PUBLIC

AGENDA

Held on 21 July 2021
Location: Boardroom, Pilmuir House, Hutt Hospital
Time: 1pm - 4pm
Zoom meeting ID: 826 6127 3900

3DHB COMBINED DISABILITY SUPPORT ADVISORY COMMITTEE

	ITEM	ACTION	PRESENTER	TIME	MIN	PG
1	**PROCEDURAL BUSINESS**			1.00	10	
1.1	Karakia		All members			2
1.2	Apologies	**RECORD**	Chair			
1.3	Continuous Disclosure – Interest Register	**ACCEPT**	Chair			3
1.4	Confirmation of Draft Minutes	**APPROVE**	Chair			6
1.5	Matters Arising	**NOTE**	Chair			11
1.6	Draft Work plan	**APPROVE**	2DHB Director Strategy, Planning and Performance			12
2	**ENGAGEMENT**					
2.1	3DHB Sub-Regional Disability Advisory Group	**NOTE***	Chairs of SRDAG	1.10	20	
3	**SERVICE AND PLANNING**					
3.1	Suicide Prevention Postvention Annual Action Plan 2021/2022 3.1.1 Attachment 1	**ENDORSE**	Acting General Manager Commissioning, Mental Health and Addictions	1.30	30	13 20
3.2	Disability COVID-19 Vaccine Response	**NOTE***	2DHB Director Strategy, Planning and Performance	2.00	20	
3.3	Creating enabling maternity care: Dismantling disability barrier - Mums and babies’ experience at the 3DHB 3.3.1 Attachment 1 3.3.2 Attachment 2	**NOTE**	2DHB Director Strategy, Planning and Performance 3DHB General Manager – Disability	2.20	20	50 52 62
3.4	3DHB Final Annual Plans 2021/2022 Attachments – **Resource Centre**	**NOTE**	2DHB Director Strategy, Planning and Performance	2.40	10	124
3.5	Mental Health and Addiction Commissioning Forum	**NOTE**	2DHB Director Strategy, Planning and Performance	2.50	20	126
4	**REPORTING**					
4.1	3DHB Sub-Regional Disability Strategy 2017-2022 Update	**NOTE**	3DHB General Manager – Disability	3.10	20	131
4.2	3DHB MHAIDS Service Performance Update 4.2.1 Attachment 1	**NOTE**	Executive Director MHAIDS	3.30	20	136 138
5	**OTHER**					
5.1	General Business	**NOTE**	Chair	3.50	10	

DATE OF NEXT DSAC MEETING:
Wednesday 29 September 2021, 1:30pm-4pm, Boardroom, Pilmuir House, Hutt Hospital

**** No paper at the meeting – presentation only.***

Karakia

Kia hora te marino

Kia whakapapa pounamu te moana

Hei huarahi mā tātou i te rangi nei

Aroha atu, aroha mai

Tātou i a tātou katoa

Hui e! Tāiki e!

Translation

May peace be wide spread

May the sea be like greenstone

A pathway for us all this day

Let us show respect for each other

For one another

Bind us all together!

3DHB Disability Services Advisory Committee

Interest Register

29/06/2021

Name	**Interest**
'Ana Coffe *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 • Member, Hutt Valley District Health Board • Daughter is a Lead Maternity Carer in the Hutt
Yvette Grace	• Member, Hutt Valley District Health Board • Member, Wairarapa District Health Board • Husband is a Family Violence Intervention Coordinator at Wairarapa District Health Board • Member - Te Hauora Runanga o Wairarapa • Member - Wairarapa Child and Youth Mortally Review Committee Member - He Kahui Wairarapa • 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 • Employee, University of Otago • 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, Consumer New Zealand Board
John Ryall	• Member, Social Security Appeal Authority • 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 • Trustee, Hutt City Communities Facility Trust
Vanessa Simpson	• Director, Kanuka Developments Ltd • Executive Director Relationships & Development, Wellington Free Ambulance • Member, Kapiti Health Advisory Group
Jill Pettis	• Nil
Ryan Soriano	• Clinical Services Manager, Health Care New Zealand • 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	• Chairman Horo Te Pai Trust • Research Advisory Group – Māori • Kaumātua Advisory Group • Noose Monotony Committee • Chairman RGAM • Partner Secretary ICU Wellington • Daughter Managing Director Anaesthetists NZ
Sue Emirali	• Nil
Bernadette Jones	• Director, Foundation for Equity & Research New Zealand • Co-Chair, Tāngata Whakaha Roopu, Subregional Māori Disability Group • Executive Committee member Muscular Dystrophy Central Region

	• Board member, My Life My Voice Charitable Trust • Member, 3DHB Sub-Regional Disability Advisory Group • Member, Health Research Council College of Experts • Senior Research Fellow, University of Otago Wellington • Husband, Tristram Ingham, is a board member of CCDHB • Director, Miramar Enterprises Limited
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 Disability Support Advisory Committee Meeting - PUBLIC

MINUTES

Held on Wednesday 28 April 2021
Main meeting room, Masterton Hospital, Wairarapa
Zoom link:
Time: 10.30pm – 1:30pm

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

District Health Board Staff Present		
Dale Oliff	WrDHB	Chief Executive Officer
Rosalie Percival	2DHB	Acting Chief Executive
Sandra Williams	WrDHB	Executive Leader Planning and Performance
Karla Bergquist	3DHB	Executive Director Mental Health, Addiction and Intellectual Disability Services
Rachel Haggerty	2DHB	Director Strategy Innovation & Performance
Sally Dossor	2DHB	Director of Office of the Chief Executive/Board Secretary
Meila Wilkins	2DHB	Board Liaison Officer
Rachel Noble	3DHB	General Manager Disability Strategy, Innovation and Performance
Christopher Nolan	3DHB	3DHB General Manager - Commissioning Mental Health & Addictions
Matt Fribbens	WrDHB	WrDHB Service Development Manager - Planning and Performance

Procedural Note

- The Chair re-ordered the agenda to bring item 3.4 forward to follow the Item 3.2 - Disability and Mental Health Covid Vaccine Response.

1 PROCEDURAL BUSINESS

1.1 KARAKIA

Jack Rikihana 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

The committee noted an update from Bernadette Jones. The balance of the interest register was **noted** as current and any changes would to be sent to the Board Liaison Officer via email.

1.4 MINUTES OF PREVIOUS CONCURRENT MEETING

The Committee **approved** the minutes of the previous 3DHB DSAC Meeting held on 18 December 2020.

Moved	**Seconded**	
‘Ana Coffey	Naomi Shaw	**CARRIED**

1.5 MATTERS ARISING FROM PREVIOUS MEETINGS

DSAC2020-07:

- The Committee asked about progress for 3DHB’s to sign the Accessibility Charter. HVDHB and CCDHB have signed, and WrDHB are making arrangements for signing.
- Discussion about attaining support from Councils and whether there would be Council support for an LGNZ remit. Naomi Shaw indicated she may be able to take this forward.

2 SERVICE SPOTLIGHT

2.1 UPDATE ON WAIRARAPA INITIATIVE

The WrDHB Executive Leader - Planning and Performance and WrDHB Service Development Manager - Planning and Performance presented and was available for questions.

Service Spotlight -
Mental Health and /

3 SYSTEM AND SERVICE PLANNING

3.1 3DHB ALCOHOL AND OTHER DRUGS (AOD) MODEL OF CARE AND PRIORITY INVESTMENT

The 3DHB General Manager - Commissioning Mental Health & Addictions presented and spoke to the paper.

The 3DHB Disability Support Advisory Committee endorsed:

(a) The Capital & Coast, Hutt Valley and Wairarapa Alcohol and Other Drug Model of Care (the Model of Care) and its five direction-setting, key components for implementation:

- Driving equity of access and outcomes
- Privileging the voice and contribution of those with lived experience
- Growing a whole of population approach
- Building a recovery-focused system of care
- Working collaboratively.

The 3DHB Disability Support Advisory Committee agreed:

(a) To write to the Ministry of Health raising funding delays and the impact the delays are having on the 3DHB's contribution to the transformation outlined in He Ara Oranga.

The 3DHB Disability Support Advisory Committee noted:

(a) The Model of Care was collaboratively developed by a Steering Group made up of a diverse group of stakeholders from across the subregion and adopted a robust process and methodology to build the evidence-base for the development of the Model of Care.

(b) The Model of Care project found a failing alcohol and other drug (AOD) system of care in the subregion, and the picture of an invisible, disconnected sector, unmet need and inequitable access, particularly for young people, has been updated and confirmed.

(c) The Model of Care is aligned to, and can be a key enabler in the subregion, for the Government's plan to transform mental health and addiction care nationally, and for implementing the subregion's health strategies, that identify people with mental health and addiction issues as a priority major service user group.

(d) Hutt Valley and Capital & Coast DHBs submitted an investment proposal to the Ministry of Health, at its request, to increase access to primary and community AOD services and supports and the Ministry is supporting the proposal with approximately $3m investment over 3 years.

(e) The Ministry's investment will provide a significant and well-timed boost for implementing the Model of Care, enabling investment in AOD sector capacity and capability with the establishment of:

- Enhanced kaupapa Māori and Pacific counselling services delivered close to home.
- Innovative peer support network and coordination to support wellbeing and recovery.
- An AOD provider collaborative to drive an integrated approach to access, outcomes and service development.
- Mental Health and Addiction funded project management resource to enable the implementation of the Model of Care.

(f) The Model of Care provides a commissioning framework for the additional investment that is necessary for its successful implementation and the investment priorities will be developed as part of implementation planning.

(g) The Mental Health and Addictions Team is in the process of detailed project planning with a priority to establish the AOD provider collaborative and will regularly update the Board on progress.

Moved	**Seconded**	
Jack Rikihana	Jill Pettis	**CARRIED**

Notes:

- Christopher Nolan introduced the groups and individuals that were partners in the development of the model of care.
- The partners noted the value in being part of the process, which had enabled a voice at all levels and mapped a pathway that represents the whole community. Very complementary of the process taken.
- The Chair thanked the team for the presentation and contribution that all had made to the development of the model of care.

Action: The Committee, through the Chair, agreed to write to the Ministry of Health raising funding delays and the impact the delays are having on the 3DHB's contribution to the transformation outlined in He Ara Oranga.

3.2 DISABILITY AND MENTAL HEALTH COVID VACCINE RESPONSE

General Manager - Commissioning Disability Responsiveness presented and responded to questions.

Ensuring Disability Equity.pptx

3.4 3DHB SUB-REGIONAL DISABILITY STRATEGY UPDATE

The paper was taken as read. General Manager - Commissioning Disability Responsiveness, presented and was available for questions.

3DHB Disability Support Advisory Committee noted:

(a) The update on the implementation of the Sub Regional Disability Strategy 2017 – 2022.

3.3 3DHB MENTAL HEALTH AND WELLBEING STRATEGIES UPDATE

The paper was taken as read and the 2DHB Director Strategy, Planning and Performance was available for questions.

The 3DHB Disability Support Advisory Committee noted:

(a) The subregion's *Suicide Prevention and Postvention Action Plan* has been refreshed to align it with the Government's *He Tapu te Oranga o ia Tāngata: Every Life Matters – Suicide Prevention Action Plan 2019-2029* and the subregion's Māori Health and Pacific Health strategies.

(b) The Suicide Prevention and Postvention Action Plan governance group has endorsed the *Suicide Prevention and Postvention Action Plan* and the Plan will be presented to DSAC for endorsement at its May 2021 meeting.

(c) The good progress implementing a broad range of initiatives under *Living Life Well A strategy for mental health and addiction 2019-2025* in three service domains: whole of population; primary care; secondary specialist services; and in both the subregion and central region.

(d) The collaborative, networked approach to implementing the subregion's refreshed *Suicide Prevention Action Plan* in four service domains: health promotion; prevention; intervention; and, postvention.

(e) The roll out of COVID 19 vaccination to mental health and addiction clients partnering with our NGO and other lead providers.

Notes:

- The paper is an adjunct to the item 2.1 – Update on Wairarapa Initiatives.
- Development of partners has been a key focus and progress is being made.
- Investment in Mental Health area us a key issue for the implementation of the Mental Health and Wellbeing Strategy.

3.5 3DHB FIRST DRAFT ANNUAL PLANS 2020/21

The 2DHB Director Strategy, Planning and Performance and WrDHB Executive Leader - Planning and Performance spoke to the paper and were available for questions.

The Committee endorsed:

(a) The CCDHB, HVDHB, and WrDHB first draft annual plans 2021/22.

Notes:

- The Committee endorsed in principle the contents of the first draft Annual Plans 2021/2022.
- Tristram Ingham asked for recognition of accessibility to be included in the drafts.

Moved	Seconded	
'Ana Coffey	Ryan Soriano	**CARRIED**

4 OTHER

4.1 GENERAL BUSINESS

Nil.

5 NEXT MEETING

Next meeting to be advised.

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

DATED this day of 2021

'Ana Coffey
DSAC CHAIR

DSAC ACTION LOG - as at 14/07/2021

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
DSAC2021-01	28-Apr-21	21-Jul-21		In progress	Director Strategy, Planning and Performance	3.1	3DHB alcohol and Other drugs (AOD) Model of care and priority investment	The Committee, through the Chair, will write to the Ministry of Health raising funding delays and the impact the delays are having on the 3DHB's contribution to the transformation outlined in He Ara Oranga.	

DSAC Work Plan 2021: FOR FURTHER REVIEW AFTER BOARD CONSIDERS THE WORK PROGRAMME FOR THE STRATEGIC PRIORITIES ON 4 AUGUST 2021		
	29 September 2021 Hutt Valley	**24 November 2021 Capital & Coast**
Strategy		
Sub Regional Disability Strategy 2017 - 2022		Sub Regional Disability Strategy 2017 - 2022 Update
3DHB Mental Health and Wellbeing Strateg • Sub Regional Living Life Well - a strategy for mental health and addiction 2019 – 2025 • 3DHB Suicide Prevention Postvention Annual Action Plan 2021/2022	3DHB Mental Health and Wellbeing Strategy Update	
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		
Disability Investment Plan Priorities		Disability Investment Plan Priorities for 2022
System and Service Planning		
Draft Annual Plans 2022/23 (Mental Health, Addiction and Disability Sections)	Planning process for 2022/2023 – subject to confirmation of process required for Health New Zealand.	
Performance - Efficiency, Outputs and Safety		
Mental Health – Provider (MHAIDS) and System (SPP)	Mental Health – System (SPP)	Mental Health – Provider (MHAIDS)

Disability Support Advisory Committee

21 July 2021

3DHB Suicide Prevention Postvention Annual Action Plan 2021/2022

Action Required

It is recommended the 3DHB Disability Support Advisory Committee endorse, for Board approval:

(a) 3DHB Suicide Prevention Postvention Annual Action Plan 2021/2022.

The 3DHB Disability Support Advisory Committee notes:

(a) The subregion's *Suicide Prevention and Postvention Action Plan* has been refreshed to align with the *He Tapu te Oranga o ia Tāngata: Every Life Matters – Suicide Prevention Action Plan 2019-2029.*

(b) *The Action Plan* aligns with the goals *Taurite Ora Māori Health Strategy 2019-2030 and Te Pae Amorangi Maori Health Strategy 2018 -2027.*

(c) The Action Plan also reflects the purpose of *Pacific Health and Wellbeing Strategic Plan for the Greater Wellington Region 2020-2025* and the *Sub-Regional Disability Strategy 2017 – 2022 - Wairarapa, Hutt Valley and Capital & Coast District Health Boards*

(d) The Suicide Prevention and Postvention Action Plan governance group has endorsed the *Suicide Prevention and Postvention Action Plan.*

(e) The support of our *intersectoral partners* is being coordinated through our locality relationships.

(f) The implementation and progression of *The Suicide Prevention and Postvention Action Plan* and the related activities across the four domains of health promotion, prevention, intervention and postvention.

(g) That the timing of the DSAC meeting has meant the paper is yet to be presented to the Maori Partnership Board, and Subregional Disability Advisory Group and that their advice will be incorporated in the Action Plan.

Strategic Alignment	*He Tapu te Oranga o ia Tāngata: Every Life Matters – Suicide Prevention Strategy 2019–2029* *Living Life Well A strategy for mental health and addiction 2019-2025* *Taurite Ora Māori Health Strategy 2019-2030* *Te Pae Amorangi Maori Health Strategy 2018 -2027* *Pacific Health and Wellbeing Strategic Plan for the Greater Wellington Region 2020-2025* *He Ara Oranga Report of the Government Inquiry into Mental Health and Addiction Services* *Sub-Regional Disability Strategy 2017 – 2022 - Wairarapa, Hutt Valley and Capital & Coast District Health Boards*
Authors	Roxanne Leech, Suicide Prevention and Postvention Co-ordinator

Endorsed by	Rachel Haggerty, Director Strategy Planning and Performance
Presented by	Chris Nolan, Acting General Manager Commissioning, Mental Health & Addictions Suicide Prevention / Postvention Team
Purpose	As indicated in the April DSCAC board paper, this paper provides a brief update on the implementation and progress of the 3DHB Suicide Prevention and Postvention Action Plan.
Contributors	Arawhetu Gray, Director Māori 2DHB Rachel Noble, General Manager 3DHB Disability Catherine Inder, Principal Advisor, Strategy, Planning and Performance Junior Ulu, Director of Pacific People's Health 2DHB
Consultation	Dr Chris Bowden, Director Research (Victoria University of Wellington) Suicide Prevention and Postvention Governance Group

Executive Summary

The *3DHB Suicide Prevention and Postvention Action Plan* (the *Action Plan*) was developed in response to *He Tapu te Oranga o ia Tāngata: Every Life Matters – Suicide Prevention Strategy 2019–2029 (Every Life Matters)*.

The *Action Plan* aligns with *Every Life Matters,* in its aim to reduce suicide and improve people's well-being. There are four focus areas in the plan: promotion, prevention, intervention, and postvention.

The Suicide Prevention and Postvention (SPPC) team is responsible for actioning the plan. The team have taken a locality based approach and work alongside partner services to deliver, promote, and support suicide prevention initiatives.

The SPPC team developed the plan with input from the Suicide Prevention and Postvention Governance Group, people with lived experience of suicidal distress, and an academic researcher. The 2DHB Director Māori, 2DHB Director of Pacific People's Health and 3DHB General Manager Disability, were also consulted and contributed to the plan. These partners and others are engaged on an ongoing basis to ensure the actions of the plan are serving the needs of the communities which the 3DHB serve, and that we uphold our Te Tiriti obligations.

There have been several iterations of and enhancements to the *Action Plan* since its initial development in 2020. The *Action Plan* was endorsed by the Suicide Prevention and Postvention Governance group in June 2021 and will be presented to DSAC at the 21 July 2021 meeting.

Highlights in this report include significant progress developing:

- A complete SPPC team with a specialist Māori SPPCC position being appointed
- The *Action Plan* reviewed by people with lived experience, an expert in suicide prevention and the 2DHB Director Māori and Director of Pacific People's Health.
- The *Action Plan* endorsed by the Suicide Prevention and Postvention Governance Group
- Strengthened networks and stakeholder relationships
- Significant progression of activities listed in the *Action Plan*

Strategic Considerations

Service	Mental Health, Addiction and Suicide Prevention and Postvention services
People	This Plan is for the communities we serve. We are focused on thos There is a team of 3DHB Suicide Prevention and Postvention Co-ordinators
Financial	The resourcing schedule is part of the operating budget for 2021/2022.
Governance	The Governance of this work is supported by SPPC and the Suicide Prevention and Postvention Governance Group. The outcomes are reported to the Executive Leadership Team.

Engagement/Consultation

Patient/Family	Lived Experience Advisory Group
Clinician/Staff	A wide range of clinicians are engaged in developing models of care and service delivery.
Community	Multiple community providers are engaged
Expert Review	Dr Chris Bowden, Director of Research, Victoria University of Wellington

Identified Risks

Nil as this is an update.

Attachments

1. 3DHB Suicide Prevention Postvention Annual Action Plan 2021/2022.

Purpose

This paper provides a brief summary of the updates to the implementation of the 3DHB Suicide Prevention and Postvention (the *Action Plan)* and highlights key progress made to date. The title of paper, *Our DHB's Mental Health and Wellbeing Strategies* Update, presented to DSAC on 28 April 2021 agreed that DSAC would endorse the *Action Plan*. The *Action Plan* is attached to this paper as an appendix.

Development of the *Action Plan*

In November 2018 the Government published *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction*. *He Ara Oranga* made significant recommendations to suicide prevention and postvention. These included the establishment of a Suicide Prevention Office and finalising the *Suicide Prevention Strategy 2019 – 2029 and Suicide Prevention Action Plan 2019 – 2024*.

In 2019, the Suicide Prevention Office was established and the Government published *He Tapu te Oranga o ia Tāngata: Every Life Matters – Suicide Prevention Strategy 2019–2029 (Every Life Matters)*.

Every Life Matters is the foundation on which Hutt Valley, Capital & Coast and Wairarapa DHB (3DHBs) used to develop the *3DHB Suicide Prevention and Postvention Action Plan* (the *Action Plan*).

There have been several iterations and enhancements to the *Action Plan* since its 2020 development it. The primary goal however has remained the same; to reduce suicide and improve people's well-being.

The *Action Plan* focuses on achieving equity for Māori and Pacific people. Other focus groups include men, older people, people living in rural communities, youth, the disability community, the Rainbow community, and women (with a specific focus on support for women with young children or perinatal).

The *Action Plan* was endorsed by the Suicide Prevention and Postvention Governance group in June 2021 and will be presented to DSAC at the 21 July 2021 meeting.

Suicide Prevention and Postvention Co-ordinators

The Suicide Prevention and Postvention (SPPC) team is responsible for actioning the plan. Together, the team coordinates with existing agencies and services to develop:

- a programmed and networked response to preventing suicide and addressing harms.
- activities and partnerships that provide a system of consistent interventions to relieve the distress and trauma for significant others and whānau.

The current SPPC Coordinator team is relatively new and will soon be fully staffed. The team includes four Suicide Prevention Postvention Co-ordinators (SPPCC) and one SPPCC Māori.

What we know about suicide

Suicide is a devastating event in any whānau. It is a loss that we must make all endeavours, within our roles as healthcare leaders, to prevent suicide and reduce self-harm in our communities.

In the last coroner's year (June 2020 – July 2021), the average number of suicides in the sub-region was 13.1 per 100,000 people, which is in line with the 2020 national average. This however is higher than the average 3DHB rate for the past five years (11.61 per 100, 000).

Of those people who lost their lives to suicide during June 2020 – July 2021, 71% of these were male. The greatest rate was sadly in our Maori community at 13.7 per 100,000. Although lower than the NZ rate of 20.4 it is an enormous inequity. The average age of people who took their life during the same period, was 39.5, but for Maori the average age was much younger. Finally, 33% of all people who died by suicide had a history of accessing mental health services.

There is limited information about suicide in our disability community. The Disability group will continue to work to understand the issue and the appropriate actions.

What we know about self-harm

Between 2019 and 2020 there were 830 self-harm related ED presentations for youth (aged 0–19) in the sub-region. In the same period, there was an 8% increase in self-harm related ED presentations for rangatahi aged 20-24 (234 in 2019 and 252 in 2020). The majority of self-harm presentations were for women (73%) and 53% were for women from other ethnicities, 16% were for Māori women and 3% were for Pacific women. Māori youth (aged 20-24) experience the highest rate of self-harm presentation to ED per 1,000 population. 78% of individuals aged 20 – 24 years presenting to ED for self-harm interacted with Mental Health Addictions and Intellectual Disability Services (MHAIDS) services in the past three years. We have little information on self-harm in the Disability community.

The sections below provide information on the work being done to ensure a reduction in self-harm and suicide.

Progress to date

The April 2021 DSAC paper outlined the key activities that fall under the four domains of the suicide prevention continuum; Promotion, Prevention, Intervention and Postvention. This paper highlights progress that has occurred across these four areas to date.

Promotion
The SPPC team takes a locality based approach to health promotion. The team has connected with key communities and groups, including social sector agencies. The Mental Health Foundation and the Regional Public Health Office has been engaged to understand how best to deliver, promote and support suicide prevention. Since the last DSAC update, the Tertiary Student Provider Suicide Prevention Group has been re-established. This group will focus predominately on promotion and prevention in the student population.

Prevention
Prevention is a combination of recognising early signs of distress and having person-centred, culturally appropriate, flexible and wide-ranging support options to meet diverse needs. The SPPC programme team has developed a suicide prevention education package aimed at supporting early intervention for a distressed person and whānau. This programme is currently being tailored for the NZ School of Dance and staff from Wellington Hospital ED. The team is also exploring other settings where education and training is needed.

Intervention
Intervention includes responding to distress or suicidal behaviour. The *Action Plan* and the approach is guided by people with lived experienced of suicidal distress. The SPPC programme work is closely linked with the Mental Health & Addictions Crisis Support Capability (MHACS) project. The main focus of MHACS is on improving the experience and outcomes of people and their whānau who present to ED in acute distress. This includes those who self-harm or attempt suicide. The Acute Care Continuum Collective Forum is responsible for oversight and monitoring of the MHACs' programme.

Since the last DSAC update, members of the SPPC team are playing an active role in the MHACS project subgroup. The purpose of this subgroup is to facilitate Co-Develop of enhanced acute care clinical pathways. The SPPC team is able to influence the enhanced clinical pathway development to ensure the needs of those presenting to ED for self-harm or suicidal ideation or behaviour are raised and incorporated into the pathway development work.

Postvention

Postvention involves providing support following a suicide. Since the last DSAC meeting, the SPPC team have strengthened the postvention process to ensure stronger systems are in place to support whānau, friends and communities following a suicide. The SPPC team has established strong links with both MHAIDS and primary health services have been established to support resilience and reduce the risk of contagion or other suicidal behaviour. This has included revising the postvention process to address gaps and including additional follow-up information and links to resources for GPs to support whānau affected by suicide.

Working with others

Working with Māori

The SPPC team are committed to upholding our obligations between Māori and the Crown under the Treaty of Waitangi. Iwi, hāpu, and Māori NGOs have been engaged with to ensure cultural appropriateness and relevance.

Working with Pacific people

The SPPC team places emphasis on ensuring suicide prevention activities for Pacific people are Co-Developed and lead by Pacific people. Pacific leaders and community groups have been engaged to better understand and support the needs of Pacific people.

Working with Disability people

The SPPC team is working with the Disability Group to understand suicide in the Disability community and engage in the co-developed and lead by Disabled people.

Working with people with lived experience

The SPPC team seeks guidance from those with lived experience; people affected by suicide either through bereavement or their own suicidal distress. People with lived experience offer invaluable knowledge and insight. Representatives from the Mental Health Foundations Lived Experience Advisory Group have reviewed the *Action Plan* and there is lived experience representation on the Suicide Prevention and Postvention Governance Group. Input from lived experience is ongoing and underpins all activities the SPPC team initiate.

The Suicide Prevention and Postvention Governance Group

The Governance Group provides governance and stewardship, support and advice, and monitors the implementation of the *Action Plan*. The group includes representation from Public Health Organisations, NZ Police, Ministry of Education, Non-government agencies and the Lived Experience Advisory Group (LEAG). The SPPC team is currently exploring how to have the voice of rangatahi and whānau represented in the group.

Working with partners

The *Action Plan* takes a collaborative, networked approach working closely with partners, communities, other health and social services and people with lived experience and their whānau. A crucial aspect of the design and implementation of the *Action Plan* has included collaborating with stakeholders. We have commenced a stakeholder mapping exercise and commenced engaging with stakeholders.

Next steps

The SPPC team will continue to implement and progress the plan. At the 24 November 2021 DSAC meeting, an update will be provided, possibly as part of a wider Mental Health and Addictions update.

Wairarapa, Hutt Valley and Capital & Coast District Health Boards

3DHB Suicide Prevention and Postvention Action Plan

(2021-2022)

Date	Version	Comment
Nov/Dec 2020	V1.0	Draft created
January 2021	V2.0	Updated by Chris Nolan
February 2021	V3.0	Updated by Russel Baines with new timeframes
May 2021	V4.0	Updated timeframes by SPPCC team
20th May 2021	V4.0	Endorsed by Governance Group
17th June 2021	V5.0	Action / Outcome update from SPPCC Team
25th June 2021	V6.1	Chris Bowden edit and SPPCC update
7 July 2021	V7.1	Updated following ELT review

Wairarapa DHB
Wairarapa District Health Board
Te Poari Hauora a-rohe o Wairarapa

HUTT VALLEY DHB

Capital & Coast
District Health Board
ŪPOKO KI TE URU HAUORA

Contents

Foreward

THE TURAMARAMA DECLARATION

We, participants in Turamarama ki te Ora Indigenous Suicide Prevention Conference, held in Rotorua, New Zealand on 1-3 June 2016, are deeply concerned about the high rates of suicide among indigenous peoples.

1. We weep for the increasing number of our people whose lives have been cut short by suicide;

2. We respect the courage and fortitude of families and friends who have endured unexpected and often inexplicable losses of dear ones;

3. We commit ourselves to healing our own wounds and the wounds of our lineage, and in so doing to exemplify the ways in which light can be brought into the world inhabited by our elders, our peers and our young people;

4. We declare that all our people should be able to 'live well', into old age;

5. We believe that the will to 'live well' is strong when the human mauri is strong; 'living well' means being able to live as Māori, as indigenous peoples, and as citizens of the world;

6. We will strive to build safe and nurturing communities that generate confidence, integrity, inclusion, equity, and goodwill;

7. We recognise the key roles that whānau and families play in strengthening the mauri by transferring knowledge, culture, language, values, and love to their children and grandchildren;

8. We endorse the benefits of tikanga, kawa, healing, and other cultural protocols to lift the spirit and strengthen our people in schools, health centres, sporting clubs, social media, the workplace, and the streets;

9. We expect health, education, and all social service providers to offer services that are accessible, timely and effective for indigenous peoples;

10. We urge our own indigenous leaders, tribal authorities, and community champions to create opportunities for our children, youth, women, men, and our older people so they can be part of te ao Māori and the indigenous world, and can be active participants in the communities where they live and work;

11. We challenge national and local authorities and city councils to adopt and enforce regulations to reduce the availability of alcohol and other harmful substances, to ensure that homes are warm, comfortable, and affordable, to insist that streets, workplaces, schools, and the internet are all safe places for our peoples, and to combat practices that diminish self-worth and hope;

12. We call on our elected leaders in Parliament, especially those who have responsibilities for education, social services, health, housing, employment, indigenous development, and the environment, to work together in order to create a society where equity of access, equitable outcomes, and extended opportunities can prevail;

13. We recommend that our people in the United Nations Permanent Forum on Indigenous Issues make all nation states aware of the extent of Indigenous suicide and ensure that suicide prevention is highlighted in the UN Millennium Goals;

14. We pledge ourselves to work collectively so that our combined energies can create a world where the mauri can flourish and all our peoples can live well, into old age.

Declared at Rotorua, New Zealand
3rd June 2016

Purpose

The purpose of the 3DHB Action Plan is to:

1. Outline the key actions to support communities regarding the promotion of wellbeing; prevention, intervention and postvention of suicide.
2. Guide activities and funding priorities of 3DHB local communities including addressing risk in priority population groups.
3. Increase awareness of what support (national and local) is available for people who are at risk of suicide and affected by suicide including those bereaved by suicide.
4. Reduce the number of suicides and promote wellbeing for all.

Introduction

Those working in the area of suicide prevention and postvention believe/know that suicide is preventable (Ministry of Health, 2019). Most people who attempt suicide do not want to die – they just want their pain to end or cannot see another way out of their situation. By embracing the concepts of Trauma Informed Care (Fallot & Harris, 2009; SAMHSA, 2014a, 2014b; Te Pou o te Whakaaro Nui, 2018) we will focus on what's happened to people, and what matters to people, not on what's wrong with people. When people are aware that they have options, and can see a future for themselves, suicide is less likely. When people feel their life matters and that they have value, suicide is less likely. When people feel accepted and are connected to those around them, suicide is less likely (Beautrais, 2003b, Beautrais et al., 2005).

To achieve wellbeing is difficult because it means different things to different people. This means our plan and strategies need to be flexible enough to meet the needs of different people and different groups within our communities.

While all members of society can be affected by suicide, we know Māori and Pacific people are over-represented in suicide rates. Other high risk groups include men, older people, people living in rural communities, youth, Disabled People, the Rainbow community, and perinatal or those with young children.

Our job is to work collectively and collaboratively with these communities to increase both resilience and access to information and support which meets people's needs and wellbeing. Ultimately this will lead to a reduction in the number of people who die by suicide and the impact it has on bereaved whānau and communities.

Background

In 2014 the Ministry of Health (Ministry) transferred responsibility for the local implementation of the national Suicide Prevention Strategy 2012/16 to the 20 District Health Boards across Aotearoa New Zealand.

In 2019, the Ministry released *He Tapu te oranga o ia tangata Every Life Matters* (Ministry of Health, 2019), the Suicide Prevention Strategy 2019-2029 and Suicide Prevention Action Plan 2019-2024 for Aotearoa New Zealand.

In July 2020, The Suicide Prevention Office (SPO) confirmed key messages developed with the Māori Expert Reference Panel to guide and provide important touchstones for the SPO as it implements *He Tapu te oranga. These are detailed below.*

This Suicide Prevention and Postvention Action Plan (the 3DHB Action Plan) was developed on behalf of Wairarapa District Health Board, Hutt Valley District Health Board and Capital and Coast District Health Board (3DHB) has been updated to align with the goals of *He Tapu te oranga* and key messages.

- Strong, healthy, connected whānau, families and communities are the most important protective factors against suicide.
- People who die by suicide are often acutely distressed, experience situational distress but are not necessarily mentally ill or mentally unwell.
- Support and health services are available and do make a difference - they can and do help.

