study in the United Kingdom looking at transportation difficulties for people using mental health services found that transportation issues greatly affected their quality of care and made hospital stays even more stressful.[35] A recent New Zealand-based study focused on the barriers people with physical and/or visual impairments experience on a typical public transport journey.[36] Bus drivers' attitudes and lack of knowledge about disabled users' needs were identified as a common barrier to access. People with physical disabilities spoke of barriers primarily in relation to the urban environment, such as quality of the stops and footpaths. Visually impaired users noted poor presentation of information, and pathway obstructions as barriers to access.

Research highlights the significant differences between access to transport and healthcare in urban and rural settings. Most large healthcare services are concentrated in major urban centres[37] and often there are almost no passenger transport options.[38] This presents access issues for people living

[31] Haveman, M., Tillmann, V., Stöppler, R., Kvas, Š., & Monninger, D. (2013). Mobility and public transport use abilities of children and young adults with intellectual disabilities: Results from the 3-year Nordhorn Public Transportation Intervention Study. *Journal of Policy and Practice in Intellectual Disabilities, 10,* 289–299.
[32] Pfeiffer, B., Sell, A., & Bevans, K. B. (2020). Initial evaluation of a public transportation training program for individuals with intellectual and developmental disabilities*. Journal of Transport & Health, 16,* 1-9; Wasfi, R. A., Levinson, D. M., & El-Geneidy, A. (2006). Measuring the transportation needs of people with developmental disability. *University of Minnesota Digital Conservancy*. Retrieved from: http://hdl.handle.net/11299/179821.
[33] Friedman, C., & Rizzolo, M. C. (2016). The State of Transportation for People With Intellectual and Developmental Disabilities in Medicaid Home and Community-Based Services 1915(c) Waivers. *Journal of Disability Policy Studies, 27*(3), 168-177.
[34] Reichard, A., & Turnbull, H. R. (2004). Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental disabilities. *Mental Retardation, 42*, 181–194.
[35] Heyman, B., Lavender, E., Islam, S., Adey, A., Ramsay, T., Taffs, N., & Xplore Service-User and Carer Research Group. (2015). The journey effect: how travel affects the experiences of mental health in-patient service-users and their families. *Disability & Society, 30*(6), 880-895.
[36] Park, J. & Chowdhury, S. (2018). Investigating the barriers in a typical journey by public transport users with disabilities. *Journal of Transport and Health, 10,* 361-368.
[37] Rose, E., Witten, K., & McCreanor, T. (2009). Transport related social exclusion in New Zealand: evidence and challenges. *Kōtuitui: New Zealand Journal of Social Sciences Online, 4*(3), 191-203; Heyman, B., Lavender, E., Islam, S., Adey, A., Ramsay, T., Taffs, N., & Xplore Service-User and Carer Research Group. (2015). The journey effect: how travel affects the experiences of mental health in-patient service-users and their families, *Disability & Society, 30(*6), 880-895.
[38] Rose, E., Witten, K., & McCreanor, T. (2009). Transport related social exclusion in New Zealand: evidence and challenges. *Kōtuitui: New Zealand Journal of Social Sciences Online, 4*(3), 191-203; Noonan, R., Hunt, R. &

rurally.[39] For example, rural patients in the United States faced greater barriers to healthcare access due to increased travel distance and transportation restrictions.[40] The final report on the New Zealand Health and Disability Review[41] released in June 2020 comments that people living in rural towns can have poorer health outcomes, including lower life expectancy, than people living in cities or surrounding rural areas – an effect that is accentuated for rural Māori and disabled people.[42] One New Zealand-based study found that 54% of disabled adults report that they could not easily get to a public transport depot.[43] Māori disabled living rurally find it difficult to access funding for transport[44] and many rural transport services have inadequate availability.[45]

Cost of transport is another key issue for disabled people. Costs associated with travel are often passed on to family and whānau, for whom there is no ongoing transport support available.[46] Inadequate transport options and poor links to urban settings emphasize economic and social dislocation and disadvantage for disabled people living rurally.

McGregor, J. (2005). *The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport.* Retrieved from: https://www.hrc.co.nz/our-work/people-disabilities/past-projects/accessible-journey/

[39] Nikora, L., Karapu, R., Hickey, H., Te Awekotuki, N. (2004). *Disabled Māori and Disability Support Options: A report prepared for the Ministry of Health, Hamilton Office.* Hamilton, New Zealand: Māori and Psychology Research Unit, University of Waikato.

[40] Probst, J. C., Laditka, S. B., Wang J. Y., Johnson, A. O. (2007). Effects of residence and race on burden of travel for care: Cross sectional analysis of the 2001 US national household travel survey. *BMC Health Services Research, 7*(40), 1-13.

[41] Simpson, H. (2020). *New Zealand Health and Disability System Review – Final Report – Pūrongo Whakamutunga.* Health and Disability System Review. Retrieved from: https://systemreview.health.govt.nz/assets/Uploads/hdsr/health-disability-system-review-final-report.pdf

[42] Simpson, H. (2020). *New Zealand Health and Disability System Review – Final Report – Pūrongo Whakamutunga.* Health and Disability System Review. Retrieved from: https://systemreview.health.govt.nz/assets/Uploads/hdsr/health-disability-system-review-final-report.pdf

[43] Ministry of Health. (2004). *Living with Disability in New Zealand: A descriptive analysis of results from the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities.* New Zealand Ministry of Health. Retrieved from: https://www.health.govt.nz/system/files/documents/publications/livingwithdisability.pdf

[44] Hale, L., Potiki Bryant, K., Tikao, K., Milosavljevic, S., Mirfin-Veitch, B., Russell, A., & Montgomery, A. (2014). *Hauā Mana Māori: Living Unique and Enriched Lives – a Report for the Health Research Council and the Ministry of Health.* Centre for Health, Activity, and Rehabilitation Research. Retrieved from: https://www.otago.ac.nz/physio/otago066906.pdf

[45] Hale, L., Potiki Bryant, K., Ward, A.L., Falloon, A., Montgomery, A., Mirfin-Veitch, B., Tikao, K., and Milosavljevic, S. (2018). Organisational Views on Health Care Access for Hauā (Disabled) Māori in Murihiku (Southland), Aotearoa New Zealand: A Mixed Methods Approach. *New Zealand Journal of Physiotherapy 46(*2), 51-66; King, P. T. (2019). *Māori with Lived Experience of Disability Part I.* Commissioned by the Waitangi Tribunal for Stage Two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry. Ministry of Justice. Retrieved from: https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575%2C%20B022.pdf

[46] Collins, A., & Wilson, G. (2008). *Māori and Informal Caregiving: A Background Paper Prepared for the National Health Committee.* Māori Development Research Centre. Retrieved from: https://www.moh.govt.nz/notebook/nbbooks.nsf/0/933A5FFFCE411AFECC2579A5006B42E3/$file/maori-informal-caregiving-apr08.pdf

It is important to point out the links between health, transport and socio-economic inequalities. There is strong evidence that health disparities are influenced by income, educational level, and employment status.[47] Across all social indicators, disabled fare worse than non-disabled people. Disabled people, their families and whānau are poorer than non-disabled New Zealanders. This economic disadvantage is compounded by the personal financial cost of disability.[48] Statistics show that disabled New Zealanders are grossly overrepresented in unemployment rates[49] and live in some of the poorest areas in the county.

[47] Guimarães, T., Lucas, K., & Timms, P. (2019). Understanding how low-income communities gain access to healthcare services: A qualitative study in São Paulo, Brazil. *Journal of Transport & Health, 15*, 1-17.
[48] Mitra, S., Palmer, M., Kim, H., Mont, D. & Groce, N. (2017). Extra costs of living with a disability: A review and agenda for research. *Disability and Health Journal 10*(4), 475-484.
49 Kaiwai, H. & Allport, T. (2019). *Māori with Disabilities (Part Two): Report Commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575).* Ministry of Justice. Retrieved from: https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150473583/Wai%202575%2C%20B023.pdf

4. Transport options in the 3DHB areas and travel subsidies

The regions that CCDHB, HVDHB, and WDHB cover include urban and rural settings that vary greatly in transport options on offer.[50] Capital and Coast includes the city of Wellington, which has several well-connected transport options, stretching north to the town of Paraparaumu, which has significantly less options for accessing its two public hospitals in Wellington and Porirua. Hutt Hospital in HVDHB and Wairarapa Hospital in WDHB are well connected to train lines but there are less options for those living outside of areas healthcare settings are located in.

The public hospital and healthcare services within the 3DHB area are connected to the greater Wellington region through public transport services such as buses, trains, and ferries. Metlink is the region's public transport network of these services, with four rail lines, four ferry stops, and over 100 bus routes across the network.[51] Most of the region's public transport services are now contracted out by the Greater Wellington Regional Council (GWRC), who work closely with each region's District Council.

The Wellington City Council Annual Report 2018-19[52] shows that most of the region's public transport targets were not met in the previous year. This report found that less than half of Wellington residents found it easy to move around the city on public transport and public perception was low, particularly in regard to affordability (38.2%), quality (22.3%), and reliability (16.4%).[53]

In August 2019, a Transport Perceptions Survey was commissioned by GWRC.[54] It reported that there had been a significant increase in taxi/rideshare use compared with four years prior and that there had been a deterioration in perceptions toward ease of travelling around the regions. Neither of these Council reports include any insight into the experiences of disabled people living in the Wellington region.

[50] See *Appendix D* for information on the Wellington Regional Transport Network
[51] Metlink. (n.d.). *About Us*. Retrieved August 04, 2020, from: https://www.metlink.org.nz/about-us/
[52] Wellington City Council. (2019). *Te Pūrongo ā-Tau 2018/19 Annual Report 2018/19.* Retrieved from: https://wellington.govt.nz/~/media/your-council/plans-policies-and-bylaws/plans-and-policies/annualreport/2018-19/annual-report-2019.pdf?la=en
[53] Wellington City Council. (2019). *Te Pūrongo ā-Tau 2018/19 Annual Report 2018/19.* Retrieved from: https://wellington.govt.nz/~/media/your-council/plans-policies-and-bylaws/plans-and-policies/annualreport/2018-19/annual-report-2019.pdf?la=en
[54] Horizon Research. (2019). *Transport Perceptions Survey 2019: For the Greater Wellington Regional Council August 2019.* Retrieved from: https://www.gw.govt.nz/assets/Transport/Regional-transport/Regional-Transport-Analysis/Transport-Perceptions-survey-report-August-2019-FINAL.pdf

4.1. Bus

In July 2018, major changes to Wellington's bus transport network were implemented.[55] These changes included updating some of the fleet, a redesign of routes and timetables, a systems upgrade, and implementation of an off-peak discount to tertiary students and disabled people.[56] A Public Transport Operating Model was implemented, focusing on commercial partnerships. These contracts were to run 'units' of bus services rather than individual routes, of which the Wellington regional bus network is made up of 16. Contracts were awarded to four operators: Tranzit Group, NZ Bus, Mana Coach Services, and Madge Coastlines trading as Uzabus.[57]

Most Metlink buses are wheelchair accessible and all provide priority seating for people with disabilities and mobility issues. Metlink has some older buses in their fleet that do not meet current accessibility requirements. Buses are not on fixed routes, therefore Metlink suggests that passengers call their customer service line on the day to confirm accessibility. Buses do have ramps, but they may not be able to cater for larger mobility aids.[58] At bus stops, real time displays, which are beneficial for people with good vision, show whether a bus service is accessible.

Rural bus services such as those linking Wairarapa Hospital to the greater Wairarapa are less frequent than urban services and supply is limited. For example, for people travelling directly from Martinborough to Wairarapa hospital, this infrequency means there is only one morning service to the hospital and two afternoon return services back to Martinborough.[59] This can potentially create an eight-hour return journey.

The WDHB website reports that there is a bus that services the hospital four times a day on Tuesdays and Fridays.[60] However, this is inconsistent with Metlink timetables, which state that buses run Monday to Friday throughout the day linking the hospital with central Masterton.[61]

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[55] Metlink. (n.d.). *Our Metlink journey: About the review.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/our-metlink-journey/our-metlink-bus-journey/bus-network-review/about-the-review/

[56] L. E. K. Consulting. (2018). *Greater Wellington Regional Council: Wellington City and Hutt Valley Bus Network Implementation.* Retrieved from: https://www.metlink.org.nz/assets/Uploads/Implementation-Review.pdf

[57] Greater Wellington Regional Council. (2018, August 30). *Bus contracts.* Retrieved August 04, 2020, from: http://www.gw.govt.nz/bus-contracts

[58] Metlink. (n.d.). *Accessibility Guide.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/getting-around/accessibility-guide/

[59] Metlink. (n.d.). *200 Martinborough - Featherston - Greytown - Masterton [bus timetable].* Retrieved August 31, 2020, from: https://www.metlink.org.nz/timetables/bus/200

[60] Wairarapa District Health Board. (n.d.). *Hospital maps and information.* Retrieved August 04, 2020, from: http://www.wairarapa.dhb.org.nz/patients-and-visitors/maps-and-information/

[61] Metlink. (n.d.). *Masterton bus timetable.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/assets/OLD-Timetables/Misc.--Bus-200/WRC-Masterton-webJune2014.pdf

A review of these network changes took place in 2019, with feedback from public transport users in Wellington City supporting the changes.[62] Plans to consult with users in the rest of the Wellington region, including Porirua, Hutt Valley, Kāpiti Coast and the Wairarapa in April 2020[63] were disrupted by Covid-19.

