PUBLIC

	AGENDA Held on 16 March 2022 Location: Zoom Time: 1pm Zoom meeting ID: 861 3396 7687		
3DHB COMBINED DISABILITY SUPPORT ADVISORY COMMITTEE			
	ITEM	**ACTION**	**PRESENTER**	**PG**

	ITEM	ACTION	PRESENTER	PG
1.	**PROCEDURAL BUSINESS**			
1.1.	Karakia		All members	2
1.2.	Apologies	**NOTE**	Chair	
1.3.	Continuous Disclosure – Interest Register	**NOTE**	Chair	3
1.4.	Confirmation of Draft Minutes from meeting dated 24/11/2021	**APPROVE**	Chair	6
2.	**STRATEGIC PRIORITIES**			
2.1.	Mental Health and Addiction Change Programme Overview 2.1.1 Presentation Slides	**NOTE**	Executive Director MHAIDS Executive Clinical Director MHAIDS	11 12
3.	**STRATEGY**			
3.1.	Sub-Regional Disability Strategy 2017-2022 – Independent Review Findings	**NOTE**	Acting Director Strategy Planning and Performance General Manager – Disability	24
3.2.	Disability Leadership Group's Strategic Plan for 2022	**NOTE**	Acting Director Strategy Planning and Performance General Manager – Disability	32
4.	**PERFORMANCE REPORTING**			
4.1.	3DHB Sub Regional Disability Strategy 2017 – 2022 Update	**NOTE**	Acting Director Strategy Planning and Performance General Manager – Disability	52
4.2.	MHAIDS Service Performance Update	**NOTE**	Executive Director MHAIDS Executive Clinical Director MHAIDS	56
4.3.	3DHB Mental Health and Wellbeing Strategy update	**NOTE**	Acting Director Strategy Planning and Performance Executive Director MHAIDS Executive Clinical Director MHAIDS	79
5.	**OTHER**			
5.1.	Research Report: Understanding Disabled People's experiences of local healthcare services in the 3DHB region – Wellington, Hutt Valley and Wairarapa	**NOTE**	Acting Director Strategy Planning and Performance General Manager – Disability	82
5.2.	Covid-19 update	**NOTE***	Director Transformation/SRO COVID-19	
5.3.	General Business - Update on transition to Health New Zealand - Acknowledgment of final meeting		Chief Executive Chair	

* 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

16/03/2022

Name	Interest
'Ana Coffey *Chair*	• Father, Director of Office for Disabilities • Brother, employee at Pathways, NGO Project Lead Greater Wellington Collaborative • Shareholder, Rolleston Land Developments Ltd
Prue Lamason	• Councillor, Greater Wellington Regional Council • Chair, Greater Wellington Regional Council Holdings Company • 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	• Associate Professor, University of Otago (2001 – present) • Review Panel Member, PHARMAC Review (2021) • Board Member, Capital & Coast District Health Board (2019 – present) • Board Member, Health Quality & Safety Commission (2020 – present) • Chair- Muscular Dystrophy Assoc. (Tuaatara | Central Region) (2018 – present) • Director , Calls 4 Charity Limited (2021 – present) • Director, Miramar Enterprises Limited (2014 – present) • Chairperson, Foundation for Equity & Research New Zealand (2018 – present) • Co-Chair, My Life My Voice Charitable Trust (2019 – present) • Governance Representative, Disabled Persons Organisation Coalition (2018 – present) • Representative, Independent Monitoring Mechanism to the United Nations Convention on the Rights of Persons with a Disability (UNCRPD) (2018 – present) • Chair, Te Ao Mārama: Māori Disability Advisory Group, Ministry of Health (2018-2021) • Chair, Te Ao Mārama Aotearoa Trust: Māori Disability Advisory Group (2021)

	• Deputy Chairperson, Te Āparangi: Māori Advisory Group to HealthCERT, Ministry of Health (2019 – present) • Member, COVID-19 Immunisation Implementation Advisory Group, Ministry of Health (2021 – present) & Tātou Whakaha Disability Advisory Sub Committee • Member, Enabling Good Lives Governance Group, Ministry of Health (2020 – present) • Member, Machinery of Government Working Group, Ministry of Social Development (2020 – present) • Member, Māori Workforce Development Group, Ministry of Health (2021-present) • Member, Māori Monitoring Group, Ministry of Health (2021-present) • Professional Member, Royal Society of New Zealand • 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) • Wife, Member 3DHB Disability Advisory Group & Tāngata Whaikaha Roopu
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	• Chair Horo Te Pai Trust • Chair Horo Te Pai health service • 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 • Co-Chair, 3DHB Sub-Regional Disability Advisory Group • Executive Committee member Muscular Dystrophy Central Region • Board member, My Life My Voice Charitable Trust • Member, Health Research Council NZ, 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 DSAC MEETING **PUBLIC**

3DHB Disability Support Advisory Committee Meeting - PUBLIC
Wairarapa DHB   HUTT VALLEY DHB   Capital & Coast District Health Board
MINUTES Held on Wednesday 24 November 2021 Zoom Zoom link: 826 6127 3900 Time: 1:30pm

Due to Covid 19 alert level (level 2) only limited members and staff attended in person (in person marked with * and all others on zoom).

Members	Attendance	Membership
'Ana Coffey - Chair	Apology	CCDHB
Sue Kedgley	Present	CCDHB
Yvette Grace* – *Acting Chair*	Present	WrDHB & HVDHB
Prue Lamason	Present	HVDHB
Tristram Ingham	Present	CCDHB
John Ryall	Present	HVDHB
Naomi Shaw	Present	HVDHB
Vanessa Simpson	Present	CCDHB
Jill Pettis	Present	WrDHB
Jill Stringer	Present	WrDHB
Ryan Soriano	Apology	WrDHB
Sue Emirali	Present	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*	Te Upoko o te Ika a Maui Māori Council

District Health Board Staff Present		
Fionnagh Dougan*	2DHB	Chief Executive
Rachel Haggerty*	2DHB	2DHB Director Strategy, Planning and Performance
Dale Oliff	WrDHB	Chief Executive
Sandra Williams	WrDHB	Executive Leader Planning and Performance
Karla Bergquist*	3DHB	Executive Director Mental Health, Addiction and Intellectual Disability Services
Paul Oxnam*	3DHB	Clinical Director Mental Health, Addiction and Intellectual Disability Services
Sally Dossor*	2DHB	Director of Office of the Chief Executive/Board Secretary
Rachel Noble*	3DHB	General Manager Disability Strategy, Innovation and Performance
Meila Wilkins*	2DHB	Board Liaison Officer

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3DHB DSAC MEETING   **PUBLIC**

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1   PROCEDURAL BUSINESS

1.1   KARAKIA

The Committee opened the meeting with a karakia.

1.2   APOLOGIES

As noted above and noted apologies from HVDHB and CCDHB Board Chair, David Smol (not a member).

1.3   CONTINUOUS DISCLOSURE

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 24 November 2021.

Moved	Seconded	
Jill Pettis	Yvette Grace	**CARRIED**

1.5   MATTERS ARISING FROM PREVIOUS MEETINGS

The Committee noted:

- **DSAC2021-02:** have attended the Mayoral Forum. Will attend the CE's group and will continue to raise the issue with other Councils.

- **DSAC2021-03:** SRDAG dates are being set for 2022 and when they are finalised they will be shared with the Committee and opportunities explored for attendance.

1.6   WORK PLAN

Workplan noted and noted that one meeting is scheduled for 2022.

2.0 PERFORMANCE REPORTING

2.1 3DHB SUB REGIONAL DISABILITY STRATEGY 2017 – 2022 UPDATE

General Manager - Disability presented and responded to questions.

3DHB Disability Support Advisory Committee notes:

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

Moved	Seconded	
Jill Pettis	Yvette Grace	**CARRIED**

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3DHB DSAC MEETING   **PUBLIC**

Notes

- The team is being engaged on various workstreams.

- SRDAG re-issued the invitation for the DSAC Chair to attend its meetings.

- SRDAG co-Chair thanked the CE for setting up the meeting with the clinical leads and as this is very effective way to resolve operational issues fast.

2.2 REVIEW OF SUB-REGIONAL DISABILITY STRATEGY 2017-2022

Grant Cleland, Creative Solutions presented.

The Committee noted:

(a) Grant Cleland, Director of Creative Solutions, will present the preliminary findings of his review on progress with the Disability Strategy.

(b) The review was based on the recommendations made at the 3DHB Disability Forum in Silverstream 2019.

Moved	Seconded	
Yvette Grace	Jack Rikihana	**CARRIED**

Notes:

- Noted the background to the review and outlined the process followed to undertake the review.
- Grant spoke to each of the 6 recommendations arising from the review (see pages 23-26 of the agenda):
  - Progress made on the Accessibility Charter – but the review noted there needs to be more of a strategic approach to the roll out of the Accessibility Charter.
  - Getting disability recognised across communication channels has been difficult and requires support (especially ICT).
  - Improving access to services – I.e. transport to health services and disabled parking.
  - SRDAG role and involvement needs to be clarified and to manage the expectation of the role of the Advisory Group and obtain a common understanding of the role of SRDAG, governance vs operations and clarity on when co-design is appropriate (and consulting with the disability community).
  - Māori & Pacific Action Plan.
  - Systems change
- Recommendations to address the issues identified will be covered in the main report.
- One of the things to address is the ambit of the Strategy and to ensure that the Strategy is within the remit of the DHBs. This should be strategic and aim to achieve consistency across the 3DHBs
- Recommend that the 3DHBs advocate to the Ministry for more involvement of those with lived experience. The full report will be presented to the DHBs in the next few weeks.
- A disability perspective is sought on many issues – and the issues themselves are not set by the Disability Community / groups.

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3DHB DSAC MEETING   **PUBLIC**

- Question asked regarding how disability will be represented in HNZ and the MHA – and it has been identified as an issue on the early stages and that it is likely there will be Disability team going.

2.3 MHAIDS SERVICE PERFORMANCE UPDATE

The Executive Director MHAIDS and Executive Clinical Director MHAIDS presented and responded to questions.

The Committee notes:

(a) The MHAIDS Service Performance update – November 2021, included as Attachment 1.

(b) MHAIDS is currently implementing a range of improvement strategies to mitigate immediate demand and access pressures.

Moved	Seconded	
Yvette Grace	Jack Rikihana	**CARRIED**

Notes:

- It was noted that recruitment process has started for Te Haika model and have made some appointments to address the access issues set out in the paper.
- Noted experience from other parts of NZ for employment services – where the experience has been positive - noting that it starts small.

2.4 3DHB MENTAL HEALTH AND WELLBEING STRATEGY UPDATE

2DHB Director Strategy Planning and Performance presented.

The Committee notes:

(a) Hutt Valley and Capital & Coast DHBs have formally established the Mental Health and Addiction Change Programme to redesign and implement a pro-equity, whole of population system of care to support the mental health and wellbeing of the people across the subregion.

(b) the continued expansion of the Access and Choice programme across the 3DHB region, with investment increasing monthly to fund a total of 82.4 FTE by June 2023.

(c) the growth of the Primary Care Liaison Service, with the recent establishment of a full-time consultant psychiatrist role in Wellington, two nurse practitioner roles in Hutt Valley DHB, and upgrading of the two liaison roles in Wellington to nurse practitioner level.

(d) a new Acute Alternative service in Lower Hutt will be operational from mid-November 2021, serving as an alternative to inpatient care for those experiencing acute mental illness.

(e) that four Kaupapa Māori and Pacific providers across the Capital & Coast and Hutt Valley regions have been contracted to provide Primary and Community AOD Kaupapa Māori and Pacific Counselling.

(f) an updated 3DHB Suicide Prevention and Postvention Action Plan has been developed. This updated Action Plan incorporates *Every Life Matters* focus areas. It is also responsive to the 2020/2021 annual provisional suicide statistics, the Ministry of Health suicide web tool, and recent 3DHB data.

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3DHB DSAC MEETING   **PUBLIC**

Moved	Seconded	
Yvette Grace	Jack Rikihana	**CARRIED**

3   OTHER

3.1 DISABILITY SYSTEM TRANSFORMATION

Noted the recent announcements for reform and the establishment of a new Ministry for Disabled people. The establishment unit is being set up and disabled people are encouraged to apply. Initially the new Ministry is 'nested' in MSD – and then it will become its own. What happens now across many organisations will transition over-time. The changes have been welcomed by the Disability community. It was noted that while DSS is moving to the new Ministry there will still need to be a disability group within MOH.

There is a lot of hope with the new Ministry and SRDAG is engaging with the people involved to have a voice.

Discussion on how the changes will affect service provision for disabled people and how people engage with the health care system (including mental health) and to access support.

3.2 COVID-19 UPDATE

The 2DHB Chief Executive Presented and the WrDHB Executive Leader Planning and Performance.

COVID Update -
24112021.pptx

Notes:
- Updated the Committee on the Covid response as it relates specifically to our disabled and mental health communities.
- Mental health clients have a lower vaccination rates than the balance and we are working closely with our NGO providers.
- Working closely with disability community to increase vaccination rates.
- Recent cases in the Wairarapa have given some clear insights into how to work with people with Covid in the community and worked closely with our Māori provider to provide support.
- Need to look overseas to the lessons learned from the outbreaks – which show a concerning death rate for people with disabilities.

NEXT MEETING

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

Meeting closed at 2.20pm

DATED this   day of   2022

'Ana Coffey
DSAC CHAIR

Disability Support Advisory Committee

16 March 2022

Mental Health and Addiction Change Programme Overview	

The Committee notes:

      (a) The overview of the Mental Health and Addiction Change Programme and progress update.

Strategic Alignment	Mental Health and Addictions Focus Area of the 2DHB strategic priorities.
Presented by	Karla Bergquist, Executive Director MHAIDS
	Paul Oxnam, Executive Clinical Director MHAIDS
Purpose	This presentation updates the Committee on the progress of the Mental Health and Addiction Change Programme.

Executive Summary

The Mental Health and Addiction Change Programme focuses on co-creating and commissioning community mental health networks to improve local service integration and achieve equity, particularly improving Māori mental health and addiction outcomes. An overview of and progress update is included as Attachment 1 to this paper.

Concept design working groups were held late last year to test the piloting of community mental health and addiction hubs, and initial workshops were held in January with lived experience representation and a range of providers. This work will integrate, where required, with the Porirua locality prototype project, which is part of the Community & Commissioning workstream.

The Māori Expert Advisory Group has been established to provide advice and support to the design of Kaupapa Māori mental health services and the broader change programme.

The project team have held three co-design workshops for the Community Mental Health and Addiction Project (integrated locality-based mental health and addiction services). These workshops were the first in the series for this project, with additional workshops being planned for February. Initial discussions have been held with leaders in the younger persons sector to co-design and inform the Community Child and Adolescent Project.

Strategic Considerations

Strategic goals	The Mental Health and Addictions focus area of the 2DHB Strategic Priorities.

Attachment/s

    1.   Commissioning and Community Presentation: Localities Progress Update – HSC Update March 2022.

Mental Health and Addiction Change Programme Overview

Disability Support Advisory Committee - 16 March 2022

Mental Health and Addiction Change Programme

Hutt Valley and Capital & Coast District Health Boards are working with mana whenua, Māori, community leaders, people with lived experience, and our health and social sector partners, to transform mental health and addiction services.

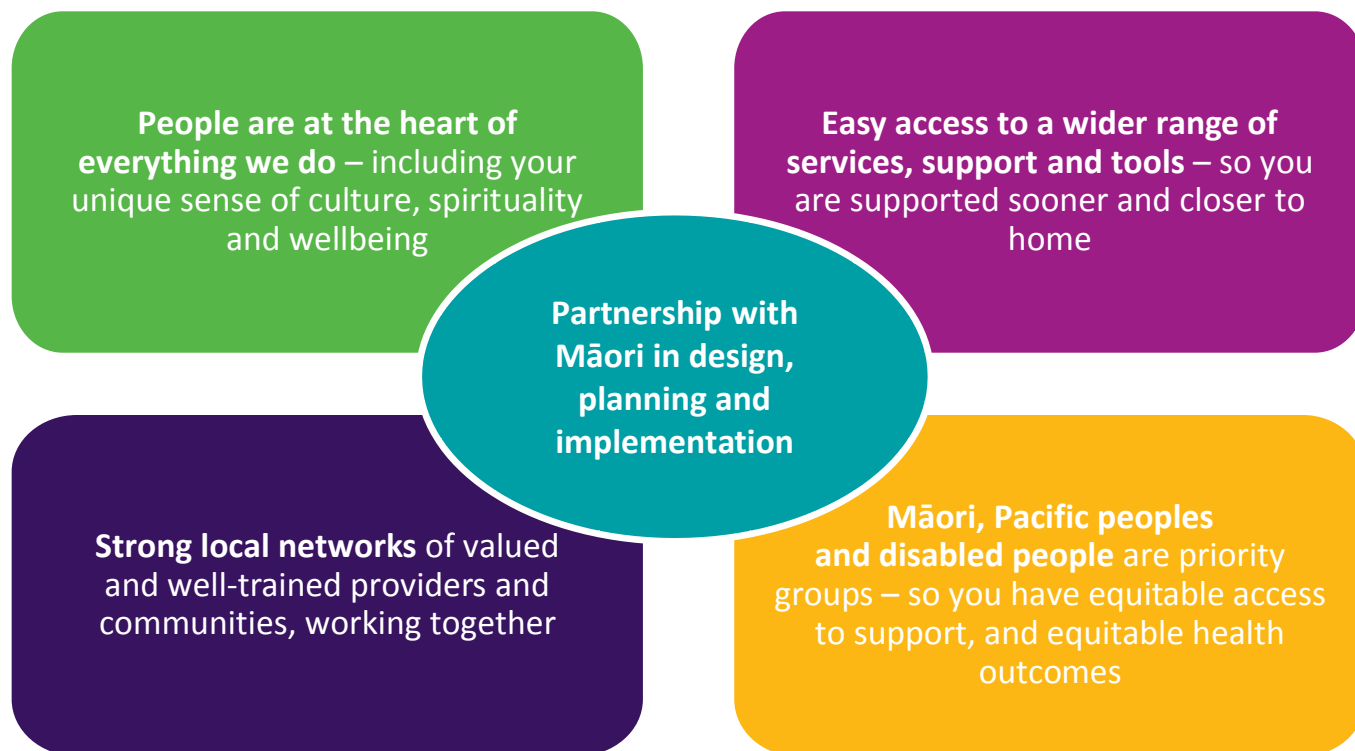We are working in partnership with Māori, honouring our commitment to Te Tiriti o Waitangi.

Our vision

> ### Mental health and wellbeing for everyone, in our communities
>
> Individuals, whānau and communities supported by trusted health services that respect people's unique sense of culture, spirituality and wellbeing.

Mental Health and Addiction Change Programme

The Programme will be guided by five principles:

People are at the heart of everything we do – including your unique sense of culture, spirituality and wellbeing

Easy access to a wider range of services, support and tools – so you are supported sooner and closer to home

Partnership with Māori in design, planning and implementation

Strong local networks of valued and well-trained providers and communities, working together

Māori, Pacific peoples and disabled people are priority groups – so you have equitable access to support, and equitable health outcomes

Our work is aligned with the changes being planned as part of the wider health sector reforms.

Mental Health and Addiction Change Programme

This programme is part of our 2DHB transition strategy

Mental Health and Addiction Services are one of our four areas of focus in Manaakitanga ā tōna wā, to June 2022 and beyond.

In all our work, we will focus on the needs of Māori, Pacific peoples, the disabled community and other priority groups, to ensure **equity of access and outcomes**.

Planning for **specialist** services; creating **new maternity, women's health and neonatal care** spaces; acute care and **hospital flow improvements; building new infrastructure and capacity**.

Renewed focus on **Mental Health and Addiction Services**

Local, equitable and early care for better health outcomes in the community rather than at hospital.

**Seeking solutions to social factors** that contribute to poor health.

Technology and how clinicians communicate across DHBs
In home diagnostics
Workforce management

Our Hospitals

Commissioning and community

Pro-equity

Mental Health and Addiction

Enablers

HUTT VALLEY DHB

Capital & Coast District Health Board
ŪPOKO KI TE URU HAUORA

Mental Health and Addiction Change Programme

Key reports to guide our work

- He Ara Oranga
- Kia Manawanui Aotearoa
- Living Life Well
- Pacific Health and Wellbeing Strategic Plan
- Sub-Regional Disability Strategy
- Taurite Ora
- Te Pae Amorangi
- Te Rau Matatini Kaupapa Māori Mental Health and Addiction Service: Best Practice Framework
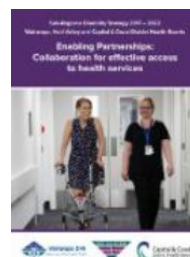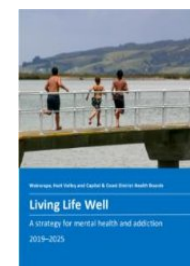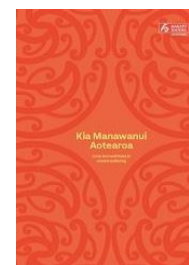
Mental Health and Addiction Change Programme

MHA Commissioning Forum	The MHA Commissioning Forum meets **monthly** and is responsible for providing overall direction to the programme and giving advice to the Chief Executive on its design and implementation.	
Programme Sponsors	Executive Director, MHAIDS Executive Clinical Director, MHAIDS Director Māori Health 2DHB Director Strategy Planning and Performance	
Programme Leadership Group	The Programme Leadership Group meets **fortnightly** and is responsible for the programme meeting its objectives, producing the agreed deliverables, and delivering the expected benefits.	
Programme Director	Responsible for oversight of all project groups	
Project Working Groups	Working groups will meet **weekly** and be responsible for the design, development and implementation of projects.	
Programme Support	This group meets **weekly** with the programme sponsors and is responsible for programme delivery across projects and maintaining oversight.	
Admin	Secretariat support to these groups will be provided by the executive assistant to executive director and executive clinical director	

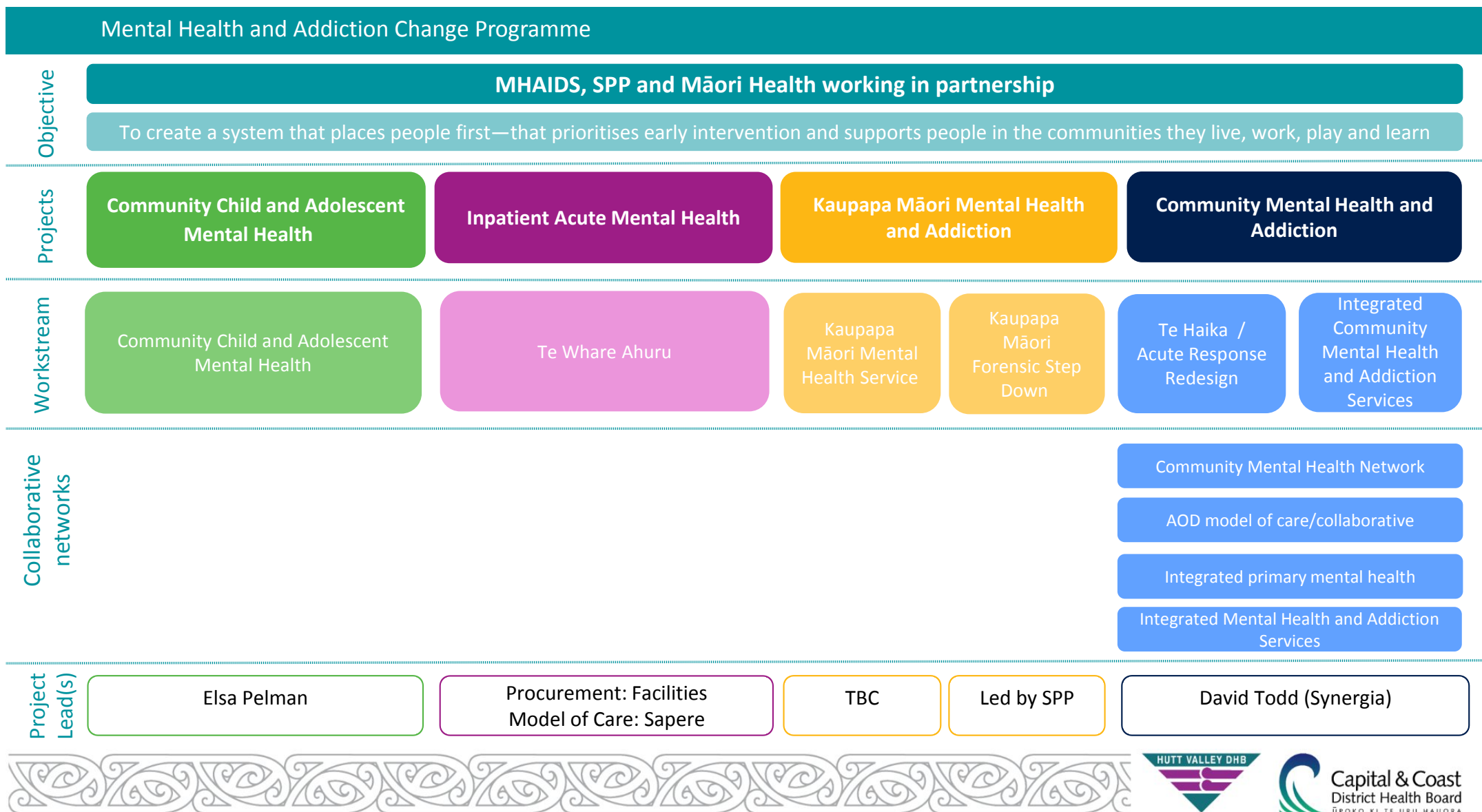**Programme support**

- MHA Commissioning Forum (decide)
- Programme Leadership Group (review and recommend)
- Project Groups (create and deliver)