- People can be effectively supported through suicidal distress, especially when support is readily accessible and of high quality (e.g., supporters have sufficient knowledge, confidence and competence to offer effective and evidence-based support).
- Suicide is not a disease, and it is unhelpful to describe our suicide rate as an epidemic.
- Collaboration across ministries and government agencies will be necessary to prevent suicide.
- The reasons that people take their own lives are complex and influenced by a combination of biopsychosocial and cultural factors that accumulate over a lifetime (including childhood adversity and trauma, exposure to risk factors, lack of coping skills), culminating in suicide when faced with an exacerbating stressful event or as a result of accumulative stress.
- There is no one-size-fits-all in suicide prevention, and groups of people who vary in terms of age, gender, sexual orientation, ability, culture and ethnicity must be supported and empowered to design and deliver their own approaches to suicide prevention. Our approach to suicide prevention and postvention needs to be inclusive and responsive to differences.
- Suicide risk is associated with inequity (in terms of access to support, opportunities and life outcomes) and differential exposure social determinants such as intergenerational poverty, homelessness, poor educational engagement and attainment, unemployment, colonisation, institutional racism and alcohol and other drug addiction. Suicide is shaped by more than mental health and addiction.
- Suicide risk is also associated with early and ongoing experiences of trauma: interpersonal violence, sexual violence, abuse, neglect and maltreatment, social isolation and marginalisation, unresolved grief, relationship breakdowns, and bullying and harassment.
- Suicide risk also correlates with intergenerational trauma (e.g., the cycle and continuation of poverty of knowledge, income and opportunities, poor parenting, state care) and adverse childhood experiences (parental imprisonment, parental drug use, maltreatment, exposure to family violence).
- In Aotearoa / New Zealand the suicide rate will not come down until inequity, trauma and adverse childhood experiences are addressed at a societal and community level and people are provide with support (specialist, peer, crisis and ongoing) and resources that promote healing and recovery.
- Suicide prevention and postvention should be evidence-based and data driven but also informed by the lived experience of individuals, whānau and community leaders and advocates. They need to be ‘bottom-up’ and supported in a sustainable manner by local and central government who can help support the community’s vision and the delivery and implementation of support from the ‘top-down’.
- These messages will continue to evolve, and they will guide our work and provide important touchstones to ensure we remain on course as we implement He Tapu te Oranga.

The 3DHB Action Plan implementation has oversight through a governance structure. This includes:

1. A Governance Group
2. Working Groups
3. Expert Advisors (who will support both the Governance and Working Groups).

The Governance Group provides governance and stewardship, support and advice, monitor, and report and make decisions on the implementation of the 3DHB Suicide Prevention and Postvention Action Plan. The Group is focused on the outcomes achieved through the Action Plan. The Governance Group meets quarterly.

The Governance Group may establish any Working Group arising from identified priority development and will work in partnership with the 3DHB wider stakeholder groups. For example, setting up a working group to address suicide in a vulnerable population, to address a specific gap in knowledge or resolve an issue in service or support delivery?

Expert Advisors will provide support to both the Governance Group and Working Group as required, and in particular issues about interpretation of data and analysis.

Each DHB catchment will also have at least one interagency group that meets locally on a regular basis.

Enablers

There are things that will help us achieve our plan and will be threaded throughout our actions:

- We will work with and seek Māori and Pacific leadership and direction to develop and deliver suicide prevention culturally responsive initiatives that are developed by Māori and Pacific people.
- We will work with the Disabled People to understand suicide and self-harm in this community.
- We will seek guidance from those with Lived Experience with their knowledge and insight. We will have this voice not only at Governance Level but at every level. We have accessed people who are on the Mental Health Foundations Lived Experience Advisory Group to review and critique our plan. Input from lived experience will be ongoing and is one of the enablers of the plan
- We will use data and evidence to inform us and help us target efforts to where there is inequity and where people are disproportionally affected by suicide and to where action is most likely to lead to largest reductions in suicide rates and/or improve wellbeing/recovery.
- We will develop capability in the workforce wider community to help those who experience suicidal distress. This is to develop a caring, consistent and trauma-informed approach (National Health Service Education for Scotland, 2017, 2018; Te Pou, 2018) at the earliest opportunity.

  Essentially our enablers will help this plan focus on what matters to people affected by suicide.

3DHB Action Plan Areas of Activity

The 3DHB Action Plan Areas of Activity – *reflecting the He Tapu te Oranga o ia tangata (Every Life Matters) Framework* focus areas for the suicide prevention continuum are:

1. Promotion – promoting wellbeing
2. Prevention – responding to suicidal distress
3. Intervention – responding to suicidal behaviour
4. Postvention – supporting after a suicide

Promotion

Key Action

Promoting wellbeing throughout people's lives. Promotion programmes will include a focus on equity for Māori, Pacific people, and women, with a specific focus on support for women with young children or perinatal. Other focus areas include men, older people, rural communities, youth and Disabled People. The overall goal is to develop resilience, community- based responses to emerging need and to recognise and appropriately support people in distress by setting goals for people to feel they have value and are connected and feel accepted in their homes, work, social circles and communities.

Method

The SPPC will take a locality- based approach to Health promotion, (Wellness promotion initiatives as outlined in Living Life Well and Every Life Matters) with the aim of connecting people with support, resources and key stakeholders/services who support wellbeing in communities / groups within each geographic area. The target partner organisations in each area for programme delivery will include the agencies and services which deliver social sector programmes as well as local lead or peak community bodies.

We will work alongside partner services (e.g. Ministry of Education, CASA, Ministry of Health, Health Promotion Agency, Mates in Construction), using mandated educational resources (e.g. MH101, Lifekeepers, 2DHB modules, Mental Health Foundation) to deliver, promote and support wellbeing, coping, resiliency, social connectedness and help-seeking and help-offering and key messages (e.g. from the Mental Health Foundation, Suicide Prevention Office).

Our health promotion work will be developed and implemented in partnership with regional public health with the SPPC plan and Regional Public Health plan sharing goals in building promotion activity leading to increases in resilience in our communities. The expectation is that we will identify and connect with existing programmes (e.g. mental health and anti-bullying programmes) in the education sector.

We will also target priority community groups, including those representing the needs of disabled people, to establish a consistent approach across each of the localities and engage with a standard approach taken to developing outreach support groups and / or at times self-organising programmes. We will support small groups in each locality to establish and apply for funding for resource to maintain activity and focus. Groups that are vulnerable will be a focus include women and children at risk.

The role of the SPPC programme will be to facilitate and support and use expertise in developing community groups to build resilience and self-sustaining initiatives that are consistently focused on promotion, linked to prevention activities. Targeted community groups and communities in each locality will be: (e.g. Men, Māori, Pacific, and members of the Rainbow community, at-risk bereaved), type of forum (e.g. social & sports clubs, churches), places of learning (e.g. secondary schools, university, Private Teaching Establishments) and workplaces.

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The SPPC team places great emphasis on ensuring promotional activities for Māori are co designed and led by Māori. Initially this may mean developing partnership / working relationships with Marae, Hapu, Iwi that enables us to develop promotional material that meets the local need.

The SPPC team recognises that intersectionality exists between identity markers like age, disability, race and gender. For purposes of this plan, the focus is on markers associated with higher rates of suicide. The team does however take into account the relationships between these markers and aims to ensure all people can access support.

Action	**Rationale**	**Outcome**	**Measures**	**Who/ progress**
Joint agency and organisational approach				

Action	**Rationale**	**Outcome**	**Measures**	**Who/ progress**
Identify and engage with promotion activities and programmes linked to reducing risk of suicide e.g. Regional Public Health Ministry of Education Health & Safety managers Human resources managers Community Centres Councils	Promotion programmes are shared across the sector and inclusive of education and other sectors (workplaces, community, sports) agencies as well as RPH and CAFs wellbeing programmes. Engagement over shared programmes will expand the scope of access and delivery. Basic general training programmes such as MH101 can be accessed.	Agencies are working together to reduce suicide Reductions to be measured compared to a 5 year average	4 interagency promotional activities held inclusive of access to MH101.	
Work with the tertiary education providers and student groups to identify and implement targeted wellbeing solutions for students	Students at in tertiary education can experience high levels of stress and isolation	Tertiary education providers are supported to develop plans that promote community resilience and support for students	Reduction of student suicides compared to a 5 year average Reduction student self-harm re-presentations to ED 2 new initiatives implemented	
Work with intersectoral agencies e.g. Police, Construction, Forestry, low pay high stress workforces especially apprentices to develop in house wellness promotion / suicide prevention programmes	Develops the skills of the front line workforce	Police are supported to develop workforce plans that promote workplace community resilience	Engagement with police health programmes evidenced by trial of at least 1 program	
Priority Populations				
Work with and seek Māori leadership to develop and deliver promotional	Māori suicide rates per head is higher than any other group and	Programs for Māori are designed and delivered by Māori	2 promotional initiatives run	

Action	**Rationale**	**Outcome**	**Measures**	**Who/ progress**
initiatives for Māori delivered by Māori	require an approach that restores equity and mana			
Work with key partners to link in with, progress, develop and implement wellbeing programmes for youth e.g. Youthquake/Ora Toa collaboration	The rate of suspected suicides in youth (11-24 year olds) is consistently high across the 3DHBs (3DHB SPR Database 2014-2020)	Programs are available in schools and places of learning	Reduction of youth suicides compared to a 5 year average Reduction youth self-harm re-presentations to ED Link with maternal mental health and midwives	
Identify and implement targeted wellbeing actions for men by • Targeting men directly • Meet men where they are • Using male friendly language • Using solution based activity orientated approaches	Men are over represented in the deaths by suicide across all age groups across all 3DHB TLA	Work with men to identify and support development of community-based wellbeing activities and resources Identify other areas to establish men's initiative in 2021-22	Men's initiatives set up in localities Kāpiti Men's Group 3 new men's initiatives commenced Develop suicide education resources for Men Training for groups working with men at risk 4 sessions held	
Identify and implement wellbeing actions for Older People and e.g. Kaumātua/Runanga a Iwi Age Concern	The rate of suspected suicides in the 80-84 age range increased nationally in 2019/20* and in 75+ age group for 3DHB	Work with Older People to identify activities, resources and system levers that reduce loneliness	Evidence of Engagements with Older People linkages identified Age Concern,	

Action	Rationale	Outcome	Measures	Who/ progress
Alzheimer NZ Grey Power	(*2020 Annual provisional suicide statistics for deaths reported to the Coroner 2007-2020 3DHB SPR Database 2014-2020)	e.g Age Concern, Alzheimer's NZ, Grey Power,	Alzheimer's NZ, Grey Power Evidence of awareness campaigns delivered	
Identify and implement targeted tailored resources about what services are available for 'at risk groups' LGBTQIA+ Refugees & migrants Rural communities Perinatal and Postnatal women and whanau	At risk groups often do not have resources developed specifically for them about what services are available	Engagement with groups to determine need from their viewpoint Existing resources identified for use or replacement Engagement with services that are in direct contact such as Midwives and Maternal Mental Health services including primary mental health.	Evidence of engagement and development of both and where possible improved systems to access resources reflective of their input.	

Prevention

Key Action

Strengthen systems and develop programs that support people who are in distress.

Method

Prevention is a combination of recognising early signs of distress including suicidal thinking and self-harm and having options for support that are responsive to the needs of each individual. Options that are culturally appropriate, flexible and wide-ranging enough to meet diverse needs.

The SPPC will work in collaboration with our DHB's Pacific and Māori Directors to uphold our Te Tiriti obligations and to develop suicide prevention resources that are specific and tailored to Māori and Pacific cultures.

Programs and activities will be developed for different sectors of the population including for younger people in places of learning and people in workplaces, clubs, residential facilities and organisations.

Workplace initiatives will prioritise first responders (e.g. Police, Fire, and Ambulance) health and wellbeing services in order to encourage the development of greater awareness and trauma-informed responses at scene. In house prevention programmes will be developed for a diverse range of areas including workplaces, Correctional Facilities, places of learning and organisations. Additionally services who are supporting at risk groups such as disabled people, perinatal and postnatal women and at risk families / whanau with vulnerable children will be supported The SPPC programme will facilitate or deliver suicide prevention education to support early intervention and culturally appropriate supports and organisational initial responses for a distressed person and whānau.

We will work with people with lived experience to provide guidance to improve the well-being outcomes and recovery for those who self-harm, as well as informing systems and programme development and delivery. The prevention programmes will connect closely with promotion and established support groups who grow local resilience. These groups will deliver some aspects of the prevention programmes alongside improved recognition of issues and response to build resilience.

Action	Rationale	Outcome	Measure	Who/ progress
Joint agency and organisational approach				
Quality and effective suicide prevention training is developed that is context specific and tailored to a range of people involved in suicide prevention.	Lack of local information about what suicide prevention training is available. The suicide prevention training currently offered (MH101, Lifekeepers, Le Va) targets gatekeepers at a very basic level and is focused on general awareness	Training guide is developed for the following: Schools, teachers and staff Counsellors Police, Ambulance, Firefighters Psychologists First responders (e.g., victim support) Crisis support workers Midwives Maternal Mental Health Disability Services Training resources are developed and made available to communities	Training guide is developed Training is evaluated and found to be acceptable (useful in terms of format) and effective (increases knowledge, confidence and competence to prevent suicide)	
Priority populations				

Action	**Rationale**	**Outcome**	**Measure**	**Who/ progress**
Develop and implement new kaupapa Māori suicide prevention initiatives.	Māori leadership and involvement is essential as tāngata whaiora and whānau involved in their own recovery and as whānau, hapu and iwi supporting each other	New approach adopted for Māori designed by Māori	Māori identify with the tailored suicide prevention approach	
Develop and implement Pacific suicide prevention initiatives.	Pacific leadership and involvement is essential as Pacific leaders and communities involved in their own recovery.	New approach designed by Pacific	Pacific identify with the tailored suicide prevention approach	
Understand Disabled Peoples experience with suicide and self-harm.	Disability leadership to understand suicide and find solutions.	New approach designed by Disable people	Disabled people identify with the tailored suicide prevention approach	
Work with people and service providers (e.g., peer support, NGOs) who support people from different demographic backgrounds who are at greater risk of suicide (e.g., LGBTQI+, men, survivors of abuse, refugees, those with mental health issues) to provide guidance on the development of trauma informed and inclusive suicide prevention practices. This includes people with lived experience of trauma and suicidal behaviour, survivors of suicide and suicide loss and people from the Rainbow community.	Both research and the recent Mental Health Inquiry reinforce the importance of having the guidance of people affected by suicide at all levels of development, implementation and evaluation of initiatives.	Process set up a working group or advisory group to ensure people with lived experience of suicide and suicide loss and people from the rainbow community have a voice and input into the development of resources, implementation of actions and evaluation of actions/initiatives and services.	All program outcomes reflect consultation	

Action	**Rationale**	**Outcome**	**Measure**	**Who/ progress**
Target groups will also include perinatal and postnatal women, at risk families/whanau with children				
Work with the Mental Health and Addiction Crisis Support Capability Project (MHACs) team to support the development of enhanced clinical pathways for tangata whaiora and their whanau in ED services at Wellington Hospital.	Review of the acute/crisis response services provided by 3DHBs have identified a number of issues and gaps related to the quality of treatment and support. The Mental Health and Addiction Crisis Support Capability Project (MHACs) has been tasked by MoH to address these.	Improved clinical pathway and care for tangata whaiora, including those who present for self-harm, suicidal ideation and suicide attempts.	Increased services specifically those for Pacific and Kaupapa Māori services. Increased Mental Health & Addictions (MH&As) acute/crisis service responsiveness Increased tangata whaiora and whanau satisfaction with acute/crisis service provision Increased staff knowledge and capability (pre and post training Increased FTE – peer support and MH liaison nurses A designated area/room in ED for people distressed	
Explore literature and research evidence and develop early	There are strong associations between family violence, risk of	Link with and provide support to police and other	Intervention developed in partnership with	

Action	**Rationale**	**Outcome**	**Measure**	**Who/ progress**
intervention programmes which target associated suicide risk factors such as family violence and alcohol and drug abuse	self-harm and alcohol and drug abuse.	community services who provide family violence programmes, with AOD services and counsellors, and family violence practitioners who work with people affected by these priority risk factors.	police AOD providers, including kaupapa Māori and Pacific providers involved	
Review national and international evidence on workplace suicide prevention initiatives and develop suicide prevention guidelines and support for workplaces for safe conversations about suicidal distress and appropriate response	Having workplaces with internal capability is a core aspect of early intervention as proven by the Mates in Construction Model. which has been recognised by WHO has an exemplar for workplace-based suicide prevention	Workplaces have an increased ability to recognise and support people experiencing suicidal distress including connecting people to community support services.	Program developed and successfully trialled At least 1 workplace is using the training independently	

Intervention

Key Action

Strengthen systems to ensure access to culturally embedded and responsive, safe and evidenced informed care for people experiencing suicidal risk

Method

Our approach will be person and whanau centred, guided by people who have experienced suicidal distress. Our approach will be to work with agencies, services and people with lived experience, Māori, first responders and frontline staff to develop, implement and share best practice and innovation. Our programmes will be evidence- informed from intersectoral) population-based data and information. This is so we can respond to suicidal behaviour safely, effectively and with compassion.

Action	**Rationale**	**Outcome**	**Measure**	**Who/ progress**
Joint agency and organisational approach				
Develop comprehensive database for the collection and reporting of suspected suicides within 3DHB Trends, evidence and knowledge is collected and used for suicide prevention communications & campaigns	There are several 'stand-alone' internal systems for collection and reporting of this confidential data. Having up-to-date and regional specific local data will allow for more targeted intervention and allocation of resources and support.	Quality and confidential 'one source of truth' is developed. Those working in services and agencies can be informed in a timely way of changes in prevalence and respond appropriately.	Secure 3DHB secure database developed that's links to relevant applications Evidence of Trend information being used	
Investigate the opportunities for peer lead support post discharge from a suicide attempt	Recommended Service detailed in Every Life Matters	Individual journeys post discharged mapped and opportunity for peer support investigated	Peer lead post discharge support investigated and trialled	
Improving crisis response services Improving experience in ED Ensuring other local services are trained in effective suicide intervention?	People with lived experience reporting negative experiences with ED and CRS staff, being turned away while in distress Mental health reports showing increased wait times Poor response from ED & CRS	Reduced wait times for seeing support staff Increased numbers of people and whanau reporting leaving with adequate safety plan and resources, knowledge of what to do to support friend or family member	Reduced time between assessment and follow-up care Reduced suicides in people accessing crisis support services	
Trends, evidence and knowledge is collected in such a way to be used in positive communication and suicide prevention campaigns Partners Health Analysis team in SPPC	Evidenced based reporting	Used in communication strategy with clear messages and boundaries	Information is reported to the Governance Group in a manner that is easy to digest and understand	
Provide effective and tailored training and support for frontline staff in Health, Police, education and	Skill development for frontline and community will lead to a more informed and	Program developed which is adaptable to different environments	Program developed and successfully trialled	

Action	Rationale	Outcome	Measure	Who/ progress
those likely to provide initial support to acute suicidal distress	compassionate intervention for those in distress.		At least 1 workplace is using the training independently	

Postvention

Key Action

Strengthen systems to support whānau, families, friends and communities following a suicide to

- Reduce Trauma
- Prevent the risk of contagion or other suicidal behaviour
- Minimise the complications of grief
- Improve informal support and encourage Coping and resilience

Method

The overall approach from the SPPC programme is to coordinate with agencies and services that are currently in place to develop a programmed and networked response. We will coordinate with partners to create an interagency community-led postvention response, where appropriate, for each suspected suicide notification. The aim will be to develop a clear process and set of activities and partnerships that can be developed and used as system of consistent interventions which relieve the distress and trauma for significant others, and whānau.

Responses will be flexible to meet the needs of people from different cultural backgrounds, gender or experience.

The postvention activity will be based on an agreed plan of action which involves agencies, services significant others and whānau which can be evaluated as part of our quality improvement process. The evaluation of the delivery of postvention services will provided input to the development of plans for promotion, prevention and development of our community and supporting services

Action	Rationale	Outcome	Measure	Who/ progress
Priority Populations				
3DHB develop and implement a community-led postvention plan,	Ensure extensive networks are in place to consistently coordinate a	Whānau/families, partners, friends, peers and wider	Evidence of community participation in	

Action	Rationale	Outcome	Measure	Who/ progress
process and activities which involves people representative of the community including people bereaved or affected by suicide.	comprehensive postvention response for people bereaved by suicide Those exposed to suicide are at greater risk of suicide, those who have close relationships with the deceased are also at greater risk of suicide	communities are well supported when bereaved by suicide	developing and implementing a postvention response which minimises risk for contagion or cluster	
Development of a Māori postvention process for 3 DHB	Māori require a culturally-safe postvention response	Whānau, friends and communities are well supported through a frontline Kaupapa Māori postvention response	Evidence of Māori participation in developing and implementing a postvention response which minimises risk for contagion or cluster	
Development of a Pacific postvention process for 3 DHB	Pacific people require a culturally-safe postvention response	Aiga, friends and communities are well supported through a frontline Pacific postvention response	Evidence of Pacific people participating, developing and implementing a postvention response which minimises risk for contagion or cluster	
Development of a Disabled Peoples postvention process for 3 DHB	Understanding suicide in Disable People is required to ensure a safe postvention response	Disabled people and communities are well supported through a frontline postvention response	Evidence of Disabled People people participating, developing and implementing a postvention response which minimises risk for contagion or cluster	
Joint agency and organisational approach				
Resources developed for Tangihanga and Funeral Celebrants are provided	Recommended action in Every Life Matters	Marae and Funeral Celebrants have suicide	Resources developed and available	

Action	Rationale	Outcome	Measure	Who/ progress
to people and services in the community.		specific information to inform them when providing services to those Bereaved by suicide Bereaved families/whānau have access to information that can help them plan a funeral/tangi and support the bereaved		
Bereavement options register is developed and kept current	Whānau/families need access to support at different times following a death by suicide	Information about the available options is regularly collated and made available	Register is current	
Supporting awareness of and increased access to local programmes and peer support groups for people bereaved by suicide	Adults bereaved by suicide need ongoing support to make sense of suicide, learn skills to manage grief, develop coping skills and resiliency.	Increased referrals to Waves programme and other peer-support programmes and increased support provided to bereaved.	Increased number of bereaved reporting access to and benefit from postvention support programmes	
Funding the development of a support programme and service for children and young people bereaved by suicide	Children and young people currently have no access to any support programmes, counselling or peer support programmes in the DHB region. Parents, family and schools often struggle to provide support to children and young people following suicide. Children and young people are a high risk population of the bereaved who are at greater risk of suicide later in life.	Bereaved children and young people have access to developmentally appropriate support provided by trained professionals and peer-support facilitators.	Increased number of bereaved children and young people reporting access to and benefit from postvention support programmes	

Appendix 1

Population Statistics

The 3DHBs are comprised of eight territorial local authorities (TLA) and according to 2018/19 data have populations of the following size and distribution. Men are approximately 49% of each DHB's population.

DHB	Territorial Local Authorities (TLA)	Total Population
Wairarapa DHB	Masterton, Carterton, South Wairarapa	45,327
Hutt Valley DHB	Lower Hutt, Upper Hutt	148,512
Capital and Coast DHB	Wellington, Porirua, Kāpiti Coast*	303,987
Total		**497,823**

Source: Health System Plan

DHB	Māori	Pacific	Other	Total
CCDHB	35,172	26,484	242,331	303,987
HVDHB	26,184	14,517	107,811	148,512
WRDHB	8,169	1,413	35,745	45,327

Source: Health System Plan

DHB	Māori	Pacific	Other
CCDHB	12%	9%	79%
HVDHB	18%	10%	73%
WRDHB	18%	3%	79%

TLA	Māori	Pacific	Other	Grand Total	Māori	Pacific	Other
Wairarapa	8169	1413	35745	45327	18%	3%	79%
Lower Hutt	19260	12003	73269	104532	18%	11%	70%
Upper Hutt	6924	2514	34542	43980	16%	6%	79%
Kāpiti District*	5157	1224	38310	44691	12%	3%	86%
Porirua City	12606	14868	29085	56559	22%	26%	51%
Wellington City	17409	10392	174936	202737	9%	5%	86%
Grand Total	**69,522**	**42,417**	**385,884**	**497,823**			

*Kāpiti District excludes Otaki, Otaki Forks and Te Horo localities

Coronial Suicide Data for the 3DHBs

Annual provisional suicide statistics for deaths reported to the Coroner between 1 July 2012 and 30 June 2020, as at the end of the financial year. Coronial confirmed suicides/ rate are 2012/13-2015/16. Provisional suicides/ rate are 2016/17-2019/20

Within the 3DHB region suicide disproportionately impacts some population groups more than others. Rates per 100,000 people, provides visibility to this inequity.

The table below identifies the 3DHB rates of Coronial provisional and confirmed suicide rates alongside the national provisional and confirmed suicide rates.

DHB	**2012/13**	**2013/14**	**2014/15**	**2015/16**	**2016/17**	**2017/18**	**2018/19**	**2019/20**
WrDHB	10	8	9	6	12	8	8	5
HVDHB	14	25	16	17	19	13	12	10
CCDHB	30	30	30	36	30	40	41	41
3DHB Total	*54*	*63*	*55*	*59*	*61*	*61*	*61*	*56*
National Total	541	529	564	579	606	668	685	654
National Rate per 100,00 popn	12.10	11.73	12.27	12.33	12.64	13.67	13.93	13.01

Source: https://coronialservices.justice.govt.nz/suicide/annual-suicide-statistics-since-2011/

Since 2013, the 3DHB have averaged 58 suicides annual. Based upon 2018 population data, the 3 DHB's rate of suicide is 11.5. While the statistics do not show that Capital and Coast, Hutt Valley and Wairarapa DHBs are amongst the highest rates, any single suicide is devastating for those family members and friends directly affected and has reverberations far beyond in their communities.

3DHB SPR Suicide Data

The 3DHB SPR Database is a database of notifications of suspected suicide deaths. The SPR Database includes suspected suicides which have yet to be confirmed by the Coroner. The database includes legacy statistics from the Regional Public Health as well as notifications reported to the 3DHB service. The database has enabled further refinement data by TLA as well as age and gender, thus providing localised data enabling tailored actions.

Tailored actions are required in the 3DHB Action Plan, as *'no one-size-fits all in suicide prevention and different cultural and ethnic groups must be supported and empowered to design and deliver their own approaches to suicide prevention' (SPO Key Messages, 2020). Profiled next is SSID data from the 3DHB's SPR database.*

On average the 3DHBs experience 58 suspected suicides per year. The suicides predominantly involve men (70%) whose ethnicity is 'other' (77%), usually NZ European, and who live in Wellington. However, when viewed as a rate per 100,000 people, some of our people and communities more vulnerable to death by or being bereaved by suicide than others. Again men remain the most vulnerable, however our Māori tane experience some of the highest rates across all age bands and nearly all localities. The 3DHB rate of suicides is 11 per 100,000 people, yet our tane can experience rates up to 45 per 100,000 people and most vulnerable when 25-44 years old and living in the Waiarapa or Wellington City. Māori under 25 years living in Lower Hutt (20 per 100,000), Pacific People in Upper Hutt (19 per 100,000) and Other ethnicity in Upper Hutt (22 per 100,000) also experience high rates.

A population lens (i.e. rates) enables a view on the 3DHB suicides that takes into account the population size differences between each DHB. Viewing the SPR Data from a DHB and a localities/ Territorial Local Authority (TLA) population perspective makes visible our most vulnerable, enabling more targeted solutions. For example, males in particular Waiarapa Māori and Hutt Pacific males.

Data sourced from the 3DHB SPR Database on suspected self inflicted deaths by 3DHB, DHB and TLA follows.

Suspected Self Inflicted Deaths 3DHB

SSID by DHB and year (1 Jan 2013 - 24 Dec 2020)

	2013	2014	2015	2016	2017	2018	2019	2020	Grand Total	Av/yr	Rate
Capital & Coast	34	28	28	34	28	52	38	36	278	35	11.1
Hutt	24	14	21	19	17	15	9	13	132	16.5	11.1
Wairarapa			1	16	14	7	8	7	53	7	14.6
Other DHB							1	2	3		
Grand Total	**58**	**42**	**50**	**69**	**59**	**74**	**57**	**57**	**466**	58	11.4

Source: 3DHB SPR Database

SSID - 3DHB by Gender 1 Jan 2013 - 24 Dec 2020

	2013	2014	2015	2016	2017	2018	2019	2020	Grand Total	Av/yr	Rate
Male - SSID	**32**	**34**	**34**	**60**	**43**	**51**	**38**	**39**	**331**	41	8.2
Female - SSID	**25**	**8**	**16**	**9**	**16**	**23**	**19**	**18**	**134**	17	6.5
X - SSID	**1**								**1**		

Source: 3DHB SPR Database

SSID by Gender, Ethnicity and 3DHB 1 Jan 2013 - 24 Dec 2020

	2013	2014	2015	2016	2017	2018	2019	2020	Grand Total	Av/yr	Rate
Female	**25**	**8**	**16**	**9**	**16**	**23**	**19**	**18**	**134**	**16.8**	**6.5**
Maori	5	1	3	2	4	4	2	3	24	3	8
Other	17	6	13	6	12	17	17	15	103	13	6
Pacific	3	1		1		2			7	1	4
X	**1**								**1**		
Maori	1								1		
Male	**32**	**34**	**34**	**60**	**43**	**51**	**38**	**39**	**331**	**41.4**	**8**
Maori	8	7	5	11	4	9	4	6	54	7	19
Other	22	26	26	46	37	39	31	32	259	32	17
Pacific	2	1	3	3	2	3	3	1	18	2	11
Grand Total	**58**	**42**	**50**	**69**	**59**	**74**	**57**	**57**	**466**		

Source: 3DHB SPR Database

Suspected Self Inflicted Deaths by DHB

SSID by Gender and DHB 1 Jan 2013 - 24 Dec 2020

	2013	2014	2015	2016	2017	2018	2019	2020	Grand Total	Av/yr	Rate
Female	**25**	**8**	**16**	**9**	**16**	**23**	**19**	**18**	**134**	**17**	**6.5**
Capital & Coast	15	6	10	4	9	18	11	14	87	11	6.7
Hutt	10	2	6	2	5	3	6	3	37	5	6.2
Wairarapa				3	2	2	2	1	10	1	5.4
X	**1**								**1**		
Capital & Coast	1								1		
Male	**32**	**34**	**34**	**60**	**43**	**51**	**38**	**39**	**331**	**41**	**8**
Capital & Coast	18	22	18	30	19	34	27	22	190	24	12.5
Hutt	14	12	15	17	12	12	3	10	95	12	12.9
Wairarapa			1	13	12	5	6	6	43	5	19.4
Other DHB							2	1			
Grand Total	**58**	**42**	**50**	**69**	**59**	**74**	**57**	**57**	**466**		

Source: 3DHB SPR Database

SSID by Ethnicity and DHB 1 Jan 2013 - 24 Dec 2020

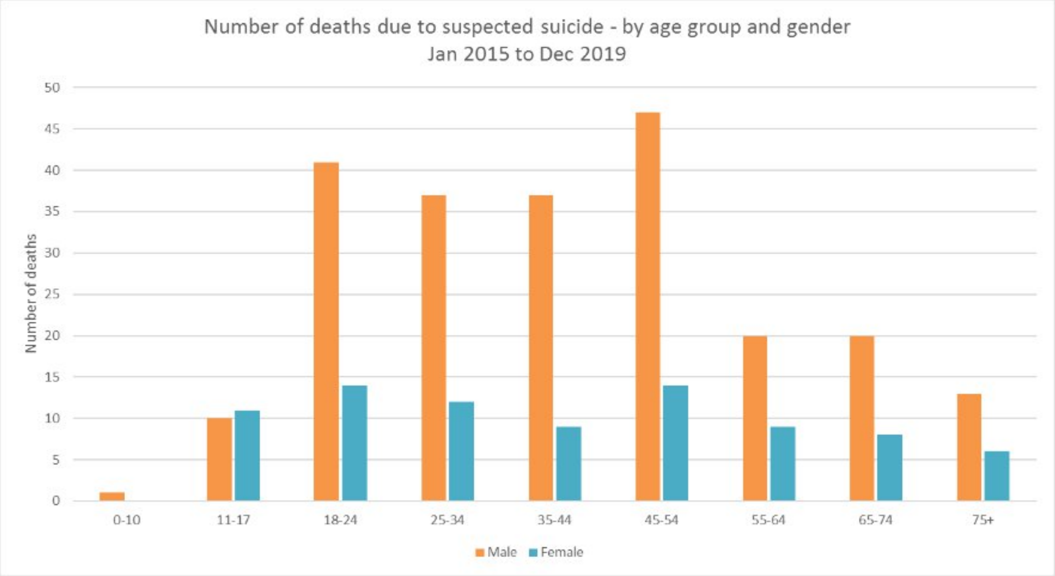
	2013	2014	2015	2016	2017	2018	2019	2020	Grand Total	Av/yr	Rate
Maori	**14**	**8**	**8**	**13**	**8**	**13**	**6**	**9**	**79**	**10**	**14**
Capital & Coast	5	5	4	6	2	9	3	4	38	5	12.5
Hutt	9	3	4	3	3	3	1	1	27	3	13
Wairarapa				4	3	1	2	4	14	2	21
Other	**39**	**32**	**39**	**52**	**49**	**56**	**48**	**47**	**362**	**45**	**11.5**
Capital & Coast	24	21	22	25	24	38	33	32	219	27	11
Hutt	15	11	16	15	14	12	8	11	102	13	12
Wairarapa			1	12	11	6	6	3	39	5	14
Other DHB							1	1	2		
Pacific	**5**	**2**	**3**	**4**	**2**	**5**	**3**	**1**	**25**	**3**	**14.5**
Capital & Coast	5	2	2	3	2	5	2		21	3	10
Hutt			1	1				1	3	0	21
Other DHB							1		1	0	
Grand Total	**58**	**42**	**50**	**69**	**59**	**74**	**57**	**57**	**466**	**58**	**11.5**

Source: 3DHB SPR Database

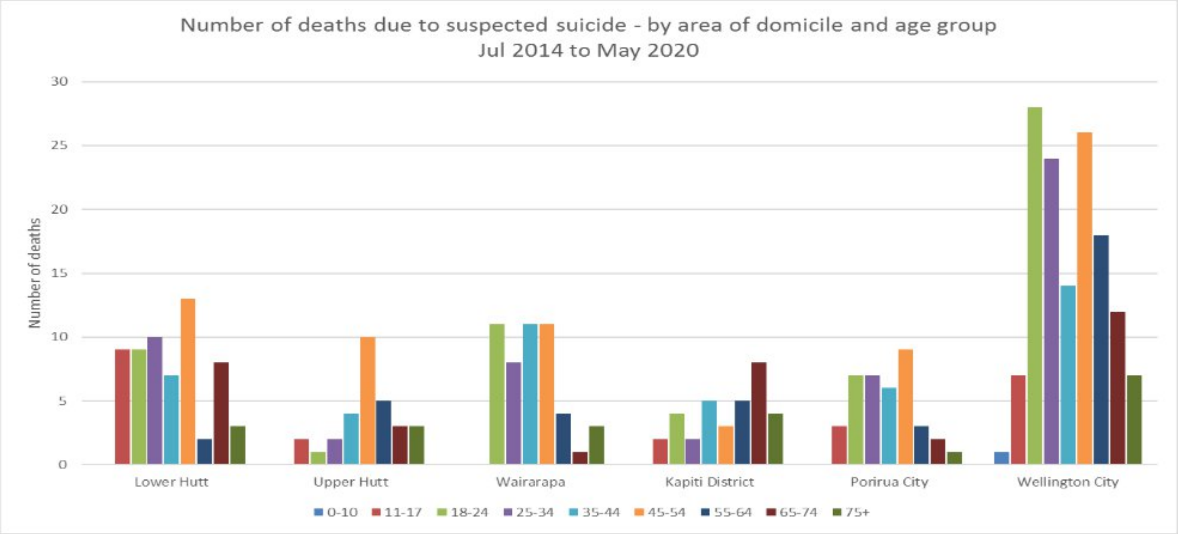
Suspected Self Inflicted Deaths by Territorial Local Authority and Calendar year (Number)

SSID by TLA and Calender year									
	Kapiti District	Porirua City	Wellington City	Lower Hutt	Upper Hutt	Wairarapa	Other DHB	Masterton	
2013	2	8	24	15	9				
2014	5	4	19	11	3				
2015	5	5	19	17	4				
2016	7	9	18	12	7	16			
2017	3	5	20	14	3	14			
2018	5	11	36	8	7	7			
2019	7	3	28	6	3	8	2		
2020	6	5	16	4	6	4		3	
Grand Total	**40**	**50**	**180**	**87**	**42**	**49**	**2**	**3**	**453**
Average by total	9%	11%	40%	19%	9%	11%		1%	

Source: 3DHB SPR Database



Source: 3DHB SPR Database



Source: 3DHB SPR Database

Suspected Self Inflicted Deaths by Ethnicity, Age Band and Territorial Local Authority (Rate)

SSID by Ethnicity and TLA by rate (Indicative Population,2018) - by Age Group and TLA - Under 25 years old

TLA	Māori	Pacific	Other	Total
Wairarapa	12.1	0.0	10.5	10.4
Lower Hutt	20.0	0.0	6.0	8.8
Upper Hutt	3.8	0.0	6.7	5.4
Kapiti District	0.0	14.4	0.0	0.9
Porirua City	5.8	13.2	5.6	8.4
Wellington City	6.0	10.3	7.7	7.7
Grand Total	**9.6**	**7.5**	**6.7**	**7.4**

Source: 3DHB SPR Database

SSID by Ethnicity and TLA by rate (Indicative Population,2018) - by Age Group and TLA - 25-44 years old

Population	Māori	Pacific	Other	Total
Wairarapa	45.4	0.0	22.6	26.5
Lower Hutt	12.2	8.0	12.4	11.9
Upper Hutt	6.4	18.9	9.7	9.7
Kapiti District	20.6	0.0	10.8	12.2
Porirua City	15.6	10.3	12.2	12.5
Wellington City	34.7	4.3	9.8	11.5
Grand Total	**22.3**	**8.0**	**11.4**	**12.6**

Source: 3DHB SPR Database

SSID by Ethnicity and TLA by rate (Indicative Population,2018) - by Age Group and TLA- over 45 years old

Population	Māori	Pacific	Other	Total
Wairarapa	11.8	0.0	11.7	11.6
Lower Hutt	13.1	0.0	12.0	11.3
Upper Hutt	0.0	0.0	21.6	18.9
Kapiti District	0.0	0.0	11.9	10.8
Porirua City	8.6	0.0	15.9	12.1
Wellington City	9.2	19.0	14.7	14.6
Grand Total	**8.4**	**4.9**	**14.1**	**13.2**

Source: 3DHB SPR Database

He Ara Oranga

He Ara Oranga (2018) describes New Zealand's suicide rates as 'persistently high' with 'far reaching impacts'. The report attempts to estimate the hidden numbers behind each suicide, but does not provide quantification of people bereaved by suicide. When extrapolated with 3DHB data it provides another dimension for the SPPC Action Plan.