4.2. Train

Wellington Railway Station in Wellington's CBD is a major interchange to the city's bus network. This central station is a starting point for rail services terminating in Johnsonville, Porirua, and Waikanae (CCDHB), Upper Hutt (HVDHB), and Masterton (WDHB).

All of Wellington's trains are reported as being accessible to wheelchairs and mobility devices, with allocated parking areas at stations.[64] However, 14 of the region's 48 stations are not wheelchair accessible due to steep ramps that Metlink describes as "challenging to access without assistance".[65]

Some trains in Wellington and the Wairarapa are fitted with hearing loops and have passenger information displays inside the train showing next station announcements. Hearing loops are located in the designated area for wheelchairs and mobility scooters. The Wellington Railway Station now uses wi-fi hearing loop technology, which allows loudspeaker announcements to connect to hearing devices and mobile phones. This doesn't appear to be available at all stations in the 3DHB area.[66]

Rail connects all three DHB areas, facilitating travel between cities. Kenepuru Station in Porirua is advertised as a 10-minute walk from CCDHB's Kenepuru Hospital and Epuni Station in Lower Hutt is advertised as a 5-minute walk from HVDHB's Hutt Hospital. However, neither of these stations are accessible to wheelchair users and fewer trains stop at Epuni Station. Trains are therefore not likely to be the only mode of transport to healthcare settings and rather used as a stage in the journey. Wellington hospital is advertised as a 10 to 15-minute bus ride from the railway station, airport and ferry terminal, and the distance from the train station to hospital in Wairapapa is around a 5-minute drive by car.

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[62] Metlink. (n.d.). *How's my bus network?: About the review.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/our-metlink-journey/our-metlink-bus-journey/bus-network-review/about-the-review/

[63] Metlink. (n.d.). *How's my bus network?: About the review.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/our-metlink-journey/our-metlink-bus-journey/bus-network-review/about-the-review/

[64] Metlink. (n.d.). *Accessibility Guide.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/getting-around/accessibility-guide/

[65] These sites are: Ava; Awarua Street; Box Hill; Epuni; Kenepuru; Naenae; Ngauranga; Paremata; Pomare; Porirua; Takapu Road; Taita; Wingate; Woburn. Metlink. (n.d.). *Accessibility Guide.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/getting-around/accessibility-guide/

[66] Metlink. (n.d.). *Accessibility Guide.* Retrieved August 28, 2020, from: https://www.metlink.org.nz/getting-around/accessibility-guide/

4.3. Ferry

Wellington Harbour Ferry services wharfs in Queens Wharf, Seatoun, Matiu/Somes Island (CCDHB) and Days Bay (HVDHB). However, there is limited capability for wheelchair and mobility devices to use this service. Access to the ferry for motorised wheelchairs, in particular, is difficult as crew have to physically lift them on board which could be a health and safety issue for both ferry staff and passenger. If people are able to get on board, there is minimal wet weather protection The Queens Wharf to Days Bay ferry route connects Wellington City with Hutt Valley, where bus services connect with Hutt hospital. There is no direct bus route from the ferry terminal to Wellington hospital.

4.4. Shuttle

Shuttles operate a variety of services between healthcare settings and some major transport hubs. Many of these services are volunteer-run and vary greatly in availability and wheelchair accessibility across the three DHBs.[67] Despite the general availability of health shuttles, there are access issues, for example the distance between a person's residence and their departure point, that create additional barriers along the journey chain.

A free shuttle is provided between the main entrances of Wellington and Kenepuru Hospitals hourly between 7 am and 6 pm on weekdays and is 30-45 minutes in duration. This shuttle is not wheelchair accessible.[68]

A Safe Kāpiti (ASK) runs the Kāpiti Health Shuttle, picking up people between Waikanae and Paekākāriki from Monday to Thursday. It leaves at 8am and returns at 1pm. This shuttle is wheelchair accessible, however the CCDHB webpage provides conflicting information about the accessibility of this service.

WDHB runs a Red Cross shuttle service to and from Wairarapa Hospital, and between hospitals in the region. The Wairarapa branch of the New Zealand Red Cross has been providing community transport service for Wairarapa residents since March 2005. This transport service has been supported by WDHB because of its strategic fit with the operational intent of the Public Health & Disability Act 2000 and the New Zealand Health Strategy (2016).[69]

[67] There have been reports that due to Covid-19, many volunteer run transport services have withdrawn their services until further notice, removing a vital transport option for many disabled people.
[68] Capital and Coast District Health Board. (n.d.). *Transport between our hospitals*. Retrieved August 04, 2020, from: https://www.ccdhb.org.nz/our-services/information-for-patients-and-visitors-to-our-sites/transport-between-our-hospitals/
[69] Edwards, J. (2020, June 22). Wairarapa Community Transport [Unpublished memo]. Wairarapa District Health Board.

Hutt Hospital provides a transport service through Te Awakairangi Health Network (TeAHN) for eligible patients to primary health or Hutt Hospital appointments. The TeAHN transport service is available Monday to Friday between 8.00 am and 5.30 pm.[70] This is delivered through the Wellington Free Ambulance, that includes in its fleet six vehicles wheelchair accessible vehicles.

4.5. Taxi

There are a wide range of taxi services operating in the greater Wellington region, ranging from budget operators to those which higher pricings. Patients discharged from hospitals in CCDHB are often eligible for a taxi voucher[71], however this needs to be requested before discharge. Hutt Valley DHB does not pay for or arrange transport home.[72] WDHB does not provide any payment for taxi services either but do advertise a payphone located at the main entrance of the hospital for taxis to be ordered from. Often in cases like this, one taxi operator is associated with the hospital phone line, limiting the choice of cost options for the passenger.

4.6. Car

For people who use private cars to access healthcare settings, there is a mix of general use and mobility parking available at each hospital. At Wairarapa and Kenepuru Hospitals, general use parking is free. However, at the other hospitals, there is a cost incurred. For example, Hutt Hospital charges up to $10 per day.

Wellington City Hospital is comprised of a cluster of separate buildings with multiple car parking areas. CCDHB provides a map of these areas[73] and provides a downloadable map that shows the location of mobility parks.[74] The Wellington City Council's website lists locations of mobility parking spaces across the city but this list does not include hospital sites due to hospital parking being privately owned. For

[70] Te Awakairangi Health Network. (n.d.). *Transport*. Retrieved August 04, 2020, from: https://teawakairangihealth.org.nz/service/transport/

[71] Kāpiti Health Advisory Group. (2019). *Hospital and local medical appointment transport options for Kāpiti residents.* Retrieved from: https://www.ccdhb.org.nz/our-services/information-for-patients-and-visitors-to-our-sites/transport-between-our-hospitals/hospital-transport-options-info-brochure-landscape-no-ccdhb-logo.pdf

[72] Hutt Valley District Health Board. (n.d.). *Leaving hospital.* Retrieved August 04, 2020, from: http://www.huttvalleydhb.org.nz/visitors/leaving-hospital/

[73] Capital and Coast District Health Board. (n.d.). *Wellington Regional Hospital car parking.* Retrieved August 04, 2020, from: https://www.ccdhb.org.nz/our-services/wellington-regional-hospital/patient-and-visitor-parking-changes-feb-2018/wrh-car-parking-19-feb-2018.pdf

[74] Capital and *Coast* District Health Board. (n.d). *Wellington Regional Hospital*. Retrieved September 01, 2020, from: https://www.ccdhb.org.nz/our-services/wellington-regional-hospital(6aae84a5-d50c-4ad7-a676-c41c90f95ee2)/updated-map-ccdhb-feb-2020.pdf

Kenepuru hospital, there is a downloadable parking map on the CCDHB website, which shows the location of onsite mobility parks.[75]

Hutt City Council provides an interactive map of the city with mobility parking spaces, including those on Hutt Hospital grounds[76], and the Hutt Valley DHB has a downloadable parking map on its website.[77] Wairarapa DHB also have a downloadable parking map on their website[78] and Masterton District Council also provides information on their website about mobility parking, such as allowing 50% extra time in metered parking spaces when displaying a mobility card.

4.7. Transport subsidies

4.7.1. Mobility parking permit

Eligibility for a mobility parking permit is determined by criteria such as whether the person is unable to walk, uses a wheelchair or mobility aid, or requires close supervision to safely get around.[79] Having a medical condition or disability does not automatically entitle someone to receive a mobility parking permit. These permits are issued by CCS Disability Action and require confirmation of eligibility by the person's doctor.

4.7.2. Total Mobility Scheme

The Total Mobility Scheme (Total Mobility) is funded in partnership with local and central government and assists eligible people in accessing appropriate transport to meet their daily needs. Total Mobility is deemed a component of the local authority's public transport network and is available for people who cannot independently use regular public transport services or private vehicles. This assistance is provided in the form of subsidised door to door transport services. In the Wellington region, it provides a discount of 50% on eligible taxi fares, up to $40 per trip. This includes wheelchair accessible services.[80] Cards can be acquired from approved support agencies after receiving an assessment in the person's home and can be used nation-wide, however, there are regional differences in the way

[75] Capital and Coast District Health Board. (n.d.). *Kenepuru Community Hospital*. Retrieved August 27, 2020, from https://www.ccdhb.org.nz/our-services/kenepuru-community-hospital-porirua/kenepuru-community-hospital-map-february-2017.pdf
[76] Hutt City Council. (n.d.). *Parking map.* Retrieved August 04, 2020, from: https://maps.huttcity.govt.nz/parking_map/
[77] Hutt Valley District Health Board. (n.d.). *Parking and public transport.* Retrieved August 04, 2020, from: http://www.huttvalleydhb.org.nz/visitors/parking-and-public-transport/
[78] Wairarapa District Health Board. (n.d.). *Hospital maps and information*. Retrieved August 04, 2020, from: http://www.wairarapa.dhb.org.nz/patients-and-visitors/maps-and-information/
[79] CCS Disability Action. (n.d.). *Mobility Parking: applications & renewal.* Retrieved August 04, 2020, from: https://www.ccsdisabilityaction.org.nz/mobility-parking/applications-and-renewal/
[80] Metlink. (n.d.). *Total Mobility*. Retrieved August 04, 2020, from: https://www.metlink.org.nz/getting-around/accessibility-guide/total-mobility/

it works. For example, the scheme is subject to some variation of entitlements to reflect local differences. In some regions, there may be transport services for which there is no Total Mobility scheme provided.[81] In some parts of New Zealand the amount you can use or claim is capped whereas in other regions it is not.[82]

4.7.3. National Travel Assistance Scheme

The National Travel Assistance Scheme provides financial support to eligible people who need to travel long distances or travel frequently for specialist treatment. It may provide funding to cover the cost of travel, accommodation and support person costs. This assistance is provided in the form of refunded costs that require receipts to be signed, stamped, and posted to the Ministry of Health after the visit.[83] This is a process that requires the ability to pay for of expenses upfront. The scheme is administered by DHBs who use the National Travel Assistance policy to guide their decision-making according to the eligibility criteria.

4.7.4. Other transport-related subsidies

The Ministry of Social Development (MSD) provides some financial support that can help people with health-related costs. The Disability Allowance is a weekly payment for people who have regular, ongoing costs because of a disability, such as visits to the doctor or hospital. The amount is means-tested and dependant on the extra costs people incur because of their disability.[84] People may also be eligible for financial support for travel and accommodation costs related to accessing health services. Eligibility for this support is means-tested, and people are not only able to access this support if they are not receiving other health-related travel and accommodation support, for example from a health agency, under the National Travel Assistance scheme or receiving the Disability Allowance. The support only covers one-off appointments.[85]

For people 65 years and over, they can use the SuperGold card which give access to free off-peak travel on public transport. Off-peak hours are 9am to 3pm and from 6:30pm to the end of service on

[81] New Zealand Transport Agency (2017). *Total mobility scheme: policy guide for local authorities.* Retrieved August 04, 2020, from: https://www.nzta.govt.nz/assets/resources/total-mobility-council-guide/docs/total-mobility-council-guide.pdf
[82] CCS Disability Action. (n.d.). *Total Mobility (discount transport service).* Retrieved August 04, 2020, from: https://ccsdisabilityaction.org.nz/services/how-can-we-help/total-mobility-taxi-vouchers/
[83] Ministry of Health. (n.d.). *Who's eligible for travel assistance.* Retrieved August 04, 2020, from: https://www.health.govt.nz/your-health/services-and-support/health-care-services/hospitals-and-specialist-services/travel-assistance/whos-eligible-travel-assistance
[84] Ministry of Social Development. (n.d). *Disability Allowance.* Retrieved August 27, 2020, from: https://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html
[85] Ministry of Social Development. (n.d). *Travel and Accommodation Costs.* Retrieved August 27, 2020, from https://www.workandincome.govt.nz/eligibility/health-and-disability/travel-costs.html

weekdays, and any time on weekends and public holidays.[86] It's important to note that the Ministry of Health, through Disability Support Services, which many disabled people receive support from, does not specifically fund travel-related costs.