HUTT VALLEY DHB

Capital & Coast District Health Board
ŪPOKO KI TE URU HAUORA

Mental Health and Addiction Change Programme

Objective

MHAIDS, SPP and Māori Health working in partnership

To create a system that places people first—that prioritises early intervention and supports people in the communities they live, work, play and learn

Projects

Community Child and Adolescent Mental Health	Inpatient Acute Mental Health	Kaupapa Māori Mental Health and Addiction	Community Mental Health and Addiction

Workstream

Community Child and Adolescent Mental Health	Te Whare Ahuru	Kaupapa Māori Mental Health Service	Kaupapa Māori Forensic Step Down	Te Haika / Acute Response Redesign	Integrated Community Mental Health and Addiction Services

Collaborative networks

Community Mental Health Network

AOD model of care/collaborative

Integrated primary mental health

Integrated Mental Health and Addiction Services

Project Lead(s)

Elsa Pelman	Procurement: Facilities Model of Care: Sapere	TBC	Led by SPP	David Todd (Synergia)

HUTT VALLEY DHB

Capital & Coast District Health Board
ŪPOKO KI TE URU HAUORA

Project objectives

Overarching programme objective:

To create a system that places people first – that prioritises early intervention and supports people in the communities in which they live, work, play, and learn

Community Child and Adolescent Mental Health
- To use the Choice and Partnership Model (CAPA) to its full potential to ensure responsive and consistent services for whānau
- To support improved consistency and collaboration across mental health and addiction services
- To improve timely access to services for whānau (reduce waiting times)
- To improve equity of access to services for Māori and Pacific peoples
- To enable positive and trusting relationships between children, adolescents, and their whānau, and service providers

Inpatient Acute Mental Health
- To develop a contemporary acute model of care to inform facility design
- To enable service improvements in preparation for the new facility
- To engage with a wide range of stakeholders in the planning and design
- To inform a design that enables flexible use of space to support enhanced therapeutic opportunities and less restrictive practices
- To improve health and wellbeing outcomes through a therapeutic environment that recognises and supports cultural identity

Kaupapa Māori Mental Health and Addiction

Kaupapa Māori Mental Health Service
- To develop, in line with Te Rau Matatini best practice framework, Kaupapa Māori mental health and addiction services in Te Awaikarangi, that support whānau Māori in a manner that preserves their unique cultural heritage, spirituality and wellbeing

Kaupapa Māori Forensic Step Down
- To implement the new Kaupapa Māori Forensic Step Down service, in partnership with Te Waka Whaiora, by March 2022

Community Mental Health and Addiction

Te Haika Acute Response Redesign
- To enable the timely and efficient management of non-urgent referrals
- To support local teams to respond and proactively manage demand
- To support local capability and capacity to respond to local needs
- To act as a catalyst to support wider system change
- To explore changes to the management of urgent/acute referrals (links to integrated locality services workstream)

Integrated Community Mental Health and Addiction Services
- To design and pilot integrated locality based mental health and addiction services
- To improve the ability of local communities and services to respond to local MHA need
- To support improved co-ordination and integration across health and social care agencies
- To improve the patient (consumer) experience of care
- To support a more holistic response to supporting people and whānau wellbeing

Possible community mental health and wellbeing Hub
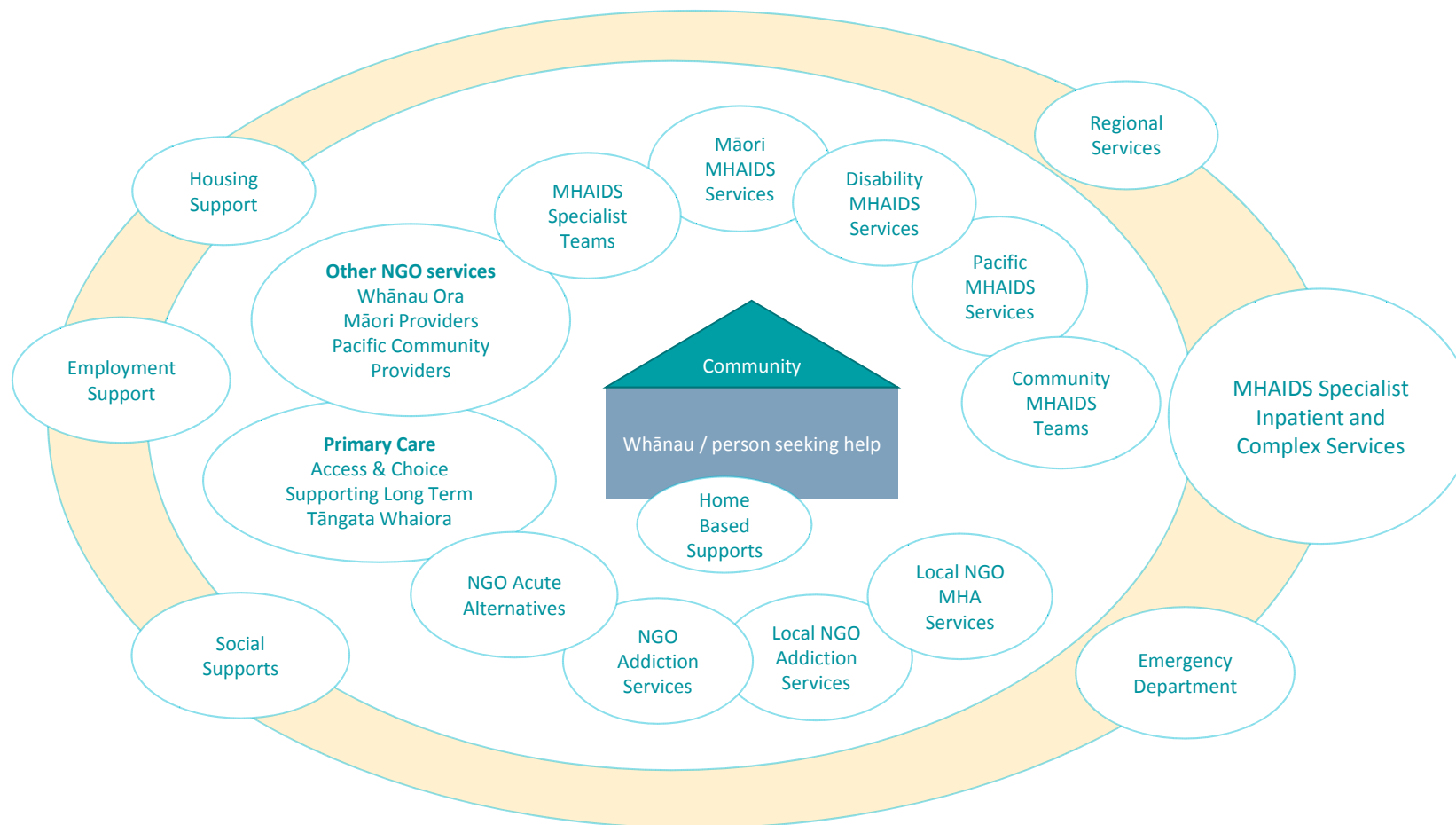
Projects and workstreams - current state

Community Child and Adolescent Mental Health

- Discussions with MHAIDS leaders in the Younger Persons Service have identified long waitlists, capacity vs demand challenges, and varied implementation of models of care as key challenges
- Two workstreams have been identified. One is specific to MHAIDS CAMHS services and addresses the implementation of the Choice and Partnership Approach (CAPA) model of care. The second is focussed on improving integration between DHB, NGO and Primary Care providers.

Inpatient Acute Mental Health

- Business case approved to replace Hutt Valley acute inpatient unit
- Agreement between the benefactor and MoH finalised
- Proposal received from Sapere to develop model of care
- Site Master Plan reviewed to confirm location on the Hutt Hospital site

Kaupapa Māori Mental Health and Addiction

- Māori Expert Advisory Group has been established to provide advice and support to the design of Kaupapa Māori mental health services and the broader change programme

Community Mental Health and Addiction

- Recruitment into CAMHS and Adult CMHT intake and assessment roles is occurring
- Initial concept development workshops took place in December 2021
- Co-design workshops have been facilitated during January-March 2022. There have been dedicated workshops for those with lived experience (including disability), Māori, Pacific and Primary Care stakeholders.

Projects and workstreams - next steps

Community Child and Adolescent Mental Health

- Gather data from MHAIDS staff to better understand workforce challenges and steps to improving model of care fidelity
- Engagement opportunities to be provided via small focus groups (e.g., providers, Oranga Tamariki, young people and their whānau). These conversations will inform and guide the project as it develops
- Explore other workstreams, including workforce development and the enabling of collaborative networks of providers in the younger persons sector. There will be a focus on bringing providers together to enhance relationships and strengthen a joined up system of care

Inpatient Acute Mental Health

- Establish working group to develop model of care and detailed design
- Engage with Health Infrastructure Unit (MoH) Project Lead
- Establish Project Control Group
- Confirm unit location and begin site preparation
- Develop business case for enabling works

Kaupapa Māori Mental Health and Addiction

- Māori Expert Advisory Group to provide advice and oversight across all four projects

Community Mental Health and Addiction

- Evaluation and debrief to be conducted once implementation of intake and assessment model completed
- Detailed project summary for integrated community mental health and addiction project be completed and presented for consultation
- Establishment of a working group that will develop a detailed implementation plan for new community mental health and addiction model of care
- Present recommendations to the Mental Health and Addiction Commissioning Forum

Projects and workstreams - by June 2022

Community Child and Adolescent Mental Health

- Model of service delivery redefined and implementation underway for Community Child and Adolescent Mental Health

- Stakeholder engagement and workforce development workstreams established

Inpatient Acute Mental Health

- Finalise the project plan and next steps for Acute Inpatient Mental Health model of care

- Engage with consultants on detailed design of the new facility

- Progress the facilities requirements for the replacement of the Hutt Valley acute inpatient unit

Kaupapa Māori Mental Health and Addiction

- Model of service delivery for Kaupapa Māori Mental Health and Addiction agreed

Community Mental Health and Addiction

- Intake and assessment approach established to enable the timely and efficient management of referrals

- Model of Care confirmed for Integrated Community Mental Health and Addiction Services with implementation plan

Disability Support Advisory Committee

16 March 2022

Sub-Regional Disability Strategy 2017-2022 – Independent Review Findings

Action Required

The Committee notes:

(a) Grant Cleland, Director of Creative Solutions, has presented the findings of his review on progress with the Sub Regional Disability Strategy (Attachment 1).

(b) The review was based on the recommendations made at the 3DHB Disability Forum in Silverstream 2019 and shows progress has been made in all areas.

(c) The recommendations from the review have been incorporated into the Disability Leadership Group's Strategic Plan for 2022 (see paper 3.2).

(d) That while the review noted that there is a need for role and relationship clarity between the Sub Regional Disability Advisory Group and the DHB, given the pending transition to Health New Zealand and the Māori Health Authority, it is appropriate for this to be addressed once the future model for relationships with priority populations is clear.

Strategic Alignment	3DHB Disability Strategy
Author	Rachel Noble, GM Disability
Endorsed by	Peter Guthrie, Acting Director Strategy, Planning and Performance
Presented by	Rachel Noble, GM Disability
Purpose	The findings of the review on the Disability Strategy will be noted
Contributors	3DHB Disability Team, Co-Chairs Sub Regional Disability Advisory Group, SPP Leaders
Consultation	3DHB Disability Team, Co-Chairs Sub Regional Disability Advisory Group, SPP Leaders

Executive Summary

Grant Cleland, Director of Creative Solutions, was contracted to review the 'calls to action' made at the 2019 3DHB Strategy Forum. Grant Cleland has presented the findings of the review, and his analysis of Key Themes (attached) was completed on 28 February 2022. It shows that progress has been made with all of the recommendations from the forum and work implementing the Sub Regional 2017-2022 Disability Strategy has progressed. The 3DHB Disability Team has driven system-based change across the three DHBs. The review acknowledges, however, that the response to COVID has slowed progress.

Work implementing the recommendations from the forum will continue. The review identified gaps and opportunities for further development. One example is the need for role and relationship clarity between the Sub Regional Disability Advisory Group and the DHBs. The forum recommendations and review findings have been incorporated into the Disability Leadership Group's Strategic Plan for 2022 (see separate paper). The forum recommendations and review will also be shared with the Transition

Unit and Health New Zealand to contribute to the development of the next disability strategy for the region.

The review will enable the three DHBs to report back to the community and to the Board on progress to date and next steps.

Attachment

1. Independent Review of the Progress with the Sub Regional 2017-2022 Disability Strategy Forum Recommendations: Analysis of Key Themes from this Review.

Independent Review of the Progress with the Sub Regional 2017-2022 Disability Strategy Forum Recommendations

<u>Analysis of Key Themes from this Review</u>

1. Introduction

In 2019 I Co-facilitated a Disability Community Forum to discuss progress with the Sub Regional Disability Strategy and to obtain feedback and make recommendations for the update of this strategy. As a result I made a number of recommendations for the update of this Disability Strategy, based on the feedback from the forum.

In August 2021 I started a project to review the progress with implementing these recommendations and the Sub Regional 2017-2022 Disability Strategy, and to provide recommendations and feedback for the next update of the strategy.

This review is divided into two reports. This report outlines the key findings of this review. A second report provides a progress review of each recommendation based on an analysis of the written information provided and the various interviews.

2. Methodology for this Review

This included:

a. A desktop review of various reports to the DSAC and SRDAG and other key information provided by the DHB staff. This provided an update of progress with the various recommendations from the 2019 forum and Sub Regional 2017-2022 Disability Strategy.
b. Rachel Noble, the General Manager Disability and her Disability Strategy Team were interviewed on two occasions. We discussed progress with implementing the recommendations and the strategy.
c. Various zoom interviews were also completed. These included the Co-Chairs of SRDAG, a designated member of DSAC, senior staff from the combined Capital and Coast/Hutt Valley DHBs, including those involved with Strategy, Planning and Performance.

The Limitations of this Review were:

a. During this review Wellington and other parts of the country went into lockdown with Covid. This impacted on gaining feedback from other DHB senior staff across the 3 DHBs and some community representatives, who were contacted.
b. This also caused some delays with this process and I was not able to talk with any senior staff from the Wairarapa DHB.
c. It was also agreed that I would only interview a few representatives of DSAC and SRDAG and that this review would not include wider community consultation. While the Tangata Whaikaha Roopu was not interviewed as a group, a key member of this Roopu was interviewed.

3. Key Themes from the Analysis of Interviews and Information Provided

1. **The desktop review and also the interviews indicated that progress has been made with all of the recommendations from the forum and in the Sub Regional 2017-2022 Disability Strategy.**

2. **All of these recommendations are a work in progress.**

3. **Those interviewed identified these key themes:**

What is going well with the implementation of the strategy?

a. Rachel Noble and the disability strategy team are highly regarded within the DHB.
b. They are completing system based work within the Health System.
c. Employing more staff within the Disability Strategy Team with lived experience of disability.
d. Progress with the Accessibility Charter.
e. The Disability Strategy Team are a strong resource within the 3 DHBs.
f. Other teams with the DHBs have increased their knowledge of lived experience of disability.

What are the blocks that have got in the way of implementing parts of the strategy?

Everyone interviewed acknowledged that the response to COVID has definitely slowed progress with the implementation of the recommendations and the Sub Regional Disability Strategy.

Other themes:

a. The current strategy lacks a pathway and vision to improve the Healthcare System.
b. The lack of a 'lived experience of disability' lens within the Ministry of Health.
c. The impact of supporting the MoH with Covid on implementing the strategy.
d. Deteriorating communication between the SRDAG and DHB management.
e. The lack of skills and resources in the community to do some work e.g. Alternate Formats.
f. More consistency is required with implementing the strategy across the 3 DHBs, in particular with the Wairarapa DHB.

What could be done to improve the strategy?

a. A smaller strategy with more specific goals in areas the DHB are responsible for.
b. A clear vision going forward so we know the things were aiming to achieve.
c. The focus needs to be on improving the systems rather than just projects.
d. Continuing to build the disability confidence of staff and consistent data across the 3 DHBs.
e. More accessible design of services across the 3 DHBs.
f. Finding out what is important for disabled people and whānau in their local communities.
g. Having DHB champions across the 3 DHBs so the DSAC, SRDAG and Disability Strategy Team hear directly from staff on the ground what their issues are.
h. More DSAC/SRDAG meetings and prioritizing funding for disability services.
i. The General Manager – Disability at ELT.
j. More resourcing for the Maori Advisor and a stronger link with the Māori and Pacific people strategies.

The Health New Zealand Reforms need to include:

a. A disability team in Health New Zealand with lived experience of disability.
b. Improving the performance of the healthcare system for disabled people and whanau.
c. The development of more consistent heath related disability data.
d. Funding based on need rather than just population particularly for rural communities.
e. Accessible information, communication and digital platforms in the Healthcare System.

4. Further Discussion and Analysis about Some of these Key Themes

a. The most significant progress has been in relation to the first recommendation: *The promotion and implementation of the Accessibility Charter.*

This has now been signed by Capital and Coast, the Hutt Valley and Wairarapa DHBs.

Rachel Noble, the General Manager - Disability acknowledges that a lot of work has been completed at a practical level and there now needs to be more strategic policy work completed in relation to the accessibility charter across the 3 DHBs. This will ensure the Wairarapa and Hutt Valley DHBs are more on board with this.

Some that were interviewed felt that a greater emphasis on the accessibility charter work had an impact on progress with other recommendations and parts of the Sub Regional 2017-2022 Disability Strategy. While others felt it was easy to underestimate the amount of time it takes to operationalize this work. This also highlighted that the current CCDHB website is old and difficult to make accessible.

The Co-Chairs of SRDAG we're particularly concerned about this. They felt that 'little attention' had occurred other than the Accessibility Charter, since Covid. This review has shown that there has been progress with all of the recommendations.

To ensure continued progress with the Disability Strategy EGL and Accessibility Charter Leads have been appointed and the Disability Strategy Team has now been split into two teams. The Accessibility Charter lead will focus on COVID work, while the rest of the team will focus on BAU to ensure more progress with Sub Regional Disability Strategy. Rachel Noble will continue to have oversight of both teams.

b. The interviews highlighted a lack of agreement and clarity between the DHB staff and the Co-Chairs of SRDAG around governance vs management boundaries, what both parties expect in terms of co-design and SRDAGs involvement in development of priorities and implementation of the work programme.

Fundamentally the Co-Chairs of SRDAG felt this group hadn't been involved enough in the prioritization of the work programme and development of actions related to the various recommendations on progressing the disability strategy.

They had this to say when asked - *What would improve the relationship with SRDAG?*

'We want it to work well, and we want to work in partnership … We have been waiting for many years to work in co-design and work out how that would work … a specific co-design and communication process … we feel like we get told afterwards, we want (DHB staff) to come to us and go, how do you want this to work? … Our intent as an advisory group is to work collaboratively to achieve our joint goals … We would like to think that the idea of co-design included us at the beginning of relevant projects and not the end.'

The DHB staff want to develop layers of engagement with the disability and Deaf communities and have tried to grow the diversity of the voices that they get feedback from about DHB services. Some DHB staff interviewed acknowledged '… *we haven't always got it quite right'* and *'some voices are not comfortable with this different type of engagement.'*

Getting agreement between the DHB staff and SRDAG about the role of SRDAG, the boundaries between governance vs management and the process for developing the different levels of engagement with the disability and Deaf community, would help to resolve many of these issues.

When other people were asked - *Does the disability strategy team maintain effective relationships with its partners and allies in relation to the strategy?* – All said they felt that the team did maintain effective relationships and example were provided.

It was acknowledged by one person that the relationship internally (with other senior staff) could be challenging at times *'… because the (disability team) are driving a leading edge conversation without being a commissioner and without having access to specific data and trying to drive pro equity agenda within the DHB …'*

c.   A common theme from people interviewed was that the Sub Regional Disability Strategy needs to be rewritten when it is updated:

'I think the strategy needs to be rewritten - it's too complicated and complex to actually implement, it's too prescriptive …

Take something like trying to create an electronic health passport - I think we've had three or four failed projects to try to do this - we're in the wrong place on the system to make that a reality. That's a good example where there was nothing wrong with the goal and it made perfect sense, but when you actually worked through its too big for the DHB …

The community at times doesn't actually realise how much of a challenge it is to get some of these things done. And I don't think our SRDAG has always understood that as well …

It is important that the strategy is realistic about what the DHBs can do.'

'There is an absence of a vision for 2021 and beyond - a final vision structure is missing and this leads to a series of disconnected themes that we're all (including Rachel and the teams) trying to piece together but can't without the overall vision as a whole that states what would the system would look like if we were to be successful in implementing the strategy. It's just four focus areas with a number of actions underneath which is almost like a checklist approach to promotion or advocacy …'

It is also important that the update of the Sub Regional Disability Strategy considers what the endorsement of a pro-equity policy and commissioning framework means for this strategy.

d.   The feedback also indicated that the update of the Sub Regional Disability Strategy needs to have a strong focus on improving the performance of the healthcare system for disabled people, particularly those parts that the 3 DHBs have responsibility.

This includes continuing:

- To build more consistency across the 3 DHBs with implementing the Sub Regional Disability Strategy. Combining Capital and Coast/Hutt DHBs will provide a platform for this, but the feedback indicates more work needs to occur particularly with Wairarapa DHB.

  This needs to include making sure that all senior managers across 3DHB's are all on board with disability strategy and taking responsibility for the various parts that they are responsible for and there are clear accountabilities.

- Training and development of the workforce across the 3 DHBs to better understand how to work with disabled people and their whānau.

- Further reviews of the 3 DHB services that include feedback from service users in the disability community.

- To have performance expectations for staff and services to change the experience of disabled people and their whānau.

- To make services more accessible from an information, communication and physical access point of view, so the 3 DHB hospital and community services are accessible, and staff receive the resources in training and learning that needs to go with this.

- To ensure the digital platforms are accessible for disabled people with different impairments and who use assistive technology.

e. The 2019 forum recommended increasing the voice of disabled people at all DHB levels.

While there has been various new appointments with 'lived experience of disability' in the Disability Strategy Team, this is still a work in progress in terms for increasing the voice of disabled people and building disabled leadership across the 3 DHBs, in these places:

a. Governance (eg. DHB) and local community advisory groups.
b. Increasing disabled staff employed at management and operational levels outside of the disability strategy team.
c. Creating short, long-term and graduate internships/scholarships for disabled people to increase disabled people gaining employment with the 3 DHBs.
d. Discussing how disabled people can add value within other DHBs teams.

Some also suggested that Rachel Noble should be part of the Senior Leadership Team like other Equity General Managers, particularly given the endorsement of a pro-equity policy and commissioning framework. This would ensure disability issues don't get lost along with other equity issues.

f. Health New Zealand Reforms

Some interviewed felt that the Ministry of Health (MoH) needs to rectify its lack of staff with 'lived experience of disability', if they are to be effective with the Health New Zealand transformation. They felt that with Covid, this lack of 'lived experience of disability' has seriously impacted on the ability of the MoH to provide appropriate policy advice and to provide information in accessible alternative formats to the disability community.

As a result the CCDHB disability strategy team, which includes staff with lived experience of disability, have needed to significantly support and to work closely with the MoH on issues such providing information in alternate formats, etc.

It was suggested that the Ministry of Health and the Health New Zealand Reforms need to include more people with 'lived experience of disability' at governance, senior management and other staff levels. People felt that without this, the Ministry of Health and Health New Zealand will continue to struggle with the development and implementation of policy relating to disabled people and their whanau. They also suggested the other ideas on page 2.

One person recommended that the Health New Zealand transformation includes Disability Equity Training becoming a minimum requirement in the health sector. They also advocated for the development of a 'disability tick' programme for health services so there is more of a specific process for auditing services from a disability perspective.

5. Key Areas to Consider with the Update of the Sub Regional Disability Strategy

This review has identified these key areas to consider with any update of the Disability Strategy:

a. How to create a strategy that is simpler, has a vision for 2022 and beyond and is realistic about what the 3 DHBs can do.

b. What the pro-equity policy and commissioning framework means for this strategy.

c. How to build more consistency across the 3 DHBs with implementing the Disability Strategy, including senior management accountabilities and performance expectations to change the experience of disabled people and their whānau.

d. The different levels of engagement with different parts of the disability community that should occur to get feedback about the update of the disability strategy, and on an ongoing basis.

   Should this involve consultation with specifics parts of the community, instead of a large community forum like previous years, or both?

e. The development of a process so the DHB staff and SRDAG reach agreement about the role of SRDAG with the development of priorities, the work programme and community engagement.

   This should include a review of whether SRDAG should have more representation from the different parts of the community who are now consulted through the different layers of engagement - those involved with the reviews of different services, local community and specific Hui with disabled people and their whānau, etc.

   This discussion should also consider how to build more of voice for disabled people and their whānau across all levels of the 3 DHB.

f. Further consultation with Māori and Pacific disabled people and their whānau/fono is required in relation to the areas of the strategy that impact on them. The DHB Māori and Pacific Disability Strategies should dovetail into the wider DHB and MoH Māori and Pacific Strategies and the work of associated teams.

g. The strategic policy work required to implement the accessibility charter across the 3 DHBs.

h. Continuing to review across different departments of the 3 DHBs the current systems for communicating and providing accessible information to disabled people and whānau.

i. The World of Difference Project, the continued delivery of the Disability Equity Training across the 3 DHBs to clinical and general DHB staff and developing consistent data across the 3 DHBs.

j. How to develop a more strategic approach across the 3 DHBs around physical access.

k. Exploring the patterns of complaints and remedies involving disabled people and their whanau across the 3 DHBs and how to report this to ELT, the DSAC and SRDAG committees.