Estimated Impact SSID	He Ara Oranga (2018) Estimates	2019/20 SSID (Coronial)		
		CCDHB	HVDHB	WRDHB
Died by suicides	1	41	10	5
Attempt to take their own lives	40	1,640	400	200
Make a suicide plan	100	4,100	1,000	500
People think about taking their own lives	300	12,300	3,000	1,500

Source: *He Ara Oranga* (2018) The Government Inquiry into Mental Health and Addictions

Bereaved by suicide

Some researchers have estimated that, on average, for every suicide a further six to ten people will be severely affected by intense grief (Pompili et al., 2008) while others estimate that between five and one hundred people may be adversely affected (Cerel & Campbell, 2008).

Estimated Bereaved by Suicide	CASA (2020) Estimates	2019/20 SSID (Coronial)		
		CCDHB	HVDHB	WRDHB
Died by suicides		41	10	5
Exposed	135	5,535	1,350	675
Closeness	45	1,845	450	125

Source: *Community Postvention Response Service v1.02 (CPRS) (2020) Clinical Advisory Service Aotearoa.*

References

Beautrais, A.L. (2003b). Suicide in New Zealand II: A review of risk factors and prevention. *The New Zealand Medical Journal*, 116(1175), 1-13.

Beautrais, A.L., Collings, S.C.D, Ehrhardt, P., et al. (2005). *Suicide Prevention: A review of evidence of risk and protective factors, and points of effective intervention*. Wellington: Ministry of Health. https://www.health.govt.nz/system/files/documents/publications/suicideprevention-areviewoftheevidence.doc

Cerel, J., Brown, M.M., Maple, M., Singleton, M., Van de Venne, J., Moore, M. & Flaherty, C. (2018). How many people are exposed to suicide? Not six. *Suicide and Life-Threatening Behavior,49*(2), 529-534. DOI: 10.1111/sltb.12450 https://www.plymouthmhn.org/wp-content/uploads/2018/05/How-many-people-are-exposed-to-suicide-Article-2018.pdf

Cerel, J., & Campbell, F. R. (2008). Suicide survivors seeking mental health services: A preliminary examination of the role of an active postvention model. *Suicide & Life Threatening Behavior, 38*(1), 30-34. doi:10.1521/suli.2008.38.1.30

Fallot, R.D. & Harris, M. (2009). Creating cultures of trauma-informed care (CCTIC): A self-assessment and planning protocol. Community Connections: Washington, DC. Retrieved from https://www.healthcare.uiowa.edu/icmh/documents/CCTICSelf-AssessmentandPlanningProtocol0709.pdf

Homes, A. & Grandison, G. (2021). *Trauma-informed practice: A toolkit for Scotland.* National Heath Service. https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland/

Ministry of Health. (2019). *Every Life Matters - He Tapu te Oranga o ia Tangata: Suicide Prevention Strategy 2019–2029 and Suicide Prevention Action Plan 2019–2024 for Aotearoa New Zealand.* Wellington: Ministry of Health. https://www.health.govt.nz/our-work/mental-health-and-addictions/suicide-prevention-new-zealand/suicide-prevention-strategy-and-action-plan

National Health Service Education for Scotland (2017*). Transforming psychological trauma: a knowledge and skills framework for the Scottish workforce.* National Health Service and Education for Scotland. https://www.nes.scot.nhs.uk/our-work/trauma-national-trauma-training-programme/#thetrainingplan4 https://transformingpsychologicaltrauma.scot/media/x54hw43l/nationaltraumatrainingframework.pdf

National Health Service Education for Scotland (2018). *The Scottish psychological trauma training plan.* National Health Service and Education for Scotland. https://transformingpsychologicaltrauma.scot/media/5lvh0lsu/trauma-training-plan-final.pdf

Pompili, M., Lester, D., De Pisa, E., Del Casale, A., Tatarelli, R., & Girardi, P. (2008). Surviving the suicides of significant others. *Crisis: The Journal of Crisis Intervention and Suicide Prevention, 29*(1), 45-48. http://dx.doi.org/10.1027/0227-5910.29.1.45

SAMHSA (2014a). A Treatment Improvement Protocol: Trauma-Informed Care in Behavioural Health Services, TIP 57. US Dept of Health and Human Services Publication No (SMA) 13-4801. Rockville, MD: Substance Abuse and Mental Health Services Administration 2014. https://store.samhsa.gov/shin/content/SMA14-4816/SMA14-4816.pdf

SAMHSA (2014b). *SAMHSA's Concept of trauma and guidance for a trauma-informed approach.* Substance Abuse and Mental Health Services Administration. https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf

Te Pou o te Whakaaro Nui (2018). Trauma-informed care: literature Scan. Wellington, NZ: Te Pou. https://www.tepou.co.nz/resources/trauma-informed-care-literature-scan/876

Te Pou (2021). *Weaving together knowledge of trauma-informed care.* https://www.tepou.co.nz/initiatives/lets-get-real/trauma-informed-approaches

Disability Support Advisory Committee

21 July 2021

Creating enabling maternity care: Dismantling disability barrier - Mums and babies' experience at the 3DHB

Action Required

The 3DHB Disability Support Advisory Committee notes:

(a) the 3DHB review of disabling barriers to maternity care at 3DHB.

Strategic Alignment	This research, and associated literature review, will inform the future design of services for families and their babies to ensure that services meet the needs of disabled people.
Presented by	Rachel Haggerty, Director Strategy, Planning & Performance CCDHB and HVDHB Rachel Noble, General Manager 3DHB Disability
Purpose	To inform DSAC of the research, and associated literature review that will inform the future design of services for families and their babies to ensure that services meet the needs of disabled people.
Contributors	Disabled people giving birth, or birthing children with impairment in our hospitals.
Consultation	This work engaged with disabled people giving birth, or birthing children with impairment in our hospitals.

Executive Summary

In 2019 Capital and Coast District Health Board commissioned DNA to complete a qualitative research project for the purpose of understanding the lived experiences of pregnant women and mothers of young children to help inform the CCDHB Māmā, Pēpi and Tamariki programs of work.

This work is invaluable for providing information to the program it was intended for, however it was identified that there are no relevant references, nor is attention given to the lived experiences of disabled women who are pregnant, who have experienced birth, or who are new mothers. In addition, there is no information on what is available for babies who are born with a known disability.

We commissioned Imagine Better to help us to draw upon and broaden the learnings in the aforementioned research report, aiming to understand more about the disability experiences of maternity care, principally insights in to whether disability rights are upheld or not upheld during maternity care delivered by CCHDB.

In summary the report identifies that Disabled women and women who have babies born with impairments face numerous barriers to quality maternity care. A combination of issues, such as discriminatory attitudes, limited skills and knowledge of healthcare professionals, resource constraints and limited availability of services, prevent disabled women and women who have babies born with impairments from accessing maternity care which is responsive to their individual needs.

Work is now happening with Midwife Educators at CCDHB and Wairarapa Midwife Educators to create a 3DHB work programme for implementing the recommendations through education. In addition future design processes will focus upon two sets of maternity experiences:

1. Disabled women and their babies
2. People who have disabled babies.

Attachment/s

1. Creating enabling maternity care: dismantling disability barriers Mums and babies' experiences at the 3DHB. Literature Review | April 2021
2. Creating enabling maternity care: dismantling disability barriers Mums and babies' experiences at the 3DHB. Research Report | April 2021

Creating enabling maternity care: dismantling disability barriers

Mums and babies' experiences at the 3DHB

Literature Review | April 2021

Prepared by:
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April 2021

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.

Introduction

This literature review focuses on the physical, attitudinal, and communication barriers that disabled women and women who have babies born with impairments face when accessing maternity health care services. It sits alongside the full research report "Creating enabling maternity care: dismantling disabity barriers - Mums and babies' experiences at the 3DHB."

Disabled women

Research shows that disabled women experience inequalities accessing maternity care and report lower levels of satisfaction than non-disabled women. One US study comparing Deaf and hearing women's experiences of antenatal care, found that for Deaf women, poor communication between clinicians and patients leads to low patient satisfaction and poor health outcomes.[1] Another comparative study of disabled and non-disabled women found that across a range of impairment groups – physical, sensory, learning and mental health –women were more likely to be unhappy with aspects of their maternity care, for example women with learning disabilities were more likely to feel dissatisfied with their interactions with staff.[2] The experiences of disabled women in Aotearoa New Zealand mirrors international studies. Findings in the two most recent Ministry of Health Maternity Consumer Surveys[3] found that disabled women were less satisfied with the overall maternity care they received compared to non-disabled women.[4]

Numerous reports show that disabled women continue to experience discrimination when accessing maternity services and do not have their specific and individual requirements met.[5] A combination of barriers, namely discriminatory attitudes, inaccessible environments and communication, and inadequate skills and knowledge of healthcare professionals, prevent disabled women from having a positive maternity journey where they are given choice, control and equitable treatment.[6]

Outdated and disabling stereotypes impact upon disabled women's experiences when seeking maternity care.[7] For example, disabled women are often positioned as asexual, not wanting to have children, and incapable of caring for a baby.[8] Evidence exists of some disabled women being encouraged to terminate pregnancies and to consider sterilisation because of perceived risks about reproducing babies with impairments, being denied access to reproductive technology[9] and feeling that their children may be taken away from them because they had been judged as 'unfit' mothers.[10]

Medicalised understandings of disability and the assumption that disability is a biological condition requiring specialised intervention has had a profound impact on the maternity care provided to disabled women. Disabled women are often viewed as 'high risk' whether it is medically warranted or not, limiting their maternity care and birthing options.[11] For instance, many physically disabled women express concerns that they will be forced to have caesareans simply because they are disabled.[12] Similarly, women with learning disabilities report feeling excluded from decision-making processes about their birth based on healthcare professionals' assumptions that they are incapable of making informed decisions.[13] Although intervention for 'high risk' pregnancies when it is medically warranted is crucially important, being labelled 'high risk' simply because they are disabled can intensify a pregnant disabled woman's fears[14], and leave her feeling less involved in decision-making about her care.[15]

Research suggests that healthcare professionals often lack the necessary knowledge and expertise to care for disabled women.[16] For example, in a 2014 New Zealand study, disabled women described struggling to find maternity practitioners who had any experience of caring for women with similar impairments and an in-depth knowledge of their impairment.[17] Other research describes how diagnostic overshadowing means that sometimes pregnancy related health issues are overlooked and instead treated as disability-related issues.[18] In relation to antenatal education, much of the material rarely takes into account the lived realities of disabled women and adaptations to teaching approaches are insufficient meaning the learning needs of disabled women are not met.[19] Antenatal education and information about breastfeeding for disabled women is reported as inadequate.[20] Similarly, disabled women have difficulty with breastfeeding support postnatally. Women with physical disabilities report that lactation consultants don't often understand their needs and do not suggest strategies for adapting breastfeeding techniques[21] and Deaf women can struggle with the learning process of breastfeeding because of communication difficulties and a lack of sign language interpreters.[22]

Disabling environments also have a huge impact on disabled women's experiences of maternity care. For women with physical impairments and mobility access needs, inaccessible buildings can prevent them from accessing antenatal classes and maternity units that are not equipped with adaptive equipment, such as bassinets that can be accessed from the side, create environments that inhibit disabled women's autonomous care for their babies.[23] For Deaf women, communication barriers can create inaccessible maternity environments. For example, one study found that around 65% of research participants felt that during labour and delivery, they and the staff did not understand each other, and that they were unable to communicate the pain they were experiencing.[24]

Women who have babies born with impairments

Research focused on the experiences of women who have babies born with impairments show the dominance of medicalised understandings of disability and the ways that understandings of disability as deficit and tragedy impacts upon the care they receive. Disability studies has identified many problems with the ways in which a medical diagnosis is handled by healthcare professionals. In much of this work, it is shown that there is an overall assumption that diagnosis is about the 'breaking of bad news'.[25] Diagnosis might happen during routine scanning during pregnancy[26] or may happen postnatally following identification of markers of impairment and may involve genetic testing.

Several studies have identified women's dissatisfaction with the way in which their babies' diagnosis was conveyed highlighting the problematic nature of communication between health care professionals and parents.[27] Research consistently points to health care professionals' use of unsuitable language, including the inappropriate use of medical terminology[28] and inability to talk about impairment and the needs of babies.[29] Mothers who receive a diagnosis for their babies following birth describe the insensitive and detached way some medical professionals deliver the news, leaving them feeling robbed of the joy and happiness of the birth of their new baby.[30] Some medical professionals even find it difficult to congratulate parents on the birth of their child following a diagnosis.[31] When impairment is identified at routine scans, some mothers describe feeling distraught at the insensitivity of healthcare professionals to their questions or need for more information.[32] The timing and setting for delivering a diagnosis is important, with some mothers reporting that they've been told the information when they are on their own, over the phone, or during a ward round.[33]

This shows that practitioners' views and ways of speaking about disability can shape parental conceptions of their children's identities, qualities, and future possibilities from the outset.[34] For example, one research project on maternity and paediatric hospital staff's perceptions of babies born with impairments showed that a tragedy model of disability informed their beliefs and hence ways of speaking to parents. It was based on a belief that the birth of a baby with an impairment goes against dominant cultural ideals about a happy event.[35]

For mothers who receive a diagnosis before the birth of their baby, they have often gone through the process of antenatal screening and diagnostic testing and describe the emotional challenges of making a 'choice' about their pregnancy.[36] Some mothers report the pressure they experience from healthcare professionals to terminate pregnancies when an impairment is detected through chromosomal testing.[37] Others discuss feeling rushed to make important decisions, having limited time to talk through their concerns and questions with healthcare professionals and feeling a sense of disempowerment.[38]

For mothers who have babies born with impairments, breastfeeding may be difficult and pose added challenges and emotional hurdles. Women who have babies that need specialist intervention and care after birth describe feeling anxious about the effect this has on their ability to breastfeed and to bond with their baby. Some report that while supportive, healthcare professionals lack the knowledge and training about feeding issues and different feeding requirements and/or methods for babies with impairments.[39] For mothers who have babies born with cleft palates, they explain that many healthcare professionals do not have the necessary expertise to meet their needs, often provide conflicting and inaccurate information about breastfeeding, and do not provide support around bottle-feeding.[40]

References

1 O'Hearn, A. (2006). Deaf women's experiences and satisfaction with prenatal care: a comparative study, *Family Medicine, 38*(10), 712–716.

2 Redshaw, M., Malouf, R, Gao, H., & Gray, R. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy and Childbirth, 13*(174), 1–14.

3 Ministry of Health. (2012). Maternity Consumer Survey 2011. Ministry of Health; Ministry of Health. (2015). Maternity consumer survey 2014. Ministry of Health.

4 Guerin, B., Payne, D., Roy, D., & McPherson, K. (2017). "It's just so bloody hard": recommendations for improving health interventions and maternity support services for disabled women. *Disability and Rehabilitation, 39*(23), 2395–2403.

5 Aunos, M., & Feldman, M. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 285–296; Prilleltensky, O. (2003). A ramp to motherhood: the experiences of mothers with physical disabilities. *Sexuality and Disability 21*(1), 21–47; MacKay-Moffat, S., & Cunningham,C. (2006). Services for women with disabilities: mothers' and midwives' experiences. *British Journal of Midwifery 14*(8), 472–477; Walsh-Gallagher, D., Sinclair, M., & McConkey, R. (2012). The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: a phenomenological study. *Midwifery, 28*(2), 153–162.

6 Walsh-Gallagher, D., Mc Conkey, R., Sinclair, M. & Clarke, R. (2013). Normalising birth for women with a disability: The challenges facing practitioners. *Midwifery 29*(4), 294–299.

7 Blackford, K., Richardson, H. & Grieve, S. (2000). Prenatal education for mothers with disabilities. *Journal of Advanced Nursing, 32*(4), 898–904; Gill, C. (1996). Dating and relationship issues. *Sexuality and Disability, 14*(3), 183–190; Kallianes, V. & Rubenfeld, P. (1997). Disabled women and reproductive rights. *Disability & Society, 12*(2), 203–221.

8 Nosek, M., Howland, C., Rintala, D., Young, M. & Chanpong, G. (2001). National study of women with physical disabilities. Final report. *Sexuality and Disability, 19*(1), 5–9; Prilleltensky, O. (2003). A ramp to motherhood: The experiences of mothers with physical disabilities. *Sexuality and Disability, 21*(1), 21–47.

9 Kallianes, V. & Rubenfeld, P. (1997). Disabled women and reproductive rights. *Disability & Society, 12*(2), 203–221; Kirshbaum, M. & Olkin, R. (2002). Parents with physical, systemic, or visual disabilities. *Sexuality and Disability, 20*(1), 65–80; Walsh-Gallagher, D., Sinclair, M., & Conkey, R. (2012). The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery, 28*(2), 156–162.

10 Malouf, R., McLeish, J., & Ryan, S., Gray, R. & Redshaw, M. (2017). We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability, *BMJ Open, 7*, 1–10.

11 Walsh-Gallagher, D., Mc Conkey, R., Sinclair, M. & Clarke, R. (2013). Normalising birth for women with a disability: The challenges facing practitioners. *Midwifery 29*(4), 294–299.

12 Lipson, J. (2000). Pregnancy, birth, and disability: women's health care experiences. *Health Care for Women International, 21*(1), 11–26.

13 Malouf, R., McLeish, J., & Ryan, S., Gray, R. & Redshaw, M. (2017). We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability, *BMJ Open, 7*, 1–10.

14 Walsh-Gallagher, D., Sinclair, M., & Conkey, R. (2012). The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding. *Midwifery, 28*(2), 156–162.

15 Redshaw, M., Malouf, R, Gao, H., & Gray, R. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy and Childbirth, 13*(174), 1–14.

16 Kirshbaum, M. & Olkin, R. (2002). Parents with physical, systemic, or visual disabilities. *Sexuality and Disability, 20*(1), 65–80; Lipson, J. (2000). Pregnancy, birth, and disability: Women's health care experiences. *Health Care for Women International, 21*(1), 11–26.

17 Payne, D., Guerin, B, Roy, D., Giddings, L, Farquhar, C., & McPherson, K. (2014). Taking it into account: Caring for disabled mothers during pregnancy and birth. *International Journal of Childbirth, 4*(4), 228–239.

18 Prilleltensky, O. (2003). A ramp to motherhood: The experiences of mothers with physical disabilities. *Sexuality and Disability, 21*(1), 21–47.

19 Blackford, K., Richardson, H., & Grieve, S. (2000). Prenatal education for mothers with disabilities. *Journal of Advanced Nursing, 32*(4), 898–904.

20 Williams, D., Webber, J., Pell, B., Grant, A., Sanders, J., Choy, E., Edwards, A., Taylor, A., Wu, M., Phillips R. (2019): "Nobody knows, or seems to know how rheumatology and breastfeeding works": Women's experiences of breastfeeding whilst managing a long-term limiting condition - A qualitative visual methods study. Midwifery.78:91–96. doi: 10.1016/j.midw.2019.08.002. Epub 2019 Aug 6. PMID: 31404778; PMCID: PMC6750183.

21 Powell, Robyn M, Mitra, Monika, Smeltzer, Suzanne C, Long-Bellil, Linda M, Smith, Lauren D, Rosenthal, Eliana, & Iezzoni, Lisa I. (2018). Breastfeeding Among Women With Physical Disabilities in the United States. *Journal of Human Lactation, 34*(2), 253–261.

22 Andrews, Erin E, Powell, Robyn M, & Ayers, Kara B. (2021). Experiences of Breastfeeding among Disabled Women. *Women's Health Issues, 31*(1), 82–89.

23 Hall, J., Collins, B., Ireland, J., & Hundley, V. (2018). *The human rights and dignity experience of disabled women during pregnancy, childbirth and early parenting.* University of Bournemouth; Payne, D., Guerin, B, Roy, D., Giddings, L, Farquhar, C., & McPherson, K. (2014). Taking it into account: Caring for disabled mothers during pregnancy and birth. *International Journal of Childbirth, 4*(4), 228–239.

24 Gichane, M., Heap, M., Fontes, M., & London, L. et al. (2017). “They must understand we are people”: Pregnancy and maternity service use among signing Deaf women in Cape Town. *Disability and Health Journal, 10*(3), 434–439.

25 McLaughlin, J., Goodley, D., Clavering, E., & Fisher, P. (2008). *Families raising disabled children: enabling care and social justice.* Palgrave Macmillan.

26 Lalor, J., Devane, D., & Begley, C. (2007). Unexpected diagnosis of foetal abnormality: women’s encounters with caregivers. *Birth, 34*(1), 80–88.

27 Davies, R., Davis, B., & Sibert, J. (2003). Parents’ stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child. *Child: Care, Health & Development, 29*(1), 77–82.

28 Vehkakoski, T. (2016). Newborns With an Impairment: Discourses of Hospital Staff. *Qualitative Health Research, 17*(3), 288–299.

29 Sooben, R. (2010). Antenatal testing and the subsequent birth of a child with Down syndrome: a phenomenological study of parents’ experiences.” *Journal of Intellectual Disabilities, 14*(2), 79–94.

30 Wright, J. (2008). Prenatal and postnatal diagnosis of infant disability: breaking the news to mothers. *The Journal of Perinatal Education, 17*(3), 27–32.

31 Vehkakoski, T. (2016). Newborns With an Impairment: Discourses of Hospital Staff. *Qualitative Health Research, 17*(3), 288–299.

32 Lalor, J., Devane, D., & Begley, C. (2007). Unexpected diagnosis of foetal abnormality: women’s encounters with caregivers. *Birth, 34*(1), 80–88.

33 Davies, R., Davis, B., & Sibert, J. (2003). Parents’ stories of sensitive and insensitive care by paediatricians in the time leading up to and including diagnostic disclosure of a life-limiting condition in their child. *Child: Care, Health & Development, 29*(1), 77–82; Clark, L., Canary, H., McDougle, K., Perkins, R., Tadesse, R., & Holton, A. (2020). Family Sense-Making After a Down Syndrome Diagnosis. *Qualitative Health Research, 30*(12), 1783–1797.

34 Avery, D. (1999). Talking “tragedy”: Identity issues in the parental story of disability. *In S. French (Ed.), Disability discourse (pp. 116–126).* Open University Press; Strauss, R., Sharp, M., Lorch, C., & Kachalia, B. (1995). Physicians and the communication of “bad news”: Parent experiences of being informed of their child’s cleft lip and/or palate. *Paediatrics, 96*(1), 82–89.

35 Vehkakoski, T. (2016). Newborns With an Impairment: Discourses of Hospital Staff. *Qualitative Health Research, 17*(3), 288–299.

36 Landsman, G. (1998). Reconstructing Motherhood in the Age of “Perfect” Babies: Mothers of Infants and Toddlers with Disabilities. *Signs: Journal of Women in Culture and Society, 24*(1), 69–9; Sooben, R. (2010). Antenatal testing and the subsequent birth of a child with Down syndrome: a phenomenological study of parents’ experiences. *Journal of Intellectual Disabilities, 14*(2), 79–94; Rogers, C. (2007). Disabling a family: Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education, 34*(3), 136–143.

37 Nelson Goff, B. Springer, N., Foote, L., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G., & Cross, K. (2013). Receiving the initial Down Syndrome diagnosis: A comparison of prenatal and postnatal parent group experiences. *Intellectual and Developmental Disabilities, 51*(6), 446–457.

38 Sooben, R. D. (2010). Antenatal testing and the subsequent birth of a child with Down syndrome: a phenomenological study of parents' experiences. *Journal of Intellectual Disabilities 14*(2): 79–94.

39 Ryan, K., Smith, L., & Alexander, J. (2013). When baby's chronic illness and disability interfere with breastfeeding: Women's emotional adjustment. *Midwifery, 29*(7), 794–800; Pantazi, M., Jaeger, M., & Lawson, M. (1998). Staff support for mothers to provide breast milk in paediatric hospitals and neonatal units. *Journal of Human Lactation, 14*(4), 291–296.

40 Johansson, B., & Ringsberg, K. (2004). Parent's experiences of having a child with cleft lip and palate. *Journal of Advanced Nursing,* 47(2), 165–173; Lindberg, N. & Berglund, A. (2014). Mothers' experiences of feeding babies born with cleft lip and palate. *Scandinavian Journal of Caring Sciences, 28,* 66–73.

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Creating enabling maternity care: dismantling disability barriers

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Mums and babies' experiences at the 3DHB

Research Report | April 2021

Prepared by:
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Imagine Better Ltd

Imagine Better

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

Special thanks go to the women who generously shared stories of their maternity journeys with us.

Thanks to our collaborator - DPA - for contributing their research and community expertise to help understand disabled women's maternity experiences.

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April 2021

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

List of Acronyms

3DHB	Coalition of Capital and Coast, Hutt Valley, and Wairarapa District Health Boards
C-section	Caesarean section birth
CCDHB	Capital and Coast District Health Board
CMT	Community Midwife Team
CPAP	Continuous Positive Airway Pressure Therapy, used in newborns with breathing difficulties
CVS	Chorionic villus sampling, or chorionic villus biopsy, is a prenatal test for chromosomal differences
CYFS	Child Youth and Family, currently known as Oranga Tamariki – Ministry for Children
DPA	Disabled Persons Assembly NZ
DPO	Disabled People's Organisation
HVDHB	Hutt Valley District Health Board
IHC	A New Zealand organisation providing support and care for people of all ages with intellectual disabilities
LMC	Lead Maternity Carer
NASC	Disability Needs Assessment and Service Coordination Services
NICU	Neonatal Intensive Care Unit at CCDHB
PTSD	Post-traumatic Stress Disorder
SCBU	Special Care Baby Unit at HVDHB
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WDHB	Wairarapa District Health Board

Executive Summary

Disabled women and women who have babies born with impairments face numerous barriers to quality maternity care. A combination of issues, such as discriminatory attitudes, limited skills and knowledge of healthcare professionals, resource constraints and limited availability of services, prevent disabled women and women who have babies born with impairments from accessing maternity care that responds to their individual needs.

The purpose of this report is to understand more about the 3DHB maternity care experiences of disabled women and women who have babies born with impairments. Findings from the project will help inform planning and service delivery to improve outcomes for women and their babies in the 3DHB region.

Eight disabled women, one disabled trans man, and ten women who have babies born with impairments were interviewed about their experiences of 3DHB maternity services. Three LMC midwives, one core midwife and seven CMT midwives were interviewed about their experiences of providing care to disabled women and women who have babies born with impairments. A literature review focusing on the disabling barriers to maternity care was used alongside interviews with women and midwives. This is available as a supporting document.

Key findings include:

1. Midwives provide individualised and woman-centred care

Midwives provide emotional support and are trusted by women. They connect with women on a personal level, creating a safe space for emotions to be shared. Midwives work to ensure disabled women's rights are upheld and are responsive to access needs. LMC midwives sometimes act as advocates for women in hospital settings, ensuring that women understand their rights and have access to good quality care. Midwives recognise the importance of community networks and, where time and resources allow, try to facilitate connections between women with similar experiences. Time restraints and lack of training in disability issues are experienced as barriers by midwives to delivering good maternity care to disabled women and women who have babies born with impairments.

2. Women have good maternity care experiences when healthcare professionals are caring and supportive

Women value healthcare professionals that are caring and emotionally engaged. A sense of genuinely being care for, and about, is central to women's perceptions of quality relationships with healthcare professionals. Clear communication, emotional support and a positive outlook are particularly important for women who have babies born with impairments. Women also value being enabled to be part of their baby's care, which helps them feel empowered as mothers and develop a bond with their baby.

3. Disabled women face multiple barriers at the beginning of their maternity journey

For many disabled women, the maternity journey begins long before their baby is conceived and can be a complicated and emotionally challenging process. They may experience discrimination by healthcare professionals about their choice to become a parent and their ability to parent a child. Negative attitudes towards disability and a lack of experience providing maternity care to disabled women mean that disabled women often have limited ability to choose a midwife and the place where they want to give birth. The emotional burden of continually having to share information about their impairment and access needs with different healthcare professionals is difficult for some disabled women.

4. Diagnosis of a baby's impairment

The communication of a diagnosis by healthcare professionals is often framed by a sense of tragedy and is deemed to be communication of 'bad news'. Often a diagnosis is given with no further explanation about what it is and what it might mean. The impacts of a negative experience around the delivery of a diagnosis can have life-long impacts on women, their baby and their families. CMT midwives are regularly involved in the delivery of a diagnosis. They try to remain clear and factual and focus on the joy of birth. Healthcare professionals sometimes don't support women in their choice to continue their pregnancy if antenatal testing shows their baby has a chromosomal difference.

5. Bad experiences with healthcare professionals

Disabled women sometimes feel a sense of surveillance from healthcare professionals and that their ability to care for their baby is being assessed. They may feel scared that their baby will be taken away from them. A general lack of knowledge or consideration of access needs and disability issues is the main reason disabled women have bad experiences with healthcare professionals. For women who have babies born with impairments, the use of discriminatory language by healthcare professionals is often the reason for bad experiences. Poor communication by healthcare professionals and not sharing information in a timely manner also contributes to poor experiences. Women often interact with numerous healthcare professionals which can impact upon their maternity journey.

6. Inadequate knowledge about disability issues

Antenatal classes have a narrow focus on 'natural' and 'normal' births and do not address disability issues. Many women feel antenatal classes have little educational value because they do not address issues relevant to their individual situation. Midwives and disabled women alike find it difficult to find reliable and relevant information about disability and pregnancy. Similarly, women who have babies born with impairments don't know where to go for information and community-based supports and are given little guidance by healthcare professionals.