[86] SuperGold. (n.d). *Free off-peak public transport*. Retrieved August 27, 2020, from: https://www.supergold.govt.nz/info_for_cardholders/q_and_a#can-i-use-my-supergold-card-to-travel-free-on-public-transport

5. Healthcare system

5.1. What enables disabled people's access to healthcare

5.1.1. Infrastructure

Hospital buildings and grounds were widely viewed as being accessible, largely due to recent renovations and upgrades.

"Wellington Hospital is great accessibility-wise." – Wheelchair user

"Kenepuru hospital has flat access and good mobility parking." – Wheelchair user

"Hutt Hospital is pretty good. It's got good lifts and it's very spacious so it's good for wheelchairs." – Wheelchair user

"Masterton Hospital is really well laid out." – Mobility

"There's clear signage wherever I go." – Low vision

"The good thing about Masterton is that they have a very nice outdoor area with nice comfortable seats set up." – Mobility

5.1.2. Appointment notices

Clear and open communication of information specific to appointment times enables disabled people to plan planning of their journey. Appointment notices were sometimes tailored to people's individual access needs, which participants explained was an important part in making healthcare accessible.

"When I deal with a new department, I give them my phone number and email and they send through my appointments that way." – Blind

"The phone number on the appointment letter is quite large, which is easier to read so I can call for more information on my appointment." – Low vision

"I like getting a letter in the post because it means I have something in my hand that reminds me of where I need to go." – Mobility

Appointment reminders are also valued because it enables people to begin planning their trip.

"When I get a text message reminder, it helps me plan my transport around how I am physically capable at that time." – Mobility

5.1.3. Staff

On-site hospital volunteers were seen as providing a much-needed service that enabled disabled people to get to their hospital appointments.

> *"The volunteers are always available to help." – Multiple*

> *"There are always Red Cross volunteers at the door to assist me." – Blind*

> *"There's usually somebody there to push me up the hill to where I need to go." – Wheelchair user*

Hospital staff and transport providers working in small towns outside of main urban settings where most healthcare services are located, were praised for offering personalised support.

> *"In the Wairarapa it's really good because the hospital knows us by name and our personal situations." – Service provider*

> *"I am in a smaller town, so everyone knows each other and service is more personal and considerate." – Mobility*

Hospital Transport Coordinators provide advocacy and advice for disabled people in relation to eligibility for travel support and subsidies.

> *"A number of elderly and disabled people ring me up because they can't get to an appointment using a Total Mobility card. If they don't meet the eligibility for travel subsidies I ask them if they have a Total Mobility card and if they don't, I ring Metlink and I make sure they get assessed, because a lot of them don't know about it. I also advocate for disabled people when they can't afford a $120 fee in companion services. They call me because they know they will get some assistance and that's what I try to advocate for to get them to their appointments so it's not a jigsaw puzzle for them" – DHB Staff*

It was acknowledged that hospital staff are aware of patient's transport needs and were willing to change the way they travelled to work to ease on-site parking congestion.

> *"Staff do want to consider other transport options because patients are the most important people and they need the carparks. Staff have said they would carpool and some would ride bikes because the DHB have invested in good secure bike parking for staff. Staff change their mode of transport and this frees up a park for someone who really needs it." – GWRC Staff*

5.1.4. Health shuttles

The wheelchair accessible shuttle that travels from Kāpiti to Wellington and Kenepuru hospitals has provided much needed access to health services for Kāpiti residents.

"It has been pivotal – for people who use wheelchairs, prams, walkers or other mobility issues who are unable to use public transport to access hospital services." – KHAG

Relatedly, the transfer system between Porirua train station and Kenepuru hospital works well, although it was noted that the vehicle used isn't wheelchair accessible.

"There is a bus stop to wait under. Been in place for a while and is starting to see an increase in user numbers" – KHAG

5.2. Barriers disabled people experience accessing 3DHB healthcare

5.2.1. Availability of healthcare services

Several people spoke about needing to travel long distances in order to access services available in other DHB areas. In some cases, an entire day would be needed to complete the return journey, and this was a particular concern for people living in the Wairarapa.

"There are so many hours either side of your appointment to wait. That makes it a six-hour day, for what could probably be a half an hour appointment." – Sensory

"From Featherston I have to drive into Wellington because taking public transport adds hours and hours onto the day and I just don't have the energy capacity for that." – Mobility

"Getting to an appointment in Wellington is basically a whole day gone." – Parent

A person who provides support to a person with learning disability recounted a twelve-hour day involving two support people bending the rules to help the person attend their DHB appointment.

"I would get up at 6 o'clock in the morning to drive her to Masterton station because she doesn't know how to get there, and then I'd call my manager in Wellington to organize for him to pick her up from the train and for him to look after her until her appointment, and to then put her back on the train after her appointment. I'd meet her at half past six in the evening to take her home. We are not funded for this but how else would she get there?" – Service provider

Disabled people living rurally spoke about needing to travel long distances to appointments within their DHB region when other DHBs were perhaps much closer and more accessible.

"It's 45min to get to Masterton and only 25min to get to Upper Hutt but of course we can't access any of the healthcare over there because we aren't in their DHB, even though it's classed as the Greater Wellington region." – Mobility

"Living in Ekatahuna means that the only transport available is a shuttle that can get you to Palmy Hospital but nowhere in your own DHB." – Service provider

5.2.2. Communication of appointments

The most common method of communicating an appointment notice was seen to be by mail. However, this method of delivery often resulted in missed appointments and delayed treatment due to appointment letters often being lost in the postal system.

> *"There have been times I have missed appointments because I haven't received a letter in time or I haven't received it all because it has been lost by NZ Post." – Parent*

> *"I've had a call saying 'where are you' and then had the appointment letter arrive two days later. Then then it's a 3-month wait for another appointment." – Mobility*

Not all departments notify people by letter and some departments make phone calls instead. For some people, phone appointments are problematic because it is easy to forget important details.

> *"I get my mental health appointments by phone, there's no letter or text to confirm them. With my depression, memory is an issue so it's really difficult to keep track of them." – Mental health*

Many disabled people felt that there was a need to actively seek confirmation of information around their appointment times and locations so that they were able to more efficiently plan their journey.

> *"They need to put more information in the letter about what it relates to. If they put appointment with sleep clinic or appointment for MRI instead of appointment with Doctor so and so there would be more clarity around the purpose of the appointment. That would save us having to call up and waste Wellington staff's time." – Service provider*

> *"People don't call you back. The process is frustrating because you have to chase people up and any form of admin has a higher burden for disabled people." – Mobility*

> *"If I have a double appointment, the letter doesn't say that. Knowing if double appointments have been booked so I have to call up to make sure which wastes everybody's time." – Parent*

It was noted that not all people have the means and ability to phone the hospital to check details of their appointments.

> *"I was sitting in an outpatient's clinic waiting for my specialist appointment and I saw a sign on the wall that said 'missed appointments cost us money. If you can't make your appointment, phone 04 [retracted]', and I was thinking where is the 0800 number? Because people don't have data, it's a missing solution within a bigger problem, that they can't make the calls free." – GWRC Staff*

5.2.3. Timing of appointments

The impact of having appointments early in the morning or late in the afternoon meant that some disabled people were required to travel during rush hour, which a number of participants suggested added onto an already long journey.

"Wellington usually puts a time close to the afternoon which is a hassle because you get caught in the traffic back to the Hutt after your appointment." – Mobility

"In Wairarapa, for some reason, Wellington Hospital send all their appointments for 3 or 4 in the afternoon which means coming back in peak hour traffic. Or they make it at 8 or 9 in the morning where you have to get up at 5 in the morning and also deal with peak hour traffic." – Wheelchair user

"A major barrier would be timing because they don't always consider that you are coming from Kāpiti Coast. If we have an appointment at 9 am, we have to get up at 6.30 am and then you're stuck in rush hour traffic. It's a major barrier because it disrupts the kids – their sleep, their meds, the whole routine - it's a nightmare." – Parent

"Sometimes the specialists don't work the hours that you hope they work. Often surgery clinics are only in the afternoon and some of the multidisciplinary team clinics 2/3/4pm and so then you're coming home in rush hour traffic, and so then you are not only paying full price on the train, $15 one way and getting to the station on a crowded bus and those things make it really really difficult". – KHAG

This became even more problematic for those living in Wairarapa.

"The way public transport through the Wairarapa is laid out, you've just got so many hours either side of your appointment to wait." – Mobility

"They don't really consider how far you have to travel." – Wheelchair user

This was further compounded for Wairarapa residents with late afternoon appointments in Wellington, as it meant taking the risk of not being able to return home because trains had stopped running for the day.

"I was given an appointment at 4.30 in the afternoon. There was no awareness of that meaning I can't get home." – Mobility

Uncertainty around the duration of a person's appointment or hospital stay was also seen as a barrier to being able to plan the return trip home.

"They couldn't tell her whether they would keep her in overnight or send her home. Now this is a person with a disability having [a procedure] and no way of organising a way of getting all the way back to Masterton on her own." – Service provider

5.2.4. Rescheduling of appointments

People spoke about needing to reschedule appointments due to an inability to access transport. The rescheduling of appointment times due to transport barriers was portrayed as a difficult process that involved delayed care.

"A couple of times I have asked to move the appointment because I couldn't get there, but I've been told I'll have to wait another three months." – Wheelchair user

Although text message reminders were praised as a useful way of confirming appointments and assisting in planning travel, their use was not consistent across departments. Therefore, any breakdown in the internal processes around rescheduling was seen to greatly impact on disabled people travelling long distances.

"I went all the way to Wellington from the Kāpiti Coast for a morning admission only to be told I was on the afternoon list. I mean, we can't just pop home. It's a big deal for us – a major issue to be nil-by-mouth, nothing to eat all day, all because we were sent the wrong information." - Parent

"I was on my way to Kenepuru Hospital and they rung me 5 minutes before my appointment to tell me it had been cancelled – I was like I'm already in Porirua after 40 mins in traffic. They said they should have rung earlier but forgot. That really messes with my autistic kids' expectations of what is happing that day." – Parent

5.2.5. Communicating where to go[87]

Some people found it difficult to know exactly where to go for their hospital appointments.

"A lot of times I will ask friends beforehand where I need to go - which entrance to use – because otherwise I could end up having to walk all the way around." – Mobility

"They don't tend to tell you which is the closest entrance. If you are using companion services, you have to trust that they will know where to take you. Sometimes they don't." – Blind

"I know where to go in Wellington Hospital just because I have been there so many times, not because I have ever been told." – Parent

"Hutt Hospital has two entrances so I have to think about where I have to be in the hospital and where the nearest entrance is to where I need to be." – Low vision

People thought information about where to go for their hospital appointments was not always clearly communicated by DHBs. When sending out appointments, some departments include a map of the hospital grounds, although this appears to be uncommon. While maps of hospital grounds are available online, these are complex and difficult to understand, often not sufficiently labelled with relevant information.

[87] Please note that since the time of writing this report, CCDHB have updated their webpage to include more specific travel information to and around the hospital campus.

"Some departments do tell you which entry is the closest but not all of them. It is not at all standardised." – Mobility

"There's not enough information about which entry to use." – Mobility

"At Wellington regional hospital, there is a set of different buildings with different ways to enter. It's like a maze. It's not always clear where you need to go from the information provided." – Wheelchair user

Many disabled people revealed that their only option for getting to their appointments was driving themselves or using companion services. For these people, it was important to know where to park to reduce the distance travelled and physical effort exerted.

"The hospital is confusing with where to go. It makes a huge difference knowing which carpark to park at to get where you are going safely without having to walk a long way." – Mobility

"The parking map on the Wairarapa DHB website is about 5 years out of date. I asked the Council to update it and they said sure, only if I went around and wrote down the available places, then they'd update it… but it's not my job to do it!" – Service provider

5.2.6. Communication of travel subsidies

Many disabled people spoke of relying on travel subsidies to reduce the cost of travelling to appointments. However, in many cases information on types of subsidies were discovered through word-of-mouth rather than through official DHB channels.