   This also includes the development of a process across the 3 DHBs for the Disability Strategy Team to bring the complainant and clinical staff together to find a win/win solution.

l. Reviewing what progress has been made in relation to the 2020 staff survey about disability and what needs to be considered in the update of the Sub Regional Disability Strategy.

The 'Analysis of Evidence' report provides further detail in relation to these findings.

Grant Cleland
Creative Solutions

28 February 2022

Disability Support Advisory Committee

16 March 2022

Disability Leadership Group's Strategic Plan for 2022

Action Required

The Committee notes:

(a) The Disability Leadership Group has reviewed the 3DHB Sub-Regional Disability Strategy and updated it by developing a Strategic Plan for 2022.

(b) The Strategy Plan applies to all areas across our three DHBs, and the Enabling Good Lives Principles and the Accessibility Charter are tools to apply disability equity alongside capability and capacity building initiatives.

(c) A critical role of the Disability Leadership Group is to provide the 'thought leadership' needed to implement the Strategic Plan for 2022.

(d) The recommendations from the review conducted by Grant Cleland have been incorporated into the Disability Leadership Group's Strategic Plan for 2022 (see separate paper).

Strategic Alignment	3DHB Disability Strategy
Author	Rachel Noble, GM Disability
Endorsed by	Peter Guthrie, Acting Director Strategy, Planning and Performance
Presented by	Rachel Noble, GM Disability
Purpose	The disability strategy was updated for use by the team to clarify our work direction.
Contributors	3DHB Disability Leadership Group
Consultation	3DHB Disability Leadership Group, SRDAG

Executive Summary

The Disability Leadership Group's Strategic Plan for 2022 includes:

• Our 'why' - what guides us, our scope and who we work for
• Our operating context - both internally and externally
• How we work - linking the strategic drivers through to our priorities
• Our strategic intentions - highlighting our priority focus areas for 2022.

The role of the Disability Leadership Group is to drive positive change towards equitable, accessible and inclusive healthcare and wellness services for all disabled people and their whānau. The strategic intentions are supported by several priority activities and business-as-usual activities. They contribute to the priorities of the Sub-Regional Disability Strategy and the objectives for the health system reforms.

The four strategic intentions are:

1. Enabling accessibility
2. Enabling good lives
3. Building capacity and capability
4. Thought leadership.

We will organise our efforts to ensure we focus on the right things with the right people and in the right way, as demonstrated with this kete. This model will be shared with Health New Zealand and the Māori Health Authority.
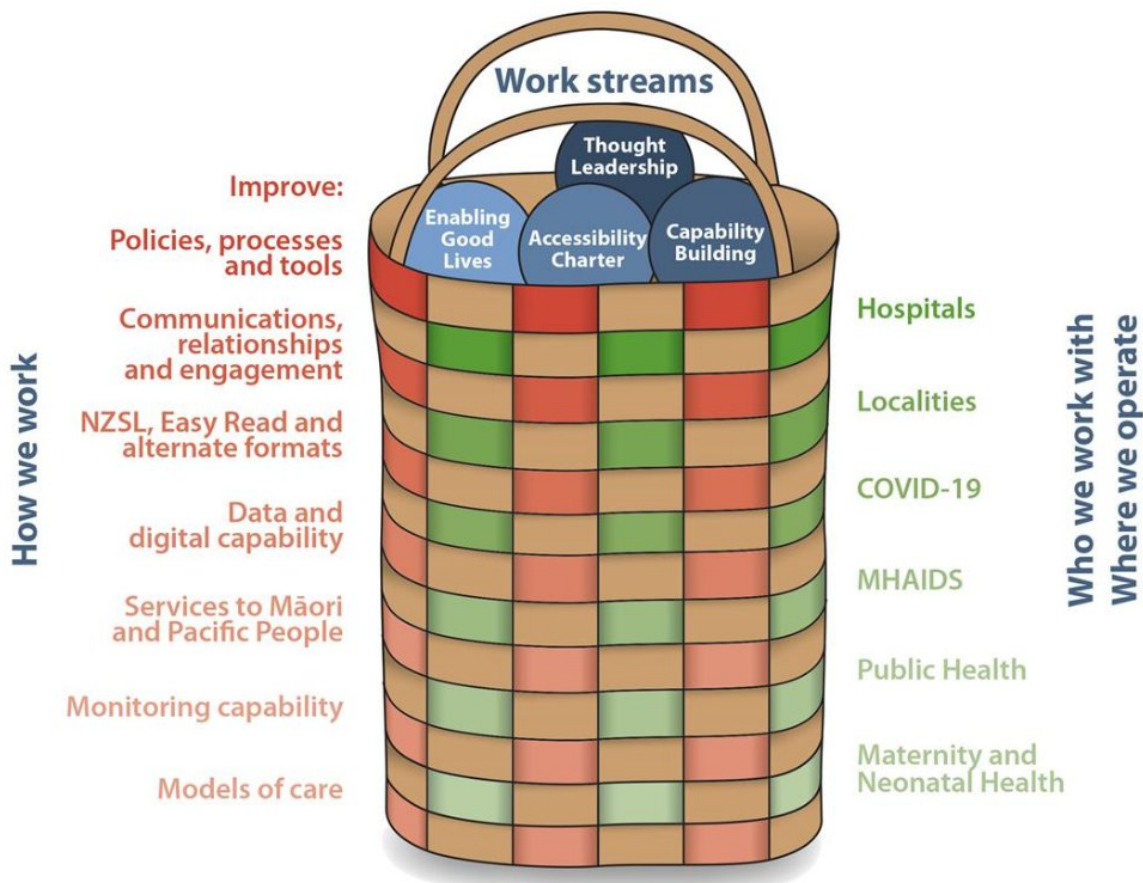
Strategic Considerations

Service	N/A
People	N/A
Financial	N/A
Governance	N/A

Engagement/Consultation

Patient/Family	N/A
Clinician/Staff	N/A
Community	N/A

Attachment/s

1. Disability Leadership Group's Strategic Plan for 2022.

Strategic Plan 2022

Disability Leadership Group

Overview

This document outlines the Disability Leadership Group's strategic plan for 2022 and includes:

- **Our 'why'**; what guides us, our scope and who we work for

- **Our operating context**; both internally and externally

- **How we work**; linking the strategic drivers through to our priorities

- **Our strategic intentions**; highlighting our priority focus areas for 2022

Our 'why'

Our role is to create positive change towards equitable, accessible and inclusive healthcare and wellness services for all disabled people and their whānau

What guides us

Relevant legislation and policies:

- Te Tiriti o Waitangi
- UN Convention on the Rights of Disabled Persons (Ratified by New Zealand 2008)
- Human Rights Act (1993)
- New Zealand Public Health and Disability Act/draft Pae Ora (Healthy Futures) bill
- New Zealand Disability Strategy (2016 - 2026)
- New Zealand Disability Action Plan (2019-2023)
- Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan
- Faiva Ora 2016–2021 National Pasifika Disability Plan
- Sub-Regional Disability Strategy 2017 – 2022
- Taurite Ora Māori Health Strategy 2019-2030
- Te Pae Amorangi Hutt Valley DHB Maori Health Strategy 2018 -2027

There are two key documents that will continue to guide us this year:

The principles of Te Tiriti o Waitangi:

These principles provide a framework for how we will meet our obligations under Te Tiriti in our day-to-day work:
- **Tino rangatiratanga**; which provides for Māori self-determination and mana motuhake in the design, delivery and monitoring of health and disability systems
- **Equity**; committing to equitable health outcomes for Māori
- **Active protection**; committing the fullest extent practicable to achieve equitable health outcomes for **Māori**
- **Options**; to provide for and properly resource kaupapa **Māori** health and disability services
- **Partnerships**; to work in partnership in the governance, design, delivery and monitoring of health and disability services

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

There are eight principles that underlie the Convention and each one of its specific articles:
- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Our functions

The Disability Leadership Group creates positive change towards equitable, accessible and inclusive healthcare services to disabled people and their whanau by identifying and addressing inequalities within the DHBs.

The team's functions across a range of initiatives include:

- providing thought leadership on policies, strategies and initiatives,

- encourage accessible thinking, inclusiveness, principles and guidelines to all work streams and projects,

- ensuring that the disabled community's voice is projected and included throughout the development and delivery of services,

- a range of education initiatives and promotion of tools and resources, and

- promoting accountability through data and monitoring initiatives.

Who we work for

Disabled people in the Greater Wellington region comprise 120,000 of all ages who are a diverse community with a wide breadth of experience with impairments.

Disabled people may have life-long impairments or acquire disability later in life. Māori and Pacific people are more likely than other members of our community to have an impairment.

Providers of all health and disability services and their staff are responsible for delivering equitable access, service quality and health outcomes to disabled people.

Our partners include disabled people, their families and whanau, and other advocates for disabled people.

Disability Community 2013:

22% — 22 percent Greater Wellington population

Māori and Pacific people had higher-than-average disability rates

Wellington Province:

Mobility - 11%   Sensory - 10%

Agility - 6%   Learning - 4%

53 percent had more than one type of impairment

The most common cause of disability for adults was disease or illness (42 percent)

For children, the most common cause was a condition that existed at birth (49 percent)

Our operating context

"Disabled people have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"

Article 25 UN Convention on the Rights of Persons with Disabilities

Health System Reforms

A far-reaching and ambitious reform of the health and disability system is underway involving an integrated set changes to the system's settings, incentive and culture.

The priority outcomes for the reformed health system are:

- **Partnership**; ensuring partnership with Māori in decisions at all levels of the system, and empowering consumers of care to design services that work for them

- **Equity**; tackling the gap in access and health outcomes between different populations and areas of New Zealand

- **Sustainability**; embedding population health as the driver of preventing and reducing health need, and promoting efficient and effective care

- **person and whānau-centred care**; empowering all people to manage their own health and wellbeing, have meaningful control over the services they receive, and treating people, their carers and whānau as experts in their own care

- **Excellence**; ensuring consistent, high-quality care in all areas, and harnessing innovation, digital and new technologies to continuously improve services.

The architecture of the reforms includes:

- a new **disability health strategy**,

- consolidation of all District Health Boards into a **single entity**, Health New Zealand,

- a more **definitive commitment** to equity of access, service quality and outcomes, and

- explicit recognition of the need to address the **range of factors** contributing to health and wellbeing, from housing to employment to social care.

How we work

A new approach to wellness and disability is needed for disabled people and whānau to experience ordinary life outcomes

There are four strategic priorities supported by enablers – with a pro-equity approach:

Our Strategic Priorities Programme was developed to **support the reform and planned changes** to New Zealand's health and disability system.

Work on these priorities will **strengthen key areas** of our health and disability system and align us with the intent of the health sector reforms.

Our focus remains on delivering **equitable health outcomes** and intensifying support for Māori, Pacific people, disabled people, and those living with mental illness and addiction.

We are working to create a health and disability system that is focussed on keeping people well, early intervention by primary and community health providers, and **high quality and safe patient-centred** specialist care for those who need it.

This requires the **most effective use of resources** for clinical and financial sustainability.

Key Goal: we will undertake activities to promote inclusive and accessible healthcare services for disabled people so all are comfortable and safe

For DHB staff and departments	With DHB staff, departments and advisory groups	For the community	For the health and disability system
• Provide thought-leadership strategic advice and guidance on disability-related matters to improve services using the Accessibility Charter and the Enabling Good Lives Principles as the foundation • Uplift organisational disability capability through staff training and awareness including NZSL and general disability training • Promote tools at both the hospital and community sites e.g. the My Health Passports • Promote equity of services throughout the DHBs • Encourage accessible thinking, principles and guidelines to all work streams and projects	• Develop and implement strategies, policies and procedures to facilitate inclusive and accessible health services to address inequities currently experienced by disabled people • Work with advisory groups to ensure that the community voice is heard throughout the development and delivery of services	• Facilitate co-design opportunities • Gather feedback and intel from community members to enable improvements • Attend advocacy and community group meetings • Speak to public groups and media about disability rights	• Offer pathfinding for new ways to support disabled people

Key goal: we will organise our efforts to ensure we focus on the right things, with the right people, and in the right way
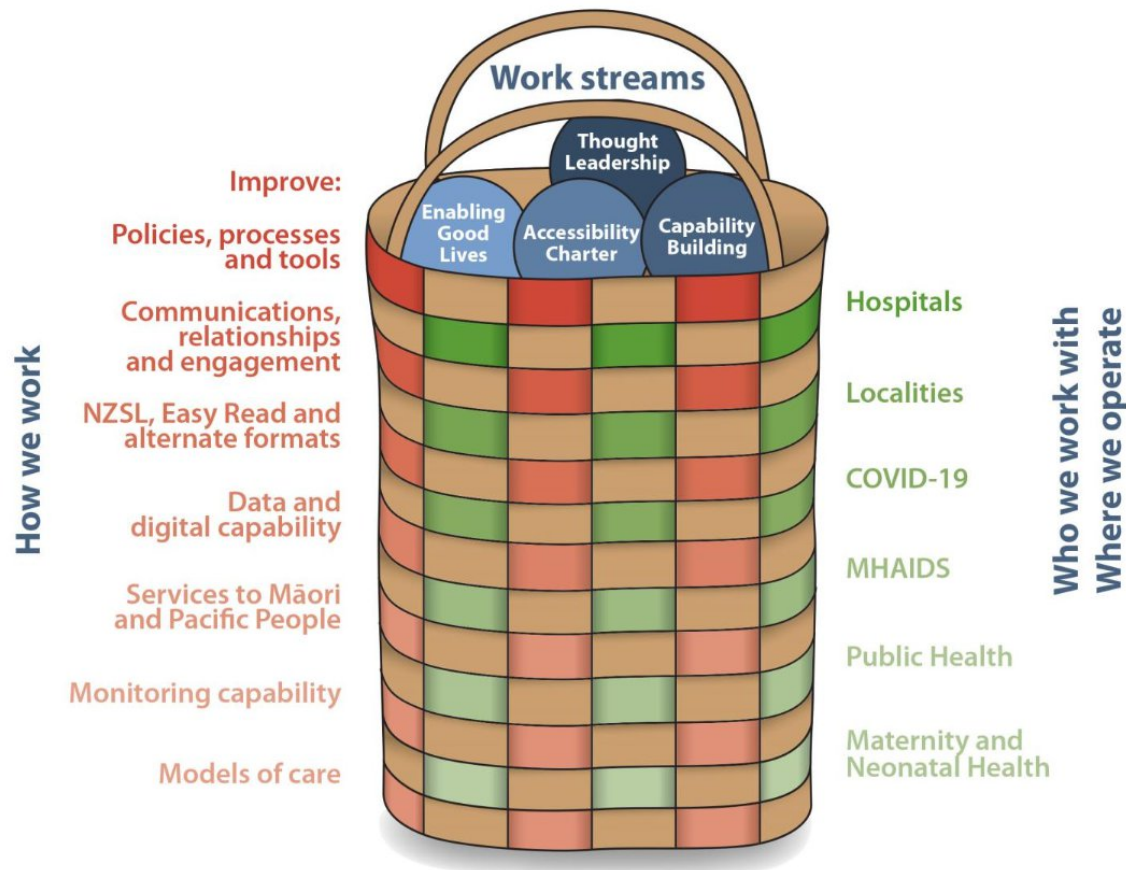
Key Goal: we will develop a scaled model based on an agreed set of indicators to lift organisational capability maturity, over time

EXAMPLE ONLY

INDICATOR	LEVEL 1: Basic	LEVEL 2: Reactive	LEVEL 3: Proactive	LEVEL 4: Innovative
• A 'disability-smart' workforce that knows how to demonstrate inclusive and accessible healthcare services for disabled people so all are comfortable and safe	• No training or disability confidence guidance for staff • Key staff (HR, front-facing, specialists, clinicians etc) have limited disability know-how • No resources are invested in improving disability-competency of staff • Frequent disability-related queries and concerns received but no knowledge of how to resolve them	• Generalist training is available for staff • Limited resources are invested in staff training • Specialist disability training delivered in response to issues • Learning and development analysis is required to identify target audiences, needs and solutions	• Training strategy is fully coordinated and resourced; training quality is regularly monitored and reviewed for effectiveness • All employees complete disability confidence training • Comprehensive disability-related guidance is available to accompany policies and processes	• Training data shows good level of disability know-how of all staff • A range of accessible, blended-learning products is available • Rights of disabled people are met at all layers and levels across the organisation • Staff report usefulness of resources • Few disability-related queries and concerns

These strategic intentions are supported by several priority activities and business-as-usual activities.

They contribute to the priorities of the DHB's Strategic Plan and the Sub-regional Disability Strategy.

Enabling accessibility

Enabling Good Lives

Building capacity and capability

Thought leadership

Enabling accessibility

What success looks like

Disabled people in the Wellington region experience barrier-free access to healthcare. Through this we will see:

- disabled people being engaged and actively involved in the development of policies and guidance impacting access to health services
- accessible design (communication, information and the environment) is understood, recognised and widely used
- decision-making is informed by robust data and evidence

Actions we will take

Our priority actions are:

- drive the implementation of the Accessibility Charter
- work in partnership with disabled people and their advocates to involve them in decision-making
- improve and streamline access to interpreters including New Zealand Sign Language
- improve access and use of information in alternate formats
- improve access to, and use of Health Passports
- create E-learning resources to build capacity and capability of DHB staff based on principles of Enabling Good Lives, UNCRPD and the Accessibility Charter

How we will assess progress

Our key performance measures are the:

- percentage of access assessments completed with no or only minor issues identified
- number of NZSL interpreters booked with a target of an increasing number year on year
- requests for information in alternate formats with a target of increasing number year on year
- number of Health Passports users increases with a target of increasing numbers year on year
- uptake of the E-Learning by staff

Enabling Good Lives

What success looks like

Disabled people and their whānau in the greater Wellington region will experience easier access to health services to create good lives:

- disabled people have more choice and control over their services
- the DHBs recognise the contribution that disabled people make to society and offer an accessible and welcoming environment
- better alignment of key enablers like commissioning, workforce and accountability measures the transformed system

Actions we will take

Our priority actions are to:

- apply the EGL principles across all localities, including specialist services, hospitals, medical centres and community
- improve the transition for children and young people from child to adult services within the healthcare system through the development of policy guidance, a fit for purpose electronic pathway, resource kits and engagement with youth networks
- begin early to enable positive outcomes from the first point of contact of health services for all children and whanau
- establish a clinical governance group that supports health professionals to be flexible and responsive to individual need
- create E-learning resources to build capacity and capability of DHB staff based on principles of EGL, UNCRPD and the Accessibility Charter

How we will assess progress

Our key performance measure is the:

- online training uptake from DHB staff
- experiences of disabled people will be monitored and engagement for feedback sought
- uptake of the E-Learning by staff
- Child to Adult Transition Project uptake monitored (electronic resource is available for transition)

Building capacity and capability

What success looks like

Our staff feel confident to actively challenging and dismantling overt, unconscious and systemic discrimination recognising that they are key to implementing a rights-based approach to disability and improving equity in healthcare. Through this we will see:

- high levels of engagement by staff and learners on clinical placement with e-learning modules and other training resources to include material that helps to shift attitudes, reduce discrimination and improve equity in healthcare for disabled people and those who experience mental distress

- education and training programmes integrate disability equity and literacy on a business as usual basis

- our staff reflect the communities they serve

Actions we will take

Our priority actions are:

- develop and deliver the World of Difference programme to staff

- continue promotion of the Disability Equity E-Learning module

- support our DHB partners to develop the capability necessary to confidently integrate core competencies, principles and values relevant to disability equity into education and training programmes

How we will assess progress

Our key performance measure is the:

- percentage of hospital staff who have completed the Disability Equity eLearning Module with a target of 100%

- Staff actively seek out input from the disability leadership group

Thought leadership

What success looks like

DHB staff value and incorporate insights from the disability leadership group in their approaches to service design and delivery. Through this we will see:

- disabled people and their allies have made opportunities for effective input into service design and delivery

- staff actively seeking out input from the disability leadership group

- services that give maximum choice and control to disabled people

- access to resources and tools and increased confidence of DHB staff in using these

Actions we will take

Our priority actions are:

- develop and implement a fit for purpose data collection, analysis and monitoring strategy

- continue to ensure the COVID-19 response accommodates disabled people

- facilitate DHB engagement with the disability community through formal and informal mechanisms

- provide input into service design and delivery through involvement on internal clinical and technical governance groups

- continue promotion of the Disability Equity E-Learning module

How we will assess progress

Our key performance measure is the:

- perceptions of disabled people about the appropriateness of health services in meeting their needs

- staff actively seek out input from the disability leadership group

Hutia te rito o te harakeke
If you remove the heart of the flax bush

Kei hea te kōmako e kō?
From where will the Bellbird sing?

Kī mai ki ahau
If you say to me

He aha te mea nui o te ao?
What is the most important thing in this world?

Māku e ki atu
I will reply to you

He tangata, he tangata,
It is people, it is people,

He tangata, hei!
It is people!

Disability Support Advisory Committee

16 March 2022

3DHB Sub-Regional Disability Strategy 2017 – 2022 Implementation Update

Action Required

The Committee notes:

    (a) This report provides DSAC with an update on the implementation of the Sub Regional Disability Strategy 2017 – 2022.

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
Authors	Rachel Noble, General Manager Disability
Endorsed by	Peter Guthrie, Interim 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 Sub Regional Disability Strategy 2017 – 2022 has four focus areas:

1. Leadership
2. Inclusion and Support
3. Access
4. Health

This progress update outlines our key areas of activity under each focus area, and includes our responses to the recommendations from the Sub Regional Disability Forum.

Focus Area One: Leadership

The Disability Strategy and Performance Team supports 3DHB initiatives to provide accessible and inclusive healthcare services to disabled people and their whanau. Key progress was made to create a Strategy for 2022 for the team to work to over the coming year (see separate paper). The strategy incorporates key elements from the 3DHB Sub-Regional Strategy and feedback we have received since. It also means our progress can been measured more easily. One key shift in our focus now is from **promoting** inclusive and accessible health care to **creating** inclusive and accessible healthcare.

1

The Disability Strategy and Performance Team is providing thought-leadership and focussing on strategic priorities and the areas prioritised by the DHBs. The team use the Principles of Enabling Good Lives and the Accessibility Charter to initiate discussions. The response from people throughout the region is very welcoming and willing. Some parts of the organisation are not aware that pro-equity includes disabled people.

The COVID team is spread across Regional Public Health, Community in Care, Planning and Operations and in Hospitals. A lot of their work has been to apply the disability lens locally, to influence planning and procedure and prepare our healthcare and welfare teams to work well with disabled people. They also continue to work alongside the Ministry of Health's disability directorate to advocate for more equity and inclusion of our communities in the national response. The team has also been working closely with our equity partners to ensure that disabled Māori, Pacific people, rainbow, migrant and refugee communities are able to get what they need in culturally appropriate ways.

The Disability Strategy and Performance Team has a vacancy in the Wairarapa DHB. The now vacant position in Hutt Valley DHB is being transferred from the Capability Team to the SPP team. One person left the team to become an independent built environment accessibility consultant.

Focus Area Two: Inclusion and Support

Enabling Good Lives - Highlights

Planning is underway to develop an e-learning modules on EGL Principles and the Accessibility Charter. This will build on the disability equity e-learning resource already available and have a focus on promoting reflection as well as practical suggestions. A co-design group is currently being created

The Kāpiti Enabling Good Lives workshops with the community will take place soon. The five workshops with local healthcare staff were very successful. The key workshop will be the final one with both the community and staff together identifying actions to adopt to improve the accessibility of healthcare services.

We are helping to ensure the EGL Principles are applied in the Strengthening the 3DHB Family Violence health response prototyping project.

WE are engaging with ENT, procurement, breast screening, and the localities team about self-reviewing their departments against the EGL Principles. We are also encouraging ways to gain input from disabled people who use those services.

Focus Area Three: Access

Key areas of progress include:

- Intranet: Priority has been given to improve access to our information and knowledge using the intranet and a similar location for PHOs to access.

- Easy Read: With two Easy Read contractors trained and contracted part time we are now seeing some Easy Read resources come in.   We are working with the communications team to determine where to store them so they are used for patients who request Easy Read resources.

- Developing new e-learning module.

- Health Passport particularly for COVID. Also partnering with Advance Care Planning

2

Focus Area Four: Health

Disability Quality and Safety Committee

Our 2DHBs have a well-established Clinical Governance Framework, which comprises a Clinical Governance Board with several specialist committees that report to it. A new committee is being established to drive operational objectives to achieve the 2DHB priorities of quality, continuous improvement and patient safety for disabled people. The Committee is called the 'Disability Quality and Safety Committee' and will influence behaviours and system and process design to enable the two DHBs to achieve these priorities, maximise opportunities to create rights based accessible and inclusive healthcare services, and improve outcomes for disabled people.

The first meeting will take place once the Terms of Reference are finalised and approved by the Clinical Board, which is scheduled for 17 March 2022.

The objectives of the committee are to:

- Ensure disability is a focus area for 2DHB clinical governance.
- Support implementation of the Accessibility Charter and the Enabling Good Lives principles
- Promote organisational strategies which develop a disability competent and capable workforce and practices which will influence behaviour and culture to reduce health disparities for disabled people.