7. Lack of feeding support

Disabled women encounter numerous attitudinal barriers to breastfeeding. Often they are denied the choice to breastfeed. They can experience a sense of failure and the bonding process with their baby can be disrupted. Ableist assumptions by healthcare professionals that babies with impairments cannot breastfeed impacts upon some women and their decision to breastfeed, while a lack of support makes bottle-feeding complicated for women who have babies born with impairments. For women who have babies in specialist care wards, they sometimes feel excluded from their baby's feeding routine and want to be enabled to be an active part of it. Resource constraints mean that women aren't always receiving the supports they need to establish a good feeding routine with their baby.

8. Stretched mental health services

Many disabled women feel they are ill-prepared for, and not well-supported to manage, their mental health during their maternity journey. Women who had babies born with impairments described a need for mental health support at critical times in their maternity journey, such as around diagnosis and when their babies are in specialist care units. When requiring mental health care, many disabled women feel they cannot access support unless they are critical. Midwives note the growing rate of mental distress in women and are concerned about increasingly stretched mental health services.

To conclude the report, we offer several recommendations in line with the findings. Key recommendations include:

- provide disability awareness training, which is necessary to help reduce discriminatory attitudes and inadequate knowledge of healthcare professionals;
- provide antenatal education that understands and embraces the experiences of the disabled community;
- improve access to community-based supports and services that contain adequate information, education, and wraparound support for the disabled community;
- remove barriers to midwives providing enabling care;
- increase access to mental health services for women at all stages of their maternity journey; and
- improve data collection on the intersection between maternity experiences and disability.

Introduction

The ways in which impairment and disability are constructed, understood, and negotiated impacts upon the provision of maternity care services for disabled women and women who have babies born with impairments. Traditional medicalised discourses of disability as an individual tragedy, dysfunction, and deficit, and as something requiring medical diagnosis and cure,[1] impact upon maternity care delivery and experience. Research consistently demonstrates that disabled women and women who have babies born with impairments report low levels of satisfaction with their maternity care.

The purpose of this report is to understand more about the disability experiences of maternity care, particularly perceptions of if and how disability rights are upheld during the delivery of 3DHB maternity care. Drawing upon the lived experiences of women who have used 3DHB maternity services, this report advocates for improved maternity care for disabled women and women who have babies born with impairments.

It addresses five phases of the maternity journey:

- **Path to conception**
- **Pregnancy**
- **Labour and birth**
- **Postnatal care**
- **Early days**

The project builds upon a previous DHB-commissioned piece of work that examined the experiences of mothers of young children in the Porirua region to help inform their 'Māmā, Pēpi and Tamariki' programs of work. No disabled women nor women who had babies born with impairments were included as part of that research.[2] In order to address the omission, Disability Strategy 3DHB commissioned this additional research project to draw upon the framework of the previous research and extend it through a focus on disability. The women who participated in this research wanted to share stories of their maternity journeys in the hope they could inform the development and delivery of maternity care that better responds to disability issues and rights.

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[1] Goodley, D. [2016]. *Disability Studies: An Interdisciplinary Introduction.* Sage.

[2] One baby spent time in NICU but there was no mention of impairment or the impact of disability upon the experience of maternity care.

We spoke to women who had recent experiences of using 3DHB maternity services and women who reflected upon their maternity journey from several years ago. There was little difference between their experiences in terms of wider perceptions of disability with outdated and discriminatory attitudes experienced by women regardless of when their child was born. This is in line with international research that shows many disabled people believe there has been little progress made towards improving the way in which disability is understood and disabled people treated.

Approach

This project promotes a human rights-based approach to maternity care and draws upon the social model of disability, which shows that people are disabled by society rather than impairment.[3] 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…".[4]

Social and human rights approaches to disability show that the problems disabled women and women who have babies born with impairments face using 3DHB maternity services are shortcoming of healthcare settings and systems as opposed to problems inherent in disabled people. The disability-related inequities presented in this report are therefore considered a symptom of wider social, political, environmental, and economic conditions that drive poor health and wellbeing outcomes for disabled people in Aotearoa New Zealand. A social and human rights approach calls for maternity care that is enabling for disabled women and women who have babies born with impairments.

For disabled women, enabling care:

> accommodates their access needs, focuses on their strengths, partners with them to develop maternity plans, prioritises the knowledge they have over their bodies and life situations, and supports them to make the most appropriate choice for their own situation.

For women who have babies born with impairments, enabling care:

> recognises the inherent value of babies born with impairments, supports them and their families to understand their baby's impairment, and provides them with the resources and knowledge to best care for their baby in a way that helps them realise their full potential.

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[3] Oliver, M. (2009). *Understanding disability: From theory to practice*. Macmillan International Higher Education.

[4] United Nations. (2006). Article 1 – Purpose. *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.

Report Limitations

Resources and timeframe limited the scope of the project. The research aimed to obtain individual perspectives from a small group of disabled women and women who have babies born with impairments about their experiences to increase disability equity in maternity care. The relatively small sample size means we cannot, nor do we wish to, generalise the experiences of these women.

The report is limited in terms of participants' ethnic background. A number of enquiries were made to recruit disabled Māori / whānau hauā, including emailing specialised services, social media accounts of Māori disability advocates, and targeted calls for participation, however, this proved unsuccessful. All the disabled women identified as European or Pākehā, with a small number of women who have babies born with impairments identifying as Māori. Disabled Māori experience poorer health outcomes than disabled non-Māori because of the impacts of colonialism and racism.[5] Future research should look to work with Māori health and disability providers and NGOs to address the particular issues faced by disabled Māori / whānau hauā when accessing maternity services.

Similarly, the report is limited in terms of contributions from other healthcare professionals. The initial project design aimed to understand more about the maternity experiences of women and midwives. However, as the research progressed, it became clear that the nature of maternity care received by many women meant they came in to contact with a wide range of 3DHB healthcare professionals, including paediatricians, lactation consultants, and nurses. We were not able to include any of their perspectives in the report. Any future research would need to be sure to include these additional experiences given the critical role they play in the provision of quality maternity care to disabled women and women who have babies born with impairments. It would also be useful to explore the ways in which women's maternity care intersect with disability support services, as they move through the latter stages of their maternity journey.

While focusing on the experiences of women from across the 3DHB region, this report does not offer any comparison of maternity care experiences across the different DHB sites. It is important to note, however, that each DHB location will present with issues and challenges specific to geographical location and socio-demographics. Future research could usefully unpack some of the similarities and differences between and across DHB sites.

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[5] Health and Disability System Review. (2019). *Health and Disability System Review - Final Report.* Hauora Manaaki ki Aotearoa Whānui – Pūrongo mō Tēnei Wā. HDSR; 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.

Report outline

We begin this report by detailing the methodology used, including providing information about the participants involved in this study and the interview process. The bulk of the report draws upon interview material with women and midwives, highlighting what is working well and what isn't working well. Following this, we make some recommendations for improvement. A summary of literature on disabling barriers to the maternity care of disabled women and women who have babies born with impairments is available as a separate supporting document.

Methodology

Recruitment

Participants were recruited through a variety of methods, including email lists, websites, and social media accounts of disability-related organisations. We made the criteria for participation open to women at different stages of their maternity journey, including women who had recently given birth, women who wished to provide retrospective accounts of their maternity journey up to 10 years ago, and women who were pregnant. This approach is consistent with other research on women's maternity experiences. We asked to speak to 20 women in total:

1. 10 women who have physical, sensory, learning impairments and/or mental distress; and,
2. 10 women who have babies born with impairments (physical, sensory, or intellectual) who found out about their baby's impairment and/or health condition either antenatally or soon after birth.

We opened participation up to women from across the 3DHB area to ensure adequate participant numbers and with the knowledge that women often interact with more than one DHB during their maternity journey.[6] Additionally, we spoke to some healthcare professionals:

1. One core midwife;
2. Seven community midwives as part of a focus group;
3. Three LMC midwives;
4. One representative from a local Disability Needs Assessment and Service Coordination (NASC).[7]

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[6] In order to not identify specific hospitals, their names have been omitted. When referring to NICU at Wellington Hospital or SCBU at Hutt Hospital, the term 'specialised care ward' has been used instead.

[7] We had anticipated that disabled women would speak about their funded disability supports in relation to their maternity journey. However, there this did not come up during the interviews. We spoke to a NASC representative about their perspective of some of the barriers they face providing support to disabled women but given that these issues weren't raised by women, this interview material has not been included in the report.

Participants

Disabled women

We faced challenges finding ten disabled women willing to share their experiences. Eight women and one trans man contacted us to be part of the project. In the end, participants represented a good variety of impairment types and spread across the 3DHB region:

- Age: ranged from 24 - 44 years old
- Ethnicity: nine people identified as NZ European/Pākehā
- Number of children: Most are first children. One woman had another child in a different DHB, and one had her child before acquiring an impairment
- Ages of children: pursuing pregnancy; 7 months; 8 months; 2 years; 2 ¾ years; 3 ½ years; 4 years; 4 ½ years; 8 years
- Type of impairment of gestational parent: paraplegic, amniotic banding amputee, Blind, Deaf, neurodiverse, learning disabled, genetic chromosomal difference, mental distress, and PTSD
- Location of maternity care: five used CCDHB, one used HVDHB, one used both CCDHB and HVDH, and one used both HVDH and WrDHB
- LMC: five had a private midwife or obstetrician during pregnancy and were supported by core midwives during labour, and four used the CMT
- Child's impairment: Some of the children of disabled women were born with impairments such as global developmental delay, and genetic chromosomal differences

Women who had babies born with impairments

We had an overwhelming response to the call for participation from women who had babies born with impairments. Over 20 women contacted us to be part of the project. Many of these women did not fit the criteria for participation – mainly because of the age of their child – but still wanted to share their story. This reinforced the importance of this piece of work, as well as the lifelong impact the maternity experience can have on women and their families.

To capture a diversity of experience, we tried to ensure a good mix of ages, type of impairment and spread across DHB sites. Participants were diverse:

- Age of mother: ranged from 31 - 48 years old
- Ethnicity: eight women identified as NZ European/Pākehā/European, and two women identified as Māori
- Number of children: ranged from 1 child through to 5 children
- Ages of children: 6 months; 7 months; 8 months; 15 months; 20 months; 2 years; 3 years; 4 years; 6 years; 7 years

- Location of maternity care: five women used CCDHB, two used HVDHB, one woman used both CCDHB and HVDH, and two women used WrDHB
- LMC: most women had a private midwife or obstetrician during pregnancy and were supported by core midwives during labour. Three women used the CMT.
- Child's impairment: chromosomal and genetic duplications and deletions, intellectual impairment, cleft lips, palates and hands, and hearing impairment. Many children also had associated health conditions, such as heart conditions and seizures[8]
- Diagnosis: six women found out their child's diagnosis antenatally, three found out postnatally and one woman had an antenatal diagnosis with further diagnoses made postnatally

Healthcare professionals - midwives

In line with the 'Māmā and Pēpi' report, we undertook interviews with midwives to understand from their perspective some of the challenges that women face, as well as some of the barriers they experience, providing maternity care. We aimed to speak to an LMC midwife as well as CMT and core midwives.

When organising to speak with the CMT and core midwives, we worked closely with the charge midwife to organise a suitable time and format. We were aware of their busy schedules and did not want to take up any more time than necessary. We made ourselves available at any time that would suit them and remained flexible in terms of the interview format.

We had difficulty recruiting LMC midwives to participate in the project. Despite following up several suggested contacts through the 3DHB, we were not able to recruit any LMC midwives this way. We subsequently asked some of the women who participated in the project if they could facilitate an introduction to their midwives. This proved successful and we were able to speak to three midwives working as LMCs.

Semi-structured interviews and focus group interview

Semi-structured interviews with women took between forty-five minutes to one and a half hours. Most of the interviews were conducted face-to-face, with a small number of interviews happening over Zoom or over the phone. The majority were conducted in people's homes, with some taking place in public spaces such as a board room at the Imagine Better or DPA offices in Wellington. At many of the interviews, particularly those conducted in people's homes, children were present, and we had the pleasure of meeting them as well. Participants were given the details of some community-based support organisations in case the interviews raised feelings and/or issues they would like help with. They were given a koha to thank them for their time and contribution.

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[8] In some cases, we refer specifically to a child's impairment or diagnosis if it aids understanding, while at other times we do not include this information for the purposes of confidentiality.

Dr Carey-Ann Morrison, Senior Researcher for Imagine Better, conducted the interviews with women who have babies born with impairments. Carey-Ann is an experienced qualitative researcher and is a mum to a young disabled son. Angela Desmarais, Researcher for DPA, conducted the interviews with disabled women. Angela is an experienced qualitative researcher and is disabled.

We conducted one semi-structured interview and one focus group interview with DHB midwives. Three semi-structured interviews with LMC midwives were also conducted. These interviews took about an hour. Interviews were conducted both face-to-face, over Zoom and over the phone. Carey-Ann and Angela each conducted an equal number of these interviews but were both present for the interviews with the core and CMT midwives.

We joined the CMT for one of their weekly meetings and midwives contributed for as long as they could before leaving to attend clinics and/or appointments. To start, we had seven members of the CMT present, with three remaining by the end of the discussion. Immediately after the focus group with the CMT, we spoke to one of the core midwives. Another staff member covered for her so she could participate.

Interview questions were developed in consultation with Disability 3DHB. We drew upon the framework from the previous 'Māmā and Pēpi' report and adapted it to include disability-related issues informed by the literature review. We gave disabled women and women who have babies born with impairments a demographics questionnaire to complete.

All stages of the project were conducted in an ethical manner. The privacy and confidentiality of all those who agreed to participate was ensured. Informed consent was sought, and all participants were supported to feel safe to share their experiences. Upon consent, conversations were recorded. Plain English was used in all documents. All interviews were audio-recorded and transcribed.

Midwives provide women-centred and individualised care

Midwives offer emotional support and are trusted by women

Midwives were overwhelmingly described as caring, understanding, and supportive. It was emphasised by women and the midwives we spoke to that, if women were well supported and cared for, their babies were too. Many women talked about the way in which midwives connected with them on a personal level, listening in a non-judgemental way and creating space for them to talk and share their emotions. Similarly, midwives were aware of the significant role they play in women's lives and the lifelong impact a quality midwife relationship can have on their maternity journey. They spoke of gaining a great sense of satisfaction from their relationships with the women in their care.

Women who had babies born with impairments emphasised the special nature of their relationship with LMC midwives. They spoke fondly of their midwife and some maintained a relationship beyond the standard six-week period of midwife care.

> "Our midwife had a wonderful caring nature, and she was focused on how I was and how I was doing, and she was in my corner and I felt like she was a cheerleader for me." – Woman
>
> "She was supportive and encouraging and just reminded me that I am a great mum, and I can do this, and that was so powerful." – Woman
>
> "That connection as a human and as a mother is a really important part of that job, more so than checking the heart rate, and scheduling the scans, it's a human connection." – Woman
>
> "She just took care of me, knowing that if I was ok, then baby was ok. She was really positive and supportive." – Woman

For disabled women who had an LMC midwife, there was a strong emphasis on the trust they built and the consistency of this relationship throughout their maternity journey. Having an LMC midwife meant they didn't have to repeatedly tell their story. Disabled women also talked about how midwives were reassuring and encouraging when they expressed concerns about parenting or worries about the future. This emotional support was important for countering some of the negative attitudes disabled women encountered early on in their maternity journey.

> "I was questioning whether I would be a good mum, whether I would be able to cope. I was really emotional but after each appointment with the midwife I would feel better about it."
> – Woman

CMT and core midwives were applauded for their ability to build deeply connected and trusting relationships. Core midwives, in particular, were described as skilful at quickly establishing rapport and trust while gathering necessary information vital to the safe delivery of babies. For women who had babies born with impairments and who knew about their baby's diagnosis antenatally, the birth of their baby was a time when they needed additional support and care. They knew, for a variety of reasons, that their birth wasn't going to be 'straight forward'. Core midwives were trusted by the women they cared for and were a reassuring presence throughout labour.

> "I remember saying to her 'is my baby going to die?' and she was looking at me and reassuring me. It was incredible that even though she didn't really know me, I trusted her implicitly. She built that relationship with me so quickly." – Woman

> "I was really scared to see my baby. I was worried that I might look at her and not feel the immense love that you feel for your other children. I had told the midwife I was a bit concerned about that, and the midwife was just wonderful and beautiful, and was really supportive."
> – Woman

Extensive experience working as part of a multi-disciplinary clinical team means core midwives are knowledgeable about the clinical care needs of babies, as well as the different ways they can support women during birth. Previous experience delivering care during medically complex births is one way they can reassure women they will be well-cared for.

> "We do this every day, this is what we are trained for, being able to provide that stability and that comfort to people... we can say 'it's the first time you have been in this situation, but it's not the first time I have. I know what I am going to do, I can provide you with support and I can provide you with the knowledge that we've got this', and I think that can provide a lot of comfort for people. Even though they can think that their world is spinning out of control, the team around them have got it." – Core midwife

Midwives support disabled women's rights to quality maternity care

Conversations with midwives showed that they recognise the rights of disabled women to have autonomy and control over their bodies. This is an important way that midwives individualised their care. Many midwives expressed that while disabled women's pregnancy care can be challenging, having a baby is a 'normal' experience for most women and so it should also be a 'normal' experience for disabled women.

> "If they have a disability, our job is to understand that person and individualise their care… and ask them 'what can I do to assist you?'" – CMT midwife
>
> "We are providing more and more care to women with very complex health needs that probably 20 years ago they were told that they couldn't have a baby. The focus has to be on the person… It is about fostering all the good things and looking at the individual." – CMT midwife
>
> "Disability is so varied that you've just got to work with the individual and work out how best to tailor their care. Everybody's different and I do think that we generally do a pretty good job of individualising care." – Core midwife

The delivery of individualised maternity care by midwives and a focus on ensuring disabled women had choice and control during their maternity journey helped them feel safe and respected as a person with their own unique experience and needs.

> "They were always asking what I wanted, all the way through they really put my decisions at the forefront of everything and I felt really in control of those decisions… I've never felt so supported by a hospital service. I can't fault the care that the midwives and the maternity unit gave me." – Woman
>
> "The midwife always made sure I understood everything that I needed to know. She was really good in that respect." – Woman

Core midwives spoke of situations where they provided individualised care in response to women's impairments, drawing on their training to provide practical solutions during birth. It was explained that midwives have good clinical knowledge of women's bodies and birth techniques and can draw upon this knowledge to support disabled women.

> "A lot of our skillset in training is being able to help women have their babies in very different positions… knowing what is going to be best physiologically for a baby to be born… and I think that is just general midwifery knowledge." – Core midwife

These midwives also considered the ways in which individualised care reduces the chance of making assumptions about disability, noting that similar impairment-types do not necessarily result in the same access needs. LMC midwives spoke about their care being responsive and catering for the uniqueness of each woman's experience.

> "It is just that awareness and respecting differences and being open to how you can support that woman and her family." – CMT midwife
>
> "Meeting individual needs whatever that might be, finding out what they are, and not making assumptions or ignoring something because it's easier." – CMT midwife
>
> "We work in a way so that we are responsive when we come across these situations and scenarios." – LMC midwife

Midwives respond well to disabled women's access needs

Many disabled women appreciated midwives' attempts to ensure small and consistent teams that catered to their access needs. Disabled women praised midwives on the effort they took to research and understand the support they needed.

> "I felt the maternity services went above and beyond with things like helping me work out what baby bath would work best." – Woman
>
> "They gave me this stretchy thing I could put over my body so I could sleep with my baby on me safely, it was really nice." – Woman
>
> "My midwife would let me put my hand on her so I could feel the baby's heartbeat as well… she would listen to the rhythm and tap it on to my hand to give me the experience of the baby's heartbeat, which is really lovely." – Woman

Most disabled women described their birthing experiences as positive in relation to access. This was particularly the case for the Blind and Deaf women, whose birthing teams communicated various stages of the birthing process to them in accessible ways.

> "Quite early on my midwife asked if I wanted to do a tour of the maternity unit and I was quite lucky because I'd had my first daughter there, so had been there when I was sighted. They put a big emphasis on feeling comfortable in the space and knowing not only my rights as a patient but also what I could ask for to make it as comfortable as possible. It was great." – Woman
>
> "My husband is also Deaf so the midwife would speak, and the interpreter would sign to my husband and then he would tell me to breathe or push or whatever the instruction was… it was really great to have an interpreter there because it really helped my husband to be able to support me." – Woman
>
> "My midwife was talking me through absolutely everything… every little step she verbalised to me and my partner. She told me what everyone was doing at all points – they had a screen up, but she stood on the other side. It was a peek behind the curtains, literally! A few seconds

> before it happened, she'd confirm what was happening. There was nothing surprising. I felt really informed." – Woman

Many of the disabled women interviewed spoke positively about the process of booking appointments with CMT and LMC midwives, describing them as flexible and understanding of the need to sometimes change appointment times. One LMC midwife acknowledged appointments can be particularly challenging for disabled women who live rurally.

> "I had home visits from my midwife. I feel like they really went out of their way to make it easy and accessible as possible for someone who doesn't drive." – Woman

> "Transport is a big thing and midwives do a lot of accommodating in doing home visits. Some women could live over an hour away from us but, at this point in time, there's nothing from that secondary care service that is going out to the women in their neighborhoods." – LMC midwife

CMT midwives tried to remain flexible about where they met women, sometimes visiting them at home or on the maternity ward, and ensured that upon discharge, they were connected with relevant community-based supports.

> "We see them here at hospital and at home, for that continuity and we support them through that and then once the midwifery side is finished there are the other providers like Plunket and we would support that transition so they can continue that support, to their GP, or other specialists, and so not just run away – make sure somebody else is there, whether that is a medical person or a social service person." – CMT midwife

LMC midwives sometimes act as advocates

Sometimes LMC midwives acted as advocates for women in their care. This meant that in addition to the standard LMC care, they also spoke up for women if they felt something wasn't right, asked questions to help aid their understanding, and worked to ensure their rights to good maternity care were upheld. Several women who had babies born with impairments spoke about having their LMC midwives advocate for them in hospital settings.

> "I had a midwife who was an advocate for me, and she continued along the journey, she had been a midwife for another local woman who had a baby with the same diagnosis." – Woman

> "Something I remember about my midwife is that we had an appointment at the hospital, and they were trying to tell us about the chromosome thing and I didn't understand it very well, they made me feel confused and a bit unsure and my [LMC] midwife said 'alright I'll make an appointment with the head at the hospital to talk about it properly' and I really felt that she was in my corner." – Woman

> "It's important to be supportive and an advocate for the woman and family, it means intervening sometimes, helping with a conversation, being sure that the woman's point of view is being heard, even if she is not able to do it herself." – LMC midwife

One LMC midwife recounted a time when she advocated for a woman who had a baby with a suspected diagnosis of a genetic difference. The hospital paediatrician wasn't planning on telling the woman and her family, instead suggesting they go home and have tests done in the preceding weeks. The LMC midwife challenged this course of action and advocated for the woman's right to be involved in decisions about her baby's care.

Midwives support community-based supports and services

All the midwives we spoke to reflected upon the importance of community-based supports and services. They noted that although it can be difficult at times, they try to provide women with the opportunity to connect with other people who have had similar experiences.

> "I think that the most valuable thing is to say 'here are some people that have gone through that, it's a great resource if you want to engage with that.'" – CMT midwife

> "Being able to connect with other parents who have been there was so valuable and apart from everything else that the medical side of things were saying, that was what they really latched on to and felt was the most helpful part of everything." – CMT midwife

Disabled women also reflected upon the community-based supports suggested by midwives, noting that the information and services were helpful.

> "There's a lot of information on parenting a blind child but not a lot on parenting as a Blind person. My midwife ended up finding another Blind mum in Christchurch who had done it blind and gave me her number. She gave me some tips and tricks and I felt really supported the whole way through." – Woman

> "I got some information from my midwife about a voluntary community group that makes frozen meals for the first six weeks and delivers them to your home. It was so helpful, really helpful." – Woman

However, one LMC midwife commented that the lack of availability of community-based supports and services meant disabled women were disadvantaged.

> "There's a huge gap there for women in our community with regards to support networks."
> – LMC midwife

Midwives experience time restraints and lack of disability training as barriers to delivering good maternity care

When asked about barriers they experience providing care to disabled women and women who have babies born with impairments, it was mainly CMT midwives and, to a lesser extent, the core midwife who spoke about the challenges they face. Lack of time and resources were the main barriers identified. Stretched resources means they can't always put in the time needed to build connected and trusting relationships with women, which they know to be fundamental to a positive maternity journey.

> "Lack of time is a problem to giving good quality of care and meeting institutional requirements around clinical work." – Core midwife
>
> "We have a half hour appointment and an hour for booking so being able to ask, 'what are your access needs and how can I support those', and then investigating that a little bit at each subsequent visit can be one of the last things on the list. We are here to look at your baby, check your blood pressure, tick, we are done and on to the next person, and so being able to support that woman with what she needs is why we are here, but it is hard to do in a half hour appointment." – CMT midwife
>
> "The postnatal midwives at the hospital, when they have the time, are excellent at providing that support but they don't usually have the time to give women feeding support. They have a lot of pressure there." – LMC midwife

In particular, CMT and core midwives face barriers to supporting women emotionally and when looking for resources and community-based supports and services.

> "Some of the work postnatally is between being that sympathetic ear plus doing our clinical work and then also meeting the needs of everyone else we need to see that day, and so that can be challenging thing if they need more than what we are able to provide." – CMT midwife
>
> "It's resources. Having the time to go find those online or community resources – that takes time. Thinking about what resources are available, where can we go, what ones do we already know about, and are they even out there?" – CMT midwife
>
> "Some of the groups are easy because we already know them, and there are others where you have to do a fair bit of googling, which can take a bit of time, especially for some of those conditions that are uncommon and rare, that can be a bit harder or even those which are just poorly recognised." – Core midwife

All midwives reflected on a lack of disability education and training. This included when studying to become a midwife as well as opportunities for ongoing professional development. Lack of disability knowledge and experience is a significant barrier preventing them from providing good maternity care that is responsive to disability issues and rights.

> "I haven't had any specific training in any areas of disability, certainly nothing throughout my midwifery training at all or since." – LMC midwife
>
> "I have never attended a specific training workshop around knowledge about disability or a particular disability. It is always a responsive way of finding information for a woman rather than a preparedness. I would love to change how we do that." – LMC midwife
>
> "There is very little formal education around these issues, there are breastfeeding courses that midwives are supposed to attend but they would never address issues like sometimes babies with impairments struggle to latch and suck, and how to help a mother with that, they don't discuss stuff like that in mainstream courses." – LMC midwife
>
> "I have felt disempowered by my training when it comes to working with families who have, either mum herself or the child that has different conditions, a lot of stuff I had to pick up on my own along the way." – CMT midwife
>
> "Given that midwives do the head-to-toe check on the newborn, a bit more of a focus on this, and what an examination looks like and when you discover something, this is what it looks like." – Core midwife

It was noted by the CMT midwives that the 3DHB provides some training around disability. However, it is not a requirement to attend and does not include robust information about disability rights that could assist midwives to individualise their care for disabled women. For the most part and because of their training, midwives' knowledge is informed by medical approaches rather than by a social or rights-based approach to disability. However, they seemed to have a good general understanding of high-level disability issues and expressed a willingness to engage in learning about the systemic factors that influence disability identity and discrimination.

The lack of disability training available to midwives can be seen in some of the language used to speak about disability. One midwife reflected upon having a good understanding of language and diversity and yet it was noted that the language drawn upon is not necessarily the language used by the disabled community. This raises questions around whether any guidance has been sought from the disabled community on disability language.

Good experiences with other healthcare professionals

Women value healthcare professionals who are caring and emotionally engaged

Where women spoke about good experiences with healthcare professionals other than their midwives, a recurring theme was the quality of the relationship they formed. While most women praised healthcare professionals on their delivery of babies' clinical care, there was a strong emphasis on the relationship and connection healthcare professionals formed with them and their babies. A sense of genuinely being cared for, and about, was key to the women we interviewed. When healthcare professionals made the time and space to listen and respond in open, empathetic, and informative ways, women felt cared for and better equipped to manage any challenges or uncertainty.

When talking about the ways in which healthcare professionals fostered positive relationships, women used words like 'warm', 'sensitive', 'compassionate', 'empathetic', and 'caring'. Healthcare professionals who demonstrated these traits were seen by women as connecting with them and their babies on a personal level. This meant healthcare professionals were emotionally engaged and present in all their interactions with women. They provided space for women to feel and express their emotions in a safe way and, where appropriate, felt these emotions with and alongside them.

Women value being enabled to be part of their baby's care

Women spoke positively about relationships with healthcare professionals when they were actively enabled to be part of their baby's care. This applied throughout all stages of the maternity journey. Being enabled to be part of baby's care helps women feel empowered as mothers and develop a bond with their baby. For women who have babies born with impairments, extra care needs to be taken by healthcare professionals to support them to engage in 'typical' mothering practices, particularly if their baby's care and/or medical needs make this difficult.

For some women, being enabled to be part of their baby's care meant they were able to stay in a parents' room to maintain feeding while their baby was in a specialist care ward, or being taught basic care tasks such as how to change nappies. Some women appreciated a ‘hands on’ approach to breastfeeding support, where nurses took the lead and showed them how to breastfeed their babies who had trouble latching.

> “I found the specialist care staff amazing. The nurses and the ones doing the hands-on care for him were really supportive and really open and they really enabled me to be part of his care.”
> – Woman

> “I saw the lactation consultant at the hospital… she showed me how to hand express. I thought that was really important, it made me feel like there was something I could do to care for him if I couldn’t breastfeed. I felt empowered.” – Woman

> “She did show me on a knitted boob how to express colostrum, which was really helpful.”
> – Woman

Additionally, a few women talked about the value of being able to visit the specialist care ward during their pregnancy as it was anticipated that their baby would need this level of care after birth. Similarly, the core midwife reflected upon the importance of preparing women for birth if they were having a baby with impairments because the process may be different to what they learnt during antenatal class.

> “I think it’s important that they are aware of the processes or anything we will need to do different from the ‘normal’ way of doing things. Because many women will attend antenatal classes and they all get told the same thing, ‘baby will be born, you will do this, this will happen, we will leave you alone having a great cuddle, dim the lights’, all that kind of stuff, but sometimes that’s not what we are able to do, so preparing them for what is important.”
> – Core midwife

Women who have babies born with impairments value clear communication, emotional support, and a positive outlook

Women who had babies born with impairments wanted factual, non-judgemental, and up-to-date information delivered in a clear and concise manner. Sensitive communication, particularly around issues of genetic testing, was essential. Many women recalled conversations with healthcare professionals that provided comfort during challenging times.

> “The obstetrician was factual and not-judgemental, which was a good thing. She was open about options. She didn’t go in with the assumption we would terminate and didn’t say ‘I am really sorry’ about your baby. She just focused on the facts.” – Woman

> “The health professional was warm, positive, reassuring and instructive, explaining ‘now we are going to do this, and you need to do this, and this is going to happen.’” – Woman

Notably, healthcare professionals who held a positive outlook were valued by women as they sought reassurance about their baby’s future. On hearing the unexpected diagnosis of their baby’s impairment, all women were frightened about what it could mean for them and their family. Healthcare professionals who held a positive outlook focused on a baby’s strengths and the characteristics that made them unique individuals. They provided space for hope and optimism during a time of uncertainty.

Women also valued the support of healthcare professionals who took the time to respond to their queries, reached out to them, and provided information about support groups.

> “One thing that was really great was a paediatrician came around and asked for our case because he had a special interest in our son’s condition and he wanted all new diagnosed cases to be under him, and he came in, and he was fantastic. He gave us the phone number of another family that he worked with so that we could talk to them, and so that was all through his personal doing, and it was really, really great.” – Woman

> “It was a personalised approach. We weren’t just a number. We were a family the paediatrician was caring for. It was a 2-minute phone call, but it made all the difference.” – Woman

Disabled women face multiple barriers at the beginning of their maternity journey

The maternity journey begins long before baby is conceived

Many of the disabled women interviewed had planned pregnancies through funded fertility services. For these women, funding restrictions and eligibility criteria made this part of the maternity journey long and arduous. They made the important point that, for women in these situations, the maternity journey often begins long before a baby is conceived. They also stressed it is important for healthcare professionals to be mindful of the emotional labour and toll this can take on disabled women.

> "I used IVF to get pregnant. That was a whole journey on its own… we had ten years of not getting pregnant" – Woman
>
> "I conceived using a sperm donor so my journey with healthcare professionals and pregnancy kind of started a long time before I even became pregnant." – Woman

Once under the care of a fertility clinic, many women experienced access barriers which negatively impacted their maternity care experience. One woman described receiving IVF care that was standardised and inflexible. She felt as though healthcare professionals focused on 'getting the job done' rather than working with her on an individualised approach to ensure she had a good experience. She was worried about the fertility treatment process because of a history of sexual trauma and concerned about the effect hormone therapy would have on her mental wellbeing. When requesting accommodations around this, she felt as though healthcare professionals disregarded her access needs. A disabled trans man who was embarking on a journey towards becoming a gestational parent reflected on the way in which fertility and maternity services use highly medicalised and feminised language. He described experiencing multiple barriers to quality maternity care related to the intersection of his trans and disabled identities.

Successful fertility treatments resulted in many women knowing they were pregnant within the first few weeks of pregnancy. Aware of the possibility they may encounter difficulties finding a midwife they could connect with and trust to support them and their access needs, these women valued knowing early on that they were pregnant.

Discriminatory attitudes towards disabled women becoming mothers

Many of the disabled women we interviewed encountered discriminatory views from medical professionals about their decision to have a baby. Ablest views by healthcare professionals negatively impact on disabled women's maternity journeys and can influence their decisions to delay and/or not proceed with a pregnancy.

Several disabled women recounted having their choice to become a parent, as well as their ability to parent, questioned. They spoke of healthcare professionals' concerns that they might 'pass on their impairment' to their babies.

> "My GP turned to me and said, 'but how will you teach a child how to climb a tree?' and I was really taken aback because that was not a concern that I had about raising a child. I was flabbergasted. I came away in tears and was like, is this just a stupid decision?" – Woman
>
> "During the pregnancy I still had moments of worry that people would ask me questions about what happened to my legs and hand, and healthcare professionals did ask questions like 'is that genetic?', 'will your child... ?'" – Woman
>
> "This nurse said to me 'why are you having a baby if you can't see? Don't you think that's a bit unfair on the child?' I was already pregnant at that point and I was thinking, have I just ruined this child's life?" – Woman

Disabled women were shocked that healthcare professionals would openly share discriminatory and ableist assumptions about their capacity to care for a baby. When healthcare professionals react in this way to a disabled women's choice to have a baby, the implication is that they are not fit to be mothers and will not be able to provide a good home environment to raise a child. In these instances, disabled women's rights to parenthood are undermined.