"You don't know about the travel subsidies unless someone tells you." – Multiple

"I don't understand why the information we need is not given to us." – Parent

"There are services or concessions that they don't tell you about. You have to find out everything out on your own" – Mobility

"My daughter was staying in Wellington Hospital for a week and I wasn't told until the very last day that if I took in my parking thing they could validate it." – Parent

Some participants were not aware of the Total Mobility card nor National Travel Subsidy until our interviews took place. Others shared experiences of discovering different subsidies.

"The National Health Travel assistance thing, I didn't find out about that until I had been travelling to Wellington and back for two years. I didn't know you could claim costs back and this is the sort of thing I feel that they should be a bit more upfront about. I only get it because I go to Wellington, I don't get it for driving 45 minutes to Masterton." – Mobility

"Wow. Really? I wish I was given a heads up about all these things when I was diagnosed." – Mobility

"I just found out the other day that with a community services card I can claim for travel costs. I didn't even know that existed!" – Parent

5.2.7. Awareness of disability, access and transport issues within DHBs

Although nurses and volunteers were seen as having a good amount of awareness around disability and access issues,[88] it was suggested that booking clerks needed some awareness around access issues, such as the difficulties some disabled people faced in attending their appointments on time, or at all.

"Hospital staff need to know what accessible is – to each disability group – and know whether each service provider is accessible or not." – Wheelchair user

"No-one seems to know if a [transport] provider is accessible or not, or they say it is but then you show up and it isn't." – Wheelchair user

"I think Capital and Coast should set up a booking system where they go right this person is flagged as wheelchair user and so they do what they can to make their appointment after 10am and before 2pm. So if they do that, they have a great chance of getting a ride, but if they keep doing it around the peak hours that's when the trouble will start." – Transport Provider

It was also suggested that there be an openness to booking clerks collaborating with service providers, who at times need to assist people with intellectual disabilities in following up on their appointment times.

"We're not asking for any medical information. It's just times and days." – Service provider

5.2.8. DHB health shuttles

Although there is a variety of shuttle services available, there is variability in cost, availability and accessibility across the 3DHB locations.

"No DHB shuttles from Hutt Valley to Wellington." – Wheelchair user

"There's only one run for the shuttle a day [from Kāpiti] so when you've got two special needs kids, you don't want to be waiting around for an hour or two for your ride home." – Parent

"Mobility parking at Kenepuru Hospital is limited and the shuttle is not wheelchair accessible so basically, it's not an option for me." – Wheelchair user

[88] While not necessarily specific to themes around transport and healthcare accessibility, it is important to note that many participants talked at length about medical professionals' limited understanding of disability beyond a medical framework and the negative experiences they had interacting with medical professionals.

"There's a cost suggestion for the shuttle from Paraparaumu – it's about $40 return so it's cheaper to take the car, or even to pay a friend." – Parent

"There is the Kenepuru shuttle but it isn't wheelchair accessible. This is another barrier." – KHAG

It was also noted that Wellington hospital offered no direct shuttle links between Wellington train station, Wellington Hospital and Hutt Hospital.

"There is no DHB shuttle from Wellington station to the hospital. You have to catch a taxi and it costs $12 with Total Mobility one way or you can catch bus if you can get out of the station, but there are lots of ramps and quite a bit of physical effort. Capital Coast offers no shuttles apart from Kenepuru. There are no transport links between Wellington and Hutt Valley." – KHAG

Limited funding and resources were identified as a key barrier.

"There are a lot of patients that need access to a mobility vehicle so if we are able to have access to another vehicle that has that, I think it would be better, a vehicle that is able to help most patients. But money is the main thing. Money to pay staff and to get a vehicle." – DHB Staff

Shuttles have irregular schedules and pricing and are not always accessible or reliable.

"The shuttle companies generally arrive on time but if they are late – one occasion they forgot about me and I had a panic about whether I could get to the hospital on time." – Wheelchair user

"The shuttles up [in Porirua] aren't wheelchair accessible." – Wheelchair user

The parents of disabled children found challenges with sharing transport with members of the public.

"Being in a shuttle with other people is overly stimulating for them and there's too much noise and they can have outbursts that other people wouldn't understand. That's why we can't use public transport." – Parent

For people who rely on shuttles to attend appointments in Wairarapa, services such as the St Johns and Red Cross shuttles were appreciated, but not without their own issues.

"The service is free and volunteer run but you've got to know your appointment time because they've only got the one van in the Wairarapa. You've got to book weeks out and if you have an appointment the same day as somebody else, you're out of luck." – Wheelchair user

"St John shuttles only go as far as Featherston and they tend to get filled up with the elderly, and it ends up being more expensive than driving." – Mobility

5.2.9. Parking

For disabled people who drove to their appointments limited hospital parking was a barrier, even to those with parking permits.

> *"Catching public transport means not having to go through all the drama of finding a park, but it takes so much longer and I just can't do it physically… so I drive." – Mobility*

> *"I can't claim travel-related costs because on ACC I have a van and I am expected to use that, but there aren't always parks available. Wellington hospital doesn't have enough mobility parks. It's quite competitive now – it's not just for wheelchair users. I can use some of the other parks but then I am in danger of being hit by a car coming past." – Wheelchair user*

> *"There are not enough mobility parks, which adds a lot of time to the whole process, especially in Wellington." – Wheelchair user*

> *"There's often not enough parks so getting a mobility park is not guaranteed. You have to drive around a lot. And then you have to walk around a lot because there isn't enough information about which services use which carparks. It's confusing to know where to park." – Mobility*

Several people we spoke to used mobility scooters as their primary method of transport but due to distance they needed to travel, risked running out of battery.

> *"Just enough battery for a return trip but there is nowhere to charge it when you arrive at the hospital." – Wheelchair user*

Some people found it difficult to find easy access to ticketing machines following their appointments.

> *"I had an early morning appointment with my son at Hutt Hospital, so was already stressed from getting there on time and from the actual appointment, and then I had to drive around the hospital grounds to try find somewhere I could park close enough to the pay machine to be able to leave him in the car, because it's too hard to take him with me. They should have credit card facilities at the ticket machines so you can pay while exiting, like at Wellington Hospital" – Parent*

6. Transport system

6.1. What enables transport access to disabled people's 3DHB healthcare appointments

6.1.1. Planning tools

For those using buses and trains to attend their appointments, route information was readily available on the Metlink website and mobile apps.

> *"The website is pretty accessible." – Blind and Low vision*

> *"I use the journey planner on the app because it I find it more accessible than the timetables on the website." – Low vision*

A brochure containing transport options and information was put together for Kāpiti residents.

> *"The transport working group drafted put together a transport brochure showing all the transport options from Kāpiti to Wellington. I also looked at drafting a wider document wider document outlining both the benefits of the Total Mobility scheme, and national assistance scheme, and all those other things and actually writing them out so they are all in a pamphlet form." – KHAG*

The Metlink call center was identified as providing good support around journey planning.

> *"Metlink have a great call center and are able to give specific information about public transport options and routes to hospitals" – GWRC Staff*

6.1.2. Staff

A perceived increase in drivers and transport employees' disability awareness has led to improved travel experiences for disabled people.

> *"When Tranzit/TransUrban took over the Hutt Valley, attitudes and awareness has been a bit better." – Mobility*

> *"Attitudes towards guide dogs are positive. That's a credit to awareness training." – Blind*

> *"The conductor will pull out the ramp for you to get on and they always do that with good cheer." – Wheelchair user*

Disability transport providers sometimes offer a personalized service beyond standardized transport options.

"It's not just transport, because the people who use our service know that we go the extra step to look after them, it might be helping someone up their stairs. We build important relationships with clients" – Transport Provider

6.1.3. Mode

Certain types of transport, because they were accessible, resulted in the service being well-received.

"The buses in Wellington are really good because if you miss one, there'll be another one coming along soon after." – Mobility

"The new buses are easier to get on." – Mobility

"Buses in the Hutt are now wheelchair accessible." – Wheelchair user

"The St John shuttle works well." – Multiple

"The St John health shuttle people are really good, and they'll do their best to accommodate you." – Mobility

6.1.4. Transport subsidies

Subsidized transport is appreciated, especially in cases where it reduces the overall cost of attending appointments:

"The Total Mobility card gives me half price travel, which helps keep the cost down when I have to get a taxi from Upper Hutt to Wellington." – Low vision

"The Total Mobility scheme is wonderful." – Blind

"I get a 10-trip ticket at Wellington Station and it's half price with Total Mobility." – Mobility

"If you have Cerebral Palsy and you are a member of the Society, you can apply for $200 worth of vouchers a year and they can be used for transport on top of Total Mobility." – Wheelchair user

6.1.5. Work by the Greater Wellington Regional Council

The council is beginning to engage in collaborative work that aims to provide innovative transport solutions for people accessing hospital services.

"We have worked with CCDHB on some ideas for better access to hospital services, for example on-demand transport services, ride sharing applications, so that you could have peer to peer ride sharing software to help match with someone going your same way, and that was coming from a congestion reduction point of view, but we thought about how the transport services to hospital could be enhanced by a tool like that" – GWRC Staff

Other accessibility issues are on the agenda, including the accessibility of the Metlink website.

> *"On website design and making sure in terms of the readability and color contrast and font size and things to make it as easy as possible for people to use it and find information and to be able to read it. At a digital level there is some good work that is starting. We are completely redesigning the website and its being launched soon" – GWRC Staff*

Customer engagement has also increased. Recently the WRGC set up a transport advisory group, which is made up of representatives from a range of organizations that support people with accessibility issues or disabilities.

> *"The intention is to get fresh perspectives of lived experiences and where that can feed into the public transport offerings that we have. We've tried to get a range of views and needs and thoughts on public transport services." – GWRG Staff*

The council attempts to be responsive to accessibility issues and adapt infrastructure as necessary.

> *"In the last couple of years, we redesigned bus stops [on the Wellington Hospital route] because they are really, really busy stops, there are a lot of people getting on and off those locations. We made the bus stops longer, and the signage bigger and brighter, and on one side has shelters and the other side has shop canopies to provide shelter, and we've made it as accessible as possible, the curbs are very high there so people don't have too much of a step up to the bus so when it does stop it is almost level to the footpath. Knowing that was such a busy stop and that we needed to get that right, was certainly a focus." – GWRC Staff*

Additionally, accessibility education and training for bus drivers has become a recent focus.

> *"In terms of their training they pretty much go off and do their own thing. Before lockdown we'd kickstarted a process, we'd asked each operator to give us their training material as it relates to disability or accessibility with the intention that we would compare it and pick the best of each of their training material and then coordinate a better and consistent set of training and then work with bus operators to cascade that back down through the operators so that it doesn't matter which operator you are using, you get the same service" – GWRC Staff*

6.2. Supply and access barriers within and across DHBs

6.2.1. Health outcomes and transportation barriers

People made clear links between their health outcomes and transportation barriers. Conversations revealed that on numerous occasions, disabled people have missed or cancelled their appointments and delayed care due to transport barriers.

> *"Often it's delayed me receiving the treatment that I need because – because it's two buses to get to an appointment, if I'm not feeling well, it's more difficult to get there. I might have to*

make a couple of appointments and miss the first one or two just to even get there. It definitely delays my treatment. It puts me at higher risk as well." – Mental health

"Sometimes it's too difficult to get there so I just cancel. Then I'm not getting the treatment I need." – Mental health

"If I was reliant on public transport I would go to the doctors and hospitals so much less." – Wheelchair user

"If you've been waiting for a specialist appointment for a few months you can't just say I can't take that appointment because I can't get a taxi! You might have to wait several weeks before you can get another appointment and if your illness is time critical then you're gonna be in trouble." – Wheelchair user

"Just from the difficulty of figuring out how to get there in the moment has meant I haven't actually been able to go." – Mental health

Many of these negative health outcomes resulted directly from a lack of availability and accessibility of transport services.

6.2.2. Accessibility and availability of transport services

People talked about extremely limited availability of transport options and those living in rural locations often had no transport options at all.

"It's not just appointment times, it's being able to get there at all." – Wheelchair user

"Ekatahuna people comes under a different shuttle so Ekatahuna people with disabilities can't get a health shuttle to Masterton. They can get to Palmy – which isn't their DHB. And there's no bus, no train, no taxi in Ekatahuna." – Service provider

"There aren't enough wheelchair accessible vehicles in the whole system." – Wheelchair user

A lack of viable transport options can sometimes lead to unnecessary overnight stays due to not being able to return home.