The draft terms of reference were discussed with SRDAG at its meeting in February 2022 and changes were made following that discussion to reference the Treaty. SRDAG also asked whether the terms of reference could name SRDAG as having a representative on the Committee. This has been discussed this with the Director of Clinical Excellence and clarified with the Clinical Board team who have carefully considered the membership in light of the Clinical Governance Framework and also their specialist knowledge regarding the role of our specialist Quality and Safety Committees in the Hospital environment. They have confirmed that the work of the committee is largely operational in nature and that Consumer representation in the Disability Quality Safety Committee is drawn from the 2DHB Consumer Advisory Group.

That said, it is recognised that it is important to keep SRDAG (or its successor - given that there is not yet clarity on the future state post the transition to HNZ) informed of the work of the Committee. Therefore taking on board SRDAG's request and interest in being involved, an additional clause has been added to the Terms of Reference as follows:

Sub-Regional Disability Advisory Group (SRDAG)

The committee will share its yearly report and work plan with the Sub-Regional Disability Advisory Group (SRDAG) or its successor. Any feedback from SRDAG on the yearly report or work plan will be considered by the committee. In addition, SRDAG can escalate operational issues to the committee via the chair.

Maternity

We are currently recruiting for a Disability Equity Lead to drive the implementation of the disability action points within the Maternity & Neonatal System Plan: Principle 2: Enabling and respectful. The strategic shift is that all people, including disabled women and families who have a baby with impairments, experience responsive care that is enabling and respectful.

3

Understanding Disabled People's Experiences of Local Healthcare Services

Findings of the research report are the subject of a separate paper. The findings are particularly relevant to the 'localities' approach to the delivery of healthcare services, which is being implemented across some of the 3DHB region. This type of approach enables DHBs to partner with local providers to improve health outcomes of communities, address the social determinants of health, and support the work of local networks to meet health and wellbeing needs**.**

Capability Building

We continue to promote the Disability Equity E-learning modules. The number of requests for education continues to increase. One way to address the increasing demand is to deliver Study Days, where staff can access a programme we have designed to elevate the voices and experiences of disabled people and introduce a framework to improve accessibility of services.

Given the range of programmes being delivered we are working to streamline them across the three DHBs to maximise learning opportunities for more people. Requests for us to be involved with individual patients in hospital continues to increase. This issue will be considered by the Disability Quality and Safety Committee, as a resolution needs to be found.

4

Disability Support Advisory Committee

16 March 2022

MHAIDS Service Performance Update	
Action Required	
Board note the attached report from MHAIDS.	
Strategic Alignment	Service Access
Presented by	Karla Bergquist, Executive Director MHAIDS
	Paul Oxnam, Executive Clinical Director, MHAIDS
Purpose	Update the DSAC on MHAIDS Service Performance data

Executive Summary

People accessing services

- MHAIDS is currently seeing 7156 service users in the community and 203 service users in inpatient units.

- In the past 12 months MHAIDS received 12577 referrals for individuals

- The chart shows an additional 2,564 people accessed MHAIDS services in 2020/21 than in 2014/15. The increase for Māori is 1,480 (58% of the total increase).

- 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%)

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 in April/May 2020. 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.

Crisis Resolution Service

- The Crisis Resolution Service saw a significantly higher number of people in the months post COVID-19 lockdown last year than in previous years. The number of people presenting in crisis since then has remained above the average from previous years, but has decreased in recent months.

- Again the biggest increase has been in presentations by young people (aged 24 years and under) and the monthly total has remained at a higher level than pre-COVID until December 2021.

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 and Wairarapa, with less presentations in the last 12 months at Hutt ED.

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

Community Caseloads & Wait times

- 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 mean since Jan 2020 is 56% seen within 3 weeks and 83% seen within 8 weeks.

- The Adult Community & Addictions sector has slightly higher wait times results – the mean since Jan 2020 is 59% seen within 3 weeks and 87% 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 in three months since January 2020.

Workforce

- Nursing vacancies are affected by the additional CCDM roles. The decrease shown is due to the recruitment of NESPS.

- Allied Health vacancies have increased particularly in some of the CAMHS teams.

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

Mental Health, Addiction and Intellectual Disability Service Service Performance Update 16 March 2022

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

7,156 Current Service Users in the Community

1,718 Māori (24.0%)	426 Pacific Peoples (6.0%)	326 Asian (4.6%)	4,686 Other Ethnicity (65.5%)

203 Current Service Users in Inpatient Units

81 Māori (39.9%)	16 Pacific Peoples (7.9%)	6 Asian (3.0%)	100 Other Ethnicity (49.3%)

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

In the past 12 months MHAIDS received referrals for 12,577 individuals

3,153 Māori (25.1%)	587 Pacific Peoples (4.7%)	581 Asian (4.6%)	8,256 Other Ethnicity (65.6%)

1,208 individuals had inpatient stays during this period across Forensic, Rehabilitation, Intellectual Disability, Acute Inpatient and Eating Disorders units

395 Māori (32.7%)	89 Pacific Peoples (7.4%)	43 Asian (3.6%)	681 Other Ethnicity (56.4%)

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

People accessing MHAIDS services

The chart shows an additional 2,564 people accessed MHAIDS services in 2020/21 than in 2014/15. The increase for Māori is 1,480 (58% of the total increase).

Individuals with MHAIDS Activity recorded by Financial Year
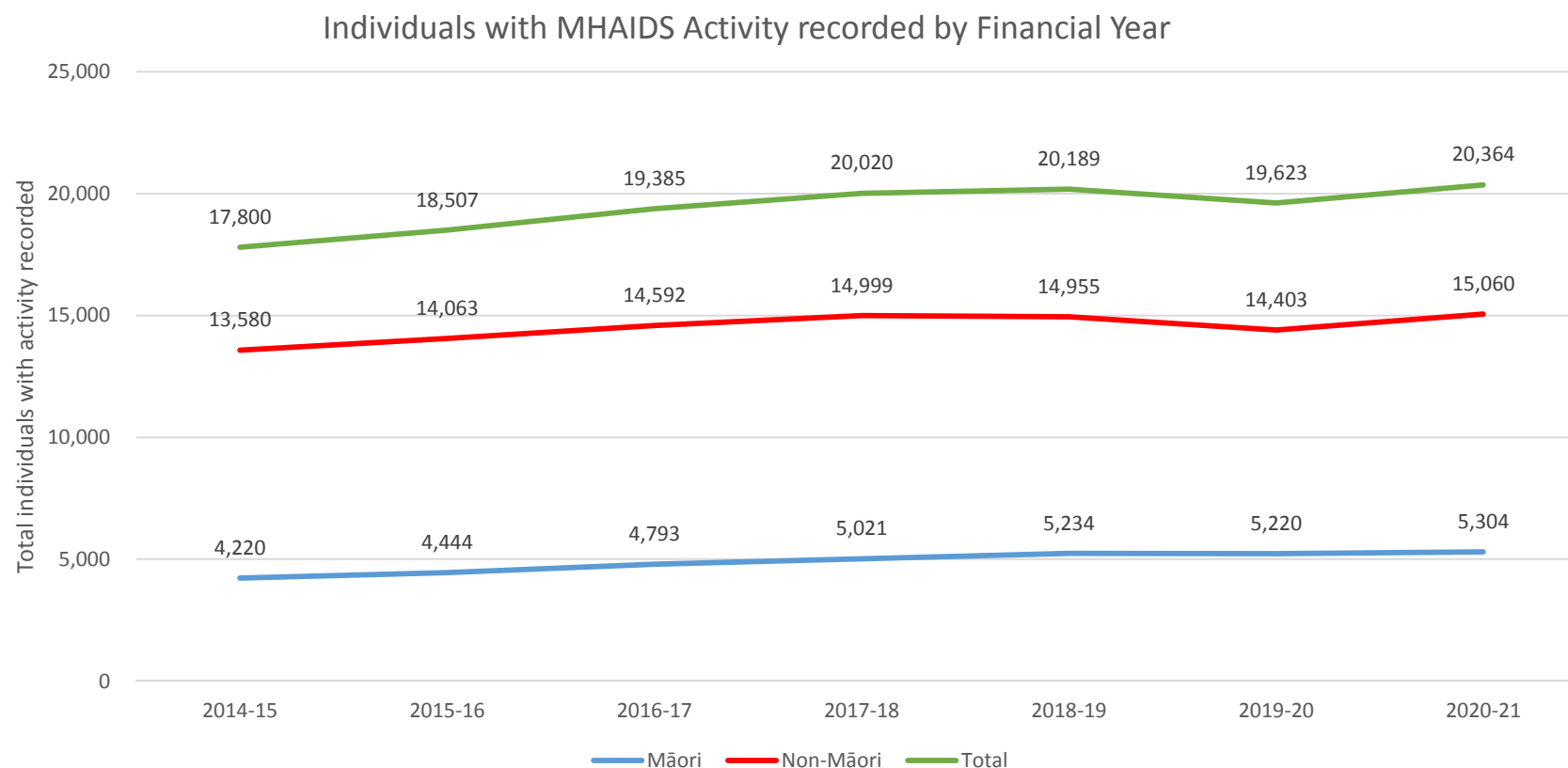
People accessing MHAIDS services

The patterns are similar across DHBs although the rate of Māori accessing services in Hutt has dropped slightly in recent years (from high of 7.2% in 2018/19 to 6.5% in 2020/21)
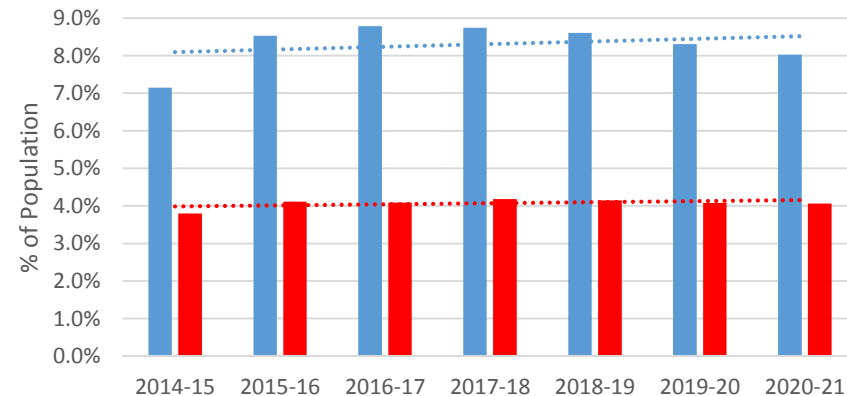
Legend:
- Māori
- Non-Māori
- Linear (Māori)
- Linear (Non-Māori)

% of Population with MHAIDS Activity Recorded - Hutt Valley DHB
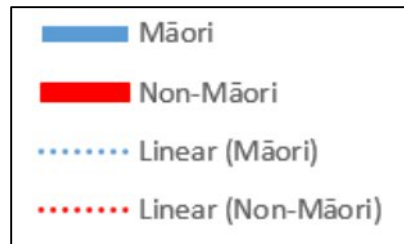

% of Population with MHAIDS Activity Recorded - Capital & Coast DHB
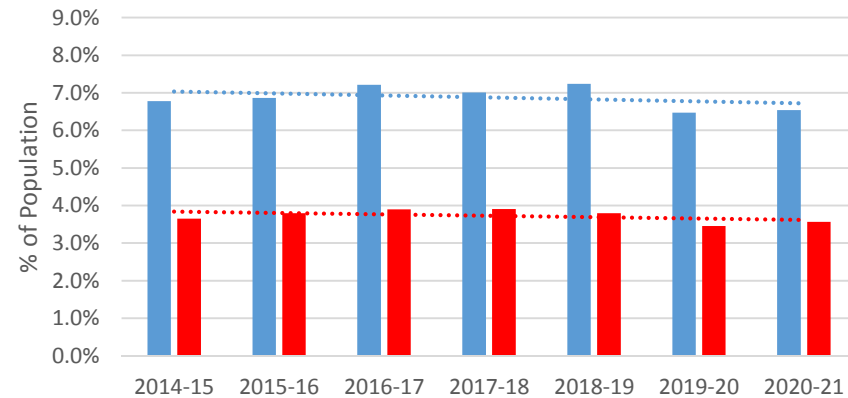
% of Population with MHAIDS Activity Recorded - Wairarapa DHB

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

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.

Total New MHAIDS Episode Referrals Created by Ethnicity
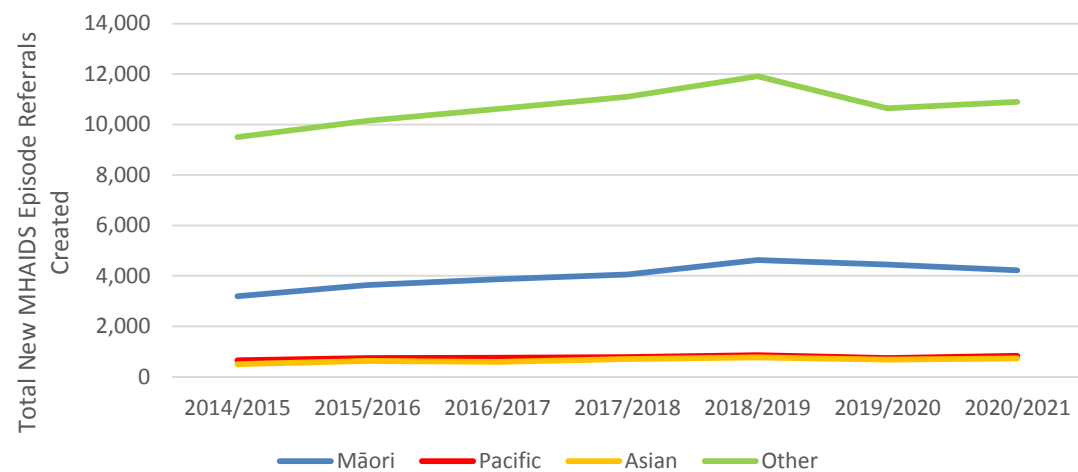
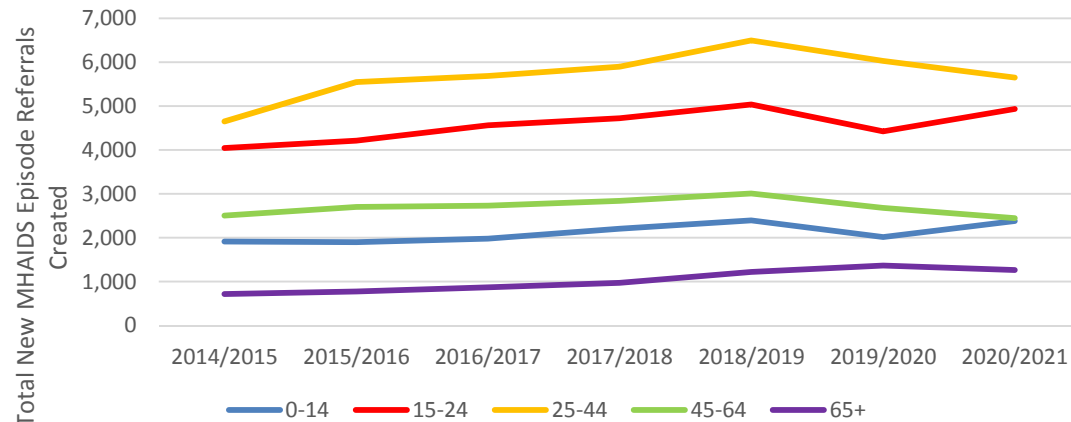Cumulative Growth in Referrals Created since 2014/15 by Ethnicity
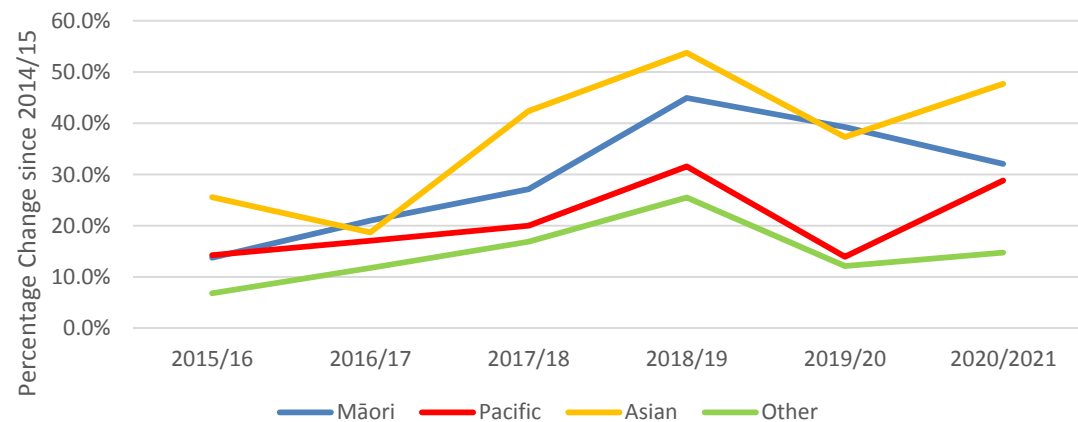
Te-Upoko-me-Te-Karu-o-Te-Ika
**Mental Health, Addictions and Intellectual Disability Service**

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.
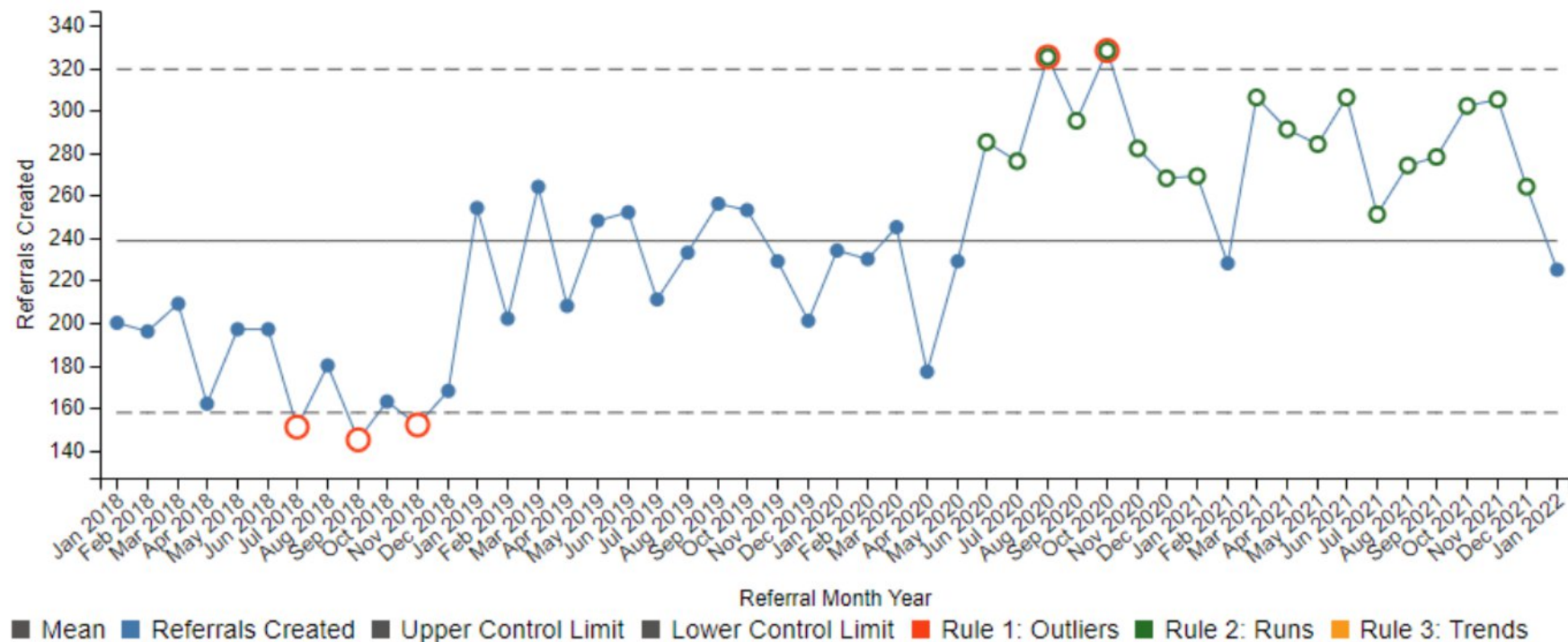

Total New MHAIDS Episode Referrals Created by Age Grouping

Cumulative Growth in Referrals Created since 2014/15 by Age Grouping

Te-Upoko-me-Te-Karu-o-Te-Ika
Mental Health, Addictions and Intellectual Disability Service
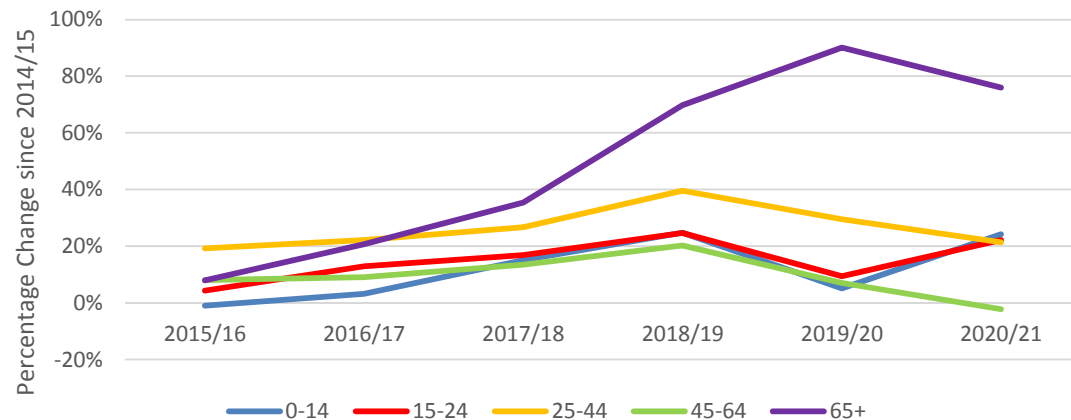
Urgent Referrals to MHAIDS

Since the end of the initial COVID-19 lockdown in April/May 2020 overall referral numbers have returned to levels similar to previous years, however there has been a marked increase in urgent referrals received. This pattern continued in 2021. January's figure is lower but this is somewhat expected for the New Year period.

Control Chart (I Chart) Showing Urgent Referrals Created

■ Mean ■ Referrals Created ■ Upper Control Limit ■ Lower Control Limit ■ Rule 1: Outliers ■ Rule 2: Runs ■ Rule 3: Trends

Te-Upoko-me-Te-Karu-o-Te-Ika
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. Again totals for recent months are lower which could be due to an expected quieter period at this time of year.