The impacts of these discriminatory attitudes are deep and long-lasting. For some disabled women, they questioned their decision to have a baby, others began to doubt their capacity to care for a baby, while others delayed their decision to start a family.

> "It took me many years to have the confidence to have a child because I was so wound up in worry that people would think that I was irresponsible because they might be born like me." – Woman

For the disabled trans man we spoke to, he experienced discrimination related to his trans identity as well as his disabled identity. He explained that healthcare professionals did not understand how the two parts of his identity and maternity care needs intersected. This meant that his trans identity became the focus and, as a result, his access needs related to his impairment were not addressed. He described the challenges as a trans man navigating a healthcare system that deemed him ‘broken’ and in need of cure, and the difficulty of having to disclose his impairment and risk further judgement.

Disabled women have limited ability to choose their midwife and place of birth

Disabled women described having little power to choose a midwife they connected with and trusted. This was particularly the case for disabled women seeking an LMC midwife. Often their choices were limited because midwives lacked experience providing maternity care to disabled women. LMC midwives similarly commented they did not have a lot of experience supporting disabled women.

> “I contacted a lot of LMCs very early on, I mean at this stage I was probably only five weeks pregnant and a lot of them didn’t feel confident in taking me on, so it wasn’t a case of they didn’t have space – it was that they felt they didn’t have the skills they needed to support me in pregnancy.” – Woman

When trying to find a midwife who had lived experience of disability or previous experience supporting a disabled woman, recommendations would be sought from the disabled community. In cases where disabled women had difficulty finding an LMC midwife, it was noted both by women and by one of the LMC midwives that some midwives blame capacity issues for not taking new clients when, in fact, it was because they didn’t have the experience or the inclination to care for a disabled woman.

Disabled women who saw private obstetricians or the CMT felt there was little to no choice over which midwives would be supporting them. Obstetricians were the preferred option for the trans man we spoke to as he believed it would provide continuity of care. Similarly, one woman spoke of choosing an obstetrician because she thought she would benefit from having a dedicated midwife team, but later realised that the obstetrician’s team of midwives were not permitted to practice in the hospital where she planned to give birth. She ended up birthing with midwives she had never met before.

For one disabled woman who discovered her pregnancy in the third trimester, engaging with the CMT was described as a difficult process due to rotating staff. She found it hard to build trust in the little time she had with each midwife at each appointment.

> “I found out at 22 weeks, so it was hard to find a midwife… everyone was booked out, so I had to go to the CMT, and they changed every time we went… it was difficult because I had to explain everything again and again.” – Woman

For another disabled woman, her pregnancy was deemed high-risk by healthcare professionals inexperienced at providing maternity care to disabled women. She confirmed the designation of 'high risk pregnancy' was not related to any actual medical risk, rather it was because healthcare professionals lacked experience. She was instructed to birth at a different hospital which meant her support person would struggle to join her. As a single woman with a disability, it was incredibly important to her that her support person was able to attend the birth. One midwife acknowledged that a hospital's inexperience with disabled women would often be a factor in the transfer of care, but that once healthcare professionals have an opportunity to provide impairment-specific care, they are more confident providing it in the future.

> "I do feel that it's often easy to say 'no, that woman isn't able to birth here, she'll need to go elsewhere' but sometimes when women actually rise to that and say 'no, it's my choice and I want to understand why I can't and if you can't provide me with the research that it's not going to go terribly wrong then I want to be here', then it makes us respond to her and be able to provide that care." – LMC midwife

Disabled women find having to repeatedly disclose their impairment and access needs difficult

The emotional burden of disclosing their impairment and access needs can be hard for some disabled women. Having to repeatedly share their story with different healthcare professionals was described as exhausting.

Some disabled women disclosed their impairment directly to healthcare professionals involved in their maternity care. Others found that their GP or obstetrician had passed on this information in their medical notes. Disabled women felt, for the most part, it was important that this information was shared with healthcare professionals because of the impact it may have upon their maternity care needs. Disclosure of impairment was seen by healthcare professionals as important because it helped them provide individualised care to disabled women.

> "I disclosed that I have a history of depression, mainly for my benefit, so if I felt like I wasn't coping I had a clear plan of what to do." – Woman

> "It was really important to me as a Deaf person not having to explain again about how to use interpreters, language use, what Deaf culture is. All of that awareness, information, takes a while to explain." – Woman

In cases where impairments were non-visible and there was a lack of visual cues to indicate any access needs, disabled women felt an added burden of having to explain themselves. We spoke to a woman who was hard-of-hearing who described lacking confidence to ask for her access needs to be met. She stated that it is important that healthcare professionals remember that not all people with impairments identify as disabled, and not all people with impairments understand their access needs and rights.

> “I did tell them, but I think it’s difficult for people to remember because they don’t have anything visible to remember I am hard-of-hearing.” – Woman

The CMT and core midwives appeared to have a good awareness of the challenges that can come with disclosure of disability. They were aware of the emotional labour involved and the stigma that can be attached to identifying as disabled. One of the LMC midwives bought up the availability of the 3DHB Health and Disability Passport as one way to reduce the burden of disabled women repeating their stories. Only one disabled woman interviewed indicated she was aware of the availability of the Health and Disability Passport.

> “I can understand why someone might not want to disclose as well because some people don’t want to be labelled or feel like they are being judged or perceived differently.” – CMT midwife

> “Although we have access to medical records, if there is something glaring there, if it’s written on the medical notes but not disclosed then we need to tread carefully around that.”
> – CMT midwife

> “I think we do our best to provide a linear pathway in the sense that not every new staff coming on is starting at square one of the conversation about disability or what is going on. We are able to learn as much as we can in our interactions and then pass that on both in the notes and verbally but I do think there is a lot of element of repetition for mums, a lot of it is unavoidable unfortunately… we also try not to speak for the mum.” – Core midwife

Diagnosis of a baby's impairment

Healthcare professionals frame diagnosis as a tragedy and there is little consistency in how and when the news is delivered

In most cases, the communication of a diagnosis by healthcare professionals was described as communication of 'bad news'. For many women, they felt the experience was unnecessarily framed by a sense of tragedy.

> "I just remember the look of grief on their faces when they were telling me the information, I felt like it made it worse than what it was." – Woman
>
> "It could have been framed in a different way instead of as entirely a tragedy." – Woman
>
> "Don't make me feel like you are giving me a death sentence. 'Cause that's how it felt, she was like 'I am so sorry'. I honestly had such a bad experience, all round negative." – Woman

Some women found out early on in their pregnancy that their baby had an impairment(s) while others found out after they were born. All of these women heard about the news of their baby's diagnosis in a range of different ways. Some heard it over the phone from their midwife or a paediatrician, some face-to-face with doctors in specialist care wards or maternity wards, and some found out from technicians during routine scans. Some women reported hearing the news casually from healthcare professionals during ultrasound tests or during ward rounds leaving them with little time to process the information. If genetic or other tests were being carried out, most women reported that it took only a few days to receive the news and were pleased with the quick turnaround of results. Nevertheless, they all described this as the longest few days of their life and waiting for the results was one of the hardest parts of the experience.

> "I was sitting up and getting ready to leave and she said 'oh, we noticed that he has got a cleft lip' and pretty much rushed through and said 'he has got a cleft lip and this is what we'll do' but there was no time taken and she gave me a box of tissues because I burst into tears because I knew what it was. My husband didn't know anything about it and so I had to sit in the car and

> google images and show him what a cleft lip looked like, which was extremely difficult to try and explain to him when I was very upset. And then we had to go and pay afterwards, and my husband was really confused because he didn't know what was going on." – Woman

> "They just talked to us like we already knew. They just said 'oh yeah, she has got a genetic duplication, she has got some problems' and we were just like 'what?'. And it was just some nurse, like she was talking, she didn't realise we hadn't been talked to, and we were like 'what? What does this mean, we didn't know?' and she said 'oh I don't know, I'll see if I can find the report.' We just got given the report. It was totally confusing. So it was very blasé, nothing formal." – Woman

> "They got the results on the Wednesday, but they didn't bother to tell me until the Friday. They had them for two days and then told me on discharge that the test had come back with a genetic deletion syndrome." – Woman

One of the LMC midwives reflected on the difficulty of sharing news of a diagnosis with women, but explained it helped to focus on ensuring women were well-informed and connected with support.

Little information is provided to help women understand the diagnosis

When receiving a diagnosis for their babies, several women explained they were given a name and no further explanation. This was particularly the case for women who were receiving a diagnosis of a rare disorder. For some women, the stress of receiving a diagnosis was compounded when they had to pass on the information to their partners and attempt to explain what the diagnosis meant while having little understanding themselves.

> "The diagnosis was just a name given to us without any explanation or idea of what to expect. It was just a whole lot of numbers and letters being thrown at me. I had to explain those letters and numbers to my husband who was at work." – Woman

> "The paediatrician was a bit crude with it. Boom, this is what he has got and then full stop. Nothing else was given. No other information." – Woman

Women wanted information about their baby's impairment but found, in many cases, healthcare professionals did not have any information to pass on. A lack of information from healthcare professionals added to their distress.

A negative experience around the delivery of a diagnosis can have life-long impacts

The impact of these types of experiences for women cannot be underestimated. The devastating effect of a negative experience around the delivery of their baby's diagnosis has lifelong implications for women and their families.

> "It's really difficult to remember it. Sometimes it's easier to put a lid on it and move on."
> – Woman
>
> "I felt like this fear had been instilled in me, like is she going to die? Is something terrible going to happen? That catastrophising thinking unfortunately became part of my mindset because there was so much negative thinking that was surrounding the whole pregnancy." – Woman
>
> "Even now, seven and a half years later, I still cry when I talk about it. I don't deal with it very well." – Woman
>
> "The whole experience was so traumatising, and it took me a good couple of years to get my head around how I had been treated. In the end, I just jammed up." – Woman

One woman spoke at length about her and her husband's experience of receiving a postnatal diagnosis for her daughter. The woman explained that the doctor focused on pointing out all the 'abnormal' features that indicated their baby had a chromosomal difference.

> "She said 'she has low set ears, and her eyelids are like this, she has a small head' and I didn't really need to hear all of that actually 'cause, for us, she looks fine, she looks beautiful. My husband was really offended. He was like, 'come on she is fine, nothing is really obvious.' We just didn't need to hear that." – Woman

CMT midwives' experiences of delivering a diagnosis

Women didn't speak to their experiences of being supported through the process of receiving a diagnosis from CMT midwives, but CMT midwives did speak about their experiences of providing women and families with news of a diagnosis. They noted that as part of a multi-disciplinary team they are often in the position of delivering a diagnosis. This can happen antenatally, at birth or sometimes up to several weeks post birth. They were highly aware of the life-long impacts the experience can have on women.

> "When getting a diagnosis for their baby, women remember very clearly who it was, how they were presented the information, what information they were given or didn't get at the time." – CMT midwife

> "We usually have a meeting in 'that' room, and everyone knows about 'that' room and we work really hard to present it in a caring and kind way but that doesn't always come across to people, so people's feedback is very different." – CMT midwife

CMT midwives were mindful of the need to individualise the support they provide women around the time of receiving a diagnosis.

> "It depends on the relationship you have with the person and where they are, and the experience they bring. Is it first child or second child? What other family members do they have? What disabilities do they have? Every person you would approach differently depending on their situation. Everyone's experience is very different, and their beliefs are different as well." – CMT midwife

They described attempting to deliver the news in a way that was factual and clear without robbing women of the joy of having a baby.

> "I approach it from this is not the end of the world, it might be the end of your initial planning and imagining, but life doesn't stop here, there are things you can do." – CMT midwife

> "We try breaking the news with being realistic but without dashing too many hopes and dreams." – CMT midwife

Antenatal testing is a difficult experience and some women feel pressure to terminate their pregnancy

Two women found out early on in their pregnancy through antenatal testing that their baby had a chromosomal difference. Both women described a lack of support by healthcare professionals in their choice to continue their pregnancy, as well as pressure to terminate their pregnancies. Both women were clear about their decisions to continue their pregnancies but stated healthcare professionals disrespected their choices.

> "Because the advice goes one way and only one way – termination – and that continued throughout. It continued once I was in hospital and I told them really early on that I had no intention of a termination regardless of the anything that they showed me." – Woman

> “I said we are going ahead with the pregnancy and there is nothing that would change my mind, and yet on three occasions I was told it wasn’t too late to terminate the pregnancy and have I really thought about the repercussions of having a baby so late in life and a baby with disabilities. This affected my pregnancy hugely.” – Woman
>
> “At the next foetal maternal appointment, their first option was a termination, a termination was the first thing that was offered to me.” – Woman
>
> “And then I always remember that just before 22 weeks, which is the cut-off point, I got a phone call reminding me that it was the last week that we could terminate. It just doesn’t sit well with me, especially just being a phone call, to remind me that this is my last chance to terminate.” – Woman

One woman felt pressured to have an amniocentesis and described the experience as hugely traumatising. Another woman sought additional information about adoption but discovered healthcare professionals had little information to share with her. It took several weeks for the information to come through and for her to be connected with relevant social services. Having to wait for that information added to an already stressful time.

Bad experiences with healthcare professionals and built environments

Disabled women experience increased levels of surveillance

Many disabled women described a sense of being under surveillance and the need to prove their ability to care for their baby. Increased levels of surveillance by healthcare professionals are founded upon the assumption that disabled women are not competent mothers.

> "When I said I was under maternal mental health, they decided they were going to ring us every day to check on baby's wellbeing. I felt like I was being monitored." – Woman
>
> "I felt the whole time that I had to prove to everyone that I was fit and able to be a mum. It was so hard to come to terms with." – Woman
>
> "We had one of those group meetings about what was going to happen... They would talk about me as if I wasn't even there." – Woman

Sometimes feelings of surveillance were directly related to access barriers. For one Deaf woman, who was staying in the parents' room while her baby was in a specialist care ward, she worried that she would be judged as incompetent by healthcare professionals if she miss the phone calls that were meant to alert to her feed her baby. Similarly, she worried that if she didn't perform her babies' care duties in the ways outlined by healthcare professionals she would not be allowed to take her baby home.

For some disabled women, the effects of this type of discrimination created in them a deep fear that their babies would be taken away from them. They recounted stories of healthcare professionals disclosing details of their impairment to Oranga Tamariki without their knowledge and with no explanation of why this information was shared. They believed that apart from having an impairment, there were no legitimate concerns for the welfare of their baby.

> "I had heard all these horror stories of disabled people being contacted by Oranga Tamariki and having to do these parenting courses and be assessed for their ability to be a parent, so I was really concerned." – Woman

> “A mum I provided care for had quite a fear of her baby being taken from her because she had a disability. That was a big learning experience for me.” – LMC midwife

For one learning disabled woman, her baby was uplifted soon after birth. Upon finding out she was pregnant, a GP reported details of her impairment to Oranga Tamariki. After months of assessment to determine her capability to parent and being advised that she would be able to continue to care for her baby, she was shocked to find out a few days after birth that this decision had been reversed and her baby would be taken into State care. The process was described as hugely traumatising.

Disabled women face access barriers and attitude problems

Failing to respond to access needs and a general lack of knowledge or consideration of disability issues was reported as the main reason for poor experiences. A Deaf woman described the difficulty she experienced navigating hospital wards due to a reliance on audio-based equipment such as doorbells and intercoms. An LMC midwife similarly spoke to the challenges Deaf women experience in maternity settings, suggesting that maternity services, and more broadly healthcare services, should proactively address disabled women’s access needs. She believed a failure to do so leads to inequitable maternity care outcomes for disabled women.

> “You start off in the ward and then every four hours you need to do the walk through the ward and push the buttons. Basically, I would get locked out of the ward where my baby was because I had to push an intercom to speak to someone then push another button and speak into an intercom to get into the ward. This system didn’t work because it relies on verbal communication. I would say the same thing each time to get in and hope that the door would get unlocked.” – Woman

Many disabled women spoke about wanting to give birth at the hospital where they and their family members were born but encountered access barriers that prevented this from happening. A lack of lack of accessible equipment meant that one disabled woman did not receive complete medical examinations as part of her maternity care.

> “There was no wheelchair scale anywhere, so I wasn’t weighed at all throughout my whole pregnancy, right up until the day before I was induced. I got to the hospital and they wanted that information, and I was like, ‘I’ve got no idea’… I had seen everybody else being weighed in the waiting rooms and figured that if it hadn’t been offered to me then it mustn’t be that big a deal. I didn’t realise it was an issue.”– Woman

Disabled women also spoke about negative experiences when receiving scans at various locations outside hospitals.

> "It was frustrating having the scan people not gauging that I couldn't see and saying things like 'can you see this?', 'look at that'. I said 'can I take a photo on my phone so I can zoom in?' and the person said, 'I'd prefer it if you didn't.'" – Woman

One woman's birth plan included instruction to keep her prosthetic leg on during labour. However, this was not communicated clearly to birthing staff resulting in the misunderstanding that they should be making sure her prosthetic leg was covered up.

> "Somehow the birthing plan where I said I had wanted to keep my leg on, the obstetrician had interpreted that to mean that I wanted my leg to be covered up and for some bizarre reason they were all obsessed with covering my leg up and I didn't want it covered up because it needed to be as flexible as possible. That was creating stress and my husband was equally distressed." – Woman

Health professionals sometimes use discriminatory language when talking about babies born with impairments

When women who had babies born with impairments spoke about poor experiences with healthcare professionals, they described interactions that were informed by a deficit- and tragedy-based model of disability. This meant that their babies were talked about in ways that were overly negative, with an undue emphasis on all the 'problems' associated with their impairment. When this happens, impairment and disability are constructed as inherently 'wrong' and tragic. This way of thinking and talking about disability devalues the lives of babies born with impairments. In these situations, the language used by healthcare professionals is clinical and overly medicalised. It attaches stigma to disability and reduces babies to a list of health conditions and medical diagnoses.

Some of the language used by medical professionals to talk about babies with impairments was outdated and discriminatory. Examples of this included describing babies with impairments as 'mentally retarded' and asking women what is 'wrong' with their baby. This type of language constructs babies with impairments as deficit, lacking and abnormal. Women found this type of language hugely upsetting and offensive.

> "All this language was used that I don't think needs to be used in front of the parents. There is an overuse of medical terminology." – Woman

> "I think a lot of the information I was given was out of date, like she said a common outcome is that 'you can expect a mental age of eight'." Woman

Similarly, women spoke about the cold and detached way some healthcare professionals spoke about their babies during examinations and when teaching trainee doctors. Most women seemed happy for student doctors to observe examinations if it provided an opportunity for them to learn about impairments in a way that recognised their babies as people first. When women were dissatisfied with these interactions it was because medical professionals objectified and pathologised their babies as 'objects' of medical enquiry. Interactions such as these perpetuate deficit- and tragedy-based understandings of disability within the healthcare profession.

> "The doctors came along and they talked over me and they said to the student 'this is what you will see with Down syndrome', they didn't even look at my baby or ask about her, they just said this is what you see with Down syndrome and they just did things and it was just horrible. And they shouldn't do that to people, that is not ok. I will never forget all that happened." – Woman
>
> "She said to me 'you do realise that babies like this just don't make it, do you?' and she talked to her offsider who was a student or whatever, and I just didn't know what to say, it just came out of the blue, from nowhere. I was so emotionally affected by what she said to me and there was no reason for her to say that. There was no medical reason, apart from the baby having Down syndrome, that the doctor would say that." – Woman

Underlying women's reflections about poor interactions with healthcare professionals was a belief that they lacked empathy. Time and time again, women commented that they couldn't believe that healthcare professionals could speak about their babies in front of them with no awareness of how it might make them feel.

> "Doctors weren't that great, coming in and saying 'oh look, her ears are lower, her eyes are almond shaped', for the doctor there was no connection with him talking about my baby to his offsider and how I was feeling right then and there. He had no conception that what he was doing was just adding to my already massive load." – Woman

Healthcare professionals not communicating or sharing information

Lack of communication by healthcare professionals was consistently raised by women. Across all stages of their maternity journey, women found information wasn't shared with them in a timely manner.

> "I wasn't given information readily, I had to wait. I was really anxious and stressing about what the scans might show and worrying about what this would mean and had to keep following up to find out further information." – Woman
>
> "Nobody had told me whether I would need to have a caesarean or a vaginal birth. None of that information was shared with me so I was super worried about that and it was quite far along that I had to ask the midwife 'what's going to happen and how does this change the delivery?'" – Woman

> "I didn't get to see him until the next day. I wasn't taken in to see him. I didn't get told where he was." – Woman

For women who had babies born with impairments and knew antenatally about their baby's diagnosis, the provision of information was paramount to their sense of safety and satisfaction in their maternity care. Women who are informed about their maternity care are better equipped to respond to uncertainties. It is important that women receive simple and specific information, particularly when they are feeling overwhelmed by the situation.

Women reported that during scans or examinations of their babies, there would often be no explanation of what was happening and why. This left them feeling as though things were being 'done' to them or their baby without their active involvement.

> "It was alarming because each time they were obviously seeing things of concern and going to speak to their superior without telling us what was going on." – Woman
>
> "If you are having a look at my child's palms to see if there is a crease or not, I want to know what you are doing." – Woman
>
> "There was no explanation of what they were doing so when they did take him off to put him on CPAP they didn't explain where they were taking him and what they were doing, they just took him. No communication and no thought as to how we would feel." – Woman
>
> "The paediatricians who had been examining her for something else were actually looking for markers of Down syndrome and trying to decide whether she had it or not. That conversation had been happening without me so, at that point, I felt a bit betrayed that the conversation was being had without me." – Woman

One woman described the lack of communication and empathy from a technician performing some tests on her baby as 'horrendous'. She was astounded by the lack of understanding about the emotional dilemma of parents when their baby's require specialised care and the insensitivity of the technician towards their need for answers to questions about what was happening. Some women also reported a lack of information about delivery plans or care management that could help them prepare. Often, they found out information at the last minute, which took them off-guard and created added uncertainty.

> "I felt shocked and disappointed and hearing something that was being done to me at the time of labour was pretty traumatic for me." – Woman
>
> "You just don't get any information, you don't know what is happening, you know that at some time near 12 weeks you will hear there is a surgery happening, but you don't hear anything until they call you to tell you are booked in for the next week." – Woman

Disabled women reported poor communication between them and healthcare professionals, as well as between healthcare professionals. Poor communication between women and healthcare professionals disempowered women and took away their sense of control.

> “Communication could be better. They need to work more on the anaesthetist. There should be a lot of communication coming from him. Because he didn’t tell me he was going to prick me with a needle. He was rough.” – Woman
>
> “Nothing was communicated to me because they thought they would traumatise me, so it was all through the organisations and my support worker in the background.” – Woman

Disabled women also reported a breakdown in communication between services both within and between DHBs, as well as with external services such as mental health providers. Breakdown in communication between DHBs was a recurring theme for disabled women being transferred to different hospitals postnatally. This also occurred in the shift of care from midwives to nursing staff. For some women, poor communication of notes and of access needs increased the impacts of their impairment, particularly for disabled women experiencing mental distress.

> “They didn’t have access to my notes and there was a lot of confusion about who I was under. They had to go and have a conversation with midwives at the other hospital. I’d just given birth – dancing between the two DHBs, the communication wasn’t very good and they weren’t checking up on me very often or well enough with the mental health stuff.” – Woman
>
> “My diagnosis at the time was borderline personality disorder but I don’t think they knew about that. There was a lot of lack of communication. Because we were back and forth between the DHBs we felt we had fallen through the cracks because they didn’t have access to each other’s notes. There wasn’t much support for us, and it all contributed to my postnatal psychosis.” – Woman

Women have multiple care relationships with healthcare professionals

The sheer volume of healthcare professionals involved in maternity care for disabled women and babies born with impairments can be overwhelming for some women. It was acknowledged by many women that the type of care they and their babies needed meant there was a range of healthcare professionals involved.

At different points in the journey, and at any one time, women were interacting with midwives, nurses, paediatricians, general practitioners, obstetricians, genetic counsellors, social workers, lactation consultants, community care teams, NASCs, support workers, physiotherapists, occupational therapists, community mental health, speech language therapists, and other technicians and specialists in areas like sonography, audiology, cardiology, and ophthalmology.

> “My daughter had a lot of people involved in her care, she had occupational therapists, speech language therapists, a special care baby nurse. Then I had my own team of people, I had my community mental health worker and I had Plunket and the midwife as well, but she finished up while I was on the ward, and my psychiatrist and my nurse and a social worker.” – Woman

Staff rosters and scheduling also contributed to the number of interactions women have with healthcare professionals. Shift changes, along with staff going on holiday or leaving the organisation, meant that women may interact with numerous healthcare professionals over a 24-hour period depending on who is working at the time. Some women also received maternity care across DHBs, which increases the number of healthcare professionals they come into contact with.

Inadequate knowledge about disability

Antenatal classes have a narrow focus on 'natural' and 'normal' births and do not address disability issues

Many women felt that the information provided in antenatal classes had little relevance to their personal situation. They described feeling underwhelmed by the classes on offer, mostly gaining new friendships over knowledge.

Many disabled women remarked that their impairments were not acknowledged during class and no opportunities were created for them to discuss how their impairment and access needs might impact upon their maternity journey. They felt class instructors were reluctant to discuss issues that were relevant to their situation, such as caesareans and feeding support. Many of the disabled women had planned caesareans and found antenatal classes to be anti-intervention and geared towards vaginal births. They noted a general unwillingness to address the questions they had about their own individual birth plans.

> "I knew at this point that I was going to have a caesarean and it was quite difficult being the one person in the room who knew they were having a caesarean when the classes are focused on only having a natural birth, because as soon as you have an epidural it starts a cascade of interventions and if you have a caesarean it's like the worst thing in the world – that was the way it was put forward." – Woman

One disabled woman who acquired an impairment following the birth of her first child described feeling completely unprepared for the birth of her second child because she now had access needs to consider. For some disabled women, access needs meant that bottle-feeding would need to be considered and planned for. These women found the instructors similarly unwilling to discuss bottle-feeding.

> "They were very much about breastfeeding. They wouldn't talk about bottles. They wouldn't talk about expressing milk or anything." – Woman

Mental health, in particular, was described as being brushed over during classes and those who experienced extreme mental distress post-birth reflected on being completely unprepared for such an outcome.

> "They talked about postnatal depression for a few minutes and talked about how everyone gets the baby blues but if it goes on for more than a couple of weeks, call your GP and that was it. I remember thinking, this is terrible." – Woman

Women who were having babies with impairments similarly remarked that antenatal classes had limited educational benefit.

> "The content of the antenatal class was ridiculous. Very natural birth focus, breastfeeding focus, pain-relief-free focus, it is really hard when you are sitting in those classes and you know that you won't be able to breastfeed because of your child's diagnosis." – Woman
>
> "It was challenging because a lot of the stuff we were talking about I knew I wouldn't be able to do, like breastfeeding, and I knew that I would be induced." – Woman
>
> "People were expecting that they would have a natural delivery, that they would take their baby home after a few days, they would breastfeed their baby, and our experience was just so much more uncertain. I did find that quite hard." – Woman
>
> "I talked to the class about what we were going through, but every time something came up the person who lead the class ended up saying 'oh, but it will be different for you'. We were the abnormality in the antenatal class." – Woman

One woman who found out about her baby's diagnosis not long after starting antenatal classes chose to leave the class because she felt marginalised by the narrow focus of the material.

> "It was not a safe space for me to be able to talk about what I was going through. I couldn't express my shock, my grief, my fear. I couldn't ask questions about what does all of this mean for the delivery? What will it mean for the birth? What will it mean for breastfeeding? What will it mean for me as a new mum? I didn't go back, that was it. I didn't feel safe even bringing it up to the teachers." – Woman

CMT midwives also reflected upon the relatively narrow focus of antenatal classes, speaking specifically to classes run by the DHB. It was noted that if there was a woman in the class who was expecting a baby with an impairment, their educational needs would likely not addressed. It was also mentioned that although there are classes for young mums or for non-English speakers, there aren't classes for disabled women and women who may be expecting a baby with impairments.

Midwives and disabled women don’t know where to access information on disability and pregnancy

Midwives and disabled women alike spoke about not knowing where to go for information about disability and pregnancy. Many disabled women spoke of gaps in healthcare professionals’ knowledge and their need to rely on word-of-mouth and the advice of others in the disabled community. In some cases, the search for information was left up to disabled women to complete, resulting in a sense of frustration and worry about the unknown. Following their maternity experiences, some disabled women felt a responsibility to address this gap in knowledge and wanted to contribute their lived experience in a way that could be accessed by healthcare professionals to assist other disabled people in their care.

> “What I distinctly remember was nobody could answer any of the specific disability questions I had, like, how would the pressure affect my legs? The increased weight and how a circulation problem might impact on me? Neither the obstetrician nor midwives could answer that, neither could the artificial limbs service, neither could my GP so no one really – you sort of felt like you were entering this major life change and nobody could really answer those questions.” – Woman

> “I needed a really honest conversation with someone who knew about child development and about disability and all these different topics and there was no one so I had to take myself through that process and talk to other mums and they provided a lot of information to me but there was no professional willing to have that conversation with me… about what I would need in those first few weeks, what could wait, what were the challenges likely to be.” – Woman

> “One thing I’ve found is that you really have to do your own research and seek out help… My [LMC] midwife found it really frustrating not being able to find any information to help. She obviously wanted to but didn’t really know where to look… you need to ring five different places to get the information that you need.” – Woman

Midwives spoke about being resourceful and using a range of channel to source information but noting limited availability of robust evidence-based material. In one case, a midwife had to approach colleagues overseas to obtain the information she needed.

> “We have really good sharing of information through Kiwi midwifery forums on Facebook. It might be that you could put a shout out ‘oh, I’ve just got a baby that’s just experienced this, has anyone ever encountered this?’ and if there’s evidence out there obviously they will share that.” – LMC midwife

> “We should have stuff at our fingertips, then that ensures that we know what we are doing providing care. We need to be informed as healthcare professionals to share that information so they can make that good, informed choice and feel good about the choices they are making. There certainly are gaps.” – LMC midwife

Women who have babies born with impairments don’t know where to go for information or community-based support

Not knowing where to go for information and community-based support was a huge concern for many women who had babies born with impairments. Eight of the ten women spoke about their need for information to access community-based support but not receiving guidance from healthcare professionals. These women were desperate for information that would help them make sense of what to expect for their baby and their family.

Most women who had babies born with impairments realised they did not have much personal knowledge about disability. They started searching for information on the internet, looking for medical facts as well as pictures and stories about families of children with impairments. Navigating the plethora of information and identifying sources of support was difficult for these women and added to their emotional dilemma.

> “The paediatrician didn’t connect us with any other organisations. There were nights where I didn’t sleep for like three nights in a row because I was up all-night researching.” – Woman
>
> “I researched a lot and did not sleep, whereas if I had just been given the support group, the actual places to go, the Facebook groups and stuff, perhaps it would have been a bit gentler, and not out on our own.” – Woman
>
> “I recall sitting here at home in the wee small hours, feeding her in my rocking chair, and googling and finding the support groups. I found all that on my own.” – Woman

A sense of having to fend for themselves and do it ‘all on their own’ dominated these women’s experiences. A lack of direction by healthcare professionals on appropriate sources to seek out information from, or support groups to connect with, meant that many felt overwhelmed by the enormity of the task. They wanted healthcare professionals to ‘signpost’ or point them in the direction of online information and/or community organisations.

> “They just gave us a brochure and left it up to us to contact people. We were just left to fend for ourselves.” – Woman
>
> “It was really hard because it just felt like we were out there on our own, and that was a time when we really needed it.” – Woman

> "They didn't give us any pamphlets. They didn't give us any information. It was pretty much just go home and process this on your own." – Woman

> "We just got left to do it all ourselves on top of dealing with it all and processing it." – Woman

One of the challenges women who had babies born with impairments faced trying to gather information was difficultly knowing which sites to trust. They were unsure about the accuracy of information, explaining much of the material found online focuses on the 'worst-case scenario' or insensitively portrays antiquated images of babies with impairments and disabled people. They wanted a few trustworthy sources of information made available to them from healthcare professionals.

> "When you look it up on the internet you see everything severe, it was a really difficult few months, and not only was it not easy, we were lost." – Woman

> "To have someone to go through some resources, I didn't really get handed anything tangible, brochures, anything like that, it would have been helpful to be handed a list of resources and websites to go to for support." – Woman

Many of the women who had babies born with impairments explained that they would have valued the opportunity to connect with others in similar situations for emotional and practical support. For many of them, this was a significant gap in their maternity care.

> "There was no 'here are the people you can talk to about who have gone through it before', it's all entirely up to you. It's really hard to know who to contact." – Woman

> "We were not put in touch with any community organisation. Nothing while I was pregnant. It would have been useful to meet someone with Down syndrome, I hadn't even met anyone with Down syndrome before then. I didn't know what it meant, and just thought about the worst-case scenario." – Woman

> "If I could have been connected in with other families straight away, seeing families living a normal life, seeing their children, would have just made such a difference rather than just being told the news over the phone in isolation and left to it." – Woman

In addition to emotional support, these women believed that meeting people with lived experience, either parents caring for a child with disabilities or a disabled person, would have provided a fuller picture of what it like to care for and/or have an impairment.

> "I joined Facebook groups and that gave more information about the experience of having a child, a human being, as opposed to all this medical stuff." – Woman

> "Real parents' experience is important, having actual human experience of raising someone with an impairment, not just the medical stuff, to balance it out." – Woman

Lack of feeding support

Disabled women don't feel supported to breastfeed

Disabled women recounted experiencing numerous attitudinal barriers towards feeding, particularly in relation to breastfeeding. Some disabled women commented they were not given a choice to breastfeed their baby. Often bottle-feeding would be implemented because it was presumed too difficult and time-intensive to support disabled women to breastfeed their babies and, in many cases, this was done without talking to them first.