"My sister had to stay overnight in the hospital because she had no way to get home that night. She had taken her daughter up in the ambulance because she had had an asthma attack and they had to stay at the hospital and catch the bus back the next morning." – Mobility

6.2.2.1. Public Transport

While Metlink's train and bus services were used by many participants to get to their healthcare appointments, journey routes meant that they often needed to transfer across multiple modes of transport and not all aspects of the journey chain were accessible.

"Not all appointments can be done at Hutt Hospital so it is more difficult because you have to get a train into Wellington – or two buses - and then a bus out to the hospital because there's no hospital shuttle. That's not so easy for all people." – Low vision

"One time it was raining, and the first bus wasn't accessible – an old school one with 3 steps and the driver said 'sorry mate you'll just have to wait'. It was pouring down and I got soaked." – Wheelchair user

Wheelchair users talked about breakdowns and unreliability of train services and how inaccessible buses were used as alternative.

"Once I was on the train home and it just stopped. They said they would organize a bus to take us to the next station so I asked how they were going to get me off the train. In the end the power came back on but they didn't have a plan for what to do with my chair." – Wheelchair user

"How do the buses accommodate your wheelchair if the train service is cancelled? That deters me from wanting to use the train." – Wheelchair user

"If you are going to get the train you really have to check the website because often they aren't running. You have to check they haven't been replaced by buses." – Wheelchair user

"reliability and punctuality across the network, whether you are going to your bank, your lawyer or your healthcare appointment, is not where it needs to be, and we published statistics on website about how performance is going." – GWRC Staff

Additionally, the availability of sufficient wheelchair seating on public transport was mentioned.

"There are limited number of spaces on public transport for wheelchair users." – Wheelchair user

"I can't take a bus if there is another wheelchair user on it." – Wheelchair user

"Wheelchair space and priority seating area for people that need it and the pram space, like everyone is competing for quite a limited amount of space. It is not the driver's role to prioritise customers and to say who should/shouldn't have a seat." – GWRC Staff

Once on public transport, disabled passengers who are Blind or have low vision often rely on apps not associated with Metlink to tell them when it is time to get off.

"I take a bus route that goes past the hospital then splits off and goes to the northern suburbs. They don't all have the automatic announcement, so I use an app called BlindSquare that announces streets and bus stops." – Blind

Supply and availability of public transport vary across DHB areas. Compared to Capital and Coast, the Wairarapa DHB area is greatly affected by supply issues, with options being significantly reduced.

"If you can drive, you're okay but if you rely on public transport you are absolutely stuffed." – Mobility

For those living in Masterton, train and buses are available, however, services are infrequent.

"There are only commuter trains from Masterton. The last one in the morning leaves at 7.30 am. There's one around the middle of the day but it doesn't leave enough time to get to most appointments at Wellington Hospital." – Mobility

For those living in smaller, more rural towns, accessing Masterton Hospital was also challenging.

"While the train does go to Masterton, it's easily an hour and a half walk from the train station to the hospital so it becomes a non-viable option." – Mobility

"Anyone outside of Masterton has to rely on private vehicles. Like in Greytown, there isn't a bus service and the train station is a 10-minute drive out of town." – Mobility

The accessibility of transport infrastructure at all points of the journey chain is key to being able to rely on the transport system as a whole. When purchasing tickets, it is possible to buy discounted fares, such as the 10-trip ticket for Metlink train travel. This is not a disability-specific subsidy, but disability concessions can be applied to their purchase. However, these discounted ticket purchases are not easy obtained.

"If you live outside the centres, where there is no one stationed at the station, you have to pay full cash fare because you can't buy a 10-trip on the train. You have to go out of your way to go somewhere to buy it, which costs you extra anyway." – Low vision

When travelling by bus, passengers use the Snapper Card system; a microchipped card that provides a cashless experience. Although Metlink provides an extensive transport network of buses, trains and ferries, there is not one integrated payment system.

"I can't use my Snapper card on the trains." – Multiple

"Train tickets are paper tickets." – Multiple

Topping up Snapper cards was seen as difficult at times.

"In Lower Hutt it's more difficult. There was a machine at the library but that's been removed." – Wheelchair user

Access to information about the Total Mobility scheme was described as problematic.

"The Total Mobility card should be more accessible. I think the communication is pretty bad and you have to know where to look to find the information on the website" – DHB Staff

While signage at bus stops and stations was mostly described as accessible, people with low vision, still experienced some access issues.

> *"All of the stations and some of the bus stops have real time electronic signage but if it's scrolling, I can't read it." – Low vision*

> *"The normal bus signage on the pole with the timetable isn't accessible to me so I use the app to track the buses." – Low vision*

Additionally, many of these bus stops and train stations were described as being open to the elements and thus not suitable to use in wet or cold weather.

> *"One of the bus stops I use is a bit older so you can't fit your wheelchair in to stay out of the rain." – Wheelchair user*

> *"If I get the train, it's a 15-minute wheel to the hospital but that's a problem if it's cold and wet." – Wheelchair user*

> *"You are exposed to the weather waiting at uncovered stops." – Mobility*

> *"The train platform is outside so it's freezing cold in winter and the cold affects my mobility." – Mobility*

It was noted that several bus stops around Wellington were in front of shops with large awnings, which restricted a bus's ability to pull in next to the curb.

> *"Some shops have got big awnings so the buses can't pull right into the stop." – Wheelchair user*

> *"There are some places in Petone and Wellington itself where it's quite difficult for buses to get right into the curb and sometimes that's because of overhangs of shop awnings." – Blind*

> *"When the drivers pull in, it might be flat with the curb, but there will be a huge gap that I have to jump. They need to learn to parallel park a bit better." – Blind*

Safety is also an issue for people getting on and off public transport and crossing roads.

> *"It's not ideal because you're dealing with bus lanes and hoping that they'll stop." – Blind*

> *"Being low vision, I have a lot of difficulty finding safe places to cross the roads." – Low vision*

This was seen as adding a lot of time onto the journey.

> *"There's a lack of traffic lights or safe crossings around [Masterston], which adds time and energy." – Wheelchair user*

> *"Across the two main roads in central Masterton there's one pedestrian crossing so getting anywhere safely you have to take a real long route." – Mobility*

The Metlink journey planned was described as not considering the time a person with a mobility impairment or using a wheelchair might need to make a journey.

> *"When you need to get connection transport, the Metlink website will tell you the times but if the first bus is late, I'll miss the connecting link and have to wait for the next one… then I'm late." – Mental health*

> *"The journey planner is gauged on a non-disabled person travelling at a certain speed. It can't work out that it might take you longer to get to that destination or that the path is not accessible or you can't cross the road safely." – Wheelchair user*

6.2.2.2. Taxi and Companion Driving

Barriers to accessing taxi services relate both to availability and supply.

> *"In the Hutt there is just the one taxi company so there's lots of demand." – Low vision*

> *"If an able-bodied person can simply call any taxi they want, how come I can't? I have to book beforehand or wait until they can find a taxi that is available." – Wheelchair user*

Many taxi operators are contracted to supply accessible transport for school runs, therefore obtaining an accessible taxi was not always possible.

> *"Taxis will be doing school runs so between 8-10am and 2-4pm you can't get a wheelchair taxi." – Wheelchair user*

> *"If it's around school start time or school finish time, forget it." – Wheelchair user*

Some transport services outside of Wellington city have limited services or only operate during business hours.

> *"Drivers operate on logbooks. So they can only work a certain number of hours. Some don't operate on evenings or weekends." – Mobility*

> *"I have a lot of problems with booking wheelchair taxis – the drivers only work a certain number of hours a week." – Wheelchair user*

As a result of these reduced operating hours, people living in Hutt Valley DHB and Wairarapa DHB areas were greatly affected by taxis not operating in evenings or weekends.

> *"I can't attend make-up appointments on weekends." – Mobility*

> *"If a family member is in hospital, I can't visit them because I can't get there in the evening or at the weekend." – Mobility*

At times, appointments run longer than expected. Any delays caused by this has a domino effect on any taxis that have been booked.

> *"I have waited hours for a taxi that I've booked because my appointment was delayed and they had other pickups to get to." – Wheelchair user*

> *"I have come across people who have been waiting for their taxi driver and have been told they've left because they have had to go to another pickup because appointments have run late." – Wheelchair user*

The health and safety of some taxi services was raised as an area of concern.

> *"They don't all go through the whole health and safety procedure […] some drivers are inconsistent in the way they do their service" – Wheelchair user*

> *"Some of the taxis are run down and shoddy." – Wheelchair user*

For people who use companion driver services, supply, access and affordability issues also apply.

> *"Driving Miss Daisy in Upper Hutt doesn't take appointments in the weekend." – Low vision*

> *"Companion services don't take larger chairs." – Wheelchair user*

> *"If you need the driver to stay with you during your appointment, that gets really expensive and you can't use Total Mobility for it." – Blind*

6.2.3. Drivers' disability awareness

Negative experiences with the people providing transport solutions often results in disabled people seeking to avoid that mode of transport. This is particularly problematic if it is the only available mode of transport.

> *"If you get one driver who does or says something that puts you off, you're not as likely to go and try it again." – Mobility*

> *"I don't get public transport because bus drivers are dicks. I live on top of a hill. I'm in my car anyway so I may as well keep driving an extra 5 mins to Porirua instead of getting on the bus and going through all that anguish." – Wheelchair user*

> *"Some of the local taxi drivers are horrifically rude and if you are in a wheelchair, they are abusive with you or even have the audacity to charge you extra. I find it terrifying to complain at the time because you are at the mercy of someone. If your wheelchair is still in the boot – I'm not going to get very far without it so I feel like I have to be nice to them and play their game for my own safety so I end up paying the extra. I don't complain about an abusive taxi driver because I'm scared he'll come to my house and beat me up – there's a lot of fear." – Wheelchair user*

"There's one particular taxi driver in Masterton that refuses to pick up people with disabilities." – Service provider

"The drivers are nosey, they ask what you were in for and I don't want to talk about that." – Mental health

"I rely on other passengers a lot to pull the ramp down for me because the driver won't do it." – Wheelchair user

Most issues were related to a lack of awareness of disability issues.

"The bus drivers here in Wellington want to know where the dog's vest is because they know the puppies wear them. And they sometimes have issues accepting guide dog breeds that aren't labs." – Blind

"Sometimes you have to ask the driver to lower the bus because they don't always think that will matter." – Wheelchair user

"There is a lot of misunderstanding around types of chairs. I am allowed on buses but sometimes they won't let me on because they think it's a mobility scooter." – Wheelchair user

"I was doing a trial with a different type of harness and I was challenged on it by a driver and I think that's because of a lack of training." – Blind

"Some taxi drivers are kinda clueless about the Total Mobility card." – Blind

"It's taken a long time for public transport team to really focus on the customer experience." – GWRC Staff

7. The personal cost of transport and healthcare barriers incurred by disabled people

7.1. Emotional

Disabled people spoke of the emotional stress and frustration of transport barriers and the effort involved in attending DHB appointments. They often bear the heavy burden of both emotional and physical labour to attend their DHB appointments. The added burden of time and energy going into the planning of journeys also negatively affected disabled people's wellbeing.

"The added emotional labour and stress all builds up". – Wheelchair user

"It's just that extra effort to bend the rules. It's frustrating." – Mobility

"It's not easy to get to, which is frustrating." – Wheelchair user

"There are all these layers of emotional and physical and mental labour to just get there let alone the appointment and the medical stuff." – Mobility

"If you are having physiotherapy and there's nothing close by, that's not going to make you want to go to treatments. It causes a lot of mental distress getting to those treatments." – Mental health

"I get confused when I'm not well so figuring out how to get the bus can be a big deal. It's too much. It's pretty daunting." – Mental health

Sometimes disabled people think that the barriers they experience are their individual problem rather than a systemic issue, meaning they thought they were something they simply needed to accept.

"I guess I just have to bite the bullet and find a way." – Mental health

"It takes a lot of effort to travel that far but that's just the way the cookie crumbles." – Parent

"A lot of it is explaining yourself while remaining calm and polite." – Blind

For some disabled people, negative past experiences influence whether they seek help in the future because the added emotional labour was too difficult to manage.

"Sometimes it's easier to just not go. In my earlier days, I'd think oh, I know how those drivers are like, I can't be bothered going through all that, I'll just cancel my appointment and go another time. It does affect your health outcomes." – Wheelchair user

"It's not just the transport. All those people just make it harder to deal with and I think maybe I just won't go." – Parent

"When my kids are over stimulated and start acting up - the way the other passengers look at me – it adds to the stress and because of that, you just kinda think do I really want to go to this appointment, can I get away with putting it off." – Parent

7.2. Physical

For people who experience fatigue, transportation delays sometimes create additional physical exertion.