Control Chart (I Chart) Showing Urgent Referrals Created – Age 0-24 Years
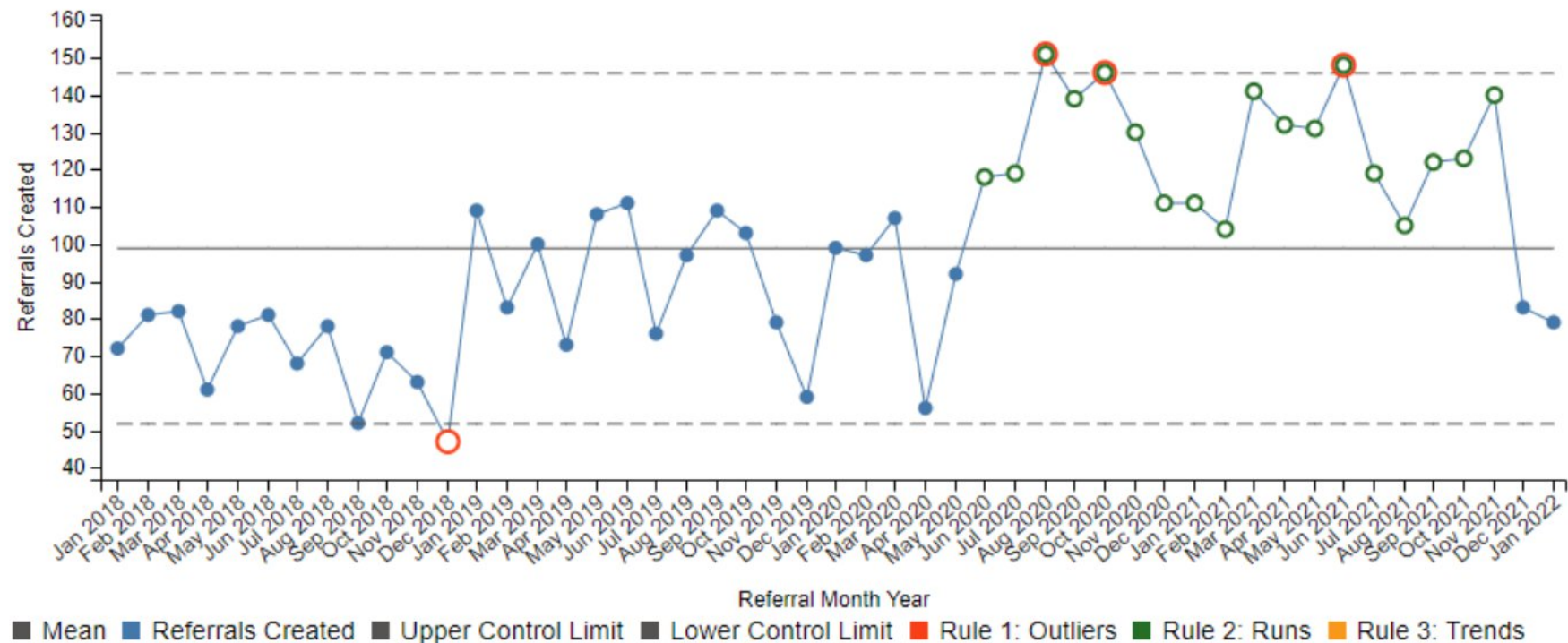
Te-Upoko-me-Te-Karu-o-Te-Ika
Mental Health, Addictions and Intellectual Disability Service

Crisis Resolution Service

The Crisis Resolution Service saw a significantly higher number of people in the months post COVID-19 lockdown (from June 2020) than in previous years. The number of people presenting in crisis since then has remained above the average from previous years, but has decreased in recent months.
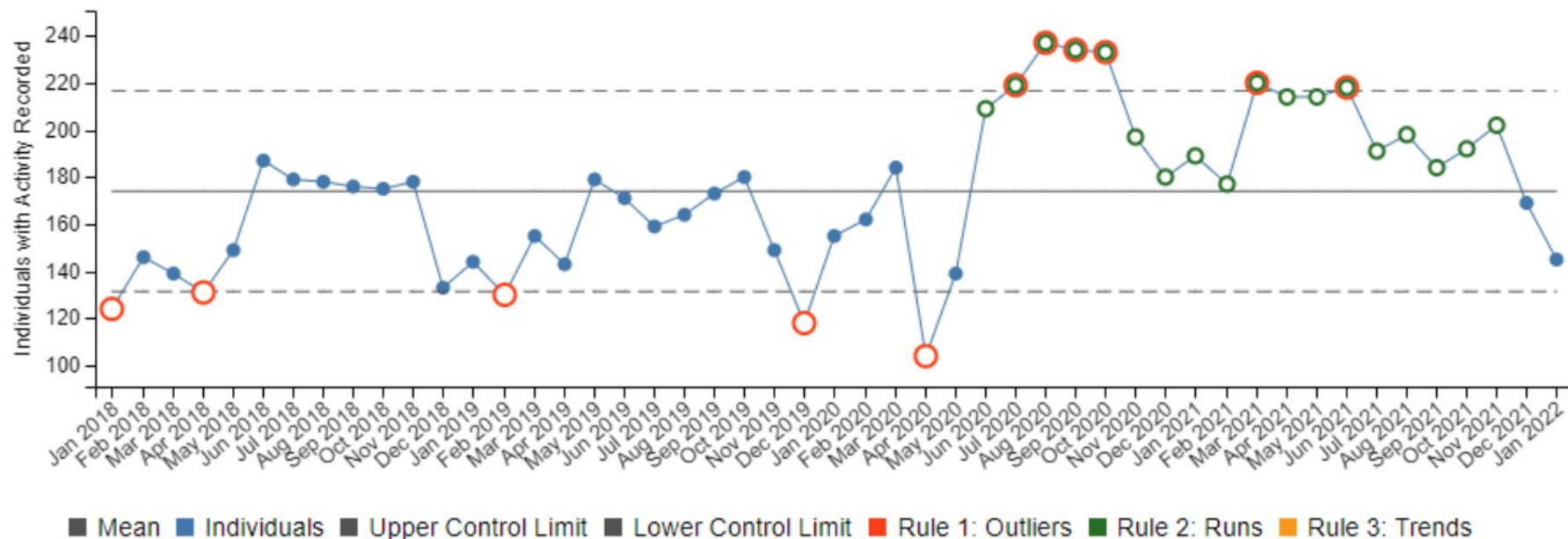
Control Chart (I Chart) Showing Individuals seen by Crisis Resolution Service
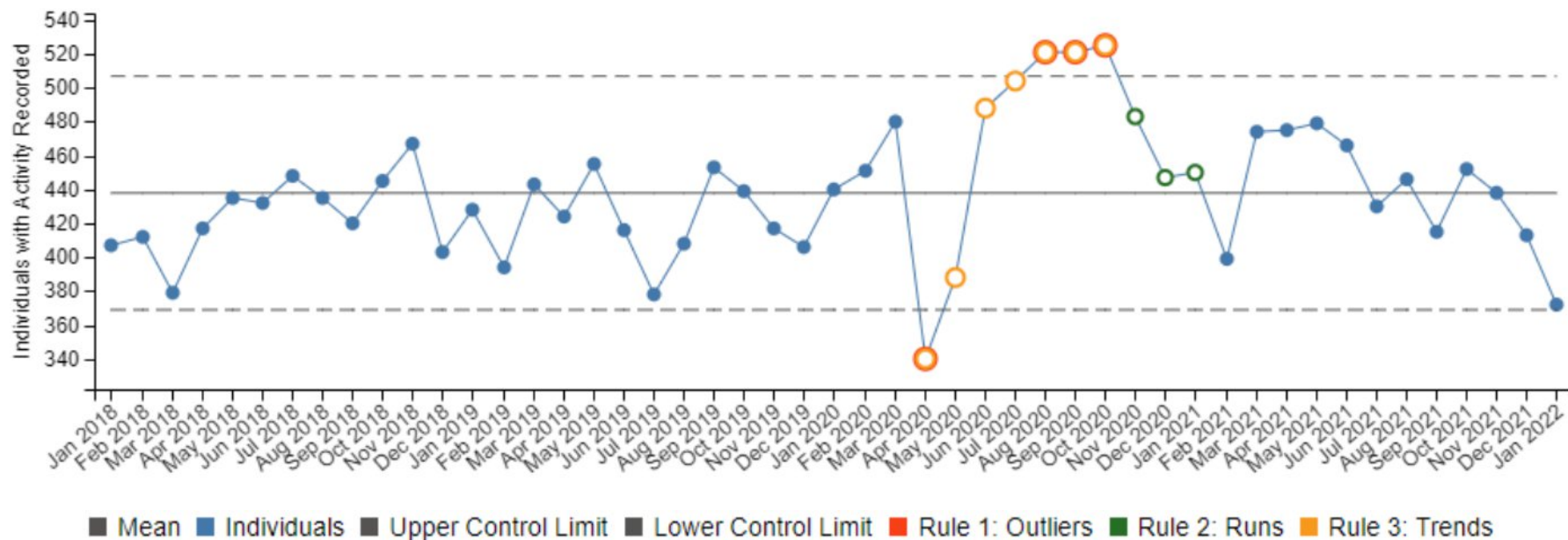
Crisis Resolution Service

Again the biggest increase has been in presentations by young people (aged 24 years and under) and the monthly total has remained at a higher level than pre-COVID until December 2021.

Control Chart (I Chart) Showing Individuals seen by Crisis Resolution Service – Age 0-24 Years

Mean ■ Individuals ■ Upper Control Limit ■ Lower Control Limit ■ Rule 1: Outliers ■ Rule 2: Runs ■ Rule 3: Trends

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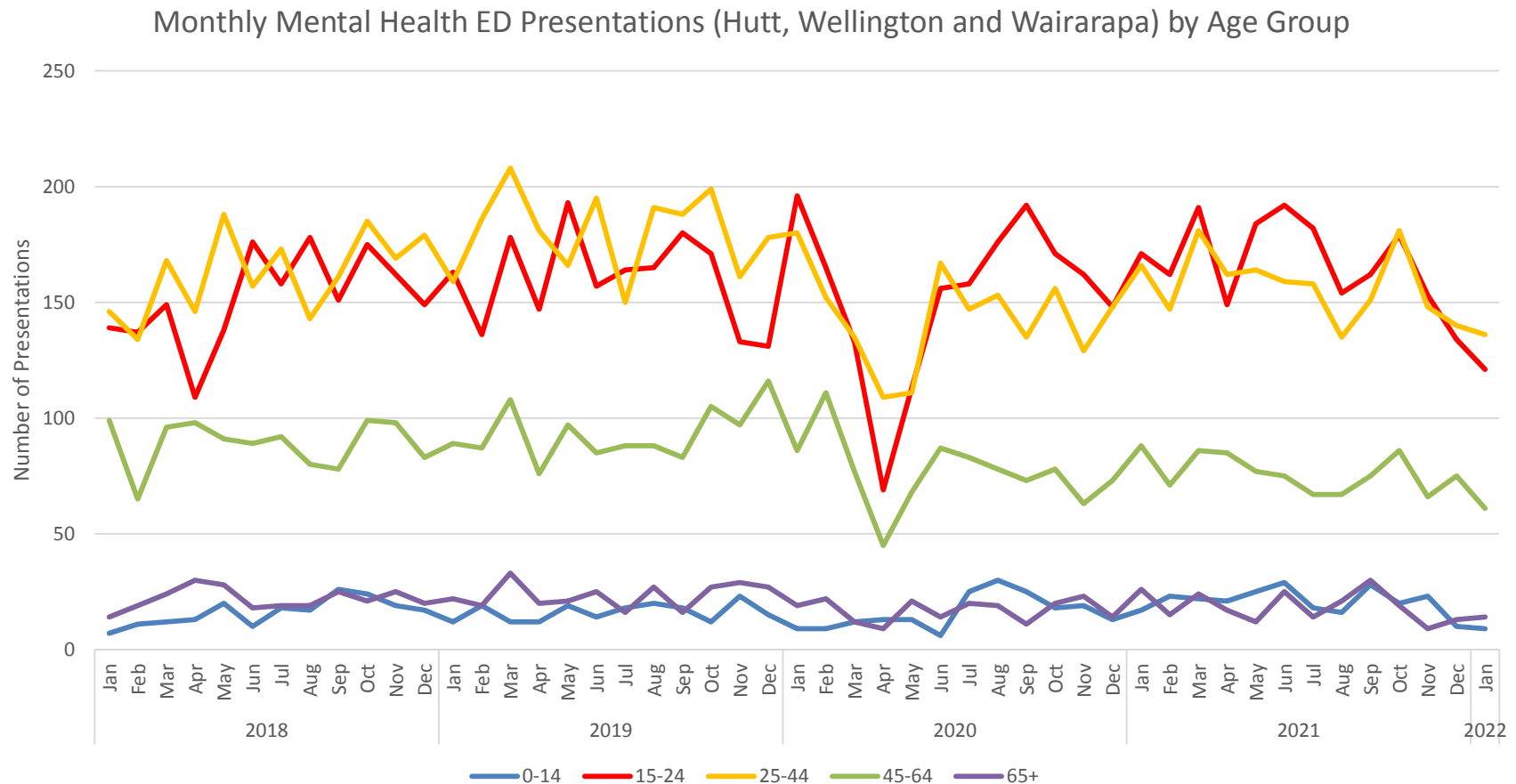**Mental Health, Addictions and Intellectual Disability Service**

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 and Wairarapa, with less presentations in the last 12 months at Hutt ED.


Monthly Mental Health ED Presentations
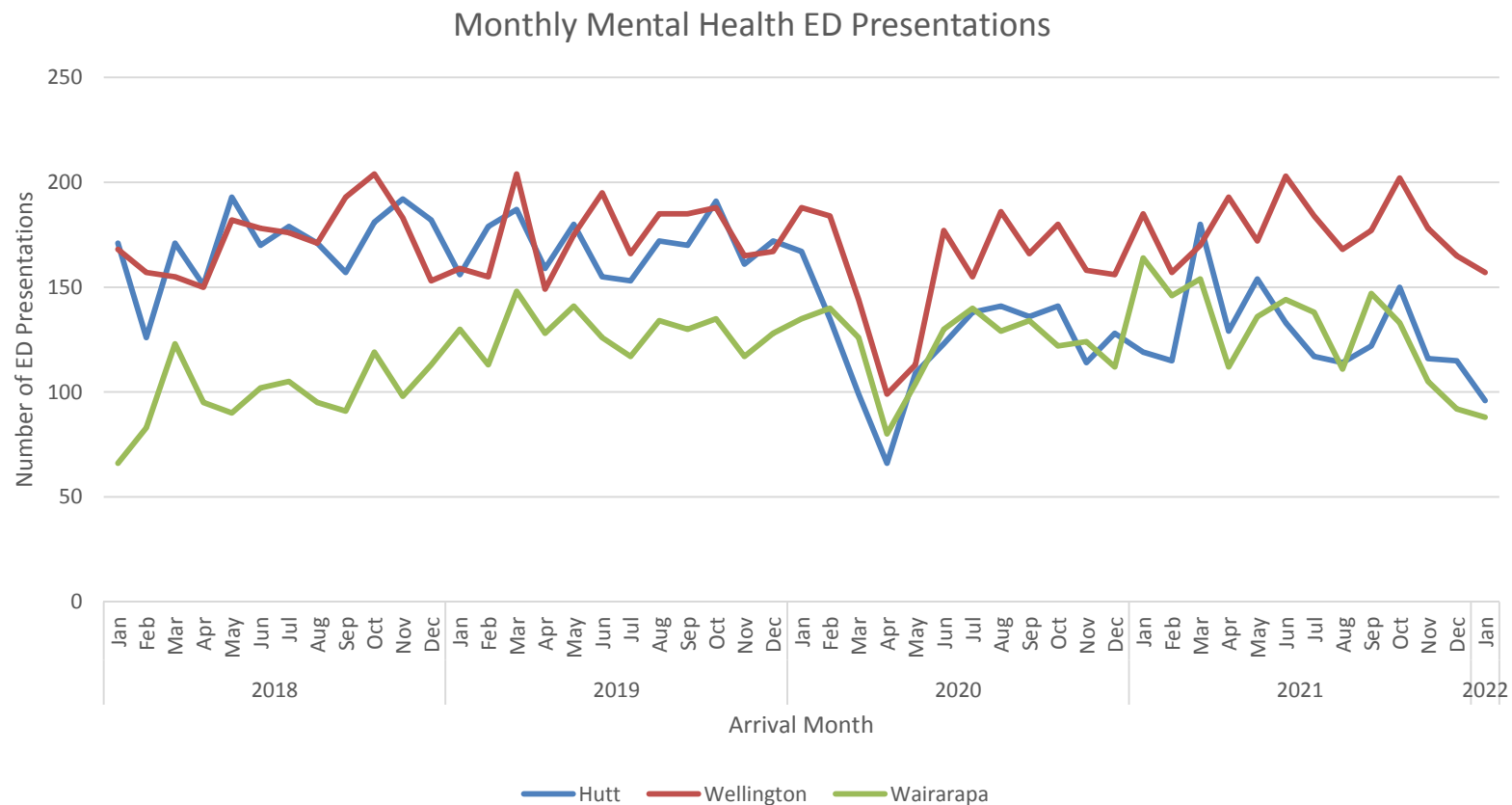
Presentations at ED

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

Monthly Mental Health ED Presentations (Hutt, Wellington and Wairarapa) by Age Group

Legend: 0-14, 15-24, 25-44, 45-64, 65+

Te-Upoko-me-Te-Karu-o-Te-Ika
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 mean since Jan 2020 is 56% seen within 3 weeks and 83% seen within 8 weeks.
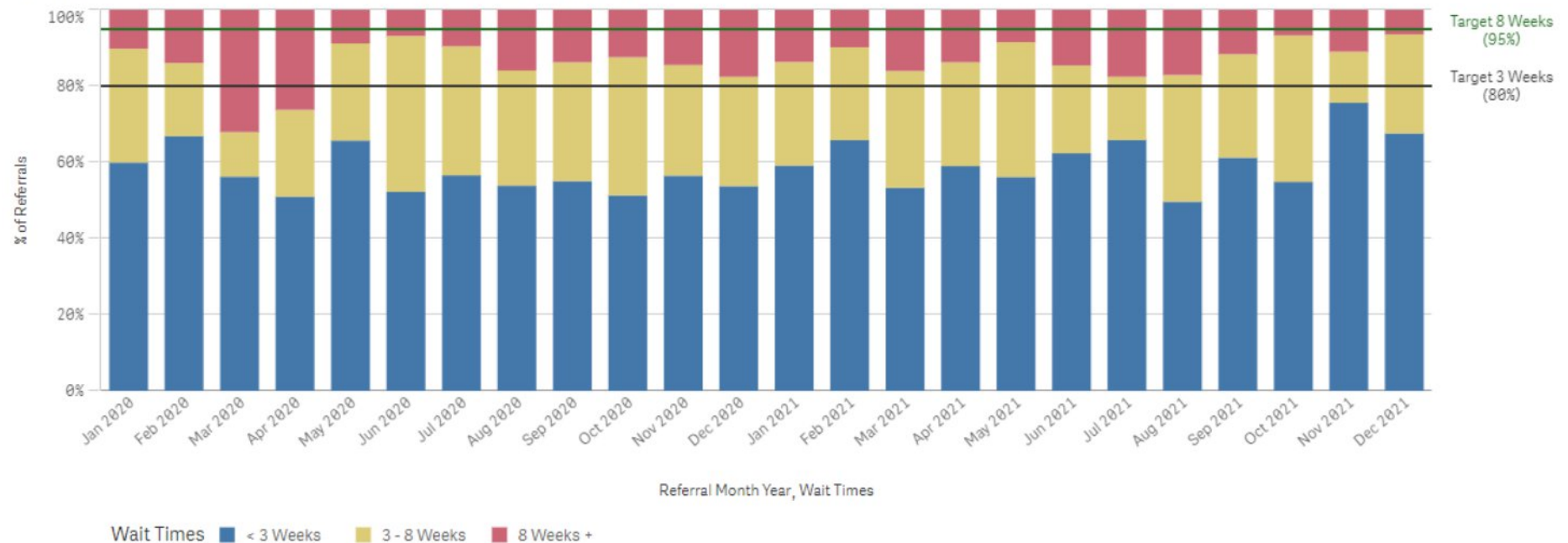

MHAIDS Referral Wait Time Percentage - First Face to Face Contact
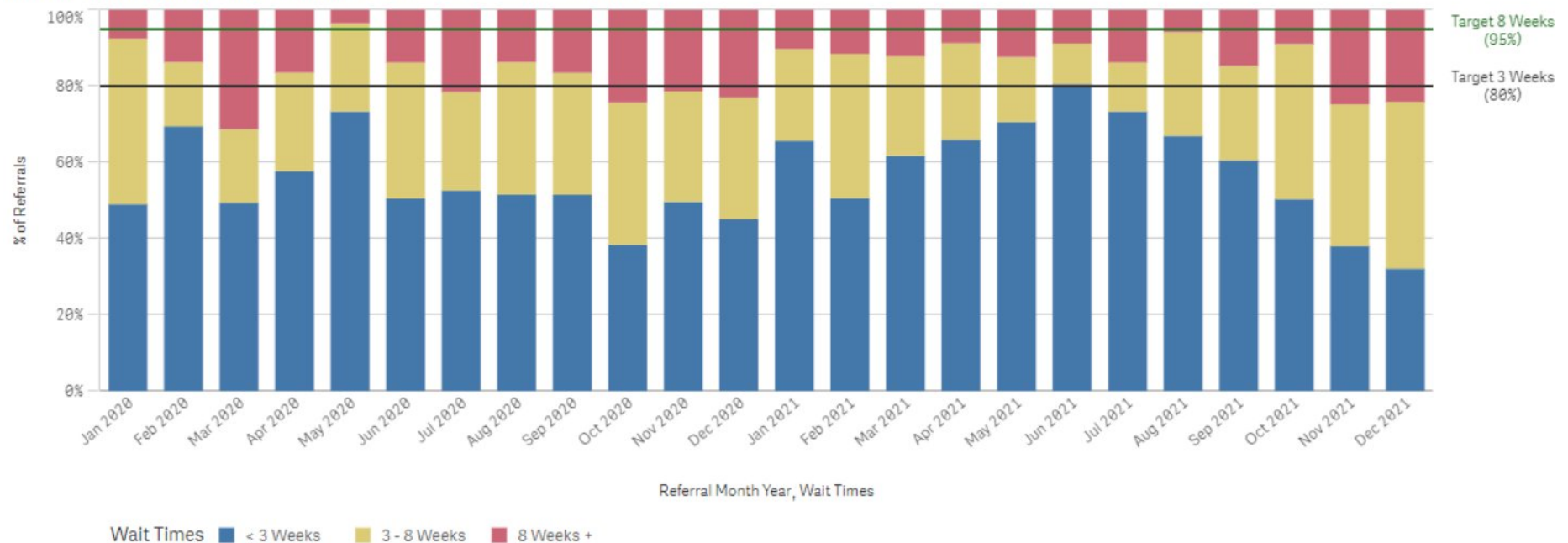
# Wait Times – Adult Community & Addictions Sector

The Adult Community & Addictions sector has slightly higher wait times results – the mean since Jan 2020 is 59% seen within 3 weeks and 87% seen within 8 weeks.

MHAIDS Referral Wait Time Percentage - First Face to Face Contact
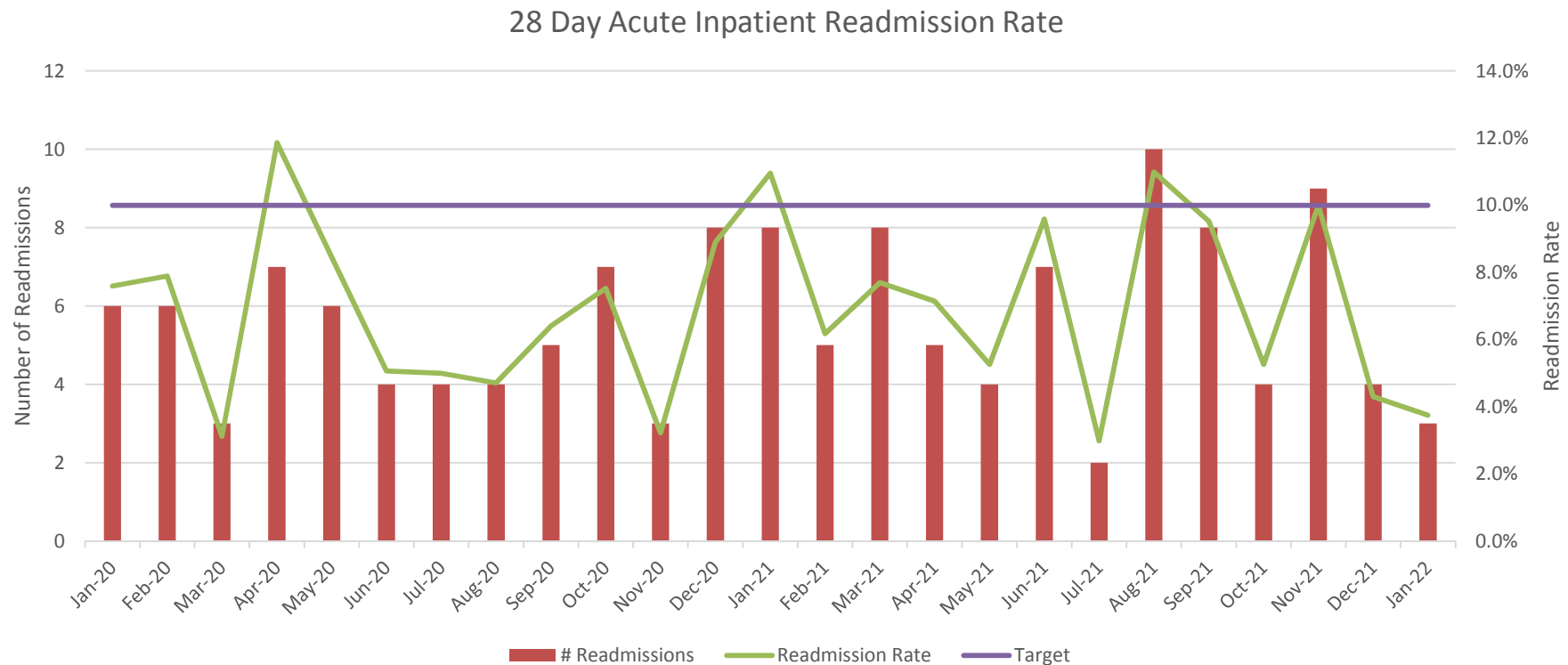
Target 8 Weeks (95%)
Target 3 Weeks (80%)

Referral Month Year, Wait Times

Wait Times ■ < 3 Weeks ■ 3 - 8 Weeks ■ 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.
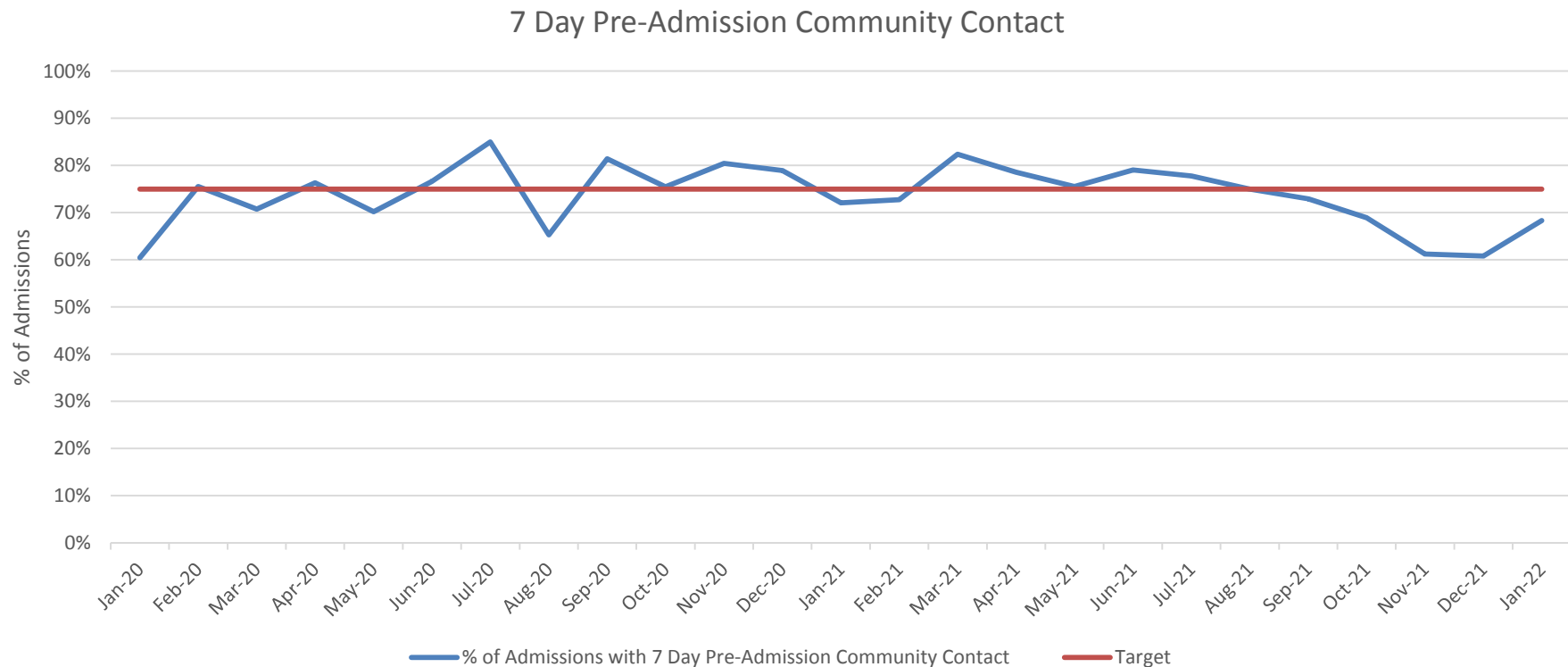