One woman with a physical impairment recounted a story where, because of lack of access support, she was prevented from breastfeeding and her baby was instead given a bottle by healthcare professionals.

> "There didn't seem to be any logical reason why the configuration of the room couldn't change. I remember saying we have a problem, and that I had had a couple of falls, and it felt to me like I was a complete inconvenience to the staff because they now had a baby they needed to feed themselves. For whatever reason, they made a decision that it was faster to formula feed him and settle him than it was to bring him to me and try and work on breastfeeding." – Woman

For one disabled woman, ableist and gendered assumptions by healthcare professionals meant that her right to feed her baby was taken away. As a disabled woman not in a relationship it was presumed that she was a surrogate for a family member and consequently wasn't enabled to be part of her baby's care.

> "That I was a single mother by choice obviously hadn't been communicated to the ward and they kept not coming to get me to change his nappy and I didn't understand what was going on, I wanted to do as much as I could. The nurses on the ward would always feed him through his tube and not really give me the chance to breastfeed him and I didn't understand why that was. I later found out from a conversation with one of the nurses where she said directly 'it's so nice you're having this baby for your sister' and I was like hold on, no, my sister is my support

> person. It was a really big shock to them… there was this really weird presumption. He was probably 4 days old before I changed a nappy." – Woman

Being denied the choice to breastfeed created in some disabled women a sense of failure, and impacted upon the bonding process with their baby.

> "I distinctly remember the very first night, this lady came in and she said 'I'm going to get him some formula'. She went out, she came back and there was no conversation. It had pretty disastrous impacts on my bonding with my baby in those first days. It was a complete and utter sense of failure." – Woman

> "Because I wasn't mobile, by the time I pressed the button and they came in, baby was too distressed, and their solution was to give him formula and no one really thought about expressing or a plan for this. That created a real immediate sense of failure around not being about to breastfeed him and not be able to get to him sufficiently quickly and not be able to pick him up properly. It was kind of like being more disabled than ever." – Woman

Ableist assumptions that babies with impairments cannot breastfeed

There seemed to be a strong underlying assumption by some healthcare professionals that babies born with certain impairments cannot breastfeed. Some women were told outright that their babies would not be able to breastfeed. For others, they described an over-emphasis by healthcare professionals on the challenges they would face breastfeeding because of their baby's impairment.

> "They said 'oh you probably won't be able to breastfeed'. There was so much focus on how she wouldn't be able to do it and her poor muscle tone. She needed a little bit of support, but we just finished breastfeeding before she turned four." – Woman

> "It's good to identify that there may be some challenges but there was a real emphasis on how it probably won't work for you. They spent a lot of time warning me that I probably wouldn't be able to breastfeed. I breastfed my son until he was about four years old." – Woman

> "The doctor said 'she almost won't be able to breastfeed, there is almost no chance that she will be able to do it' and we went ok. It was gutting." – Woman

Receiving advice of this nature meant that some women who had babies with impairments didn't want to try breastfeeding at all. For others, it made them determined to breastfeed their babies and prove healthcare professionals' assumptions about their babies wrong. CMT midwives similarly reflected upon the ways in which some healthcare professionals presumed a baby's inability to feed based solely on their impairment, impacting upon women's decision to breastfeed.

> “There is good by-in from a lot of professionals around breastfeeding or expressing and bottle-feeding, because of health benefits. There is still a struggle of the perception that your baby is different, they are not going to be able to breastfeed. We are trying to encourage what we see, and know, can be possible, but sometimes we are butting heads with others in different professions.” – CMT midwife

Lack of support can make bottle-feeding complicated for women who have babies born with impairments

Feeding with a special bottle, particularly by women who had babies born with cleft lips and palates, was described as complicated, and the process of trying different bottles, stressful. It was noted staff did not seem to have knowledge in this area, nor did they have the time to spend working things through with women.

> “After birth I saw a lactation consultant very briefly but she just gave me pamphlets and said ‘read them when you have time’ but I didn’t have the time, and then she brought me a pump and stuff and said ‘here you go’, she didn’t take the time to sit with me and explain how to pump, so I was stuck with this machine that I didn’t know how to use.” – Woman

> “The speech language therapist left a bottle on the ward for the nurses to practice putting together but nobody on the ward knew how to put it together. I don’t think even the speech therapist knew, a lot of people don’t come across them very often and so they don’t have to use them.” – Woman

These women felt alone in their efforts and would often turn to alternative sources such as YouTube for insight on how to put bottles together and use them.

> “The nurses didn’t know what to do with the bottle because they had never seen one, we literally had to google it to find out.” – Woman

One woman talked about healthcare professionals’ lack of knowledge about community-based supports, and how she spent four hundred dollars on a breast pump, finding out later that she could have hired one for free from a community-based organisation.

Women feel they are not supported to engage in baby's feeding routine while in specialist care

Although most women had only praise for the way their babies were cared for in specialist care wards, a few women talked about the way in which they weren't enabled to be a part of their baby's feeding routine. They were alert to time pressures and resource constraints but thought more emphasis could be put on enabling them to be part of their baby's care, particularly in relation to establishing feeding routines. Women described feeding routines as being essential to forming a bond with their baby, whilst helping them prepare to care for their baby when they went home.

Two women said they couldn't properly bond with their baby because they were not supported to participate in their baby's feeding routine.

> "There was never any real bond between me and baby. Because they just did it all for you, and if you weren't there, they just did it anyway." – Woman

For some women, intervention by healthcare professionals meant they missed out on enjoying some of the important 'firsts' with their babies. Other women felt as though their input about their babies care needs were not respected. They commented that acknowledging and integrating their knowledge and experience would help enable them to feel better involved in their baby's care.

> "It was one of the nurses that gave him his first bottle, I wasn't even there. That felt funny at the time." – Woman
>
> "It was really hard and frustrating time. The staff just acted like 'we know what we are doing, just give us your child and stay out of it.'" – Woman

Resource constraints impact upon feeding support

During the focus group, several CMT midwives brought up resource constraints around feeding supports. It was noted that there was a huge demand for feeding support and not enough trained staff to keep up with the demand.

> "It's a tricky situation because there are only two lactation consultants doing the staff education, the public education and with the ward support to do as well." – CMT midwife
>
> "I know on the ward they don't have the luxury of sitting with them for hours and talking through every single step and just being there for them and the baby." – LMC midwife

With DHB-run breastfeeding classes consistently overbooked and lactation consultant supports underfunded and resources stretched, there was a concern that a lot of women are not receiving the supports they need to establish a good feeding routine.

> “The DHB run about 30-35 breastfeeding classes a year, several in Wellington, some in Johnsonville in Mandarin, and some in Kenepuru. They are always overbooked.” – CMT midwife

Stretched mental health services

Mental distress is disabling and can occur alongside other impairments

For some women in this project, mental distress was disabling. For others, mental distress occurred alongside other impairments. Some disabled women had existing relationships with community mental health services, while others received care through maternal mental health. Several disabled women in this project experienced postnatal depression, with three of them experiencing postnatal psychosis. One disabled woman had an extended stay in the mental health ward and was not able to go home with her baby for some months. For another disabled woman, the trauma associated with her maternity and mental health care informed her decision to not have any further children.

Early intervention was described as key to mitigating the potential impacts of mental distress in the early days following birth. However, many disabled women felt they were ill-prepared for, and not well-supported to manage, their mental health during their maternity journey.

> “It would have made a massive difference if maternal mental health been involved earlier because I think plans would have been in place and I think we would have all gone home knowing that things needed to be managed carefully.” – Woman
>
> “I just wish that my mental health worker had mentioned to me that things could go wrong. I don’t think it crossed his mind what complications could arise after the birth… if he had come and even had one meeting about what could happen or if he had met with my midwife and they had been on the same page.” – Woman
>
> “I said to community mental health ‘why did you not warn us about postnatal psychosis?’, and he said I didn’t even know it was a thing.” – Woman

Women who had babies born with impairments similarly reflected upon requiring mental health support, particularly when their baby was receiving long-term care in specialist care wards and around the time of diagnosis.

> "If someone is stuck there for a month there needs to be a plan put in for mental wellbeing. I was stuck in a weird alternative universe, no daylight, no circadian rhythm." – Woman

> "Looking back, it would have been beneficial to our family if I had been offered some mental health support, which I wasn't. It was really hard because it just felt like we were out there on our own, and that was a time when we really needed that." – Woman

Accessing mental health care is near impossible

It was acknowledged that accessing mental health care is incredibly difficult due pressures on mental health services. Disabled women noted that they didn't feel they could access support unless they were critical. In cases where a mental health plan was in place during pregnancy, disabled women noted feeling more supported and prepared.

> "You basically have to be saying you're going to kill yourself or harm your baby before they will see you." – Woman

> "While it was great for that first six weeks, the support after that is very limited. Once you are discharged from the midwife, it's a lot like, well, here you go…" – Woman

Although LMC midwives said they knew where to go for mental health support, they acknowledged increasing rates of mental distress in women and increasingly stretched mental health services. While some of the disabled women interviewed had a history of mental distress and were open in disclosing this, midwives felt that others played down aspects of their medical history which, they noted, impacted upon their ability to provide appropriate wrap-around maternity care.

> "Women with mental illness is increasing every year. It's staggering. From ten years ago, we would have the odd woman with anxiety or depression and medicated/non-medicated, to almost every second woman has anxiety or depression, half of those people are medicated, it's an epidemic in young women." – LMC midwife

> "Especially with mental health, women might say they have a history of depression, they're on medications, history of anxiety as a teenager, may have had an attempt on their life but often they will say 'but I'm okay now' and 'I'm just on these tablets' but if you investigate and they give you permission to go into their clinical notes, sometimes it just unfolds a little bit more than they have shared for you to be able to provide that good wraparound care for them… that occurs a lot." – LMC midwife

Recommendations

The recommendations in this report are specific to improving access to 3DHB services for disabled women and women who have babies born with impairments. Many of the issues identified in this project relate to systemic problems within the maternity care system, for example, resourcing and cost, and these issues are experienced by all users of the system. However, when combined with attitudinal, physical and communication barriers, these issues disproportionally affect disabled women and women who have babies born with impairments.

The 'Māmā and Pēpi' report provides a set of principles for developing an ideal future state for services: holistic and inclusive; adaptable and appropriate; thoughtful and authentic; enabling and responsive. We endorse these principles and provide some additional recommendations related specifically to disability issues and rights.

Disability rights training

The discriminatory attitudes and inadequate disability awareness of healthcare professionals often mean women do not have a positive maternity journey. Lack of education around disability rights and lack of disability training acts as a barrier to the delivery of good maternity care. By prioritising disability rights training across all maternity services, the 3DHB would be working towards creating a more inclusive and accessible environment that provides enabling care for disabled women and women who have babies born with impairments.

We recommend the 3DHB:

- provide robust training about disability issues, rights and language that would assist healthcare professionals to better individualise their care for disabled women and women who have babies born with impairments;
- educate healthcare professionals on the social and human rights models of disability and incorporate it into 3DHB practice;
- provide rights-based awareness training around the challenges that can come with disclosing disability; and
- provide healthcare professionals with training in delivering news of a diagnosis in ways that avoid ableist language and that are not framed as a tragedy.

Antenatal education

Antenatal educators have a duty to dismantle ableism by talking about impairment and disability in classes. Ensuring conversations about impairment and disability become a typical and expected part of the antenatal conversation helps to reduce wider societal stigma. We suggest a 'twin-track approach' where women are able to choose to attend 'mainstream' classes as well as some classes specifically for disabled women and/or women who are expecting babies with impairments. The designation of some antenatal classes specifically for disabled women and women who have babies born with impairments will create opportunities for peer support and mutual problem-solving.

We recommend the 3DHB:

- address the content of antenatal education to reflect and incorporate the needs of the disabled community, including education about medical interventions, caesareans, and feeding support;
- incorporate impairment and disability-related issues into antenatal education so that it becomes a 'normal' part of the maternity conversation;
- ensure that antenatal classes are safe spaces for disabled women and women who have babies with impairments; and
- engage with the disabled community in the development and evaluation of disability-related resources for antenatal classes.

Community connections

In order to provide enabling maternity care to disabled women and women who babies born with impairments, the 3DHB should strive to more firmly establish and maintain relationships with the disabled community. The promotion of community-based supports and services can provide wraparound care that demonstrates a more balanced view of disability.

We recommend the 3DHB:

- establish and maintain relationships with the disabled community;
- promote parent networks, support groups and community-based services that provide emotional and educational support through critical times, such as after diagnosis;
- link disabled women up with impairment-specific services that can provide wraparound support in all stages of the maternity journey;
- provide accessible educational resources that are created in collaboration with the disabled community; and
- create a database of impairment-specific support networks for healthcare professionals to draw from.

Mental health services

Disabled women and women who have babies born with impairments struggle to receive timely and appropriate mental health care as part of their maternity journey. Difficulties in accessing mental health services greatly impacts upon these women's maternity journeys. Similarly, stretched mental health services impinge upon midwives ability to deliver individualised care.

We recommend the 3DHB:

- provide preventative mental health support services so that disabled women with mental distress don't get to the point that they are critical;
- support healthcare professionals to understand the complexity of emotional response associated with receiving a diagnosis;
- address the inaccessibility of mental health services to ensure all women experiencing mental distress are able to gain access to mental health support; and
- ensure wraparound support for women experiencing mental distress.

Providing enabling care

Removing the barriers that exist for midwives and other healthcare professionals is one way to improve the maternity experiences of disabled women and women who have babies born with impairments. If fully supported, midwives have the potential to reduce maternity care inequities and improve outcomes for disabled women and women who have babies born with impairments.

We recommend the 3DHB:

- seek to improve wraparound services for disabled people so that midwives can focus on maximising relationships and meaningful communication with disabled women and women who have babies born with impairments;
- increase the time available for midwives to engage with disabled women and women who have babies born with impairments;
- provide professional development on disability-related issues that enable midwives to better relate to, and communicate with, disabled people and about babies born with impairments; and
- provide training and education around breastfeeding support for disabled women and women with babies born with impairments to improve knowledge on feeding issues and solutions.

Data, research and evaluation

There is a notable absence of disability data, including in relation to reproductive and maternity health, in Aotearoa New Zealand. Relevant, accurate and timely information is critical to improving the maternity outcomes of disabled women and women who have babies born with impairments. Collection of disability data enables the reliable monitoring of service quality and outcomes.

We recommend the 3DHB:

- develop a robust process for gathering reliable data on disabled women and babies born with impairments;
- develop a robust process for recording any progress made towards addressing the barriers to equitable maternity care outcomes;
- collect data on the numbers of disabled women and women who have babies born with impairments engaging in maternity care, including, but not limited to, sterilisation, fertility, pregnancy, birth and abortions;
- advocate for disability data to be included in Ministry of Health maternity experiences reporting; and
- further investigate areas of this report in more detail in order to better address the needs and rights of disabled women and women who have babies born with impairments, and better improve their health outcomes.

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April 2021

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Disability Support Advisory Committee

21 July 2021

3DHB Final Draft Annual Plans 2021/22

Action Required

The 3DHB Disability Support Advisory Committee notes:

(a) the CCDHB, HVDHB, and WrDHB final draft annual plans 2021/22.

Strategic Alignment	The draft annual plans are aligned with the CCDHB Health System Plan 2030 and HVDHB's Vision for Change, our strategic priorities, and WrDHB's eight strategic objectives.
Presented by	Rachel Haggerty, Director Strategy, Planning & Performance CCDHB and HVDHB
Purpose	Note the final draft annual plans and the actions planned in 2021/22 to improve health outcomes for disabled people.
Contributors	Peter Guthrie, Manager Planning & Performance, Strategy, Planning & Performance Nathan Clark, Manager Strategy and Planning, Strategy, Planning & Performance
Consultation	A paper on the first draft Annual Plans was provided to DSAC in April 2021. The Ministry of Health approved our initial draft 2021/22 annual plans on 9 April with a small number of technical issues identified, which have now been addressed. We have consulted with advisory groups on the draft annual plans. The Sub-Regional Disability Advisory Group (SRDAG) provided useful feedback on the draft plans, and as a result we refined the actions related to improving health outcomes for disabled people and have made 'disability' more visible throughout the plans. We provided the Ministry with our final draft annual plans on 2 July 2021.

Executive Summary

Background

1. CCDHB and HVDHB have run a single 2DHB process to develop the first draft 2021/22 annual plans. The CCDHB and HVDHB annual plans are aligned but not identical, as our populations have unique characteristics and needs. We have also worked closely with Wairarapa DHB to ensure 3DHB alignment across our plans.

2. Our first draft annual plans reflect our strategic priorities and the Government's planning priorities for health. Our Pro-Equity Approach is incorporated across all our strategic priorities. We are currently establishing specific work programmes, budgets, and governance arrangements for 2021/22 to support implementation of our strategic priorities.

3. The plans use the template supplied by the Ministry of Health. Section 2, Delivering on Priorities, includes sections on 'Health Outcomes for Disabled People' and 'Improving Mental Wellbeing'.

4. We provided DSAC with our first draft annual plans in April 2021. The Ministry of Health approved our initial draft 2021/22 annual plans on 9 April with a small number of technical issues identified, which have now been addressed.

5. We have consulted with advisory groups on the draft annual plans. The Sub-Regional Disability Advisory Group (SRDAG) provided useful feedback on the draft plans, and as a result we refined the actions related to improving health outcomes for disabled people and have made 'disability' more visible throughout the plans (within the constraints of the 2021/22 MoH planning guidance).
6. We provided the Ministry with our final draft annual plans on 2 July 2021.

Health Outcomes for Disabled People

7. For the 'Health Outcomes for Disabled People' section of annual plan, the Ministry has asked DHBs to include at least one action:
    a) to support COVID-19 recovery and/or embed key learnings from its COVID-19 response
    b) focused on our Māori populations
    c) focused on our Pacific populations.
8. Our draft plans include the following 3DHB actions for 2021/22 to improve health outcomes for disabled people:
    a) Collaborate with the Ministry, DHB staff, community stakeholders and disabled people in each region to develop new Sub Regional Disability Strategy for 2023 – 2028, which will include a specific focus on embedding the learnings from COVID-19. Development of the revised strategy will include targeted engagement with Māori disabled people and Pacific disabled people to advise and help develop tailored actions to achieve equable outcomes.
    b) Work with the Disability Support Advisory Committee to implement a process to collect information (eg standardised disability question) from people with disabilities that enables health services to respond to people with disabilities and be culturally responsive to Māori people and Pacific people.
    c) Deliver core disability responsive education with the newly completed e-learning programme of three modules that all staff must complete. This programme will ensure that all staff have foundational knowledge about disability; the rights based approach; the importance of attitude and how to make reasonable accommodations building on the gap identified during the COVID response.

Next Steps

9. The Ministry is expected to provide us with feedback on our final draft plans by 23 July. On 4 August 2021 we will ask the Boards to approval the final drafts for the Minister's sign off.
10. We are actively looking for ways to work with the MoH and the Transition Unit to strengthen the voice of the disability community in the 2022/23 New Zealand Health Plan so that any actions in the New Zealand Health Plan for 2022/23 include Māori, Pacific and the Disability community.
11. Work on the collection of information from people with disabilities is well advanced and we are ahead of the requirements of action (b) outlined above.

Attachment/s

Attachments are located in the **Resource Centre on Diligent in the folder labelled "DSAC – 21 July 2021".**

1. Final draft 2021/22 CCDHB annual plan including Statement of Performance Expectations
2. Final draft 2021/22 HVDHB annual plan including Statement of Performance Expectations
3. Final draft 2021/22 WrDHB annual plan including Statement of Performance Expectations

Disability Support Advisory Committee

21 July 2021

Mental Health and Addiction Commissioning Forum

Action Required

The 3DHB Disability Support Advisory Committee notes:

(a) The establishment of a Mental Health and Addiction Commissioning Forum to steer the design and implementation a whole of population, equitable, mental health and addiction system of care to support the wellbeing of the people in our subregion.

(b) The appointment of office holders and members to the Mental Health and Addiction Commissioning Forum from four groups: DHB system leaders; people with lived experience; Māori; and clinical/expert leaders.

(c) The Mental Health and Addiction Commissioning Forum's role to provide advice and recommendations to the Chief Executive, Hutt Valley and Capital & Coast DHBs.

(d) The Mental Health and Addiction Commissioning Forum will provide governance for our DHBs' delivery on the mental health and addiction strategic priority; driving system transformation as we transition to a new health and disability system.

(e) The plan to hold the first meeting of the Mental Health and Addiction Commissioning Forum in August 2021.

Strategic Alignment	He Ara Oranga – Report of the Government Inquiry into Mental Health and Addiction (He Ara Oranga) Living Life Well a strategy for mental health and addiction 2019-2025 2DHB Māori, Pacific peoples and Disabled people strategies, that identify people with MHA issues as a priority major service user group.
Presented by	Rachel Haggerty, Executive Director System, Strategy, Planning and Performance (SPP)
Purpose	To provide the Committee with information about the establishment of the Mental Health and Addiction Commissioning Forum
Contributors	Catherine Inder, Principal Advisor System, SPP Chris Nolan, General Manager, Mental Health and Addiction, SPP (Acting)
Consultation	N/A

Executive Summary

Purpose

He Ara Oranga - Report of the Government Inquiry into Mental Health and Addiction calls for a transformed approach to MHA in New Zealand requiring significant investment over several years and signals the need for a system of services that meets the full spectrum of need.

The Executive Leadership Team at Hutt Valley and Capital & Coast DHBs have agreed to establish a Mental Health and Addiction Commissioning Forum (MHA Commissioning Forum) to steer the redesign and implementation of a whole of population, equitable, MHA system of care to support the wellbeing of the people in the region.

The Commissioning Forum is not a decision-making body however its advice and recommendations to the Executive Leadership Team (ELT) will significantly influence the redesign of the MHA system of care, including determining the priorities and pace and scale of change.

Structure and membership

The Commissioning Forum will support the transformation of the MHA system of care through the provision of strategic advice and recommendations across a broad range of commissioning activities and will provide high-level oversight of system performance and service delivery via monitoring reports.

The Commissioning Forum will have ten members (including the Chair) from four groups:

- DHB leaders focused on health system performance and equity for our priority populations
- People with lived experience of MHA issues
- Māori partners in fulfilment of our DHBs' Te Tiriti obligations
- Clinical/experts contributing clinical and cultural knowledge.

Members	**Role**
Chair (1)	Chief Executive, 2DHBs
Māori leaders (2)	Director, Māori Health Clinical leader, Māori
Lived experience leaders (2)	Lived experience lead, Lived Experience Advisory Group Consumer lead, MHAIDs
Clinical/Expert leaders (2)	Clinical lead, MHAIDs Executive lead, MHAIDs
System leaders (3)	Director, Strategy, Planning and Performance (SPP) Director, Pacific Health General Manager, Disability, SPP
Support	**Role**
Secretariat	General Manager, Mental Health and Addiction, SPP Principal Advisor, SPP Executive Assistant, SPP

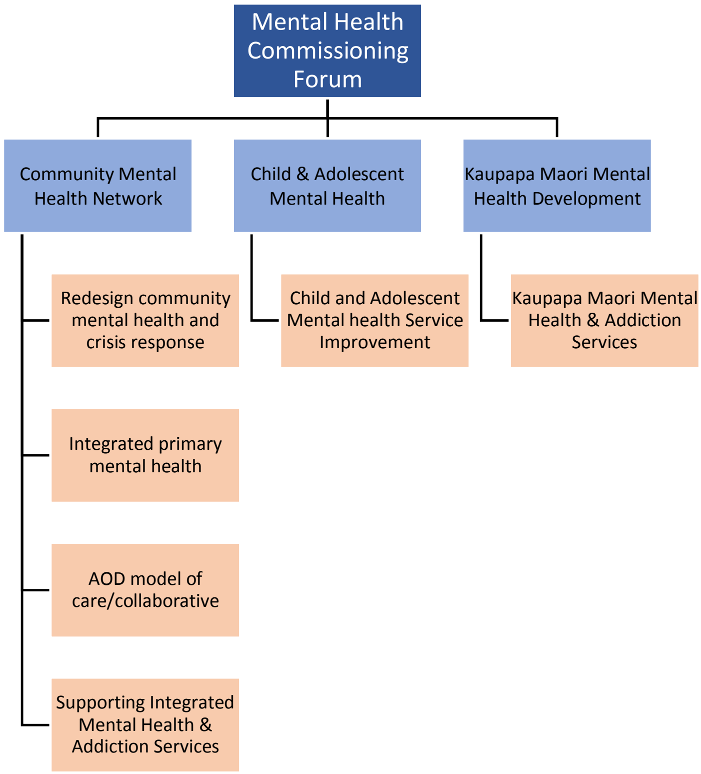
Collaborative networks will contribute to the work of the MHA Commissioning Forum and enable a coordinated approach to implementing its decisions including: the Acute Care Continuum Collaborative; the Alcohol and other Drug Implementation of the Model of Care Collaborative; and the Lived Experience Advisory Group.

Strategic priority

Mental Health and Addiction is one of three priorities to drive system transformation as our DHBs transition to a new health and disability system. The MHA Commissioning Forum will govern the delivery of three work programmes with six work streams (see diagram on the next page).

Next steps

The first meeting of the MHA Commissioning Forum is planned for August 2021 where Terms of Reference will be discussed and agreed.



Strategic Considerations

Service	The MHA Commissioning Forum will play a key role in expanding the service continuum and improving service delivery across MHA inpatient, primary, community and health promotion services.
People	The MHA Commissioning Forum will focus on upholding our Te Tiriti o Waitangi obligations developing a kaupapa Māori approach across the continuum of services and designing services that improve wellbeing and achieve equity for our priority populations: Māori, Pacific people and Disabled people.
Financial	He Ara Oranga acknowledges that significant investment is needed to transform MHA services. The MHA Commissioning Forum will provide a prioritisation process for existing and future investment through He Ara Oranga.
Governance	N/A

Engagement/Consultation

Patient/Family	Lived Experience Advisory Group
Clinician/Staff	Alcohol and other Drug Model of Care Collaborative Acute Care Continuum Collaborative
Community	N/A

Identified Risks

Risk ID	Risk Description	Risk Owner	Current Control Description	Current Risk Rating	Projected Risk Rating
	MHA providers may consider that the MHA Commissioning Forum should have provider representatives	Director, SPP	The provider collaboratives will enable providers to influence the system transformation	Medium 12	

Attachment/s

None.

Disability Support Advisory Committee

21 July 2021

3DHB Sub Regional Disability Strategy 2017 – 2022 Update

Action Required

The 3DHB Disability Support Advisory Committee notes:

(a) the update on the implementation of the Sub Regional Disability Strategy 2017 – 2022.

(b) the disability question has been prototyped included in our regional booking processes and systems established to allow people to request reasonable accommodations if required.

(c) the Disability Equity e-learning modules are now available on Connect Me, Ko Awatea and Health On Line.

Strategic Alignment	Health System Plan 2030 Living Life Well A strategy for mental health and addiction 2019-2025 (Living Life Well) Taurite Ora Māori Health Strategy 2019-2030 Te Pae Amorangi Maori Health Strategy 2018 -2027 Pacific Health and Wellbeing Strategic Plan for the Greater Wellington Region 2020-2025 Sub-Regional Disability Strategy 2017 – 2022. Wairarapa, Hutt Valley and Capital & Coast District Health Boards
Authors	Rachel Noble, General Manager Disability
Endorsed by	Rachel Haggerty, Executive Director Strategy, Planning & Performance
Presented by	Rachel Noble, General Manager Disability
Purpose	This paper provides brief updates on the implementation of our Sub Regional Disability Strategy 2017 – 2022.
Contributors	The Disability Team
Consultation	N/A

Background

The Disability Strategy and Performance team supports 3DHB initiatives to provide accessible and inclusive healthcare services to disabled people and their whanau 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 the in the Sub Regional Disability Strategy 2017 – 2022 and includes our responses to the recommendations from the Sub Regional Disability Forum.

Focus Area One: Leadership

Disability Team

The current focus for the Disability Team has been to ensure the COVID-19 vaccination programme is inclusive and accessible. The team has expanded for this work and we're very excited by the Pro-Equity approach taken. We agree that this approach has made it more possible to implement inclusive and accessible initiatives in ways that are meaningful and lasting.

It gave us the chance to 'normalise' the features we, as a team, had been working on by giving us a contained ecosystem. The value of this is that it allows us to then demonstrate its benefits into the wider DHB work programme over time.

Regional Hui and Fono

Kaunihera Whaikaha worked with an independent consultant Cathy Nesus to develop a strategic approach for the next subregional Disability Strategy.

We have contracted an independent facilitator, Hele Matatia to review the requests made by the Pacific Disability community at the 2014 and 2019 Sub Regional Disability Forums in Silverstream. This will be a joint Pacific and Disability team initiative to raise the voices of Pacific Disabled people and in turn, raise the accessibility of services to this community.

The Sub Regional Disability Advisory Group decided not to hold Locality Forums and to instead focus on reviewing the recommendations made at the 2019 Silverstream Forum and to report on progress to date. The co-facilitator from that Forum Grant Cleland has been contracted to conduct this review.

Focus Area Two: Inclusion and Support

Data and Alerts

The Executive Leadership Team has approved the process of implementing the disability question in all relevant documentation. This has been delayed due to our COVID-19 vaccination work.

The vaccination work has allowed us to apply our data work in particular with the self-identification questions. These are included in our regional booking processes and systems established to allow people to request reasonable accommodations if required. Data will be collected through this process. It is positive that after a long engagement period this will now be included in the national booking system.

The inclusion of the disability question 'what access needs do you have' is in essence the My Health Passport and the Alerts concept in action as part of the way we offer vaccination programme. The challenge is for us to respond appropriately using the 'reasonable accommodations' approach. Again, there is evident now of this work being applied nationally.

We look forward to the monitoring of the process.

Enabling Good Lives

With support from the Directors of Allied Health we were able to offer five workshops as an Introduction to Enabling Good Lives Principles. The new health system has already indicated that the Enabling Good Lives Principles are to underpin disability related services.

Imagine Better delivered the workshop to motivated staff members who are very keen to continue to find ways to orientate our services to the community in a way that sees the principles applied. Suggestions were made which will be discussed with the Directors of Allied Health.

There is an interest in holding more workshops particularly with the Strategy Planning and Performance team so the principles can be applied in our planning work.

Child and Adult Transition

A review of the Child and Adult Transition project led by the Disability Responsiveness Team in 2014 – 2016 took place recently as the project came to a halt before it was completed. As it is identified in the Strategy it was necessary to check its status and to consider if the problem it was trying to resolve at the time has in fact been resolved.

The project developed the first draft of an electronic health pathway to support GPs in managing the issues faced by young people who have been discharged from child health and child development services. These children are known to face difficulties accessing adult services when and if they require them. The General Practice, as the main health care provider for the young person, needs to be knowledgeable about individual circumstances and understand the most appropriate referral pathways to secondary services or indeed to community services.

Feedback from the zoom meeting of all Child development services in the country is clear that the problem still persists nationally. While several DHB's are looking at how they manage the process for transitioning young people, they appear to be looking within their respective DHB's only.

With the revised My Health Passport in use and plans in place to make the Health Passports and Alerts electronic it becomes a tools to be owned by the patient and can be used across all health professionals in all settings. This tool seems well placed to meet the needs of this population of people transitioning from child to adult services. It would seem unnecessary to duplicate this with a similar transitioning tool.

As result of this investigation the following recommendation was made:

The Health Passport and Alerts programme is already underway under the direction of the 3DHB Disability Team.

The next step is an educational focus, for the staff in the DHB's, PHO's, GP practises and community health groups.

A targeted educational programme is being designed for:

- families whose children will be transitioning into adult services
- all staff working with Children, both within DHB services and PHO and community services

Focus Area Three: Access

Accessible Information

COVID has provided us with the opportunity to create resources in NZSL and Easy Read for use in Vaccination sites.

One significant 'win' was the ability to engage with Nishi Wojnar a Graphic Designer with expertise in the development of accessible visual information. Posters, cards and other accessibility features were designed by Nishi to increase their accessibility for people with low vision and older people. Nishi is part of the Artificial Limbs Centre thus creating a positive connection for our work.

We continue to create COVID-19 Vaccination information in accessible formats. We also have a section in the Vaccinate Greater Wellington website for disability related information and accessible formats.

Built Environment

There has been an increase in the number of requests being made to us to advise early on both large and small building projects. We are very happy with the positive follow through our advice has.

We were thrilled to see Kenepuru Hospital succeed in their funding bid to install a path which means there will be an accessible route from the train station to the hospital.

In the atrium of Wellington Hospital our feedback has contributed to some new initiatives taking place to improve visibility and wayfinding signage.

Easy Read Photo Project

We have recruited an experienced photographer to take photographs across the health sector environment to be used in Easy Read material which is a form of information that is clear and easy for people with low literacy to read and understand.

People creating Easy Read documents require photos of the buildings, equipment, places etc. to use to illustrate where people are expected to go and what they can expect. We have access to a British catalogue of Easy Read images however many are British so cannot be used here.

In the planning work we have two people with learning/intellectual disabilities involved to provide expert advice.

We have identified/prioritised the need to have photos for Easy Read resources on the following:

- COVID (for local resources in addition to that being produced by MOH)
- Complaints/Feedback
- Buildings/clinics/locations
- Mental Health
- ED processes
- Appointment letters
- Machines, equipment, medical terms.

These images will create a ‘bank’ of images for use in our DHB Easy Read material.

Focus Area Four: Health

E-Learning Modules

Shortly after the launch of our Disability Equity e-learning modules we were asked to incorporate them as part of the national COVID programme for all DHBs. This means the e-learning is now available on Connect Me, Ko Awatea and Health On Line. It was peer reviewed (and well received with a few tweaks suggested) by other DHB Education Leads. Feedback from a wide range of people has been very positive.

It is now accessible on the Royal College of General Practitioners website with communications going to all GPs to promote it.

Deaf Mental Health Service

A proposal has been created for a specialist primary and community mental health service for deaf people as There has been no specialist mental health service for deaf people and people with hearing loss in the Hutt Valley and Capital & Coast District Health Board regions since 2010.

Access to suitable mental healthcare services is a pervasive issue for deaf people, and deaf people commonly report fear, mistrust and frustration in healthcare settings. Local and international research shows that deaf people experience greater acuity of mental health distress but have poorer access to quality culturally competent mental health care.