"Waiting for an hour for public transport adds so much to my pain and fatigue." – Mobility

"Having chronic fatigue means you can't just stand around at a bus stop for half an hour." – Mobility

"It's a lot of effort to get to a bus stop. If I have to walk 10 minutes, that's outside my ability." – Mobility

"If it's an older bus with bad suspension, I know the jumpiness is going to flare up my neck and back pain so I have to inspect every bus that goes by to check that it's the safest option. I mean, if I'm running late I'll just get the next bus but it does mean I'll probably have to spend the next few days in bed in agony." – Mobility

Connections between transport modes also added extra time and effort onto a person's journey that was seen as challenging.

"It adds another level of stress, anxiety and time, especially if you have to wait ages for connections." – Mental health

"I can't be waiting around for ages between buses, especially if there is no seating – my back gets really uncomfortable and it causes a lot of pain." – Mobility

7.3. Financial

There is a high financial cost associated with disability. All of the people interviewed commented on incurring additional costs in order to overcome transportation barriers.

"I get a disability allowance but it doesn't come close to covering my costs." – Wheelchair user

"It's very expensive taking public transport, it's not affordable for people on benefits or on supported living." – Service provider

"Cost is a huge barrier to access." – KHAG

Transportation failures often result in a high personal cost to disabled people.

"If you missed the last train at 6 pm back to Wairarapa, you are looking at about $200 or $300, if you could find a taxi driver that was even prepared to do it – which, imagine that stress and trauma. What would you do!" – Service provider

Travelling long distances for healthcare services outside of their own DHB area was something that disabled people explained as being financially challenging.

"Going to other hospitals to see a specialist has a huge price tag, which most disabled people can't afford." – Wheelchair user

"There's nothing from the hospital that will say let's help you pay for it." – Parent

The timing of appointments can also create additional financial impacts for people living in areas with limited transport options.

"If the appointment is close to after school hours, I have to pull both kids out of school because I won't be back by the time they get home, or else I have to pay for a babysitter, which becomes costly." – Parent

"Appointment are always at rush hour so what is normally a 20-min drive can take me an hour and a half and that has flow on effects to my support workers. If I have to get up earlier, they have to come in earlier too – and that costs." – Wheelchair user

"They wouldn't think that I have got carers in the morning or maybe it's peak hour traffic and it's going to be twice as expensive if I have to catch a taxi." – Wheelchair user

Inaccessibility of public transport systems meant that some disabled people relied on taxi operators, health shuttles, or companion drivers, which often came at a higher cost.

"The cost of a taxi is shocking. There is a bit more added for wheelchair users, which doesn't sit well with me." – Wheelchair user

"Some taxi drivers have the audacity to charge you extra. They say it's an extra $5 for loading my wheelchair." – Wheelchair user

"It's about $40 return to get there on the shuttle from Paraparaumu so it's cheaper to drive." – Parent

While subsidies are available for disabled people to reduce transport costs, cost saving was only significant when travelling short distances.

"Even with Total Mobility I can't afford taxi." – Mental health

"If you're on a benefit, it costs too much, even with the Total Mobility discount." – Wheelchair user

"My Blind friend in the Hutt has to see a specialist and that's a whole day trip to Wellington because whatever she needs, they can't do it in the Hutt. When you have multiple appointments, that's a huge barrier – it's an $80 round trip and even with the 50% discount, a lot of people don't have the finances." – Blind

"A lot of people within the Hutt Valley DHB miss out on the NTA because they don't meet the travel/frequency criteria. There are limitations to the NTA because people miss out on distance or frequency, so things like accommodation rates are $100 but most motels are over $130 a night so the patient needs to pay the difference on $100." – DHB Staff

For some, high transportation costs meant they weren't able to afford other basic necessities.

"From Masterton to Wellington it is $20 on the train – each way – and that's without the taxi or bus on either end. You're looking at a minimum of $60 return. That's more than most people have for a week to spend on food." – Service provider

"I have to wait until afterwards to get reimbursed for my travel so sometimes that means going without food." – Mobility

The cost of travel was also seen to be a contributing factor in delaying care.

"Even with the 50% discount, it's still very expensive and if you don't have the money, that's an issue"

"That is a deterrent from going to appointments." – Wheelchair user

8. Recommendations

8.1. Stakeholder perspectives: healthcare system

8.1.1. Communication of appointment information

"They need to put more information in the letter about what it relates to. If they put an appointment with sleep clinic or appointment for MRI instead of an appointment with Doctor so-and-so. That would save us having to call up and waste Wellington staff's time." – Service provider

"Text message reminders consistently across departments/DHBs" – Multiple

"Needs a disability-specific process that takes into account people's needs and look at the physical environment in terms of what would be the best options for people. That kind of service should be specific for disabled people but it should be designed with disabled people. It's the able bodied who put in all these processes and procedures and we're expected to adhere and conform." – Wheelchair user

"Filling out my forms at home before the appointment would save a lot of time and ensure that privacy." – Blind

8.1.2. Communication of access information

"If I knew about the disability concessions, I would be in a better situation to afford to attend appointments and not cancel" – Parent

"Put a map of the hospital building, the grounds, mobility parking and bus stops in with the appointment letter they send you." – Multiple

"I think it would be really helpful if there was a website or something set up that people were told about when they are diagnosed with a disabling condition where it has all the contacts of all the people that you need to talk to, the subsidies available and what transport you can get – like the shuttles." – Mobility

"Closer collaboration between hospital travel coordinators" – DHB Staff

8.1.3. Education

"Hospital staff need to know what accessible is – to each group – and know whether each service provider is accessible or not" – Wheelchair user

"Better understanding of social model of disability" – Wheelchair user

8.1.4. Flexibility

"If they could consider that if it's an appointment you don't actually have to be examined for, is it possible to do Telehealth, it would be easier and cheaper all round" – Parent

8.1.5. Funding

"Better organisation and resourcing is required" – Wheelchair user

"Fund specialist services in Wairarapa." – Service provider

"Better funding available for out-of-area appointments" – Mobility

"Funding for a travel support person or for accommodation to stay close to the hospital if you need attention. a support person travels for free on Total Mobility but you've still got to be paid for your time." – Service provider

8.1.6. Hospital infrastructure

"Need somewhere not so surrounded – especially if you've got sensory issues as well. That would be a good thing." – Parent

"It would be good to have a space to park up, it's quite rare." – Wheelchair user

"More mobility parking because not everyone can access public transport." – Wheelchair user

"Provide a charging area for mobility scooters at the hospitals." – Wheelchair user

"The DHB need an integrated shuttle system that goes between Kenepuru to Lower Hutt and does an 'H', so Kāpiti -Wellington-Kenepuru and Kenepuru-Lower Hutt-Wellington-Lower Hutt, Wairarapa" – Mobility

"There is will from the Kāpiti shuttle providers to do more depending on how it is structured. There is room to add another vehicle and do different runs, like two straight through to Wellington and a few to Kenepuru. That would require Capital Coast to purchase wheelchair accessible shuttles - $120k each" – KHAG

8.2. Stakeholder perspectives: transport system

8.2.1. Accessibility

"Metlink needs a contingency plan for wheelchair users when the train stops and you have to transfer to a bus." – Wheelchair user

"Make the shuttles wheelchair accessible" – Wheelchair user

"Integrate the Snapper card with the trains" – Multiple

"Fix the gaps. We need better infrastructure, better public transport, reliable taxi services, more accessible transport." – Low vision

8.2.2. Availability

"Encourage taxi services to increase operating capacity on weekends or provide people in Wairarapa with transport options if running weekend appointments" – Mobility

"Local taxi services need a kick up their backside. There's no competition so they don't have to fight for anything." – Service provider

8.2.3. Information

"Promote the shuttles" – Parent

"Safely navigating roads as part of the Metlink journey planner" – Blind

"Not many people access Total Mobility scheme because they don't know about it or they think that they don't qualify, there is a need to open the criteria up so there is free transport under the Total Mobility scheme and public transport" – KHAG

8.2.4. Education

"Driver awareness training" – Multiple

8.2.5. Innovation

"… ride sharing app - for people who could afford it least it could be a really low cos, like someone with a community services car, it's a shared vehicle you call on demand, if someone from the public wants to use it, they pay a premium because its more direct – it doesn't go all around the bus routes" – GWRC Staff

9. Transport models that enable disabled people's access to healthcare

The following services were referred to by participants as examples of transport models that enabled better access to healthcare settings:

a) Health shuttles

i) St John New Zealand Health Shuttle Service

St John provides a range of health-related services,[89] including the St John New Zealand Health Shuttle Service,[90] which takes people to and from health-related appointments. People are either collected from their place of residence or from a designated pick-up point in isolated areas. The shuttle is run by volunteers and does not operate in all areas. There's no charge for shuttle transport, however a donation is appreciated to cover costs.[91]

ii) Horowhenua Community Health Shuttle

On weekdays, the Horowhenua Community Health Shuttle[92] service provides five return trips to Palmerston North, enabling people to attend medical appointments at the hospital or nearby clinics. It also transports dialysis patients for treatments on Saturdays. The shuttle goes between Levin, Horowhenua Health Centre, and Palmerston North Hospital. The service has some flexibility built-in, with its departure time from Palmerston North Hospital shifting if waiting on dialysis patients.

iii) Waitemata Distract Health Board Shuttles

Waitemata District Health Board in Auckland provides both a health shuttle and a Community to Hospital Patient Shuttle.[93] The health shuttle is free, transporting between Waitakere Hospital and North Shore Hospital Monday to Friday. Bookings must be made 24 hours beforehand. The Community to Hospital Patient Shuttle is an outpatient service that must be

[89] St John. (n.d.). Health shuttles. Retrieved August 04, 2020, from: https://www.stjohn.org.nz/What-we-do/Community-programmes/Health-Shuttles/
[90] Weave. (n.d.). *St John New Zealand Health Shuttle Service.* Retrieved August 04, 2020, from: https://weavingchange.nz/project/st-john-new-zealand-health-shuttle-service/
[91] Lakes District Health Board. (n.d.). *Health Shuttle.* Retrieved August 04, 2020, from: http://www.lakesdhb.govt.nz/Article.aspx?ID=10548
[92] Horowhenua District Council. (n.d.). *Horowhenua Community Health Shuttle.* Retrieved August 04, 2020, from: https://www.horowhenua.govt.nz/Community/Local-Directory/Horowhenua-Community-Health-Shuttle
[93] Waitemata District Health Board. (n.d.). *Shuttles.* Retrieved August 04, 2020, from: https://www.waitematadhb.govt.nz/patients-visitors/finding-your-way/shuttles/

booked with three says notice and evidence of an outpatient appointment letter. The service departs morning and afternoon from North Shore Hospital, Waitakere Hospital, Auckland City Hospital, and Greenlane Clinical Centre. The cost ranges from $6-$30 depending on distance travelled.

a) Ridesharing apps

i) RideShark

In 2017 a group of regional and local councils and Auckland Transport collectively procured the software licence for a ridesharing system from RideShark[94] in Canada.[95] The New Zealand website and mobile-friendly application was called Smart Travel.[96] The idea was that people would be rewarded for choosing sustainable transport options such as working from home, using public transport, walking, cycling or sharing the empty seats in their cars, i.e. ridesharing/carpooling. Currently, Dunedin City Council are working on a trial of the updated App with the Canadian providers.

ii) Uber, Ola, and Zoomy

Uber[97], Ola[98] and the home-grown New Zealand equivalent Zoomy[99] are ridesharing apps. Disabled people we spoke to revealed that the benefits of these services is that they have more information and control compared to using a taxi. The payment amount is set in advance and the mobile app communicates how far away your ride is and the route the car is taking.[100] Additionally, user reviews of drivers are beneficial in deciding whether to go ahead with a journey.

[94] Rideshark. (n.d.). *Rideshark.* Retrieved August 04, 2020, from: https://www.rideshark.com/
[95] Warburton, D. (2017). *Business report.* Auckland Transport. Retrieved from: https://at.govt.nz/media/1973430/item-10-open-business-report-may-2017.pdf
[96] Smart Travel. (n.d.). *Welcome to Smart Travel Otago.* Retrieved August 04, 2020, from: https://www.smarttravel.org.nz/Public/Home.aspx?CustomSubSite=Otago
[97] Uber. (n.d.). *Earn money by driving or get a ride now. Retrieved* August 04, 2020, from: https://www.uber.com/nz/en/
[98] Ola. (n.d.) *Rideshare leader comes to NZ.* Retrieved August 04, 2020, from: https://ola.co.nz/
[99] Zoomy. (n.d.) *Zoomy: A better way to ride*. Retrieved August 04, 2020, from: https://zoomy.co.nz/
[100] Green, H. (2018, September 12). *Ridesharing apps.* Retrieved August 04, 2020, from: https://www.consumer.org.nz/articles/ride-sharing

b) Navigation apps

i) BlindSquare

BlindSquare[101] is an accessible GPS-app developed for the Blind, deafblind and partially sighted. Disabled people travelling to healthcare appointments are able to use the app to receive cues such as "*the hospital is on your left*", to safely navigate towards their destination. Participants revealed this is also used while on public transport to alert them when their stop is approaching.

c) On-demand and on-request transport services

i) Timaru on-demand public transport service

Timaru on-demand public transport service[102] is a trial that involves a shift from away from large buses on fixed routes and timetables, towards a more flexible service that uses smaller, wheelchair-accessible vans. It is described as a 'corner-to-corner service'. People book a rideshare vehicle using their smartphone, calling the customer service centre or using the website.