Te Whare Ahuru & Te Whare O Matairangi Monthly Occupancy
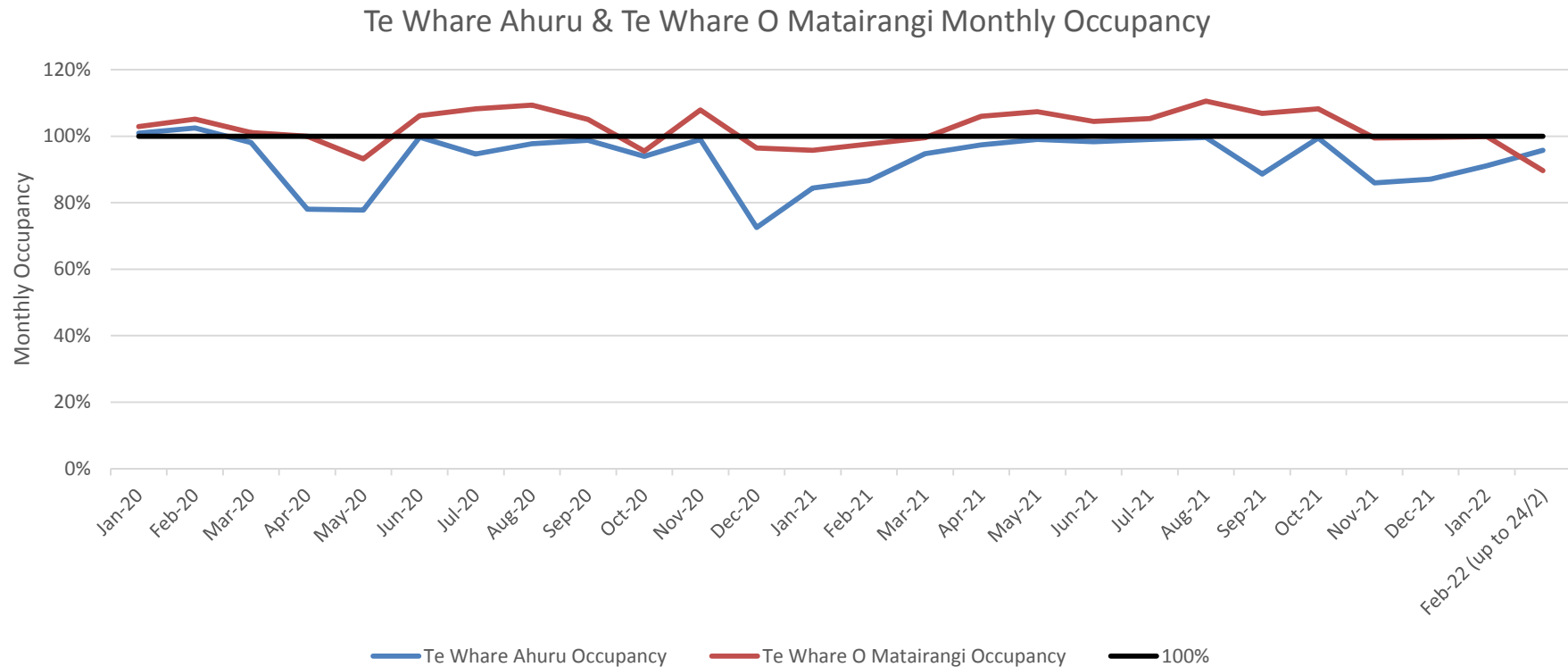
28 Day Acute Inpatient Readmission Rate

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

28 Day Acute Inpatient Readmission Rate

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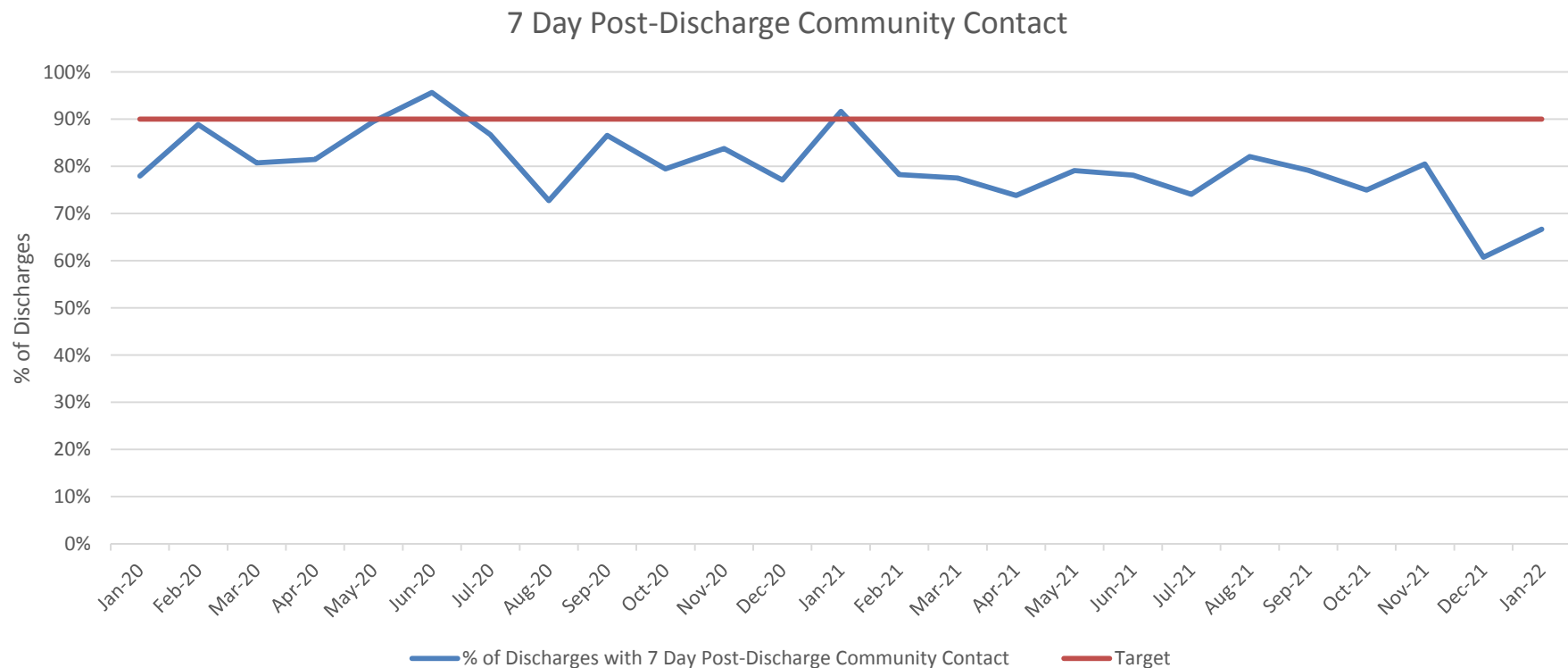**Mental Health, Addictions and Intellectual Disability Service**

7 Day Pre-Admission Community Contact

MHAIDS results for this measure have improved since January 2020 with most months reaching the 75% target. More recent months (since September 2021) have shown a slight decrease in the % of admissions with pre-admission contact.

7 Day Pre-Admission Community Contact

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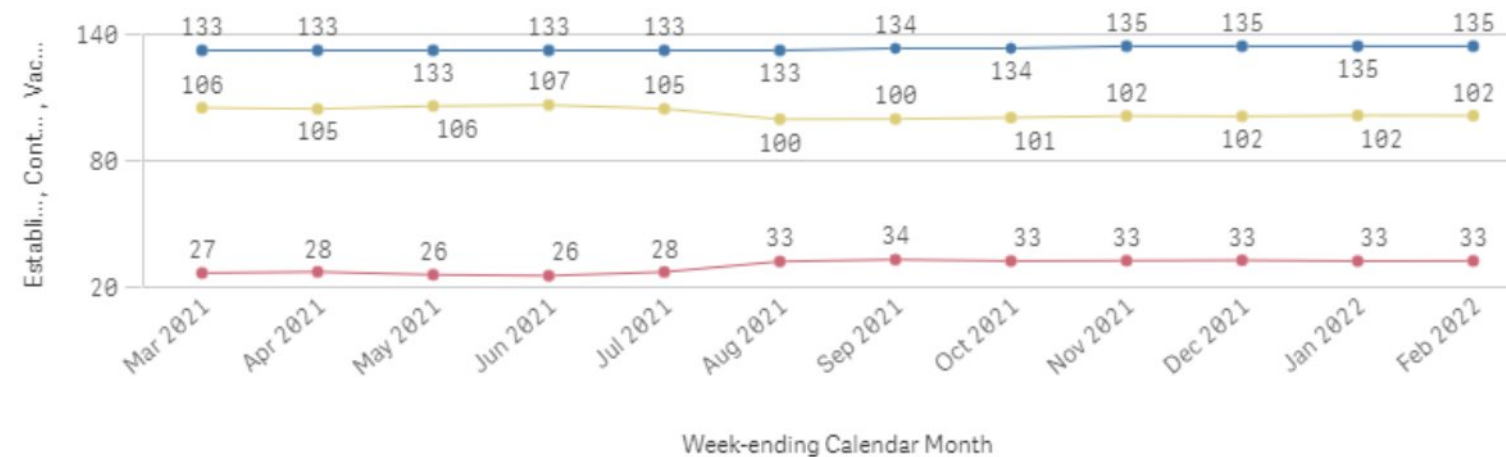**Mental Health, Addictions and Intellectual Disability Service**

7 Day Post-Discharge Community Contact

MHAIDS average for this measure since Jan 2020 is 79.9%
(MoH target is 90%)

7 Day Post-Discharge Community Contact

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

Mental Health FTEs Trend

Vacancy, Establishment and Contracted FTE - Medical Personnel

Establishment FTE: 133, 133, 133, 133, 133, 134, 134, 135, 135, 135, 135
Contracted FTE: 106, 105, 133, 107, 105, 100, 100, 101, 102, 102, 102, 102
Vacancy FTE: 27, 28, 26, 26, 28, 33, 34, 33, 33, 33, 33, 33

Week-ending Calendar Month

→ Establishment FTE   → Contracted FTE   → Vacancy FTE

Vacancy, Establishment and Contracted FTE - Nursing Personnel

Establishment FTE: 750, 750, 750, 750, 771, 786, 793, 875, 889, 893, 893, 893
Contracted FTE: 664, 652, 639, 635, 630, 635, 640, 641, 641, 641, 648, 678
Vacancy FTE: 86, 98, 111, 115, 141, 150, 153, 234, 248, 252, 246, 215

Week-ending Calendar Month

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

77

Mental Health FTEs Trend

Vacancy, Establishment and Contracted FTE - Allied Health Personnel
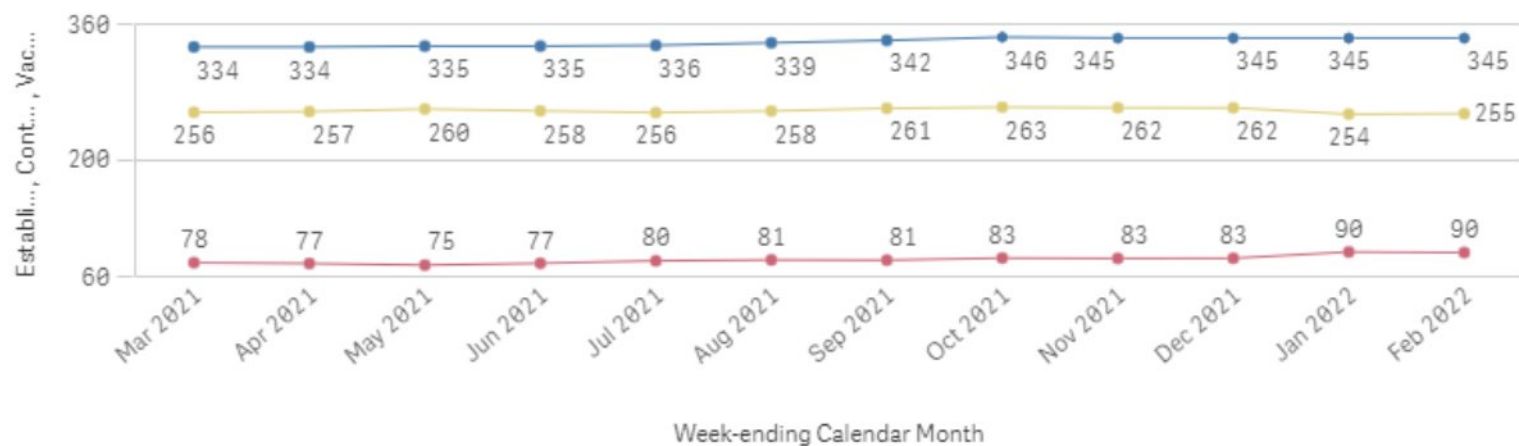
Vacancy, Establishment and Contracted FTE - Management & Admin Personnel
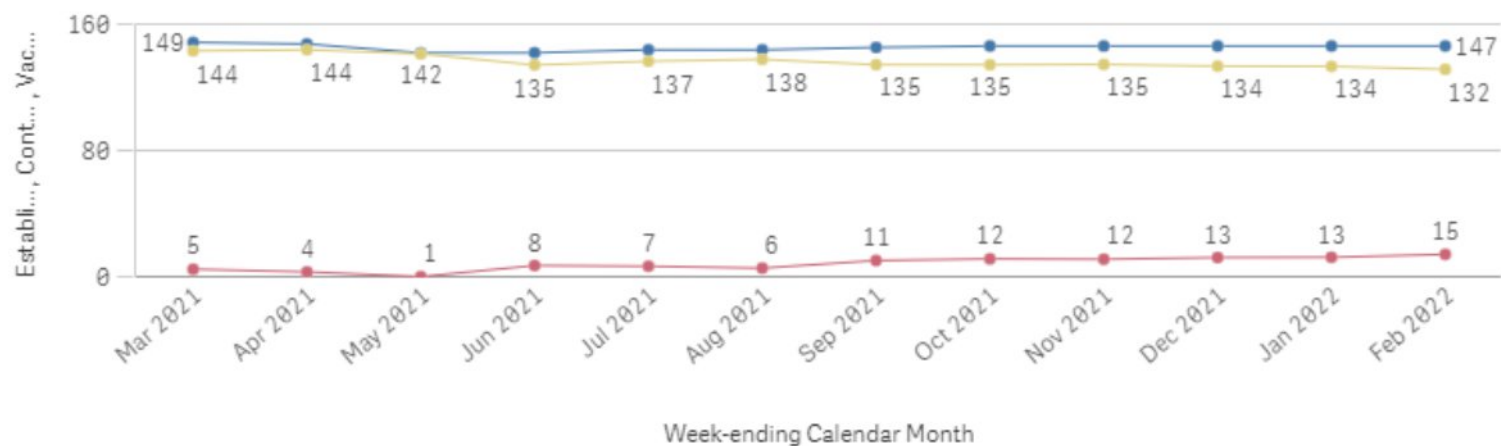
Disability Support Advisory Committee

16 March 2022

3DHB Mental Health and Wellbeing Strategies Update

Action Required

The Committee notes:

(a) Hutt Valley District Health Board (HVDHB), Capital & Coast District Health Board (CCDHB) and Wairarapa District Health Board (WrDHB) have continued the implementation of *Living Life Well: A strategy for mental health and addiction 2019-2025*, with a focus on the expansion of services to include early intervention and growth in investment in Kaupapa Māori and Pacific services.

(b) Implementation of Living Life Well has been supported by continued roll out of expanded primary mental health care across the region (the 'Access and Choice' programme), which will double in investment by June 2023.

(c) Strategy, Planning and Performance (SPP) continue to support growth of the Primary Care Liaison Service, with recruitment and appointment of two nurse practitioner roles and upgrading of the two liaison roles in Wellington to nurse practitioner level.

(d) Investment in the Acute Care Continuum initiative has progressed with further capacity in mobile and after hours NGO services in the Hutt and commissioning of the planned new Crisis Respite Service in Wellington.

(e) The 2DHB SPP Mental Health and Addictions commissioning team is working with Kaupapa Māori and Pacific providers to grow community AOD counselling service capability and integrate with adjacent services to provide more integrated care.

(f) The 3DHB Suicide Prevention and Postvention Action Plan continues to be implemented with recent approval and support for this plan by the National Suicide Prevention Office.

Strategic Alignment	This paper is aligned to our strategic plans, including our plans with a focus on equity (Māori, Pacific, and Disability) and mental health, addictions, and suicide prevention.
Authors	Chris Nolan, Interim GM Commissioning, Mental Health & Addictions, SPP Roxanne Leech, Project Manager Mental Health & Addictions, SPP
Endorsed by	Peter Guthrie, Acting Director, SPP Fionnagh Dougan, Chief Executive
Presented by	Chris Nolan, Acting GM Commissioning, Mental Health & Addictions, SPP
Purpose	This paper provides brief updates on the implementation of our DHBs' mental health and wellbeing strategies: *Living Life Well* and the *Suicide Prevention and Postvention Action Plan*.
Contributors	Tammy Kaiwai contracts and portfolio manager covering WrDHB The Mental Health and Addiction team, SPP Suicide Prevention Post Vention team and Governance Board The AOD collaborative represented by the AOD portfolio manager
Consultation	N/A

Executive Summary

Living Life Well and the *Suicide Prevention and Postvention Action Plan* together set the direction for the subregion's mental health and addiction services to improve outcomes and address inequities for people experiencing these significant challenges to their wellbeing.

The *Suicide Prevention and Postvention Action Plan* has been refreshed to align it to the Government's *He Tapu te Oranga o ia Tangata: Every Life Matters – Suicide Prevention Strategy 2019–2029* as well as the subregion's Māori Health and Pacific Health strategies and *Living Life Well*.

Both *Living Life Well* and the *Suicide Prevention and Postvention Action Plan* take a whole-of-population approach to implementing change. As such, they include initiatives that span the continuum of need, including: health promotion, prevention, primary care, and secondary specialist services.

The 2DHB SPP Mental Health and Addictions Team has continued to partner with the Mental Health and Addiction Intellectual Disability Service (MHAIDS) directors to support the Mental Health and Addiction transformation programme. Support has included identifying commissioning opportunities and funding that can be flexibly reallocated to transformation programme priorities.

We continue to implement the Mental Health and Addiction strategic priority and commission services that address equity and build provider capability and capacity.

Strategic Considerations

Service	Mental Health, Addictions, and Suicide Prevention & Postvention services
People	The resourcing schedule is part of the operating budget for 2021/22.
Financial	The resourcing schedule is part of the operating budget for 2021/2022.
Governance	The Mental Health and Addiction Commissioning Forum

Engagement/Consultation

Patient/Family	Lived Experience Advisory Group represent lived experience views to the complete transformation programme
Clinician/Staff	A wide range of clinicians contribute to models of care and service delivery.
Community	Engagement through the Partner, Provider & Stakeholder Collaborative Network, the Alcohol and Drug Collaborative and other Mental Health and Addiction networks and forums and workshops led by MHAIDS teams.

Access and Choice (SPP lead)

The Access & Choice programme aims to provide accessible support and access to treatment in primary care settings for people experiencing mental distress, mild-moderate mental illness, and/or issues associated with the use of alcohol and other drugs. This support is delivered by a mixture of Health Improvement Practitioners, Health Coaches, and Community Support Workers. Collectively, Access & Choice staff provide time-limited interventions such as brief intervention therapy, care planning, navigation of social services, and advocacy.

The rollout of the Access and Choice programme continues with a phased expansion. CCDHB received Ministry of Health funding to contract services with PHO and NGO providers in the demographic areas of CCDHB, HVDHB, and WrDHB. Access & Choice is now within 43 general practices throughout the Greater Wellington Region.

Primary Care Liaison Service (SPP lead)

The Primary Care Liaison Service aims to address a service gap for people with moderate to severe mental health issues who mostly present in primary care settings. The service aims to create an effective and productive relationship between secondary services and primary care to better meet the needs of the moderate to severe group, including enabling early intervention when service users experience deteriorating mental health.

We have supported the growth of the service with the recent establishment of a full-time consultant psychiatrist role in Wellington, two nurse practitioner roles in Hutt Valley DHB, and upgrading of the two liaison roles in Wellington to nurse practitioner level. We are also working with Te Awakairangi PHO to improve the primary care liaison service delivery model in the Hutt Valley, and we plan to work with Tu Ora Compass to improve the service across CCDHB.

Acute Care Continuum Services (SPP lead)

Acute Care Continuum services provide care to about 1200 people across the 3DHB area. The Acute Care Continuum model of care defines core services that require investment and development to create an improved and more coordinated acute care system response. Key components of the model of care are now "business as usual" activity.

Crisis Respite (SPP Lead)

Two Crisis Respite services have opened, one in Hutt Valley with a purchased facility (home) and a move from a previous not fit for purpose location and facility to a purpose designed facility in Wellington. The latter is a long standing project which has enabled a move to a sustainable NGO provided alternative to inpatient care developed by a competent and experienced provider. A new Acute Alternative Mobile service providing seven days per week mobile and after hours support services has also started in the Hutt Valley area, although some parts of this service are affected by the recent COVID outbreak.

Suicide Prevention and Postvention Action Plan (SPP lead)

The Suicide Prevention & Postvention Team (SPP) continues to deliver to the action plan, with robust governance structures and leadership in place. Over December and January, a successful recruitment process has resulted in a fully staffed team. There are four coordinators across the 2DHBs (including a coordinator Māori) and one coordinator in the Wairarapa. The team composition includes two people from the Pacific community.

The Suicide Prevention & Postvention Team's location within the SPP directorate has always been an interim arrangement. A change process has been initiated to shift the team's location to the 2DHB Regional Public Health (RPH) offices. The opportunity to relocate the SPP team to RPH will leverage RPH's strong community links, inclusive of local iwi and Māori organisations, and its distributed regional service delivery network better suited to this community-based programme. We expect the new reporting line to RPH to commence on 14 March 2022.

Integrated Community Mental Health and Addiction Services (MHAIDS lead)

Concept design working groups were held late last year to test the piloting of community mental health and addiction hubs, and initial workshops were held in January with lived experience, disability representation and a range of providers. This work will integrate, where required, with the Porirua locality prototype project, which is part of the Community & Commissioning workstream.

Kaupapa Māori Mental Health and Addiction Services (MHAIDS lead)

The Māori Expert Advisory Group has been established to provide advice and support to the design of Kaupapa Māori mental health services and the broader change programme.

Disability Support Advisory Committee

16 March 2022

Research Report: Understanding Disabled People's experiences of local healthcare services in the 3DHB region – Wellington, Hutt Valley and Wairarapa.

Action Required

The Committee notes:

(a) The attached research report was commissioned by the Strategy, Planning and Performance Directorate to understand the experiences disabled people have when accessing health care services at home, in the community, and in the hospital.

(b) This research report will be shared with Health New Zealand and will inform the design and development of services across localities, specialist services, and hospitals.

(c) The recommendations in the research report generally align with the strategic priorities and activities in the Strategic Plan for 2022 developed by Disability Leadership Group (see separate paper), although one of the recommendations about telehealth services is new and requires further consideration.

Strategic Alignment	3DHB Disability Strategy
Author	Rachel Noble, GM Disability
Endorsed by	Peter Guthrie, Interim Director Strategy, Planning and Performance
Presented by	Rachel Noble, GM Disability
Purpose	Research outlining the experiences disabled people have when accessing healthcare services across the region to inform service design.
Contributors	Imagine Better and Disability Responsiveness NZ
Consultation	Members of the Disability Community

Executive Summary

This report details findings from a project that aimed to understand more about the experiences of disabled people accessing local healthcare services within the 3DHB region. Finding out from disabled people what types of barriers prevent them from accessing local healthcare as well as what enables their access is key to addressing health disparities experienced by disabled people in the 3DHB region. Three key sites of healthcare provision (homes, community, and hospital) were examined across five geographical areas in the 3DHB region - Wellington, Porirua, Kapiti, Hutt Valley and Wairarapa.