The proposed solution is for specialist mental health service as part of a continuum of service delivery in the 2DHB region comprising an specialist community-based clinical mental health service, creating a network of support for deaf and hard of hearing people with acute mental health needs, and delivering package of care funding for patients who require specialised or customised care.

We will continue to work with Chris Nolan, Acting GM for Mental Health Commissioning to advance this proposal.

Disability Support Advisory Committee

21 July 2021

3DHB MHAIDS Service Performance Update

Action Required

The 3DHB Disability Services Advisory Committee notes:

(a) the attached data report from MHAIDS.

Strategic Alignment	Service Access
Presented by	Karla Bergquist, Executive Director MHAIDS
Purpose	Update the DSAC on MHAIDS Service Performance
Contributors	Steve McGinnity and Hope McCrohon, Senior Data Analysts, MHAIDS
Consultation	N/A

Executive Summary

People accessing services

- The number of people who had contact with MHAIDS increased by 14.4% between 2014-15 and 2020-21. The rate of increase for Māori is significantly higher than that for Non-Māori.
- The increase represents an additional 1,480 people in 2020/21 than 2014/15. Māori made up 1,084 (42%) of that number.
- In terms of the proportion of population having contact, the rate for Māori has increased from 6.5% to 7.0% (7.4% in 2018/19), while the rate for Non-Māori has barely shifted.
- The patterns are similar across DHBs although the rate of Māori accessing services in Hutt has dropped slightly in recent years (7.2 to 6.5%)

New referrals MHAIDS

- Annual referrals to MHAIDS have increased by 20.6% over the past 6 years. Referral numbers increased across ethnicity with COVID-related dips in 2019/20. The biggest percentage increase this year has been in referrals for Pacific peoples, and cumulatively since 2014/15 baseline the biggest increases are for Asian and Māori.
- Similarly referral numbers increased across age groups until 2018/19 and decreased in 2019/20. This year referrals for young people aged under 24 have increased while other categories have decreased.

Urgent referrals

- While overall referral numbers have returned to levels similar to previous years, there has been a marked increase in urgent referrals received since the end of the initial COVID-19 lockdown. This pattern has continued over the last 12 months.
- The most significant demographic group for this increase in urgent referrals has been young people aged 24 and under.

Presentations at ED

- Post - COVID lockdown the number of presentations to ED for mental health reasons has largely returned to the previous levels at Wellington, with less presentations in the last 12 months at Hutt ED.

Community Caseloads & Wait times

- In the past six years community caseload totals have generally increased year on year. There are 384 more people on Younger Persons teams caseloads relative to 2014 (20.8% increase) and 267 more people on Adult teams caseloads (7.0% increase).
- The Ministry of Health target for wait times is 80% of people to be seen within 3 weeks of referral and 95% of people to be seen within 8 weeks. The Younger Persons sector has struggled to meet these targets – the average since Jan 2020 is 53% seen within 3 weeks and 80% seen within 8 weeks.
- The Adult Community & Addictions sector has slightly better results – the average since Jan 2020 is 59% seen within 3 weeks and 88% seen within 8 weeks.

Acute Inpatient Services

- Bed occupancy in the two adult acute inpatient units remains a critical issue with Te Whare O Matairangi in particular regularly being at maximum or over capacity.
- The target for the 28 Day Acute Inpatient Readmission rate is <=10%. MHAIDS inpatient units have only breached this target on two months since January 2020.
- Results for 7 Day Pre-Admission Community Contact; MHAIDS results for this measure have improved over the last 12 months with most months reaching the 75% target.
- Results for 7 Day Post-Discharge Community Contact; the mean for this measure is 80% for the past 12 months, slightly below the 90% target.

Strategic Considerations

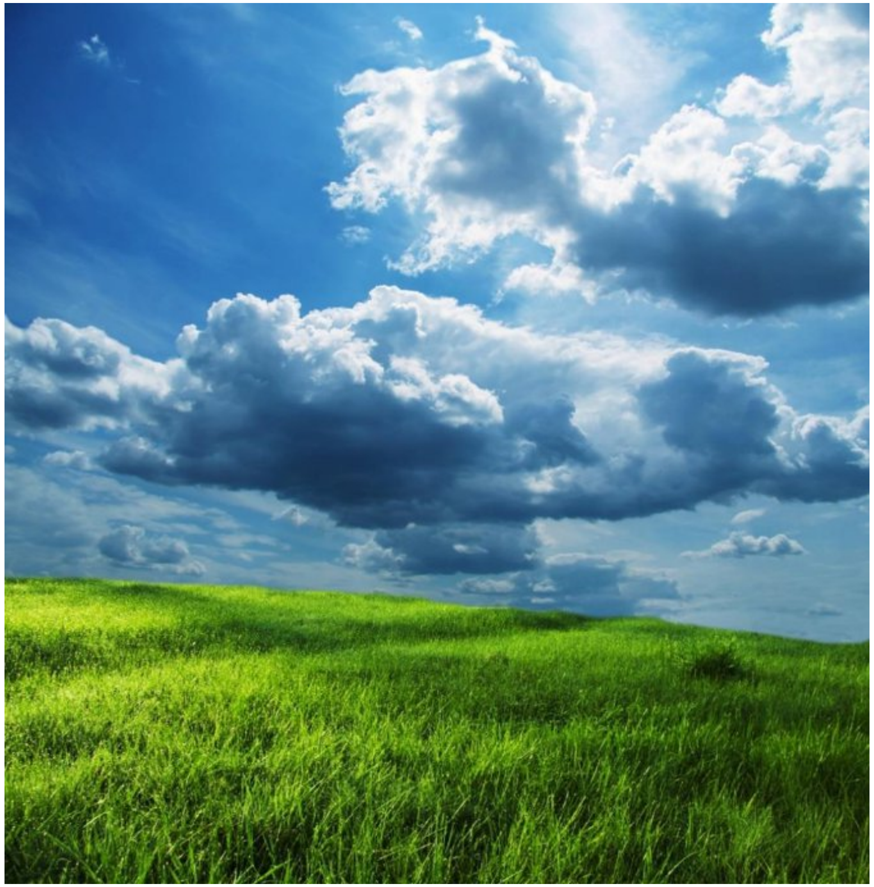
Service	All 2DHB services are committed to delivering safe, quality care to patients and whānau, and ensuring staff safety.
People	Increase understanding of patient safety, quality improvement patient / whānau experience and recognising opportunities for learning.
Financial	Poor patient outcomes and harm can have a direct financial impact on the performance of our DHBs.
Governance	We will strengthen quality and safety at every level through effective leadership, integrated governance and defined accountabilities across the health and disability system of the 2DHBs.

Attachment/s

1. MHAIDS Service Performance Update to July 2021

Mental Health, Addiction and Intellectual Disability Service

Service Performance Update to DSAC July 2021



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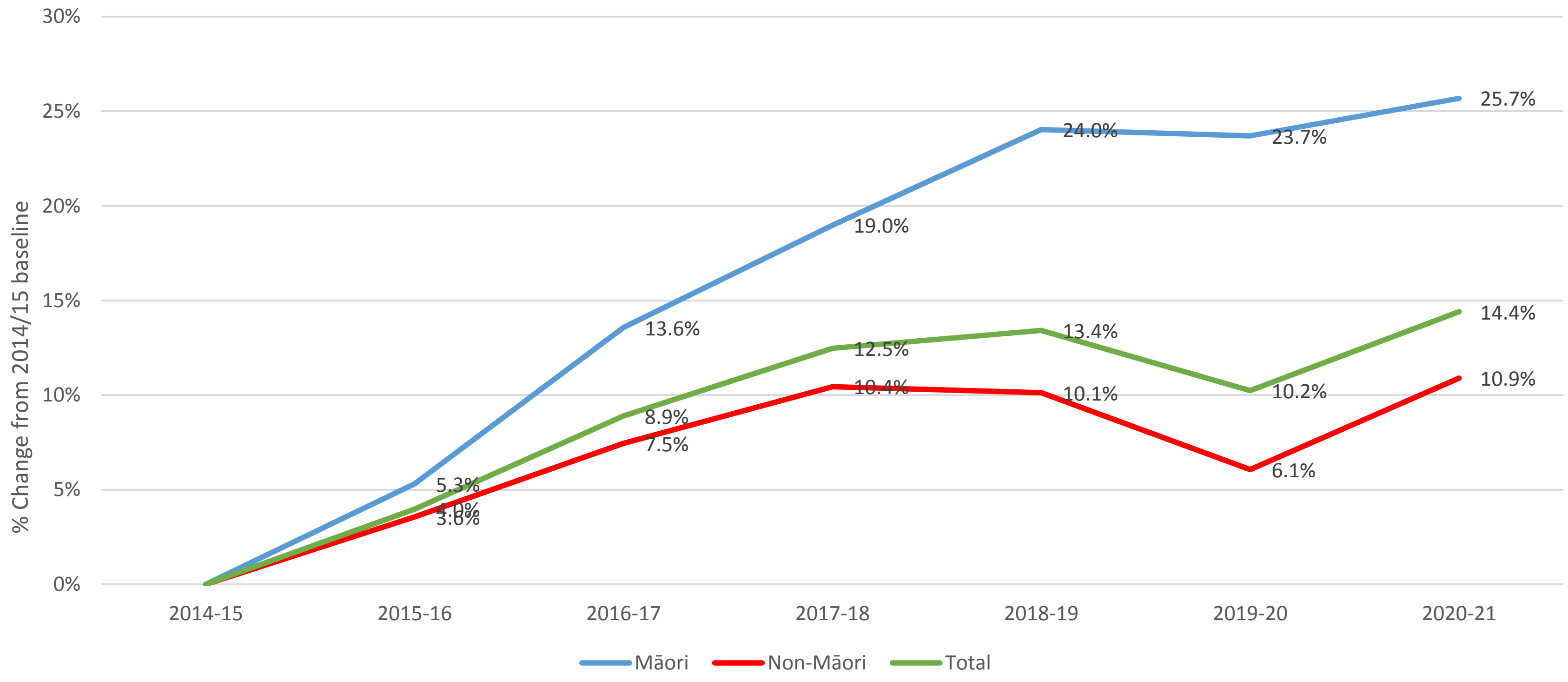
Intellectual Disability Service

People accessing MHAIDS services

The number of people that had contact with MHAIDS increased by 14.4% between 2014-15 and 2020-21. The rate of increase for Māori is significantly higher than that for Non-Māori.

% Growth in Individuals with MHAIDS Activity from 2014/15

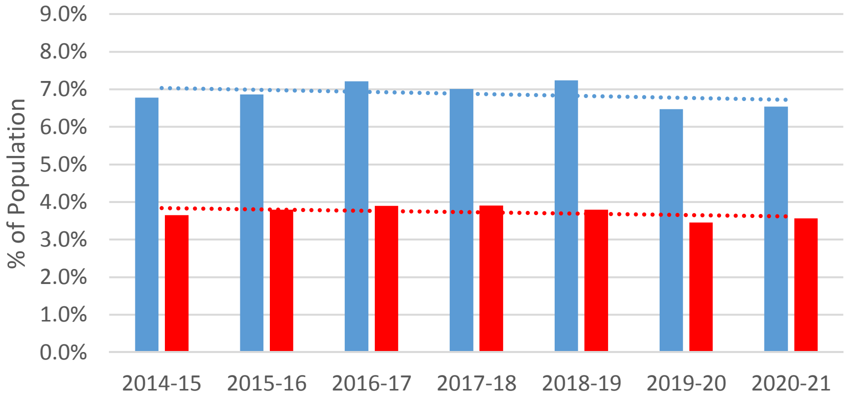


People accessing MHAIDS services

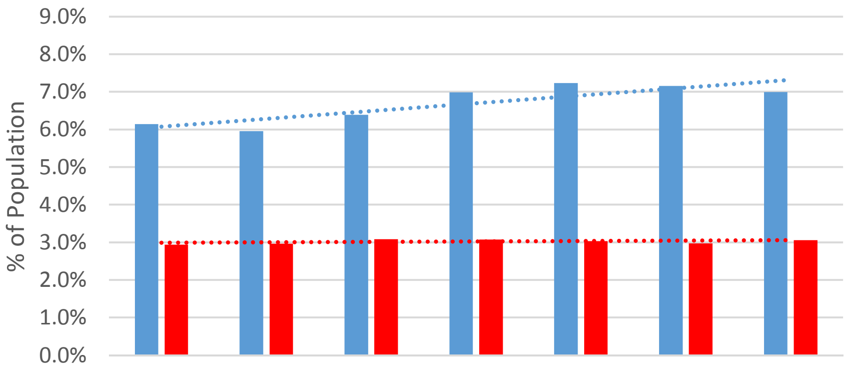
The patterns are similar across DHBs although the rate of Māori accessing services in Hutt has dropped slightly in recent years (7.2 to 6.5%)

- 🟦 Māori
- 🟥 Non-Māori
- ······· Linear (Māori)
- ······· Linear (Non-Māori)

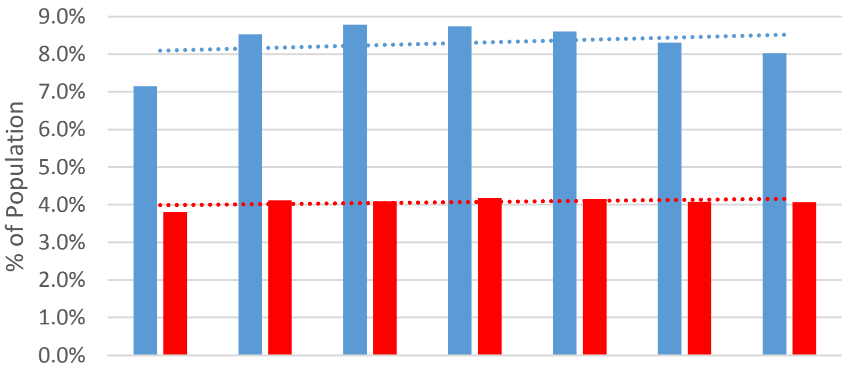
% of Population with MHAIDS Activity Recorded - Hutt Valley DHB



% of Population with MHAIDS Activity Recorded - Capital & Coast DHB

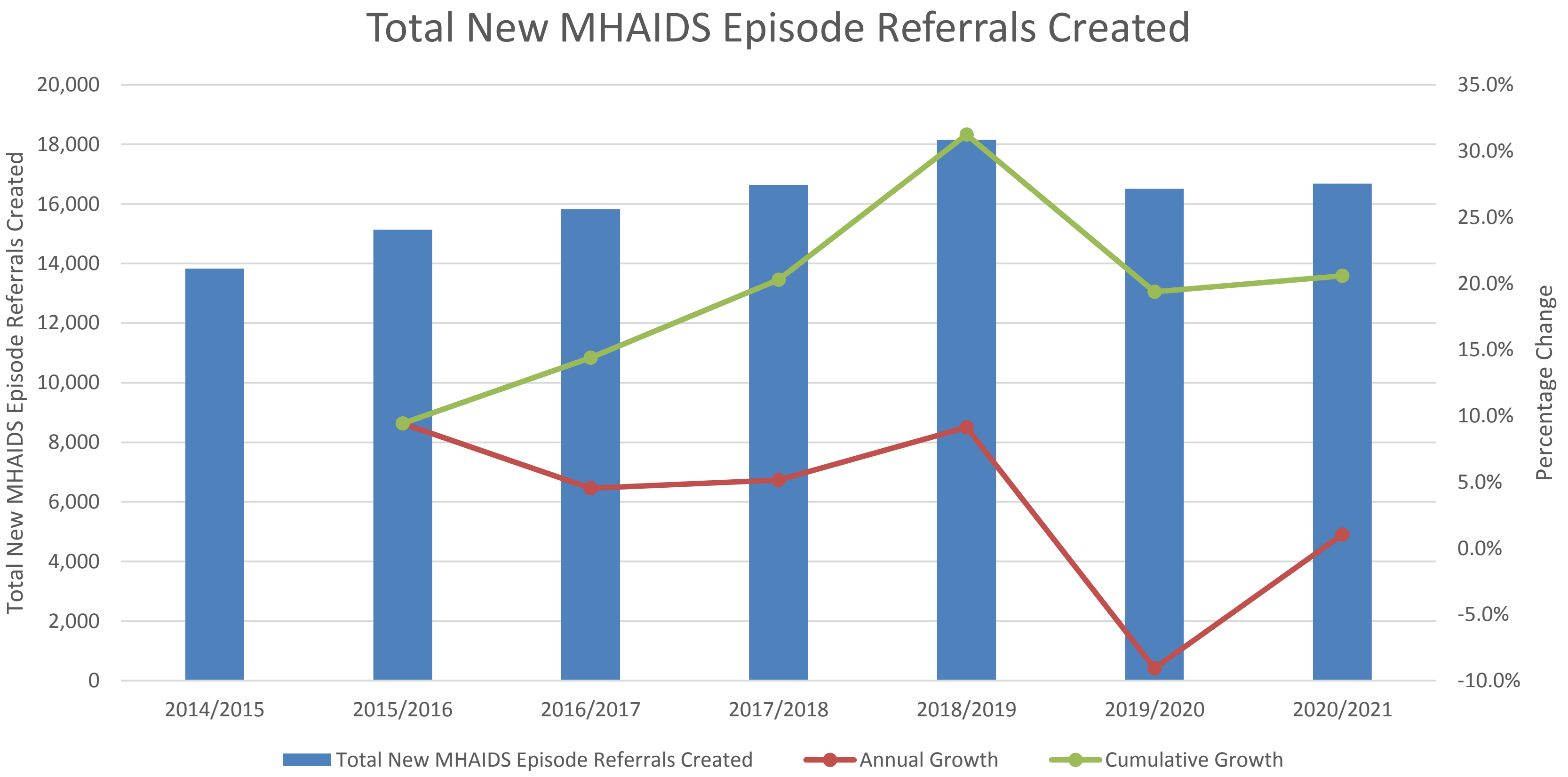


% of Population with MHAIDS Activity Recorded - Wairarapa DHB



New Referrals to MHAIDS

Annual referrals to MHAIDS have increased by 20.6% over the past 6 years.



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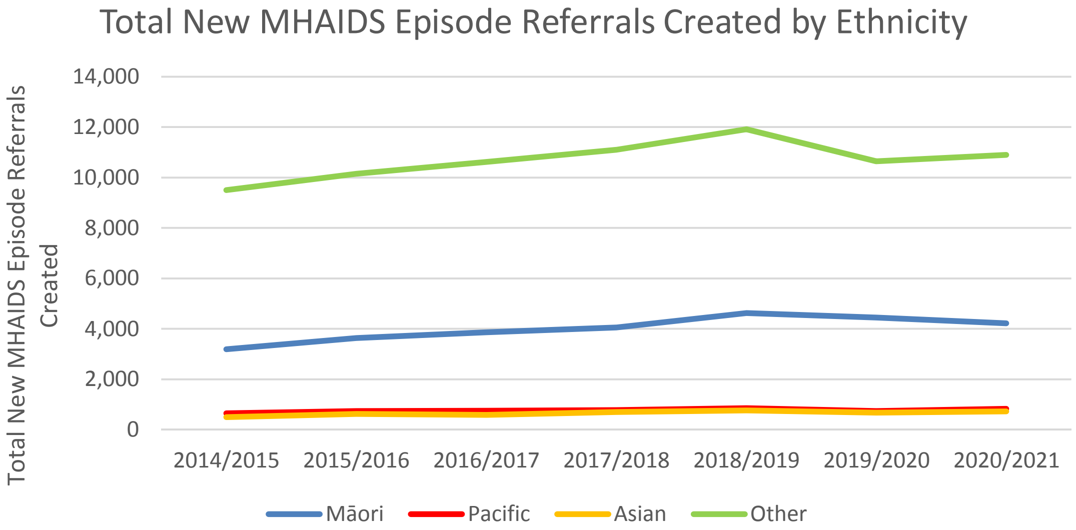
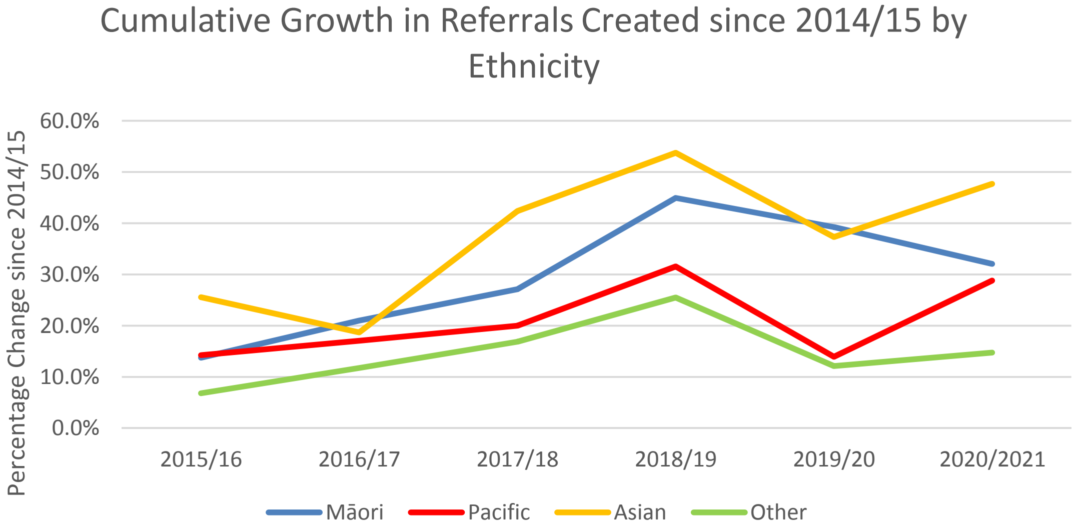
New Referrals to MHAIDS

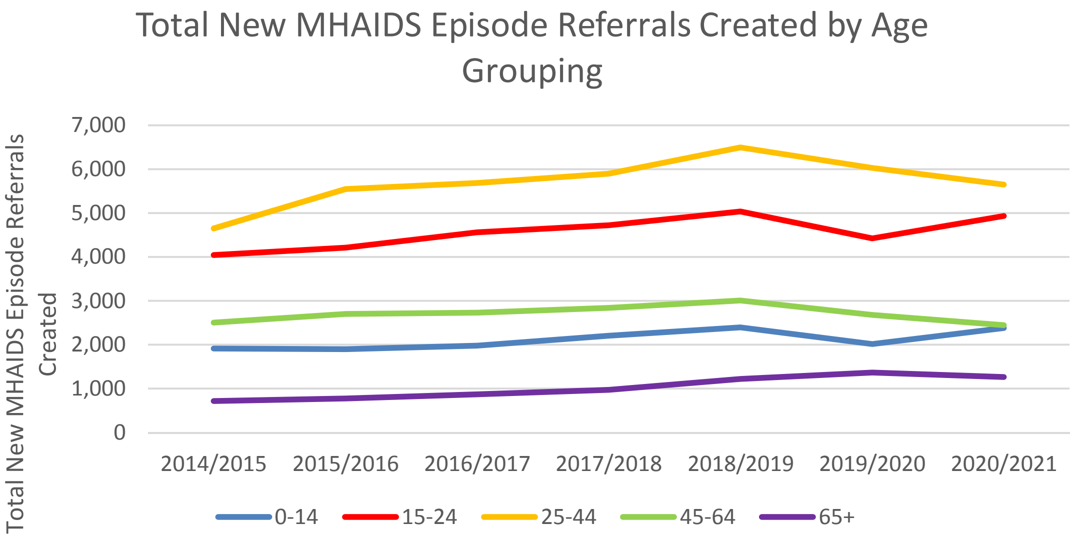
Referral numbers increased across ethnicity with COVID-related dips in 2019/20. The biggest percentage increase this year has been in referrals for Pacific peoples, and cumulatively since 2014/15 baseline the biggest increases are for Asian and Māori.

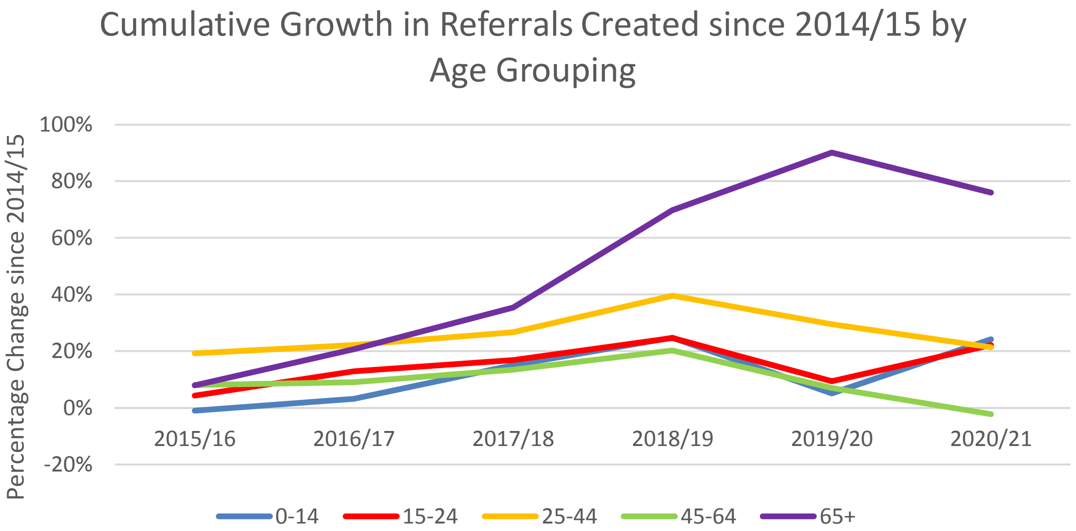




New Referrals to MHAIDS

Similarly referral numbers increased across age groups until 2018/19 and decreased in 2019/20. This year referrals for young people aged under 24 have increased while other categories have decreased.





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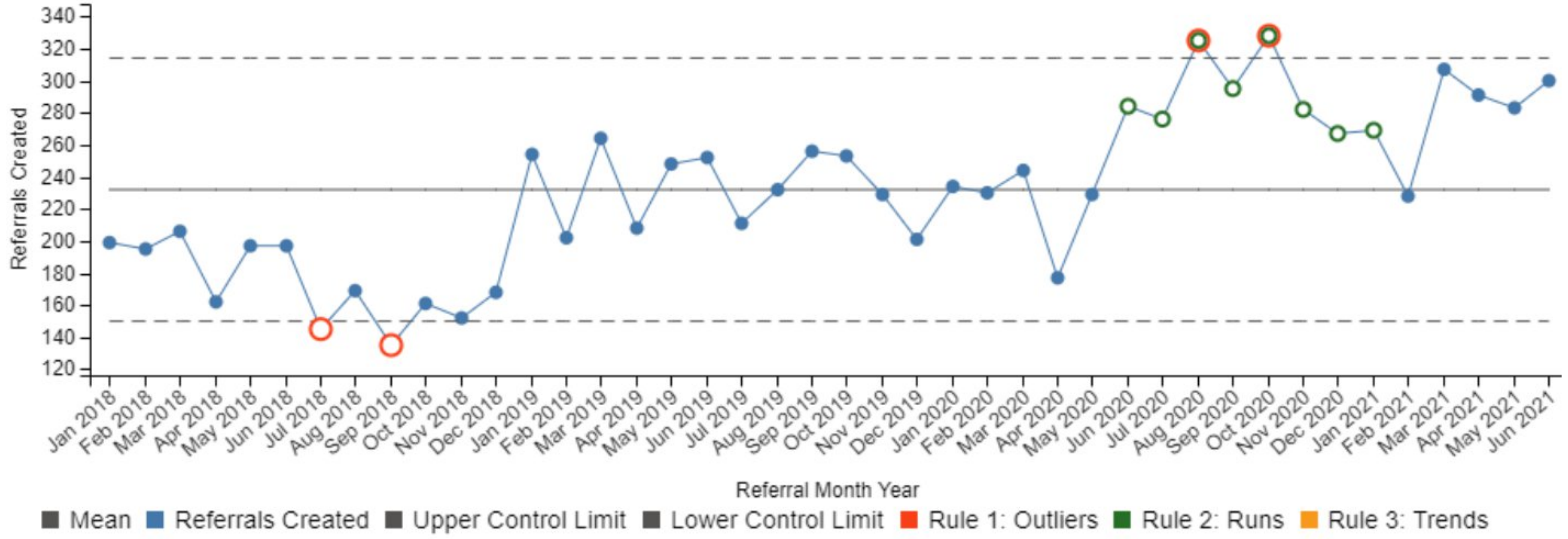
Urgent Referrals to MHAIDS

While overall referral numbers have returned to levels similar to previous years, there has been a marked increase in urgent referrals received since the end of the initial COVID-19 lockdown. This pattern has continued over the last 12 months.

Control Chart (I Chart) Showing Urgent Referrals Created



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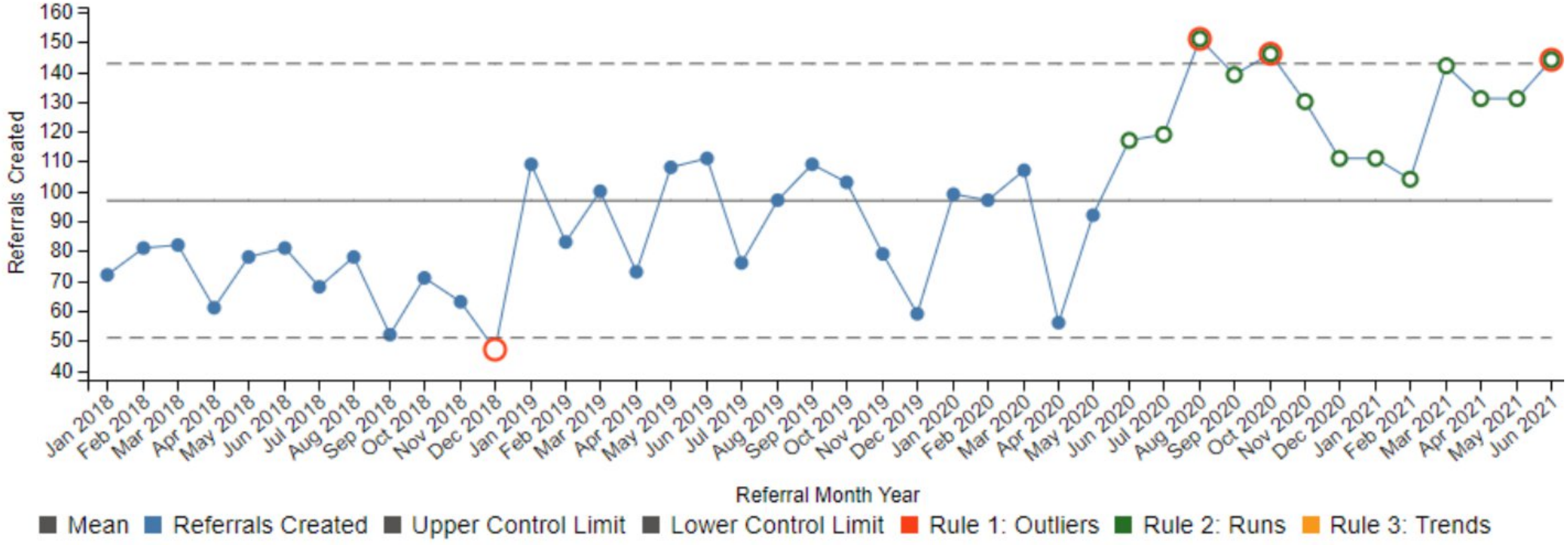
Mental Health, Addictions and Intellectual Disability Service

Urgent Referrals to MHAIDS

The most significant demographic group for this increase in urgent referrals has been young people aged 24 and under.