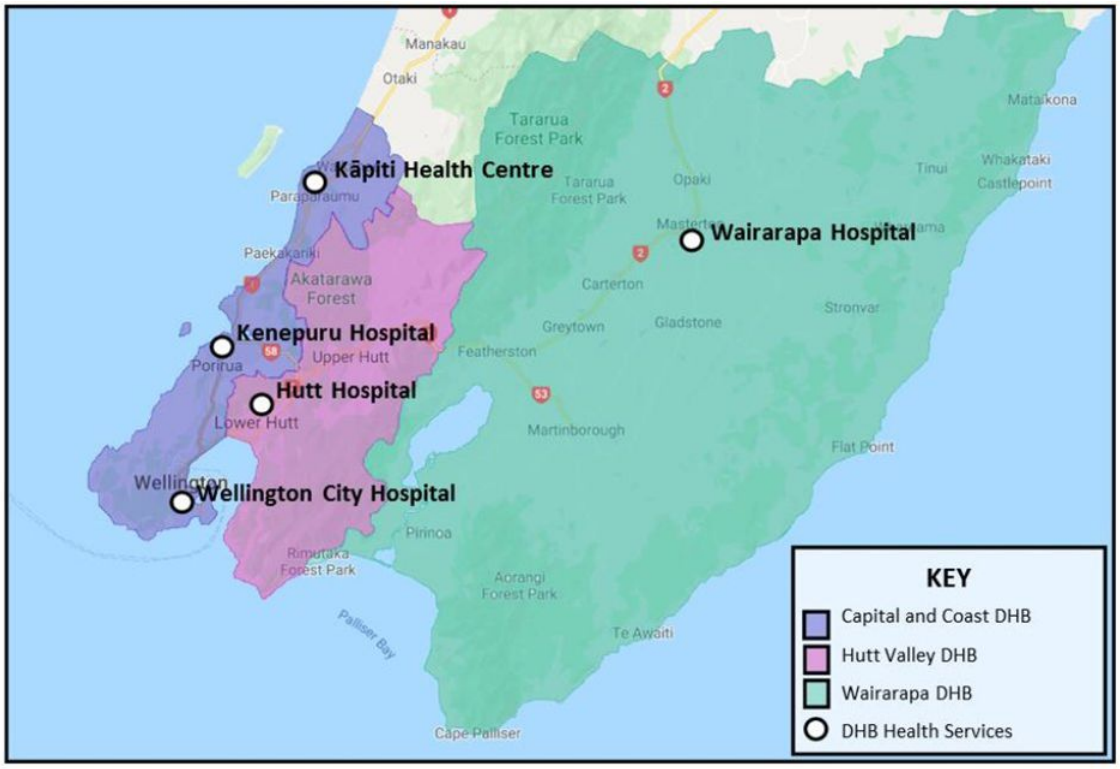
ii) Wairarapa on-request private transport service

Due to the lack of public transport options in some regions, disabled people often use online community groups to request transport to and from their healthcare appointments. For example, Wairarapa residents use a number of community Facebook[103] groups to find people with private transport nearby who are able to facilitate their transportation.

[101] BlindSquare. (n.d.). *Pioneering accessible navigation – indoors and outdoors*. Retrieved August 04, 2020, from: http://www.blindsquare.com/
[102] My Way by Metro. (n.d.). *Public transport designed around you*. Retrieved August 04, 2020, from: http://www.mywaybymetro.co.nz/
[103] Facebook. (n.d.). *Facebook*. Retrieved August 04, 2020, from: https://www.facebook.com/

Appendices

Appendix A: 3DHB Geographical Boundaries



This map shows the geographical boundaries of the three district health boards of Capital and Coast, Hutt Valley, and Wairarapa along with the location of major public healthcare services.

Appendix B: Participant Information

Age

0-25	26-45	46-65	66 and over
1	7	3	0

Ethnicity

Pākehā	Māori	Pasifika	Asian	Other
9	1	1	0	0

Disability (of experiences discussed)

Blind or Low Vision	Deaf or Hard of Hearing	Physical	Mental Health	Intellectual	Autism spectrum
2	0	7	1	3	1

Disability/Status (of Participants)

Blind or Low Vision	Deaf or Hard of Hearing	Mobility	Wheelchair user	Mental Health	Parent	Service provider
2*	0	2	5*	1	1	1

*One participant is counted in both categories

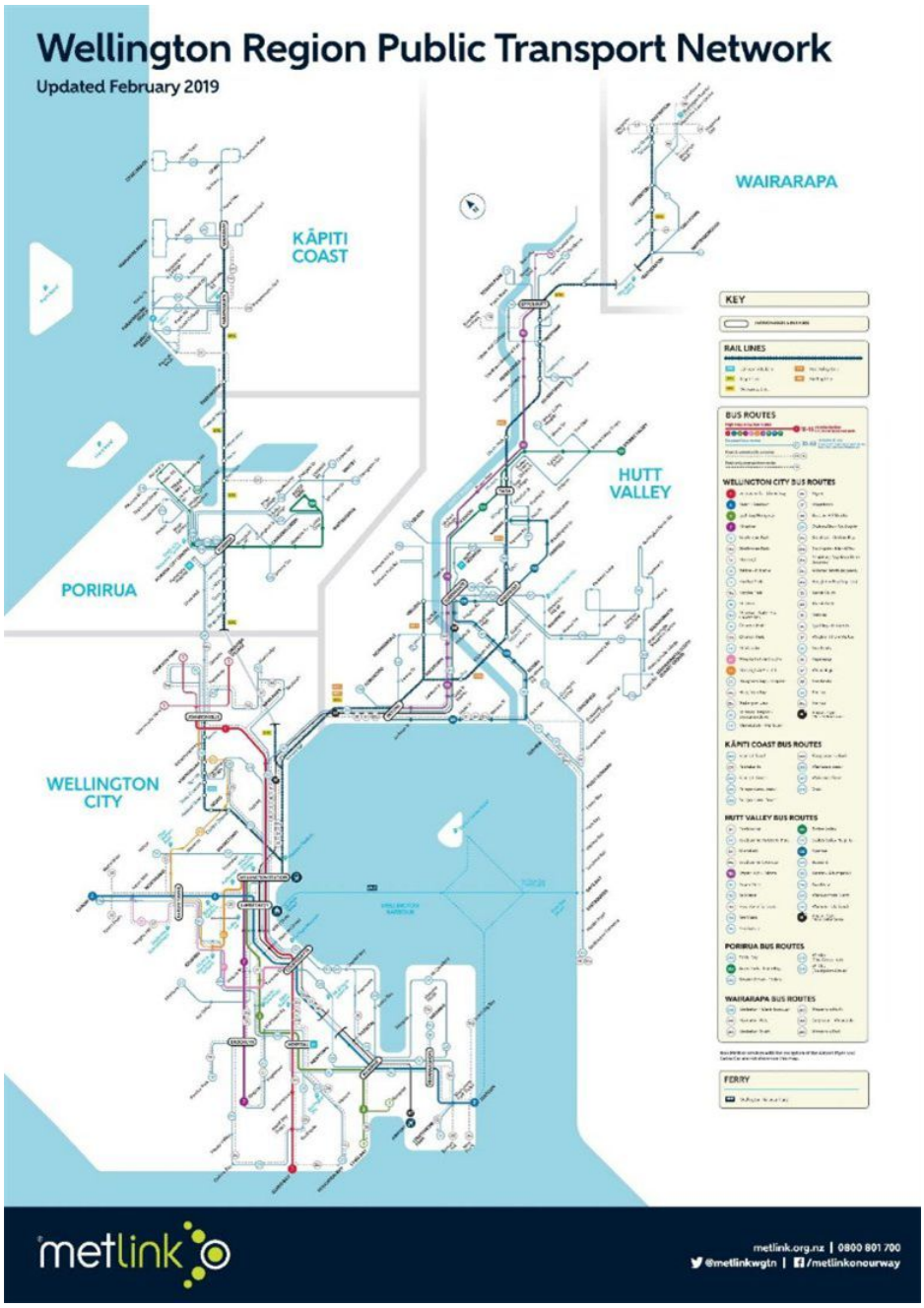
Mobility Aids

Wheelchair	Electric Wheelchair	Mobility Scooter	Walking Frame	Guide Dog	Cane	Walking Stick	Stick car	Hoist van
3	2	2	3	2	1	1	1	2

Appendix C: Stakeholder Information

Stakeholder	People
DHB Staff Members	**4**
Disability transport service provider	**1**
Greater Wellington Regional Council - Metlink	**3**
Kāpiti Health Advisory Group	**2**

Appendix D: Wellington Regional Transport Network



This schematic map of the greater Wellington region shows public transport routes servicing the 3DHB region of Wellington City, Porirua, Kāpiti Coast, Hutt Valley, and Masterton [104].

[104] Metlink. (n.d.). *Wellington Regional Transport Network.* Retrieved August 04, 2020, from: https://www.metlink.org.nz/assets/Uploads/Kiosk-Window-Sticker-A1-Network-Map-Feb19-v1.pdf

DSAC Information – Public

December 2020

Summary and Update of activities supported by the Sub-Regional Disability Strategy September 2020 – December 2020

Action Required

The Disability Support Advisory Committee note:

(a) Progress in key activities related to the implementation of the Disability Strategy implementation.

(b) Progress in key activities related to the implementation of the Accessibility Charter.

(c) Planning for locality forums across the 3 DHBs planned for early 2021.

(d) Initiatives to improve the experiences people with disabilities have when accessing health care services.

Strategic Alignment	3DHB Disability Strategy
Author	Rachel Noble, General Manager Disability, Strategy, Planning & Performance
Endorsed by	Rachel Haggerty, Director, Strategy, Planning Performance Fionnagh Dougan, Chief Executive
Presented by	Rachel Noble, General Manager Disability, Strategy, Planning & Performance
Purpose	This paper provides an update on the status of the 3DHB Disability Strategy 2017 – 2022 and highlights from the work programme for the Disability Team.
Contributors	The 3DHB Disability Team
Consultation	Sub Regional Disability Advisory Group

Executive Summary

1. The Disability Strategy and Performance team are driving a comprehensive work programme to improve the health service experience and health outcomes for people with disabilities. This work programme is supported by the Sub Regional Disability Advisory Committee, the Kaunihera Whaikaha.
2. This report reflect the three key areas: leadership, inclusion & support and access. Strong progress is being made against the strategy with wide organisation and health sector engagement.

Strategic Considerations

Service	Developing improved service access for people with disabilities.
People	Educating and developing healthcare workforce skills and system processes to better respond to people with disabilities.
Financial	No implications from this update.
Governance	Supported by the Sub Regional Disability Advisory Committee.

1. BACKGROUND

The Disability Strategy and Performance team supports 3DHB initiatives to provide accessible and inclusive healthcare services to disabled people and their whānau by identifying and addressing inequalities within the DHBs.

The team provides advice across the 3DHBs on policies, strategies and initiatives. It also promotes quality accessible services, reasonable accommodation measures, co-design while also raising awareness through a range of education initiatives. The team also promotes accountability through data and monitoring initiatives.

The key areas of activity are outlined against the Sub-Regional Disability Strategy 2017 – 2022 and includes our response to the recommendations from the Sub Regional Disability Forum.

2. FOCUS AREA ONE: LEADERSHIP

2.1 Sub-Regional Disability Advisory Group

Sub Regional Disability Advisory Group (SRDAG) meets regularly. Discussions included the transport and monitoring projects and the Pro-equity paper subsequently presented to the Board. The experiences of one disabled person who stayed in hospital recently was discussed supporting a work programme to ensure people with disabilities have their needs met when they come to hospital. Early in 2021 we will seek new members to replace recent retirements (Ruth Carter, Wairarapa and Margaret Forsyth (Porirua) from the Group.

2.2 Disability Team

Our team is stable and well connected which means we are providing collective strategic input across our work programme while maintaining leadership in particular areas based on ones are of experience and expertise.

The team continues to be guided by the UN Convention on the Rights of People with Disabilities, Equity and Better Health Outcomes. Engagement with the disability community and disability leadership is pivotal in understanding the importance of visibility and the vital role health plays in citizenship for disabled people. As an inclusive and accessible environment is built, it means all people will feel safe and comfortable.