Social and human rights approaches to disability underpinned the project and the Enabling Good Lives vision and principles provided a framework for analysis. Person-centred healthcare delivered through an Enabling Good Lives framework will help ensure that disabled people are enabled to exercise autonomy and self-determination in ways that lead to improved health outcomes. Healthcare that is delivered through an Enabling Good Lives framework is accessible, inclusive, and enabling.

Surveys and semi-structured interviews were the methods used to gather people's experiences. Thirty-seven people completed a survey and 14 people participated in an interview. A literature review focusing on the social determinants of health and barriers to accessing healthcare in home, community, and hospital sites was used alongside the surveys and interviews.

The research found that telehealth service were the most common form of healthcare accessed at home. The use of text messages to confirm doctor and other appointments was common, as well as having appointments over the telephone. Telehealth services made accessing healthcare services easier for many people because it eliminated the need to negotiate physical and environmental barriers including inaccessible buildings and transport. Telehealth can be mana enhancing as it necessitates shared input and decision-making between people and healthcare professionals. Telehealth can also result in healthcare services that are connected, easy-to-use and integrated with other systems, for example, public transport.

Interacting with healthcare professionals who have poor attitudes towards disability was the main reason people had a negative experience accessing healthcare at home. It was common for people to report that healthcare professionals did not listen to them about what they were experiencing or what they needed.

Recommendations

The report recommends:

1. Resource and run ongoing Enabling Good Lives (EGL) and disability rights training for all healthcare services working across primary and secondary care in the 3DHB region. EGL training should be delivered by suitably qualified disabled people and whānau of disabled people.

2. Promote social and human right model thinking to encourage local healthcare services to address the wider determinants of health. Thinking about health and wellbeing beyond narrow medical understandings will help address disabled people's poor health outcomes.

3. Support and invest in the establishment of local disability leadership groups across the 3DHB region to help create and oversee the development of local healthcare services. Local disability leadership groups would work closely with and inform the work of the Sub-Regional Disability Advisory Group.

4. Promote greater collaboration between primary and secondary care. This would include a particular focus on ensuring the responsibility for transferring care between services, such as specialist hospital care and care in the community, is clearly delineated as being the responsibility of the healthcare provider, and not the person.

5. Commission an audit of all telehealth services and invest in supporting primary and secondary healthcare services within the 3DHB region to provide accessible telehealth communication.

These recommendations generally align with the strategic priorities and activities in the Strategic Plan for 2022 developed by Disability Leadership Group (see separate paper). However, the final recommendation about telehealth services is new and requires further consideration.

This research report and recommendations will be shared with Health New Zealand and will inform the design and development of services across localities, specialist services, and hospitals.

Attachment/s

1. Research Report: 'Understanding Disabled People's Experiences of Local Healthcare (February 2022)

Understanding disabled people's experiences of local healthcare services in the 3DHB region – Wellington, Hutt Valley and Wairarapa

Research Report | February 2022

Prepared by:

Dr Carey-Ann Morrison

Imagine Better LTD

Imagine Better

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

Special thanks to the people who generously shared their experiences with us.

Thanks to Disability Responsiveness New Zealand LTD for contributing their research and community expertise to help understand disabled people's experiences of accessing local healthcare facilities within the 3DHB region.

Imagine Better provides resources that help disabled people, their families and whānau 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

ACC   Accident Compensation Corporation

DPO   Disabled People's Organisation

EGL   Enabling Good Lives

GP   General Practitioner

UNCRPD   United Nations Convention on the Rights of Persons with Disabilities

Executive Summary

This report details findings from a project that aimed to understand more about the experiences of disabled people accessing local healthcare services within the 3DHB region. Finding out from disabled people what types of barriers prevent them from accessing local healthcare as well as what enables their access is key to addressing health disparities experienced by disabled people in the 3DHB region. Three key sites of healthcare provision – homes, community, and hospital – were examined across five geographical areas in the 3DHB region - Wellington, Porirua, Kapiti, Hutt Valley and Wairarapa.

Social and human rights approaches to disability underpinned the project and the Enabling Good Lives vision and principles provided a framework for analysis. Person-centred healthcare delivered through an Enabling Good Lives framework will help ensure that disabled people are enabled to exercise autonomy and self-determination in ways that lead to improved health outcomes. Healthcare that is delivered through an Enabling Good Lives framework is accessible, inclusive, and enabling.

Surveys and semi-structured interviews were the methods used to gather people's experiences. Thirty-seven people completed a survey and 14 people participated in an interview. A literature review focusing on the social determinants of health and barriers to accessing healthcare in home, community, and hospital sites was used alongside the surveys and interviews.

Healthcare Services at home

Telehealth service were the most common form of healthcare accessed at home. The use of text messages to confirm doctor and other appointments was common, as well as having appointments over the telephone. Telehealth services made accessing healthcare services easier for many people because it eliminated the need to negotiate physical and environmental barriers including inaccessible buildings and transport. Telehealth can be mana enhancing as it necessitates shared input and decision-making between people and healthcare professionals. Telehealth can also result in healthcare services that are connected, easy-to-use and integrated with other systems, for example, public transport.

Interacting with healthcare professionals who have poor attitudes towards disability was the main reason people had a negative experience accessing healthcare at home. It was common for people to report that healthcare professionals did not listen to them about what they were experiencing or what they needed. Chronicity, significance, or seriousness

of symptoms were often downplayed or ignored by healthcare professionals. A shift away from face-to-face healthcare consultations and a move towards telehealth was also perceived negatively by some people, particularly in the context of inaccessible technology and telehealth platforms.

Healthcare services in the community

General practitioner, pharmacy, and dentist services were the most used healthcare services in community settings. Healthcare professionals who have positive attitudes towards impairment and disability and focus on building relationships with people were described as providing person-centred care. An important part of person-centred care was being able to see the same GP for each visit and having access needs met. Person-centred healthcare delivered in the context of a mutually trusting and respected relationship means disabled people can practice self-determination, choice, and control. The location of healthcare services, particularly pharmacies that were in or nearby doctors' clinics, was also important. Many participants valued having healthcare services located close to their homes in their local neighbourhood.

The main barriers to receiving good care in the community were in relation to lack of care-continuity, attitudes and knowledge of healthcare professionals, inaccessible environments, and cost. People spoke about delaying seeking healthcare because they couldn't see their regular doctor or they were worried about seeing a healthcare professional who held negative and/or discriminatory attitudes and lacked knowledge on disability. Inaccessible environments and equipment and the cost of healthcare was a significant barrier for many people.

Specialist healthcare services in the hospital

Participants were often accessing numerous specialist healthcare services simultaneously. Underpinning conversations about positive experiences of specialist healthcare in hospital settings was the importance of good communication, including the use of accessible information formats, and the establishment of relationships built on shared decision-making. Person-centred and flexible care that recognises people have a range of access requirements leads to good experiences in hospital settings.

Barriers to accessing specialist healthcare related to appointment times and communication of appointments, travel, and transport. Delays in receiving notice of appointment times and scheduling appointments at unsuitable times of the day resulted in missed appointments or lengthy delays as people had to wait until the next available and/or suitable appointment. A lack of information about where to go for hospital appointments and complex hospital maps was also described as a barrier to accessing specialist healthcare. Discriminatory attitudes by health practitioners impacted people's experiences of, and access to, specialist healthcare services. It was common for people to have general health issues wrongly attributed to their

impairment. The interface between specialist care at hospital and primary care in the community was described as inadequate and resulted in poorly coordinated and delivered home services following specialist healthcare.

We recommend the 3DHB do the following:

- Resource and run ongoing Enabling Good Lives and disability rights training for all healthcare services working across primary and secondary care settings in the 3DHB region.
- Promote social and human right model thinking to encourage local healthcare services to address the wider determinants of health.
- Support and invest in the establishment of local disability leadership groups across the 3DHB region to help create and oversee the development of local healthcare services.
- Promote greater collaboration between primary and secondary care in the 3DHB region.
- Commission an audit of all telehealth services and invest in supporting primary and secondary healthcare services within the 3DHB region to provide accessible telehealth communications

Introduction

The coalition of Capital and Coast, Hutt Valley, and Wairarapa District Health Boards (3DHB) plans to provide more healthcare to people locally at home and in the community. Meeting people's needs for healthcare 'closer to home' can help improve access, quality, and continuity of care and can lead to a reduction in avoidable hospital admissions. Delivering more healthcare locally will create opportunities for the 3DHB, local providers, and the community to work together to design and deliver healthcare services that are accessible, coordinated and delivered in the context of whānau and community.

The 3DHB has a commitment to ensure that disabled people have healthcare options that are accessible and available across the region as and when required. It is crucial that any attempts to improve the coordination and provision of healthcare services within 3DHB region includes the experiences of disabled people. Research consistently shows that disabled people have poorer health outcomes than non-disabled people and do not receive appropriate care. Barriers to access, including limited availability of services and transport options, inaccessible environments and communication, discriminatory attitudes, and inadequate skills and knowledge of healthcare workers, prevent disabled people from accessing healthcare across the spectrum of health services – promotion, prevention, and treatment. Disabled people are also disproportionally impacted by the social determinants of health. Compared to non-disabled people, disabled people have poorer health and wellbeing outcomes across housing, education, employment, and social connection and experience higher levels of poverty. Meeting disabled people's healthcare needs at home and in the community therefore also means addressing the structural barriers that prevent disabled people accessing the determinants of good health and wellbeing.

The focus of this research is to understand more about the experiences of disabled people accessing local healthcare services within the 3DHB region and to identify opportunities to build upon the accessibility of services that already exist. Finding out from disabled people what types of barriers prevent them from accessing local healthcare as well as what enables their access will help address health disparities experienced by disabled people in the 3DHB region. Disabled people hold specific expertise on their individual lives and community needs. It is within this knowledge that solutions for improving the accessibility of local healthcare services lie. In this report, disabled people's perspectives provide a person-led direction for change, highlighting areas for development and improvement, and helping to ensure that 3DHB healthcare services meet the needs of disabled people and the disability community.

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Bearing in mind that where you live is still a key determinant of good health and wellbeing, this research focuses on the following geographical areas: Wellington; Porirua; Kapiti; Hutt Valley and the Wairarapa. These areas have unique socio-demographic profiles and community wellbeing needs. Three sites of healthcare provision – home, community, hospital – across each area is examined. Addressing access to healthcare services across these three sites provides an opportunity to look at site specific experiences, while also providing the ability to see the connections between the three sites.

The people who shared their experiences as part of this research told us that they want more choice and control over when and where they access local healthcare services in their homes, community, and in hospital. The want to be recognised as experts in their own care and to 'tell their story once'. They stressed that healthcare services should be fully accessible, easy-to-use, and reflective of the health and wellbeing outcomes disabled people want for themselves; not those ascribed to them by others. Health and wellbeing must be understood broadly and take into consideration such things as housing, social connection, and employment. They told us that healthcare services must support their right to self-determination, choice, and control as people and not as impairments. Disabled people living in the 3DHB region want those involved in the provision of their healthcare across home, community, and hospital sites to be networked together so that services are person-centred, holistic, and seamless.

Approach

This project promotes a human rights-based approach and draws upon the social model of disability, which shows that people are disabled by society rather than impairment. 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…". Social and human rights approaches to disability show that the problems disabled people face using healthcare 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 reflective of wider social, political, environmental, and economic conditions that drive poor health and wellbeing outcomes for disabled people in Aotearoa New Zealand.

The Enabling Good Lives (EGL) vision and principles also underpin this research. The EGL vision is that all disabled people, their families and whānau have greater choice and control over their supports and lives. There are eight EGL principles:

Self-determination	Disabled people are in control of their lives.
Beginning early	Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
Person-centred	Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
Ordinary life outcomes	Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
Mainstream first	Disabled people are supported to access mainstream services before specialist disability services.
Mana enhancing	The abilities and contributions of disabled people and their families are recognised and respected.
Easy to use	Disabled people have supports that are simple to use and flexible.
Relationship building	Supports build and strengthen relationships between disabled people, their whānau and community.

While EGL has primarily been used in the context of funded disability support services, it is increasingly expected that EGL will inform the design and delivery of social sector supports and services. In the context of an impending national roll-out of EGL and the establishment of a new Ministry for Disabled People, it is vitally important social sector supports and services understand EGL and how to implement it. EGL provides a pro-equity framework for

addressing the healthcare needs and outcomes of disabled people and is endorsed by Disability 3DHB. Person-centred healthcare that is in line with the social and human rights models of disability, and the EGL vision and principles is key to improving outcomes for disabled people in the 3DHB region. This framework will help ensure that disabled people are enabled to exercise autonomy and self-determination in ways that lead to improved health outcomes. Healthcare that is delivered through an EGL framework is accessible, inclusive, and enabling.

Report limitations

Resources and timeframe limited the scope of the project. The research aimed to gather individual perspectives from disabled people living in the 3DHB region about their experiences of accessing local healthcare services. The relatively small sample size means we cannot, nor do we wish to, generalise the experiences of these people.

The report is limited in terms of participants' ethnic background. Most participants identified as European. Disabled Māori experience poorer health outcomes than disabled non-Māori because of the impacts of colonialism and racism.[1] Future research should look to work with Māori health and disability providers and organisations to address the particular issues faced by disabled Māori / whānau hauā when accessing local healthcare services.

The nature of the project meant it was not feasible to include the perspectives of healthcare professionals in the report. The research spans the 3DHB region, covers healthcare that is delivered across multiple home, community, and hospital sites, and incorporates the full spectrum of healthcare services. This broad focus meant we could not meaningfully capture or represent the huge diversity of perspectives of healthcare professionals involved in the delivery of healthcare to disabled people. However, we strongly emphasise the need for the perspectives of healthcare professionals to be gathered and woven together with the experiences of disabled people. It is important to understand from the perspective of healthcare professionals what increases as well as what inhibits their ability to deliver accessible healthcare services. Shared knowledge creation between communities and providers is essential for helping to ensure that local healthcare services meet the needs of disabled people within the 3DHB region.

While focusing on the experiences of people from across the 3DHB region, this report does not offer any comparison of experiences across the geographical sites – Wellington; Porirua; Kapiti; Hutt Valley, and the Wairarapa. It is important to note that each geographical location will present with issues and challenges specific to that area. Future research could

usefully unpack some of the similarities and differences between and across geographical sites.

Report outline

This report proceeds with an explanation of the methodology used, including providing information about the participants involved in this study. The next three sections focus on the healthcare experiences of disabled people at home, in the community, and when receiving specialist care at hospitals. Within each section, a summary of previous research is provided. Participants' lived experiences are used to highlight healthcare services that work well and that don't work well across home, community, and hospital sites. Following this, we make some recommendations for improvement.

Methodology

Recruitment

Participants were recruited through a variety of methods, including email lists, websites, social media accounts of disability-related organisations, and personal contacts. We sent out a call for participation that included information about the survey and interviews. We asked to speak to people who have physical, sensory, learning impairments and/or mental illness and who live in Wellington; Porirua; Kapiti; Hutt Valley, or the Wairarapa.

Whilst requesting that people speak to their experiences of receiving healthcare across three sites - home, community, specialist care at the hospital - we made it clear that participation was not dependant on being able to talk to their experiences in all three sites; they could choose to talk about as many or as few sites as they wanted. We also advised that people could complete an online survey, participate in an interview, or do both.

Survey

The survey was prepared in consultation with Disability 3DHB and Design and Implementation 2DHB. Questions related to the three sites of healthcare – home, community, and hospital – and focused on types of healthcare, barriers to access, and interactions with healthcare professionals. People were asked to respond to close-ended survey questions and were given space to provide additional detail if they wanted. We created the survey to gain a broad understanding of disabled people's experiences of accessing local healthcare services within the 3DHB area. We hoped it would help us access a wider portion of the disability community but did not seek to reach a representative sample size. In total, we had 37 responses to the survey.

An online version was distributed through Survey Monkey. A paper version was also available for people if they preferred, as well as an easy-read version. The researchers were also available to talk to people in person about the survey and provide support if required. Sessions were organised with Disabled Person's Organisations (DPOs) and local disability support providers who work with people with learning disabilities to share information about the project and provide paper copies of the easy-read survey.

Survey participants' demographics

Region

Wellington	Porirua	Hutt Valley	Wairarapa	Kapiti Coast
3	2	2	3	2

Age

Under 18	18-24	25-34	35-44	45-54	55-64	65+
3	4	3	4	5	6	6

Ethnicity

Pākehā	Māori	Pasifika	Asian	Other
27	2	1	0	3

Disability

Blind or Low Vision	Deaf or Hard of Hearing	Physical	Mental Health	Intellectual or Learning	Other
3	4	17	3	5	13

Housing

Private Rental	Social Housing	Homeowner	Other
11	1	13	5

Gender

Woman	Man	Transgender	Gender Diverse	Other
21	7	0	2	1

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Semi-structured interviews

We aimed to carry out three interviews in each location. In the end, we carried out 14 semi-structured interviews across the 3DHB region:

Region

Wellington	Porirua	Hutt Valley	Wairarapa	Kapiti Coast
4	1	4	2	3

Interviews happened in person as well as over zoom. The interview questions were similar to the questions asked in the survey but aimed to delve deeper into people's experiences and build upon data gathered in the surveys. Our qualitative approach to research combined with the relatively small sample size means we do not attempt to generalise experiences. People were given a koha to acknowledge their time and contribution.

Pam MacNeill, managing director of Disability Responsiveness New Zealand, conducted most of the interviews with disabled people. Pam is blind and has almost 30 years' experience working in a range of roles in the disability sector, including doing research and training. Dr Carey-Ann Morrison, Senior Researcher for Imagine Better, conducted two interviews and managed the survey. Carey-Ann is an experienced qualitative researcher and is a mum to a young disabled son.

All stages of the research 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 made to feel safe and confident to share their experiences. All work was conducted transparently, with full explanation and disclosure of what is being collected, why it was being collected and what would happen with the information they shared. If people agreed, conversations were recorded and notes taken. Plain English was used in all documents to ensure the research was accessible and participants had a clear understanding of the research.

Interview participants' demographics

Fourteen disabled people participated in interviews. Three mothers discussed their experiences of accessing healthcare with and for their disabled children. Participants came from a range of backgrounds:

- Impairments: learning disabilities, osteo and rheumatoid arthritis, polymyalgia, sensory and cognitive impairments resulting from brain aneurysms, brittle bone disease; cerebral palsy, traumatic brain injury, fibromyalgia, blind, neurological impairments, multiple sclerosis, multiple chemical sensitivity.
- Ages: ranged from 34 – 66. The mothers who spoke on behalf of their disabled children were discussing a 15-year-old, and young adults in their early twenties.
- Gender: five men and nine women; of the nine women, three spoke on behalf of disabled sons.
- Ethnicity: All participants except one identified as being of European descent. One person described herself as being British-Indo-Caribbean.
- Living situation: Eight people interviewed were homeowners, and all three mothers owned their own homes. One person lives in rental accommodation, one in social housing and one described himself as homeless. Two of the young people whose mothers discussed their experiences live at home and one lives in shared independent living accommodation, managed by a residential support service provider
- Digital access: All participants used the phone at a minimum, and many also used a computer and internet.
- Employment status: Five people were employed in full-time work. Two had part-time employment. Four were unemployed. One man identified as being semi-retired and two women who were also spokespeople for their sons, self-identified as 'full-time disability sector volunteers'.

Healthcare at home

What previous research tells us

Homes are increasingly becoming important sites of healthcare. Advances in technology are changing the ways in which healthcare is delivered and received. People can access more of their care at home through healthcare technologies, for example health information that is available online, and forms of telehealth.[2] Healthcare technologies that can be accessed at home can improve health equity, efficiency of health care delivery, and population health.[3]

Increasing numbers of people seek and obtain health-related information from the internet.[4] The ability to easily obtain accurate health information online provides people with the opportunity to make informed decisions and actively participate in managing their own healthcare outside of traditional healthcare settings. Disabled people, however, often encounter barriers to accessing healthcare information online, such as websites use of overly medicalised and complicated language, poorly designed user interfaces, and lack of compatibility with assistive technology.[5] A lack of access to health communication and information platforms, particularly during times of public health crises such as the covid-19 pandemic, disadvantages disabled people and contributes to health inequities.[6] Furthermore, broader population-based health promotion strategies rarely include disabled people in their campaigns, and seldom focus on specific targeted interventions to meet any additional needs.[7]

Research has shown that telehealth has the potential to improve disabled people's health outcomes by eliminating physical barriers and transportation costs and delivering healthcare directly to them in their homes when they need it.[8] However, without adequate attention to the design, implementation, and policy context of telehealth there is a risk that it will exacerbate health inequities for some disabled people. For example, disabled people are disproportionally affected by the digital divide and have less access to computers and internet services, and have limited digital literacy and ownership.[9] Lack of access to reliable internet and technology can result in cancelled appointments, disconnection during online consultations, and misinterpretation of information — all of which can contribute to health inequities.[10] Moreover, many forms of telehealth technology are designed in ways that makes them inaccessible to disabled people. For example, video-based telehealth services and patient portals where people can view their health records online remain inaccessible to people who have vision and hearing impairments.[11] Telehealth is largely driven by a neo-liberal agenda with the aim of creating efficiencies and cost-savings for public health, and

'empowering' people to take responsibility for their own healthcare.[12] One of the risk of this shift for disabled people is that if telehealth care fails, it becomes individualised as their fault rather than a failing of the healthcare system.

Home can also be sites of healthcare during emergencies when people interact with healthcare professionals, such as emergency call-centre operators and paramedics. Deaf and hard-of-hearing people, and people with learning disabilities, who need to call for emergency care can experience communication barriers. These access barriers can lead to an inaccurate level of aid and delayed time to dispatch, decreased patient comfort and familiarity with emergency services, and decisions to avoid emergency services altogether.[13]

What people told us works well at home

Most people who participated in an interview said they did not have healthcare professionals visit them in their homes. Survey respondents indicated that most of them received home visits of some sort, with ambulance services (50 percent), physiotherapists (38 percent), occupational therapists (38 percent), and district health nurses (35 percent) the most common. Eighty three percent of survey respondents said that healthcare services at home were in response to their general healthcare needs.

Telehealth technology worked well for many people and was the most common form of healthcare used at home. People used telehealth services to access the full spectrum of healthcare services across community and specialist care sites. Most people had access to technology that enabled the use of telehealth services. Survey results showed that 97 percent of people had access to the internet, 90 percent of people had access to a phone, and 83 percent of people had access to a computer. The use of text messages to confirm GP and other appointments was common. Survey results showed that 66 percent of people had appointment reminders and/or results text to them. Accessing GPs over the telephone was also common, with 66 percent of people in the survey indicating that they used this option to speak to their GP. Fifty-nine percent of people in the survey reported using the computer portal: ManageMyHealth.

Telehealth services were valued for making healthcare services easy to use. For many people, the ability to access their healthcare services from their home using their phone or the internet meant they did not need to contend with typical access barriers, such as inaccessible healthcare facilities and inflexible appointment times. The way in which telehealth could circumvent transport barriers was particularly valued, with 73 percent of survey respondents indicating that it was easier to use telehealth for an appointment because they didn't need to travel. One blind woman spoke of the convenience of telehealth, particularly during consultations that don't require a physical examination.

> "It means I don't have to travel, pay for transport, or find someone to be my sighted guide. So it is convenient to have that option."

For one survey respondent, home provided a safe and secure space for difficult healthcare appointments:

> "It meant I was able to be in a safe place as soon as the appointment ended, instead of having to travel afterwards often in a less than ideal mental state."

Another survey respondent highlighted how telehealth services can be experienced as mana enhancing because the appointment is grounded in a trusting relationship between them and their child's paediatrician. Typically, parents of disabled children report power imbalances between them and healthcare professionals. Telehealth can create space for people to exercise self-determination and participate in decision making processes.

> "Phone appointments show that our paediatrician trusts in my knowledge of my child and my assessment of how he is doing. I feel confident that if I was worried, we would be able to have a face-to-face appointment."

Accessible telehealth services can also facilitate the delivery of healthcare that is connected, easy to use and integrated with other ordinary aspects of life. A woman with a neurological condition affecting mobility spoke about the way in which she used her phone to view her health records, which were also accessed by her GP and neurologist, and coordinate her appointments and travel arrangements.

> "I find using the phone app really useful so I can line up appointments with bus services if needing to attend appointments in person or combine visits with other things I need to do."

While survey results showed that 72 percent of people said they looked online for health information and 41 percent of people used social media like Facebook to access health information it was not discussed in any great depth by participants.

What people told us doesn't work well at home

By far the biggest issue for people accessing healthcare at home was in relation to the attitudes of healthcare professionals. During the interviews, several people spoke about the issue of not being listened to by healthcare professionals. Similarly, survey results showed

that 43 percent of respondents said that during home visits their knowledge about their own health and healthcare needs were disregarded.

> "Physio wanted me to do hydrotherapy despite having a tracheotomy. Telling me that having one lung shouldn't unbalance me."

Thirty three percent of people said their preferences and choices about healthcare received at home were ignored. One participant spoke of having no choice once a mobility aid became necessary. She was excluded from the decision-making process; rather than working together to decide on what might suit her needs best, a healthcare professional gave her a piece of equipment and then did not provide any training on how to use it.

Outdated medicalised and ableist attitudes underpin many of these encounters at home as healthcare professionals discount and disregard disabled peoples' lived and embodied knowledge about their own lives and needs. When healthcare professionals fail to listen to disabled people it undermines their ability to self-determine and diminishes their mana. Listening and responding to disabled people's concerns early on when they first raise them is an important measure that can prevent avoidable hospital admissions.