Control Chart (I Chart) Showing Urgent Referrals Created – Age 0-24 Years



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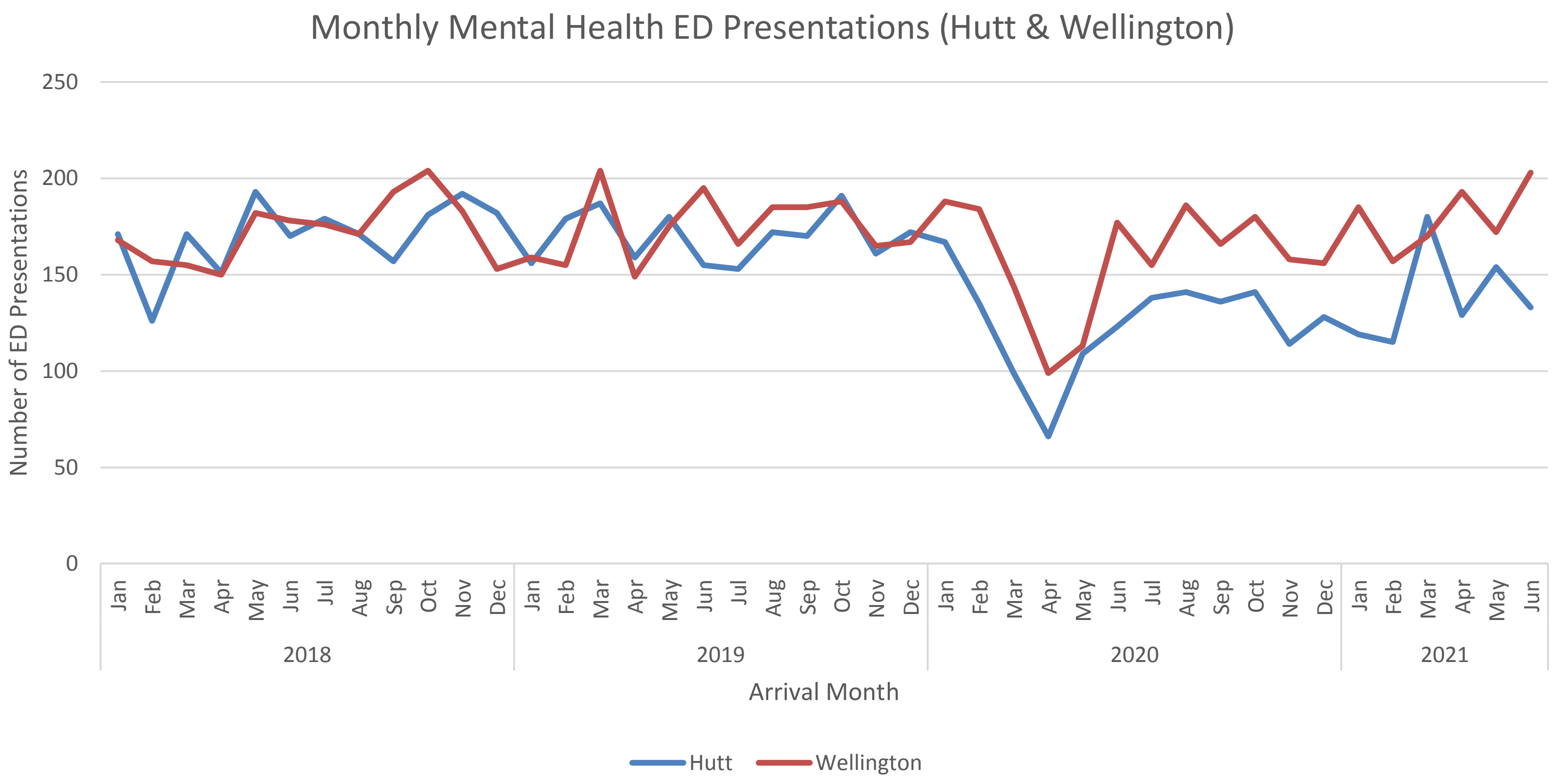
Intellectual Disability Service

Presentations at ED

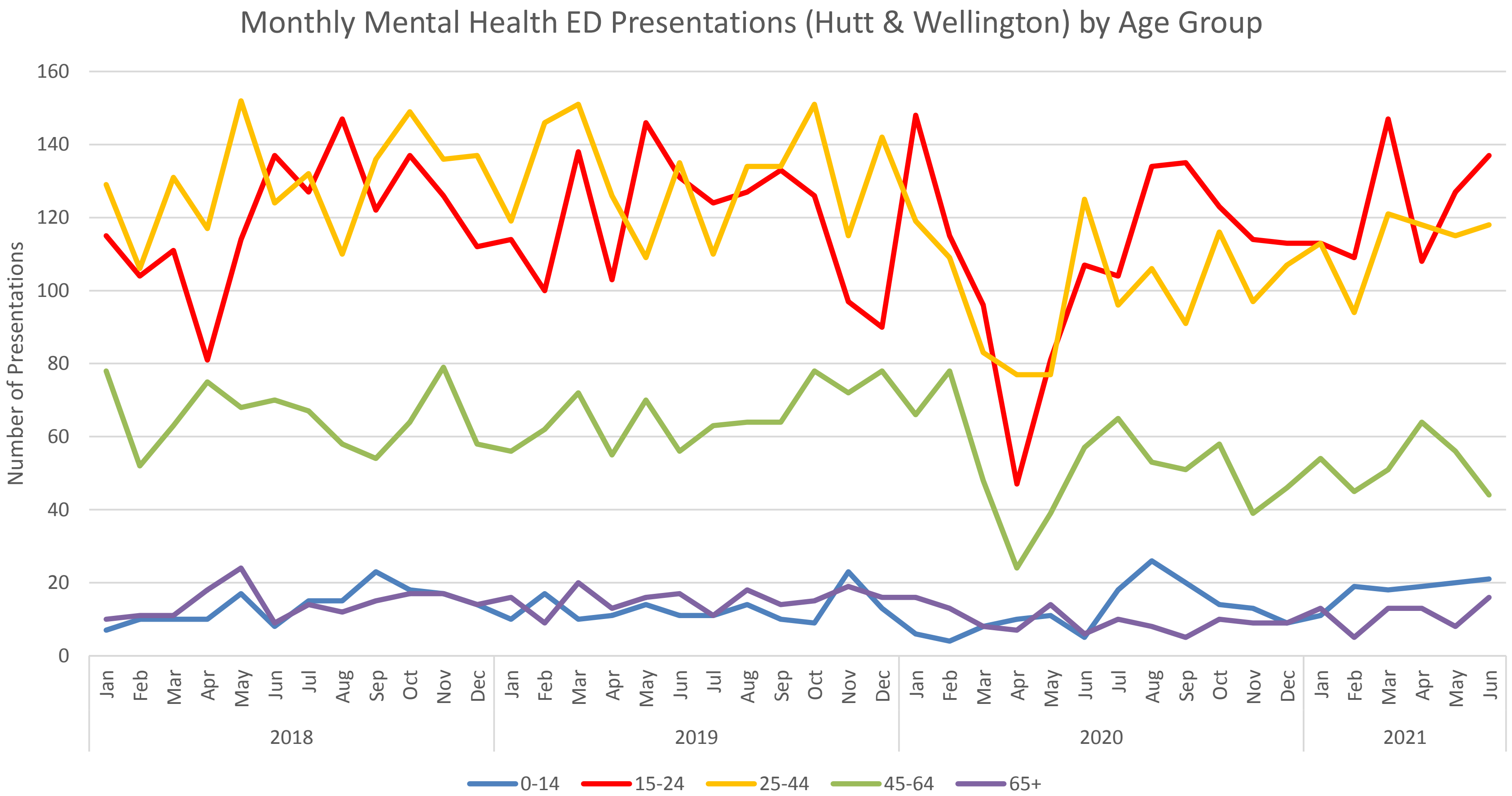
Post- COVID lockdown the number of presentations to ED for mental health reasons has largely returned to the previous volumes at Wellington, with less presentations in the last 12 months at Hutt ED.



Te-Upoko-me-Te-Karu-o-Te-Ika
Mental Health, Addictions and Intellectual Disability Service

Presentations at ED

People in the age categories 15-24 and 25-44 are the most likely to present at ED for mental health reasons.



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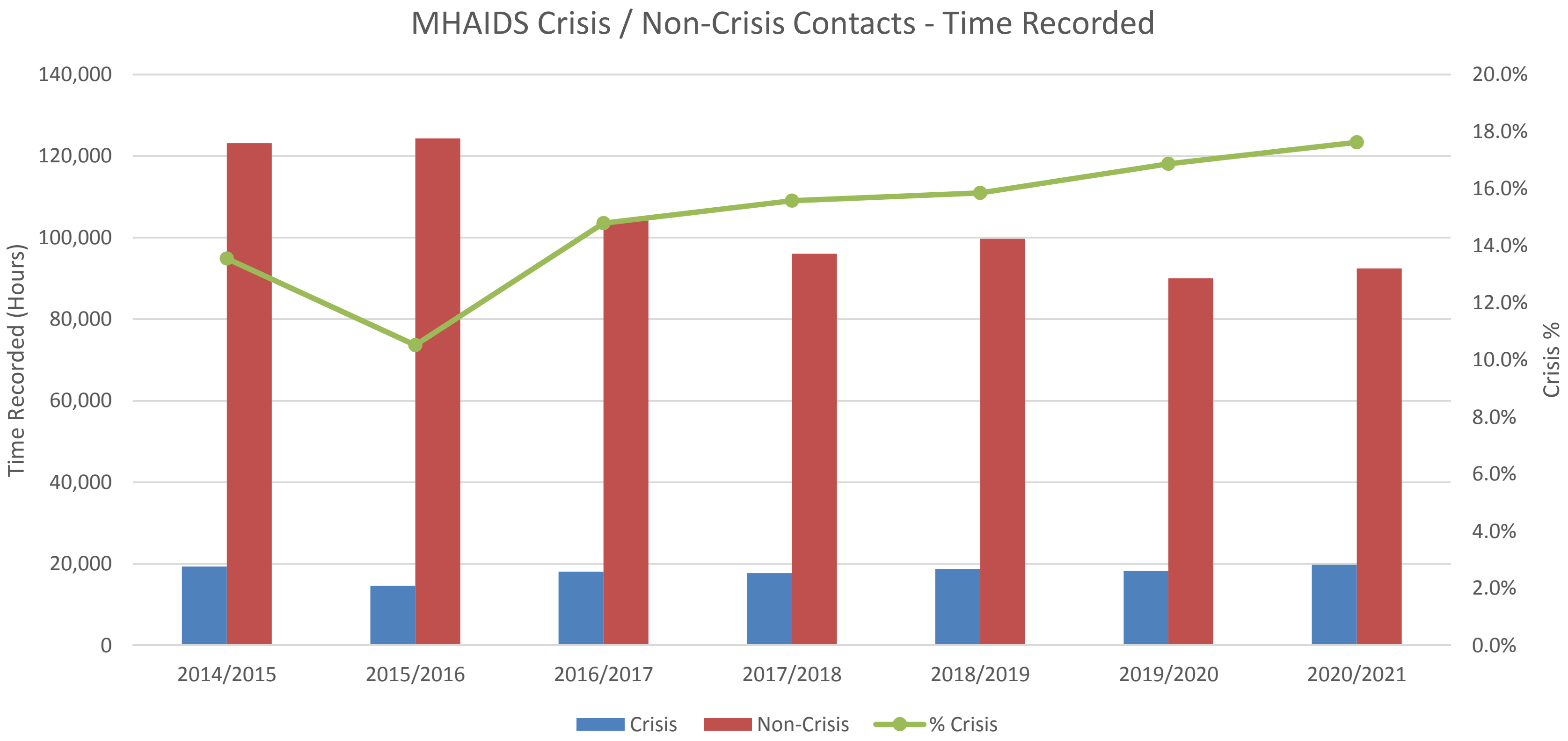
Mental Health, Addictions and Intellectual Disability Service

Crisis Work

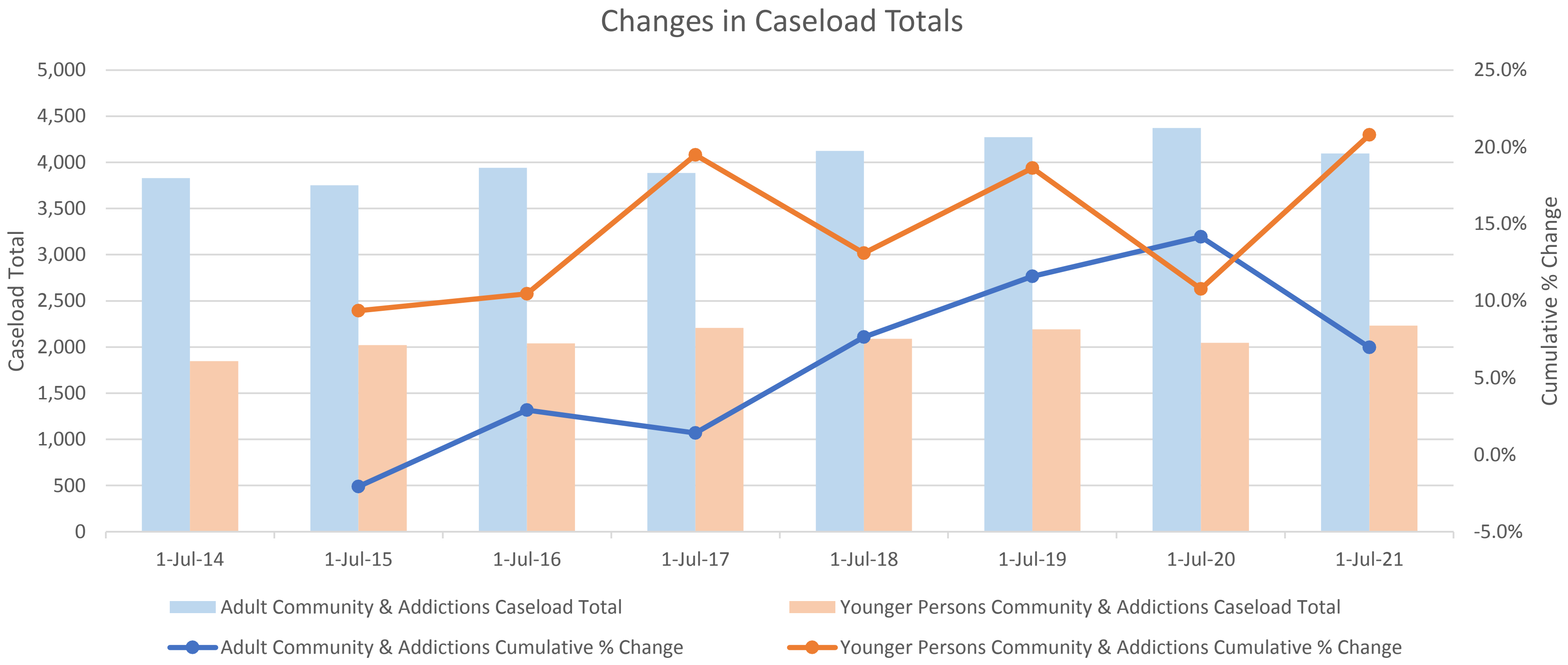
More time was recorded on crisis activities last year than in the previous six years. In 2014/15 crisis activities made up 13.6% of all recorded contacts, in 2019/20 the figure was 17.6%.



Te-Upoko-me-Te-Karu-o-Te-Ika
Mental Health, Addictions and Intellectual Disability Service

Community Caseloads

In the past six years community caseload totals have generally increased year on year. There are 384 more people on Younger Persons teams caseloads relative to 2014 (20.8% increase) and 267 more people on Adult teams caseloads (7.0% increase).



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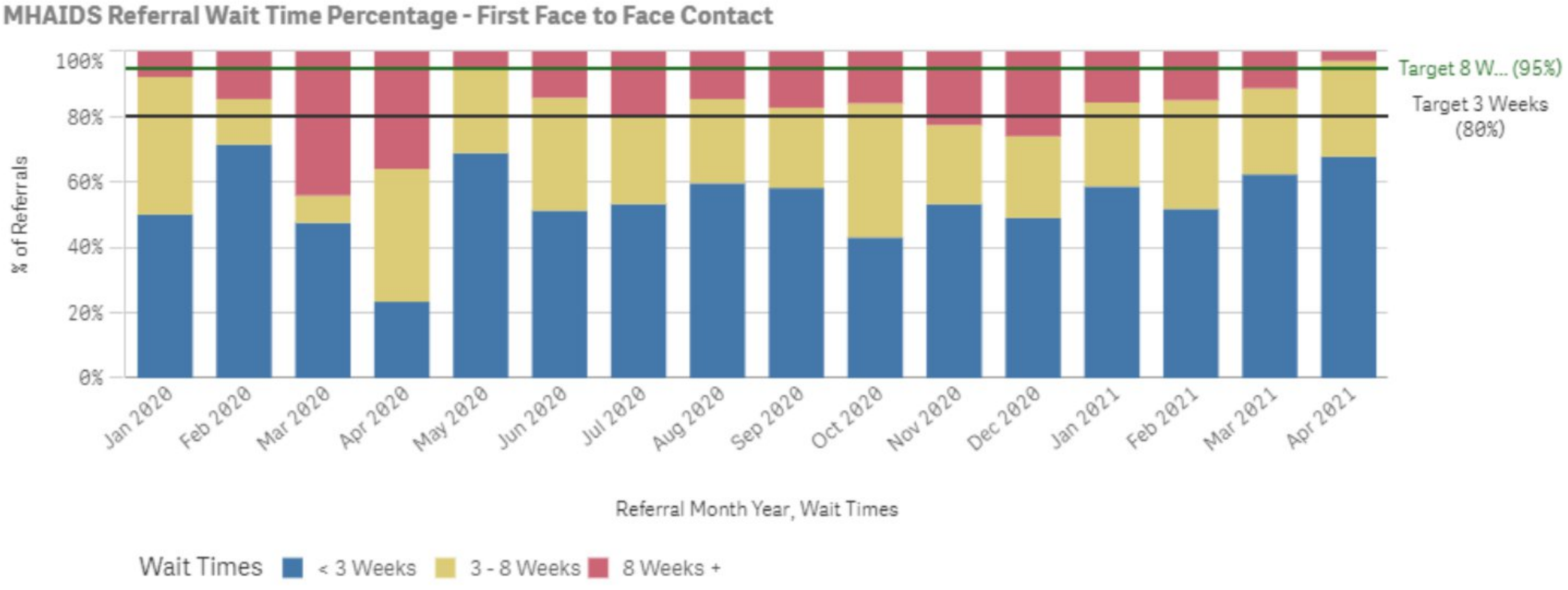
Mental Health, Addictions and Intellectual Disability Service

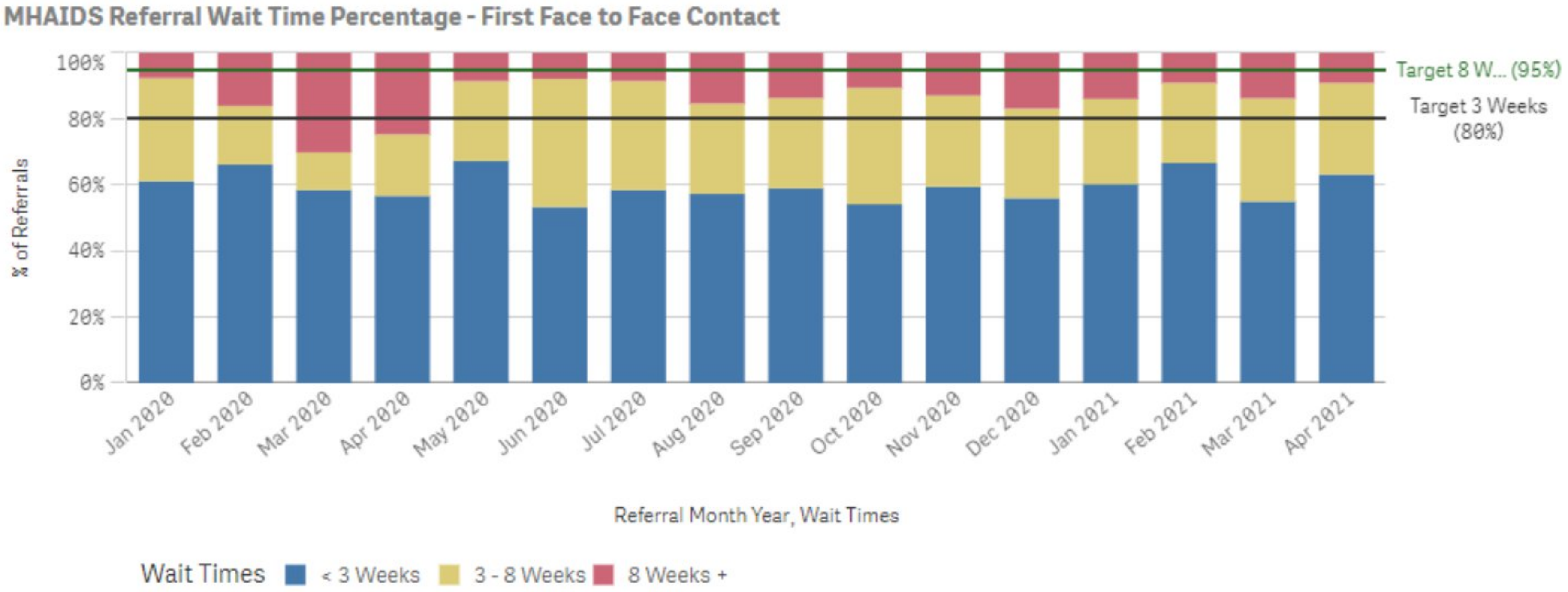
Wait Times – Younger Persons Community & Addictions Sector

The Ministry of Health targets for wait times are 80% of people to be seen within 3 weeks of referral and 95% of people to be seen within 8 weeks. The Younger Persons sector has struggled to meet these targets – the average since Jan 2020 is 53% seen within 3 weeks and 80% seen within 8 weeks.



Wait Times – Adult Community & Addictions Sector

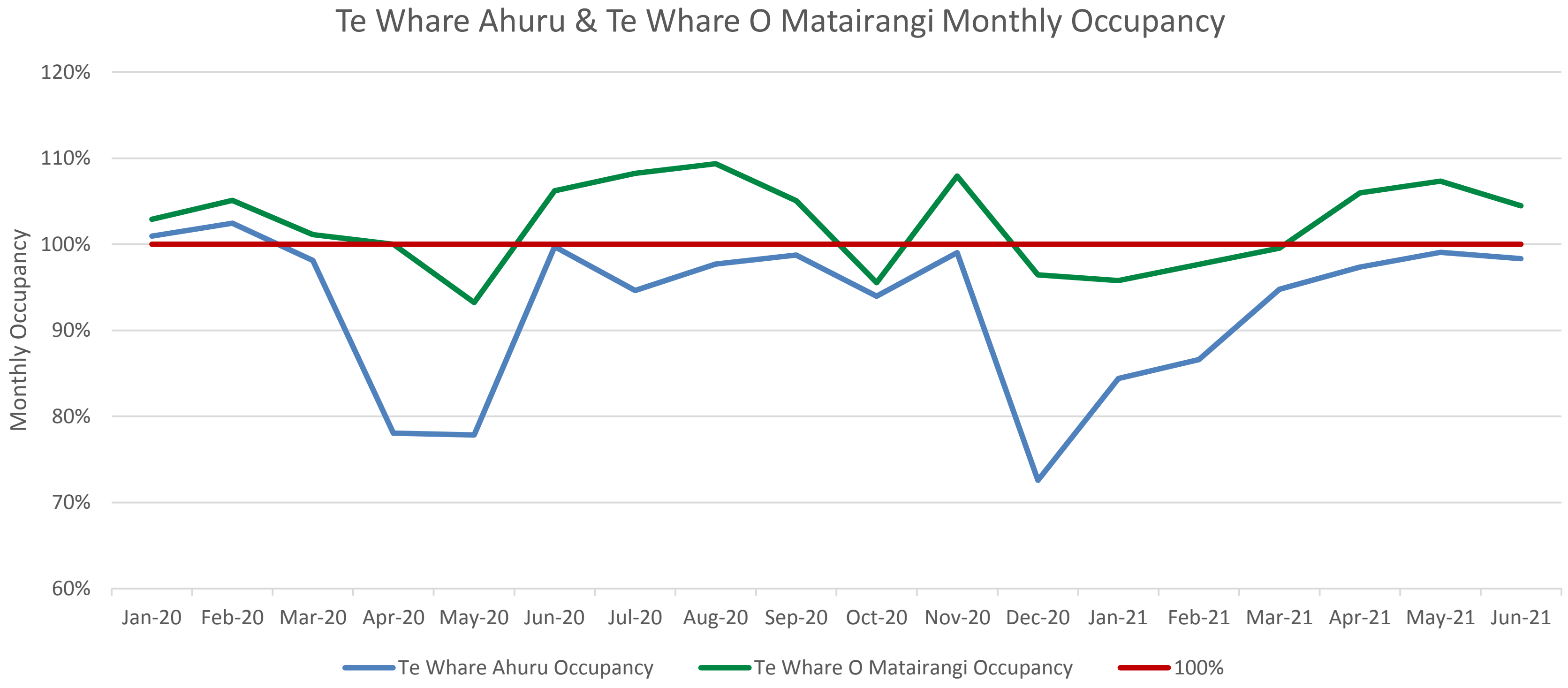
The Adult Community & Addictions sector has slightly higher results – the average since Jan 2020 is 59% seen within 3 weeks and 88% seen within 8 weeks.



Te-Upoko-me-Te-Karu-o-Te-Ika
Mental Health, Addictions and Intellectual Disability Service

Acute Inpatient Services

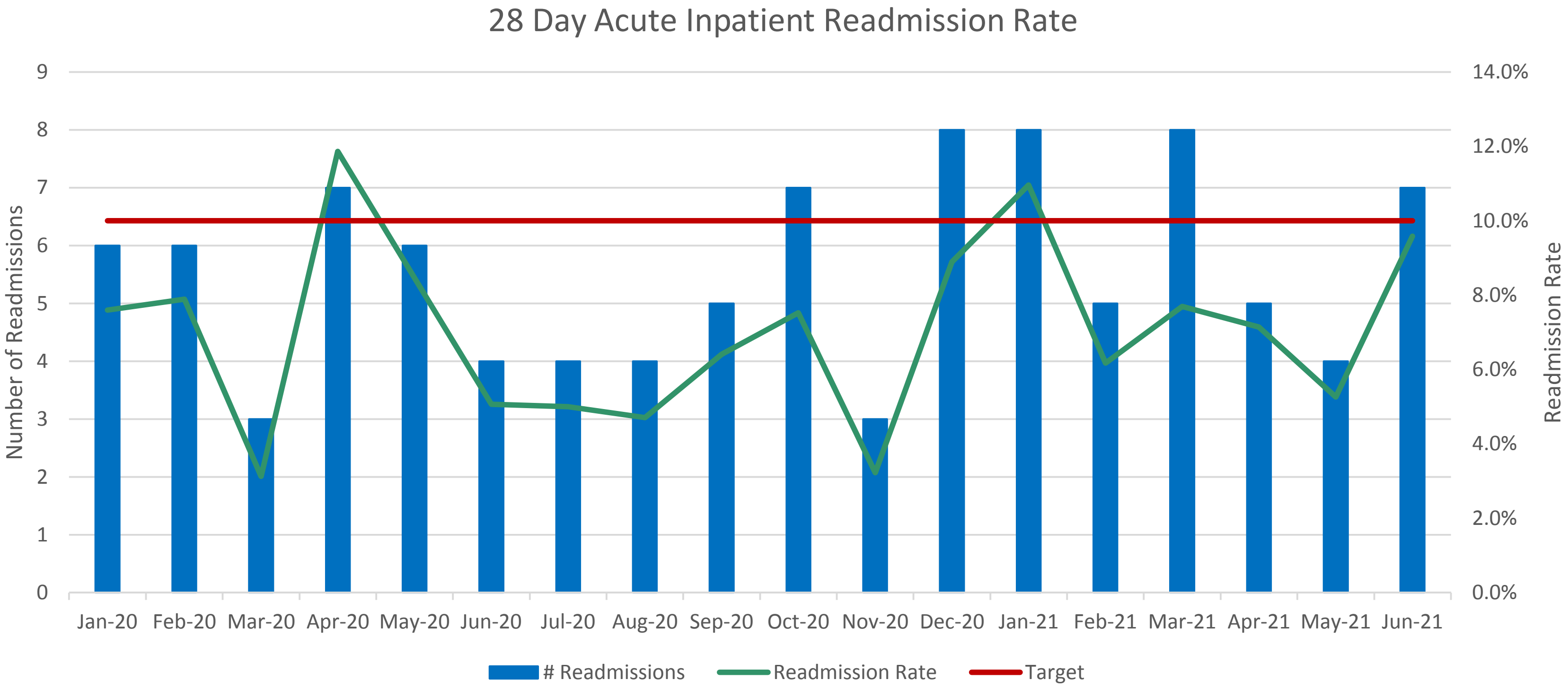
Bed occupancy in the two adult acute inpatient units remains a critical issue with Te Whare O Matairangi in particular regularly being at maximum or over capacity.



Te-Upoko-me-Te-Karu-o-Te-Ika
Mental Health, Addictions and Intellectual Disability Service

28 Day Acute Inpatient Readmission Rate

The target for the 28 Day Acute Inpatient Readmission rate is <=10%. MHAIDS inpatient units have only breached this target on two months since January 2020.



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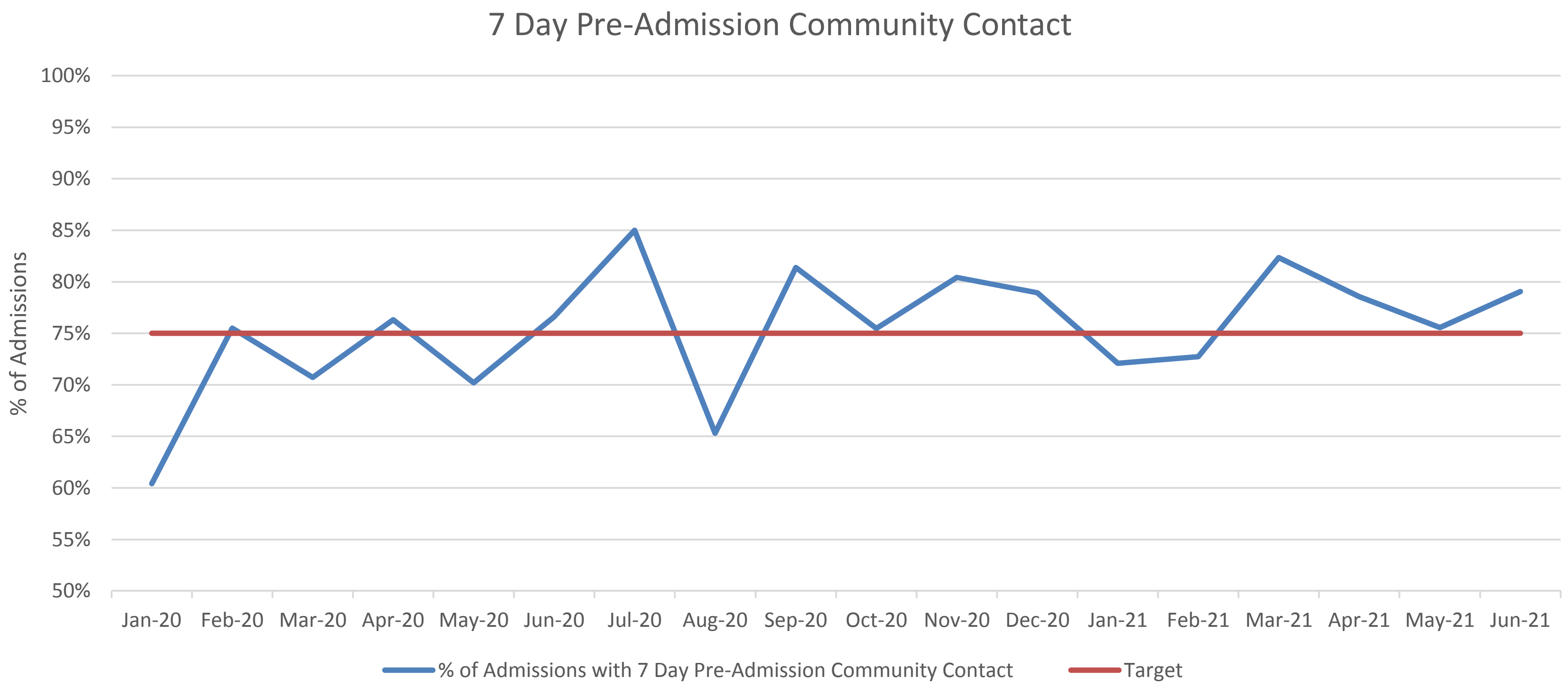
Mental Health, Addictions and Intellectual Disability Service

7 Day Pre-Admission Community Contact

MHAIDS results for this measure have improved over the last 12 months with most months reaching the 75% target.



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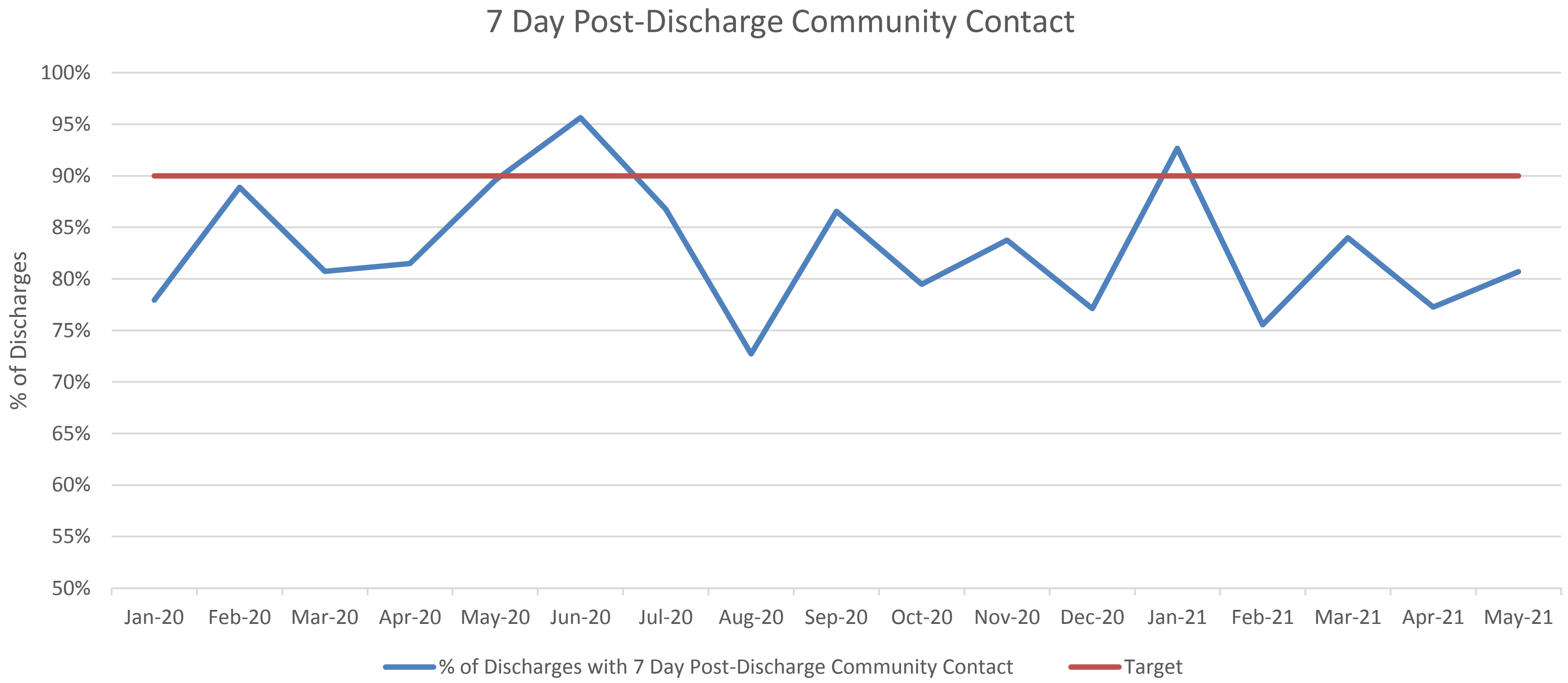
Mental Health, Addictions and Intellectual Disability Service

7 Day Post-Discharge Community Contact

The mean for this measure is 80% for the past 12 months, slightly below the 90% target.



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Mental Health, Addictions and Intellectual Disability Service