2.3 Regional Forums

In this financial year we will be holding locality forums in Kāpiti, Porirua, Wairarapa, Hutt Valley and Wellington. As there is a focus on providing health care services in the community the purpose (as developed with Pacific disabled people in Porirua) of the Forums will be to:

- Leverage the voices of disabled people to inform/guide/influence the development of the future health services within the locality
- Create a partnership model to oversee the development of the local community health services programme
- Identify key expectations from local disabled people for inclusion in the development of local health services.

Members of the Sub Regional Disability Advisory Committee will host these Forums and will be involved in the planning with the Disability Team. We expect to have both disabled people and local providers present at the forum.

2.4 Regional Hui and Fono

There are conversations developing to support a Hui and a Fono. These will inform the Disability Strategy Team work programme for the 2021/2022 year. The Pacific Disability Group has identified the purpose of the Fono to be:

- Strengthen and explore Pacific needs (reflecting on progress since the previous forum)
- Leverage the voices to inform/guide/influence the development of the 2022 – 2027 DHB Disability Strategy by ensuring there is a holistic view in place
- Strengthen the engagement/representation between Pacific People with disabilities, the DHB Pacific Directorate and the Disability Directorate

2.5 World of Difference Programme

During 2020 the DHBs have had the opportunity to adapt the Otago University *World of Difference* programme into a bespoke, organisation-wide education programme designed to shift attitudes, reduce discrimination and improve equity in healthcare for disabled people. Following ELT endorsement of this initiative, the Disability Strategy Team established an interdepartmental team across the CCDHB and HVDHB to explore options for the design, development and delivery process.

The Disability Strategy Team have undertaken significant community consultation and engagement to ensure this programme reflects the needs and wants of both disability community members and DHB staff in design process, content and delivery. Four open Hui across the wider 3DHB region showed unanimous support for developing an education programme about disability, and the feedback was thematically consistent:

While the World of Difference programme has some fantastic foundations, people would like to see the development of something quite different and new in this space rather than a direct retrofit of the existing programme. It has been identified that development, delivery and content should:

- start from a Māori perspective
- centre disabled people's experiences and voices
- focus on understanding people as individuals with holistic needs
- have immediate practical application to participants' work.

Guided by this feedback, a smaller focus group comprising diverse representation from the disability community and DHB staff met to co-design a proposed outline for content and delivery. As the project now moves into the delivery design phase the Disability Strategy Team are continuing regular consultation with the community, and working closely with World of Difference, Māori Health, Pacific Health, People & Capability, and Quality, Improvement & Patient Safety to build a comprehensive, engaging and accessible programme for all DHB staff.

Because the Disability Strategy Team is a 3DHB team working to the Sub Regional Disability Strategy, this programme is being developed with the intention of delivery across the CCDHB, HVDHB, and WDHB, including PHOs, Allied Health, and Regional Public Health.

3. Using information and technology to support the Disability Strategy

3.1 Contract Clause and Reporting Requirements

The team are supporting the implementation of the disability equity clause within all provider agreements. The clause specifically addresses the inequities that disabled people experienced as service users, or as employees of the organisations.

This clause is:
You will demonstrate to the DHB how your organisation has incorporated the updated sub regional disability strategy (Enabling Partnerships: Collaboration for Effective Access to Health Services) into your strategic and service planning, and current services.

Two Mental Health NGO networks are very motivated to take on this work as they were very aware of the gaps for disabled people accessing mental health services. They will work as a collective in each region to determine their goals. We have also spoken with one PHO and times are being established to talk with more across the region.

4. FOCUS AREA TWO: INCLUSION AND SUPPORT

4.1 Alerts and Data

We invited 20 DHBs to send representatives to a national discussion about data and alerts in relation to people with disabilities. There were three parts to our presentation Disability Data, Disability Alerts and the Passport.

Disability data is absent, not collected and under reported. There are no standards in place for collecting data, it is hard to get and is reliant on third party sources. Better data is needed to improve health outcomes, provide equitable outcomes, and inclusive health care. We discussed that at CCDHB we have disability information for less than 1% of all patients whereas people with disability make when we know disabled people make up 24% of the population.

We also explored the Health Services Quality Commission August patient experience survey. The table below identifies the overlap between people who self-identified as disabled, and those who are captured in the Washington Group short set.

	Percentage answering yes to self-identified and yes to WGSS	**Percentage answering yes to self-identified and no to WGSS**	**Percentage answering no to self-identified and yes to WGSS**	**Percentage answering yes to either/both**
Adult hospital survey (National)	7%	8%	5%	20%
Adult hospital survey (CCDHB)	6%	7%	2%	15%
Adult primary care survey (National)	5%	6%	5%	16%
Adult primary care survey (CCDHB)	6%	7%	6%	18%

4.2 Alerts

The Disability Alert is an icon that appears on a patient record which provides information about the disability-related assistance that a person may need in a hospital or healthcare setting. The information provided in the alert is in the person's own words, is based on needs, not diagnosis so does not have any clinical information or input "The patient voice in our system". It empowers people to communicate what they need, enable staff to accommodate their patients and reduces repetition, frustration, and uphold human rights. It is also a basic data collection tool.

The recommendations from the 3DHB 2019 review of Alerts are:

- Develop a single, electronic system
- Work in partnership with IT
- Support a PHO point of origin
- Commit to co-design
- Build in data collection capacity
- Consider a wider scope

There was a good question and answer session concluding with an agreement to further this work with a recommendation to:

- Progress work on establishing a consistent disability data capture mechanism across all DHBs
- Look to the implementation of a national alerts system
- Ensure this work is DHB led to ensure it is relevant and usable.

4.3 Health Passport

The My Health Passport is purposed for people being able to more independently engage with the health and disability sector by having greater control over what occurs for them. The principles of self-determination include, being person-centred, easy to use, equitable access to services, relational and strengths focused. These principles are key in developing and governing behaviour of health services now and into the future.

The second generation My Health Passport was launched on Tuesday 22 September 2020 across the 3 DHBs of the region. We had mobile stands at each DHB that will rotate around various services, in at points in the community. Posters will be used to raise awareness and the profile of the My Health Passport across health services, with FAQs available for teams to use at team meetings. Additionally, social media coverage across the 3 DHB campuses, this includes information to be released through Daily Dose, Facebook, Intranets, and websites.

In addition, Nurses and Social Workers were invited to put themselves forward as Champions for My Health Passport. Initial Training is being provided to these Champions who will continue to network and receive ongoing training as well. The focus so far has been within the hospital environment. Extension across 20DHBs and

4.4 Mums & Bubs Project

In April 2019, Capital and Coast District Health Board (CCDHB) commissioned a piece of research on the experiences of pregnant women and mothers of young children in the Porirua region to help inform their 'Māmā, Pēpi and Tamariki' programs of work. The piece of research makes an important contribution to understandings about the drivers and/or barriers women experience using CCDHB maternity services. It identifies valuable opportunities for improving services. However, this piece of work does not examine the impact of disability upon the journey through CCDHB maternity services. No disabled women nor women who had disabled babies were part of the research.

Imagine Better are now commissioned to undertake a study that applies a disability lens to women's experiences of DHB's maternity services. The proposed project draws upon and broadens the learnings in the aforementioned research report. It aims to understand more about the disability experiences of maternity care, particularly perceptions of if and how disability rights are upheld or not upheld during maternity care delivered by DHB.

It will focus upon two sets of maternity experiences:

1. Disabled women and their babies
2. Women who have disabled babies

The process includes a literature review and semi-structured interviews. The interviews will include:

- Ten disabled women and 10 parents of disabled babies
- Four midwives - DHB's Community Midwifery Team, Core midwives and self-employed LMCs
- Representatives from Well Child Tamariki Ora providers, a local Disability Need Assessment and Service Coordination (NASC), and a disabled parenting community organisation

The findings of this report will contribute to the 'Māmā, Pēpi and Tamariki' programs of work and the development of maternity services across the three DHBs. Fortunately a midwife in the Wairarapa DHB is producing a documentary on the recent experiences of three physically disabled mothers who recently gave birth. The two initiatives are expected to be complementary.

5. FOCUS AREA THREE: ACCESS

5.1 Accessibility Charter

The Capital Coast and Hutt Valley DHB Boards have agreed to endorse the Accessibility Charter. It is expected that the Wairarapa DHB Board will also endorse it in the near future. With the signing of the Charter the next stage is to develop a five year implementation strategy. Currently ELT members are exploring what the Accessibility Charter means across the 3DHBs.

5.2 Accessibility Information

In order to build our knowledge base and capacity to provide accessible information we have received training to do Easy Read documents which is very time consuming. We have also had one session of training from Blind Low Vision NZ (formerly Blind Foundation) on producing accessible documents.

The Communications Directorate is now working to implement accessibility into the written and visual work created by and for the DHB. We are also assisting the Children's Hospital with creating accessible information for the up and coming Children's Hospital renaming and kaitiaki launch.

5.3 Website Audit

Access to information on the website is an important part of the relationship between the consumer and the health service provider. The findings from this audit will also be applied to the Hutt Valley and Wairarapa DHB websites.

CCDHB engaged Intopia to conduct an independent accessibility review of select features on the CCDBH website. Accessibility is the extent to which a site or app is accessible to as many people as possible. They identified strengths and opportunities for improvement.

The Senior Advisor Digital Content from the Communications Directorate is implementing the changes suggested following the recommendations made by Intopia. Some recommendations will need to be considered with other design work (colour contrast).

5.4 Disability Responsiveness Page

The disability responsiveness page on the shared websites has been updated. In order to demonstrate how the website can become more accessible to the community we ensured the text was written using Plain English. Before being uploaded on the website it will be translated into New Zealand Sign Language, Easy Read and Audio. Hopefully other pages on the website will also follow the same format.

To further improve accessibility we have accessed resources developed externally and internationally where appropriate information readily available on line in New Zealand Sign Language and Easy Read about health conditions. We are working on a way to ensure health service providers here are aware of those resources and distribute them to their patients when appropriate.

6. Focus Area Four: Health

6.1 Education

Education programmes continue to be delivered by the Disability Responsiveness Educators. Existing presentation material has been updated over the past eight months to reflect current best practice. This work is on-going as new material is being developed and existing material reviewed and revised as required.

Educational programmes delivered across the DHBs provide core disability responsiveness information. Recently programmes were delivered to Security Orderlies, Resident Medical Officers, Patient Administration Services, Senior Nurses and Midwives, Allied Health Leads and will become regular sessions in 2021. One off sessions are also arranged on request, recently they were held for the Kāpiti Medical Centre reception staff, COVID Hospital screening and the Fracture clinic. Soon sessions will be held with volunteers and Health Care Assistants.

Core disability responsive education comprises of an initial e-learning programme of three modules that all staff must complete to gain foundational knowledge about disability; the rights based approach, the importance of attitude and how to make reasonable accommodations. There were delays with the production of the resource however, this allowed our new Maori Disability Advisor to make contributions so the programme now reflects Maori with disabilities. It is hoped that the new e-learning modules will be live before the end of 2020.

For 2021 there are plans to offer regular face to face teaching sessions where a mixer of staff can come in (a move from only being invited to small staff groups), to develop more training videos as these have proved to be effective, and incorporating disability more into the stimulation unit.

6.2 Bowel Screening Programme & Measles Campaign

Capital & Coast DHB is preparing to launch the Bowel Screening Program in our region, and have committed to making the campaign and screening process as inclusive as possible, with the intention to lead the way and set a good example of building accessibility into healthcare initiatives. The Disability Team have worked within the Bowel Screening project team to design a “born-accessible” public health campaign, prioritising accessible communication, community outreach, clear pathways for support, and robust monitoring of the outcomes for the Disability Community.

The initial production of an accessibility-focused shadow plan led to the strong, visible incorporation of disability into the CCDHB's Bowel Screening rollout Equity Plan as a priority group alongside Māori, Pacific and high deprivation populations, as well as acknowledging the intersections between these groups. The Equity Plan was well received, and its comprehensive guidance for the inclusion of disability was commended by the Ministry of Health at the readiness assessment in October. Disability community outreach, data collection, and accessible information will be prioritised in the lead up to the regional rollout in early 2021.

Based on their experience with designing an accessible campaign for Bowel Screening, the Disability Team were also invited to advise the CCDHB Measles Immunisation campaign team, resulting in the inclusion of accessibility requirements and guidance in the CCDHB Measles Immunisation Campaign Plan, the production of more accessible resources, and a presentation to representatives from the Ministry of Health and DHBS around the country about the importance and benefits of building accessibility into campaigns and processes. This presentation generated ongoing discussion with the Ministry of Health about the leadership role that CCDHB is taking in this area, and the absolute necessity for accessibility and inclusion in national public health campaigns.