One woman with a worsening health condition that meant her mobility was affected spoke about having to do a huge amount of self-advocacy to gain access to occupational therapy and physiotherapy at home to assist with rehabilitation and recovery after falling over.

> "In the end, I had to resort to asking my specialist nurse to advocate for me with the neurologist, so I could continue to get a referral for homebased services."

People with learning disabilities and neurodiverse people, and mothers of people with learning disabilities or neurodiverse people often have their experience and/or knowledge disregarded by health professionals. Several participants talked about healthcare professionals ignoring the chronicity, significance, or seriousness of symptoms, when in fact they should be addressing issues early to prevent conditions worsening.

> "If they say they are not coping, get beyond the autism diagnosis and recognise the very large red flag being waved. People with autism are more likely to attempt suicide than others."

> "I had to call the ambulance at 3am. I had stomach pains and chest pains. I called the ambulance and they said they would call me back and they didn't, so I called again. They said the same thing, but no one rang me back. The pain got worse, so I called again and they sent an ambulance. It was really scary waiting. No one told me why they

didn't phone me back. I don't think I was treated very well by the person on the phone."

Many people interviewed observed they were seeing a shift away from face-to-face healthcare consultations and a move towards telehealth. They reasoned this shift was likely influenced by the public health response to covid-19. Many participants pointed out there are limits to telehealth and that in some instances face-to-face consultations are needed, for example, a physical examination. For some people face-to-face consultations are preferred because they reduce the likelihood of health information being misinterpreted or misunderstood. People who prefer face-to-face consultations sometimes felt as though they were actively prevented from attending in-person appointments. Fifty percent of survey respondents said they preferred face-to-face meetings.

"At the GP surgery it is very much focused on no face-to-face appointments. They have put a lot of additional barriers in the way. They make you feel really unwelcome because it is very plain that they don't want you to come in unless you are dying."

"Internet sometimes fails on either my end or the practitioners end which means some things get lost in translation."

"Usually only preliminary discussions can be done. Rarely can mental health be done this way. Can be difficult accessing services for other disabled family members."

"I have a good experience with my GP and text-based communication via ManageMyHealth. However, I do think sometimes services like this are offered as an excuse not to make basic onsite accommodations."

"If you have a telephone call with a GP, they sometimes ask you to come to the surgery as well, which means paying for 2 appointments."

For some people, inaccessible technology was a major barrier that prevented them using it. Inconsistency of availability of accessible telehealth services across healthcare providers was also common.

"It's hard discussing medical things over the phone, since I am quite deaf."

"I don't use ManageMyHealth because it is simply not accessible to those of us who use computer screen readers. I have sent countless e-mails about this and been told the issues will be fixed, but they haven't been so far."

"For some reason ManageMyHealth is always in an extremely small font, and I have to magnify the text."

"Many medical professionals are insistent on phone which isn't accessible to me. My GP is great about text-based communication via ManageMyHealth, but for other services I run into problems."

Healthcare in the community

What previous research tells us

Primary healthcare in the community is often the first point of contact for most health services. Yet research shows that disabled people face numerous access barriers in community healthcare settings. Inadequate access to primary healthcare undermines disabled people's right to preventive healthcare, reduces the likelihood of early detection of illness, and impedes appropriate management of health conditions.[14]

Inaccessible healthcare facilities and poor communication practices within healthcare settings are common barriers for disabled people. For Deaf and hard-of-hearing people, insufficient provision of sign language interpreters as well as a lack of knowledge by healthcare professionals about the linguistic and cultural differences associated with being Deaf is commonly reported.[15] For Autistic people with sensory needs, lengthy delays in noisy and brightly lit waiting rooms can make accessing primary healthcare difficult.[16] People with physical disabilities can experience reduced accessibility through lack of ramps, narrow doorways, and inaccessible bathrooms.[17] Many people with physical disabilities do not receive complete medical examinations because equipment such as, examining tables, do not accommodate their impairment.[18] For people who are blind or have vision impairment, a lack of communication material in braille or large print can prevent them from accessing adequate care.[19] People with learning disability report health professionals often make assumptions about their communication abilities and direct conversations towards their support person rather than to them.[20] A lack of experience interacting with people with learning disability, and inadequate skills and knowledge, often means health professionals are ill-equipped to respond to their needs.[21]

There is a substantial body of international literature showing that, for many people, transportation is a barrier to accessing healthcare. Transportation barriers can have a direct impact on health outcomes, for example, missed healthcare appointments due to unavailability of appropriate transport options and poor scheduling, living outside of urban centres, and travel distance to health care settings. Barriers to transport can also lead to poor health outcomes through transport-related social exclusion. Transportation barriers affect disabled people's ability to fully participate in social, economic, and political activities, which impacts their well-being.[22]

What people told us works well in the community

Disabled people use the full range of primary healthcare services in community settings. GP (100 percent), pharmacy (87 percent) and dentist (70 percent) care were mostly commonly referred to by participants in both the interviews and survey. Healthcare services delivered in the community that are accessible, easy-to-use, and foster relationships are important for addressing disability inequity and improving disabled people's health and wellbeing outcomes.

When healthcare professionals working in the community have positive attitudes towards impairment and disability, and spend time investing in relationship-building, disabled people feel they are well cared for. People talked of valuing trusting, constant, and reliable relationships with healthcare professionals who address their health concerns without trying to 'cure' them of their disability. The ability to see the same GP for each visit is important for many disabled people as it enables a person-centred approach where positive relationships can be established and self-determination, choice and control can be fostered. Being able to see the same GP consistently enables people to inform their doctor about access needs, including what is in and out of scope with respect to the impact of impairment(s) on health conditions, and vice versa. It means people don't need to repeatedly tell their 'story' - which often involves having to teach healthcare professionals about their impairments and explain their access needs.

Some interviewees had relationships with their GPs that were built over many years. Care delivered in the context of an enduring relationship helped people feel safe; they were confident that they would be given sufficient time, treated with respect, listened to, and have their concerns taken seriously. Building a good relationship with healthcare professionals who work are willing to learn and consider people's individual access needs associated with various impairments, is mana enhancing for disabled people, whose views are often routinely ignored. It was within these relationships that many disabled people were able to work in partnership with their GP and exercise self-determination. This was described as important because it means that requests for specific care were responded to easily and quickly. Additionally, disabled people emphasised good practice when healthcare professionals recognised and supported their attainment of ordinary life outcomes, including fulfilling work and familial responsibilities. In some instances, this meant recognising that their healthcare needs overlap with the healthcare needs of other family members.

"She (GP) absolutely trusts that I know what I am talking about when asking for medication and it's just usually repeats of stuff she has prescribed anyway. She understands that it is hard for me to get my husband to the doctor, so sometimes she will give me a little bit more of something she has actually prescribed for both of us, so I don't have to make a separate appointment for him."

Interview participants also spoke favourably of healthcare services in the community when care was person-centred, particularly in relation to the provision of reasonable accommodations, like adjusting the length of appointments to suit people's needs.

"They booked me in for double appointments to allow time for me to transfer from my wheelchair, but only charged for a single appointment."

Punctuality was deemed important for disabled people, particularly those who do not drive and rely on other people for transport. Companion driving and taxi services, for example, require precise information about pick-up and drop-off times in order to coordinate services. Likewise, friends and family may have other commitments which need to be taken into account when disabled people attend healthcare appointments. Clinicians who run late with appointments can prevent disabled people from attending preventative check-ups which can lead to more serious issues developing.

"My dentist is incredibly punctual. He does the work in half hour slots, and if it's going to go longer, you have an hour. You get your money's worth too. He doesn't try to rip you off sending you off to a hygienist but just does all the work himself."

A blind woman spoke of her experience of recent covid vaccination services. This example illustrates a positive experience of a regular clinic which focused on each person as they entered and moved through the service. The service was easy-to-use and promoted the mana of disabled people, by showing respect for individual needs.

"First of all, there was someone to direct you when you walked through the door. They checked if the person I was with was a personal connection or a paid driver. He then directed us where to go to the desk, and the person behind the desk gave us clear directions about where to go to wait. The person giving the vaccines came out and offered assistance if required and then gave us clear instructions about where to wait the 15 minutes after the injections. I felt as though if I had been there on my own with no sighted guide, it wouldn't have been a problem",

The location of healthcare services was also important, and many participants valued having healthcare services located close to their homes in their local neighbourhood.

> "I like that our GP is in our neighbourhood. It takes me a couple of minutes to drive there. I can park directly outside the clinic in the mobility parks, and it also has an onsite pharmacy. We can also wait in the car until our appointment or after if we have to hang around for observation. It makes it so much easier to go to the GP."

Many peopled valued pharmacies that were beside or very near GP clinics. Having pharmacies located within or nearby GP clinics makes accessing healthcare services easier for disabled people as it reduces the need for additional travel and the associated travel costs.

> "Getting to the chemist is much easier if it is near the doctors, as then you don't have to find and pay extra for transport."

Interview respondents spoke of valuing the way in which shared GP and pharmacy services facilitated continuity of care and allowed relationships with staff to be formed. It creates a seamless delivery of care between GP and pharmacy services based on an awareness of the people's medical history and access needs which means that prescriptions can be filled quickly if medication has run out. Pharmacies that provided home delivery of medications were also referred to by some participants as contributing to good experiences of community healthcare. They talked about home delivery of medication in terms of self-determination - the ability to manage and monitor medications independently through ease of access was valued and lead to an increased sense of mana as people felt in control of their medication needs.

What people told us doesn't work well in the community

The main barriers to receiving good care in the community identified by people were in relation to lack of care continuity, attitudes and knowledge of healthcare professionals, inaccessible environments, and cost of healthcare. When asked if there were things that prevented them from accessing healthcare in the community, people shared experiences about rigid and inflexible appointment times, lack of availability of same day appointments, and not being able to see their regular GP.

> "If wanting to see your own doctor, you need to book 2 or 3 weeks ahead. You need to go at certain times of the day, and you may not necessarily see the same GP each time, depending on the situation."

For people who have disability home supports, it was difficult to book GP appointments that worked around the availability of carers.

"I often can't get attendant carers to shower me so I am ready at times when appointments are available."

These issues were exacerbated by, what several people observed as, an increasing trend towards GP practices use of temporary locums. This type of operating model reduces continuity of care and negatively impacts upon people's ability to build relationships with their local healthcare provider. Lack of relationship continuity was associated with a commercialised approach to healthcare delivery and short, impersonal consultations. People felt at risk of adverse outcomes when medical decisions were made by locums with whom they had no prior relationship.

"When using locums, they need to keep away from the regular GP's diagnosis and not decide this is incorrect and prescribe some random medication that is irrelevant or even dangerous."

"Locums could make a note on patient file suggesting a different course of drugs or different diagnosis, but should not act on a hunch when they don't know the patient."

Poor treatment in community settings because of outdated and/or discriminatory attitudes as well as inadequate knowledge of impairment and disability was also described as a reason for poor experiences. Survey results show that in community healthcare settings sixty three percent of people have had their own knowledge about their health and healthcare needs disregarded, 50 percent of people have their preferences and choices about their healthcare ignored, and 75 percent of survey people have had to teach healthcare professionals about their impairment

"My GP still can't get over the fact that I am blind but function quite well. So I have educated her over the years and she is a lot better than she was."

"I often feel like GP's don't really know anything about neurofatigue after a traumatic brain injury (TBI). Same goes for mental health therapists but I find that sometimes easier (as long as they can be open minded) but it's been difficult when doctors haven't always been able to help me with my neurofatigue and TBI symptoms, sometimes dismissing them or not going into the depth I was seeking."

"I use a wheelchair. I have experienced two occasions when health professionals complained that I might damage their furniture."

"They try to attribute presenting symptoms to my other conditions, or my presenting issues may be dismissed altogether"

"The GP doesn't have the knowledge or understanding of the issues my son and I are managing. For instance, when having to renew government funded support, we are

forced to reconfirm impairment-related information that never changes or goes away. This is confusing for the GP and frustrating for us."

"I was unhappy recently when visiting the dental hygienists who treated me like a little kid. This made me quite upset."

The attitudes and knowledge of healthcare professionals working in the community was one of the main reasons that people decided not to seek or delayed accessing healthcare services. For example, people were worried health professionals wouldn't know enough about their impairment and/or health condition (50 percent), or they were worried they would be mistreated or disrespected (45 percent).

Inaccessible environments and equipment were referred to by many participants. Often mainstream health services in the community are not designed or built with the needs of disabled people in mind.

"GPs don't have accessible examination tables, and the same problem occurs with screening services, dental services."

"I need to be transferred onto an examination-tables by hoist, which community-based dentists and radiology services don't have. Many dental services don't even have basic wheelchair access."

"Accessibility issues e.g have a loud busy waiting room".

The mothers interviewed for this study noted that GP waiting rooms are difficult environments to bring disabled children and youth to, especially when medical professionals are running late.

"Waiting rooms tend to be open and there is no separate area for people to wait if needed. It's hard for everyone when a child acts out because they don't want to be there and sometimes with the best will, nurses can make things more difficult by interfering."

Cost of healthcare was also a concern for many people. The prohibitively high cost of healthcare services in the community is a significant barrier for disabled people and must be considered in the context of disabled people's high rates of unemployment. Survey respondents had low levels of employment with 20 percent of people in full-time work, 27 percent of people working part-time, 17 percent in voluntary work and 47 percent of people who don't have job. Fifty five percent of survey respondents indicated they have not accessed healthcare services in their community because it was too expensive.

"I don't qualify for a Community Services Card but only earn around $20,000 a year, which makes me think twice about going to the doctor"

"It costs $32 for a prescription appointment and $61 for a visit to the GP, and this doesn't include the cost of having prescriptions filled."

"Dentists pass you along to hygienists at an additional cost, to undertake cleaning etc that dentists themselves always used to do as part of the visit."

"The GP seemed to expect me to make an additional appointment about that issue, as this would mean an additional fee."

Several people interviewed spoke of limitations on prescribed medications requiring the constant monitoring of quantities by patients, to ensure supplies are available. Rationing of medication by pharmacists presents challenges for many disabled people not only in terms keeping track of when repeat medications are due for collection but can also mean having to pay additional transport costs to collect medicine. Greater choice and control would be demonstrated if disabled people could choose whether to have medications staggered or collected/delivered as one package.

"You have to remember to check with them about when your next repeat is due and you have to physically go to the chemist to pick this up."

"There is a tight-fisted mentality even when resources are plentiful."

Specialist healthcare at the hospital

What previous research tells us

Research shows that disabled people have higher rates of avoidable hospital admissions because primary care delivered in community settings often doesn't address their specific health care needs. Deaf people may delay using primary health services due to communication barriers, and instead present to emergency or specialist services when a condition is worse.[23] For people with learning disabilities, limited opportunities for engaging in preventive health care[24] a primary health care system driven by administrative rather than medical and preventive health factors,[25] and general practitioners lacking confidence in providing health care for people with intellectual disability.[26] The use of emergency departments persist even as people with learning disabilities and healthcare providers acknowledge that emergency departments are inappropriate and more expensive alternatives to accessible, quality primary medical care.[27] Low number of dental professionals who have the expertise to work with these people with autism can act as a barrier to access and receipt of dental care and can lead to avoidable hospital admissions.[28]

For some disabled people, the interface between primary and secondary care can be difficult and can lead to unmet need and health inequities. Children with autism may be less likely to receive a referral for specialist care from their primary care physician than children with other types of learning and developmental disabilities[29] and parents of children with autism express greater dissatisfaction with the communication and coordination of care among primary care physicians compared to families of children with other learning and developmental disabilities.[30] Disabled women, describe having their health concerns discounted and dismissed[31] by medical professionals which can affect their access to specialist care. 'Diagnostic overshadowing' is common for disabled people, particularly people with learning disabilities, with their reports of physical ill-health viewed by healthcare professionals as disability-related and so not investigated or treated.[32] Additionally, the emotional toll of having to repeatedly disclose information about their disability and access needs, can be amplified when disabled people move between primary and secondary care.

The physical, communication and attitudinal barriers disabled people face accessing specialist care in hospitals are similar to those experienced in community settings. For example, people with learning disabilities report feeling ignored by hospital staff[33] and

health staff may talk to the carer before, or instead of, the person with intellectual disabilities.[34] Communication and advice about treatment, procedures, medication and discharge can be unclear and complicated.[35] For Deaf people, the absence of visual alert systems in most outpatient clinic waiting rooms means they have to watch reception staff intently to try to discern when their name is being called.[36] Parents of disabled children report having their knowledge about their children and their children's impairment disregarded when accessing specialist healthcare and their child's physical ill-health dismissed as disability related.[37]

What people told us works well in specialist hospital care

There was a large variety of specialist services referred to across the interviews and surveys.[38] For most people, they were accessing numerous specialist healthcare services simultaneously. Underpinning conversations about positive experiences of specialist healthcare in hospitals settings was the importance of good communication and the establishment of relationships built on shared decision-making. Building a respectful working relationship at the hospital enhances the mana of disabled people.

> "His specialist would ring me and discuss when surgery would suit me, depending on what was going on at my work and what he could manage in his schedule."

Similarly, choice and control support about where appointments occur facilitates positive experiences.

> "I like that I can choose to have our specialist appointments at either Kenepuru or Wellington hospital. We still see the same specialist. For some reason it was only recently I was given this option. Now that I have the option to choose, I prefer to go to Kenepuru because the parking is easy and free. They also schedule our appointments earlier in the morning which means we don't have to spend ages in waiting rooms."

For a man with learning disability, good communication meant medical professionals speak directly to him. It is common for people with learning disabilities to be excluded from conversations and decision-making processes that affect them. The use of plain language, easy-read documents and making time for people to understand information supports good communication.

> "Appointments go well when doctors and nurses talk to me and not my parents or support workers."

This man further pointed out that whenever he attends medical appointments, he takes his 'health passport' to give to staff. His health passport is a tool that facilitates communication and is an important method for sharing medical information as well as other details he deems to be significant, such as how best to communicate with him when he is feeling anxious and who his emergency contacts are. He feels secure knowing that the health professionals have this important information.

Person-centred and flexible care that recognise people have a range of access requirements leads to good experiences in hospital settings. Information must be conveyed in ways accessible and useable by disabled people and the best people to advise on this is disabled individuals themselves. For example, important information such as the Health and Disability Commission's code of consumer rights should be brought to the attention of disabled people and read aloud if required. The mother of an adult disabled child explained that she and her husband were allowed to stay past the end of visiting hours to help support their son and to offer access advice specifically related to his autism. In this instance, the expert knowledge they hold as parents is recognised and respected and drawn upon in a partnership model to help create an environment that works for their son.

What people told us doesn't work well in specialist hospital care

Participants faced numerous barriers when accessing specialist healthcare. Barriers resulted in missed appointments or lengthy delays to care as people had to wait until a next available and/or suitable appointment. Survey results show that 50 percent of people didn't attend their specialist appointment because the appointment was either too early in the morning or too late in the day and 55 percent of people didn't access specialist healthcare because the wait to see a specialist was too long. Specialist healthcare services should be accessible and easy-to-use so that disabled people can access care early to avoid situations worsening.

> "I often had to get an appointment changed because the suggested time is impossible for me… This afternoon means facing a delay in seeing the specialist."

> "Cost, time, changing appointments without asking me if it was convenient or works with transport, then when it didn't suit, I was made to be the idiot."

> "I experience barriers to accessing hospital services – have to travel a long, costly distance, bathrooms with hoists are not available to outpatients."

Barriers reported often related to appointment times and communication of appointments, travel, and transport. Several people spoke about needing to travel long distances to access

specialist healthcare services. The impact of having appointments early in the morning or late in the afternoon meant that some disabled people were required to travel during rush hour, adding time and cost to an already long journey. Uncertainty around the duration of a person's appointment or hospital stay was also seen as a barrier to being able to plan the return trip home.

> "It's often unclear how long a hospital appointment will last, which makes it very difficult to arrange taxis."

Many participants advised they would greatly prefer to attend hospital outpatient appointments at certain times of the day. Mothers of younger disabled people interviewed expressed a preference for first thing in the morning, so they could avoid crowded waiting rooms and the stress of trying to explain to their children why meals and drinks are not possible.

> "If appointments are in the afternoon, I have had to come up with diversionary tactics to take my son's attention away from food, since he often has to have a general anaesthetic for various procedures."

There was also a preference for specialist care appointments to be coordinated so that they could happen all in one day. As highlighted in the survey results, disabled people often are receiving a range of specialist care. Mothers of disabled children spoke of specialist healthcare services taking an impairment-specific and individualist approach, as opposed to a whole-of-child and/or whole-of-family perspective. When delivering specialist healthcare to disabled people and their whānau it is important to do so in a way that supports disabled people's access to ordinary life outcomes, whether that be work, family or education responsibilities.

> "I once counted up to 20 appointments in a year where I had to take days off work. Specialists assume you will fit your life around what suits them, forgetting you might be in a critical professional role too and simply unable to drop everything."

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

> "Details of my appointment were never communicated to me but the hospital says they did, therefore I got marked as unreliable and got pushed further down the waiting list."

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

> "I received a letter outlining the process. There was no information on where the Pain Clinic actually was in the hospital. First, we were taken by a volunteer to Orthopedics, they had to then find someone else to take us to the Pain Clinic itself. This was an early morning appointment which meant we had to leave from Palmerston North by 6.30 am to allow for traffic."

Discriminatory attitudes by health practitioners impacted people's experiences of, and access to, specialist healthcare services. In relation to accessing specialist healthcare, survey results show that 64 percent of participants have had their knowledge about their own health and healthcare needs disregarded; 59 percent had to teach a health professional about their impairment and/or health condition; 55 percent had their preferences and choice about their healthcare ignored; and 45 percent of people didn't access specialist health care because their concerns weren't taken seriously, and they didn't get a referral. It was common for participants to have general health issues wrongly attributed to their impairment.

> "It took me three months to get a simple cataract operation to enable me to go off strong pain medication and go back to work, but the specialist fought it all the way, because I would still be blind at the end of it!"

> "My experience with GPs and hospital specialists has always been condescending. Like how dare I know more about my conditions than them?"

A disabled woman whose husband became unwell and required hospital treatment described the difficulties associated with being a disabled person advocating for a non-disabled person. She believes that healthcare professionals dismissed her knowledge about her husband's healthcare needs because she was disabled.

> "They didn't take me seriously or want to engage with me, and were unhappy about me being part of his treatment."

A blind woman described a situation where because of a technician's lack of understanding about how to interact with disabled people, her autonomy was taken away and she was left with a sense of disempowerment.

"So she literally tried to push me in to a chair, and manhandled me, and in the end, I just stepped back and said, 'if you place my hand on the back of the chair, that will tell me where the chair is and which way it is facing.' I didn't tell her off or anything, I just told her what I needed and why, and she seemed quite embarrassed."

The issue of expecting nondisabled family members to act as carers post specialist care was also raised. A blind woman reported receiving no follow-up support post specialist care and was angered by the expectation that her husband would take on the role of disability support carer.

"I view my husband as my partner, not my nurse. He is not my carer, and as a disabled woman I absolutely resent the inference. The roles are quite different."

For one participant, who had experienced major brain trauma due to an aneurysm, she was refused community nursing and occupational therapy services upon discharge, since her husband was staying at home to assist her and care for their small children. She was completely unable to access home help, even to clean the bathroom, which she said would have taken some of the pressure off her husband.

Several study participants found the interface between specialist care at hospital and primary care in the community difficult to understand. The coordination of services between secondary and primary care was tenuous. A number of participants said they felt very let down by the lack of support and access to follow-up services after having been in hospital. For participants who needed follow-up services after receiving specialist care, such as home support, they need to strongly advocate. Others were offered no support, even though their time in hospital had involved surgery. These participants reported having not received any advice about how to access ongoing support, or the advice received was to seek help themselves. Most said they felt too frail and tired at this point so gave up on this. A sense of having to 'fight' for at home support following specialist care was common.

"I am so tired of having to find out how to get services and support because health professionals simply do not tell you what is available."

"You have to push for everything yourself and you're not really in a position to be assertive when you are ill and have no energy. So you just give up."

"Have had to be very assertive when I've been ill and vulnerable."

"When you are really sick and vulnerable and highly medicated, you are not in the space where you can advocate for yourself, even when you are normally good at this."

Upon discharge from specialist care, people did not receive the support they required.

"I was in Wellington hospital for 3.5 months and they were meant to sort some home aftercare out for me but didn't. They had all that time to organise the care but the excuse was that the social workers weren't doing their job."

"It was an ACC claim, but there was no join up with the specialist service at the hospital and ACC. If I had wanted home help, I would have had to be the one to have somehow known to organise it."

"I was criticised by medical staff at the hospital for continuing to occupy a bed, but nothing had been put in place to support me to go home."

While most participants reported that their GPs had been kept in the loop by specialists about their treatment, progress was not necessarily enquired about or discussed with people and it was often the case that they had to follow up with specialists to receive their results.

"My results were sent to the wrong practice, and I had to ring and get them to send them to my nurse practitioner."

Conclusion

Local healthcare services within the 3DHB region need to take urgent and sustained action to make sure they are accessible, person-centred, coordinated and delivered in the context of whānau and community. Healthcare that is designed and delivered in line with the social and human rights model of disability, and the EGL vision and principles is key to improving outcomes for disabled people in the area. Increasing choice and control, building relationships and 'seeing the whole person' is the foundation upon which accessible, inclusive, and enabling local healthcare service can be built.

The experiences of disabled people and whānau shared in this report show that too often health care professionals working in people's homes, across community sites, and hospital settings fail to treat disabled people in inclusive and non-discriminatory ways and don't work together as a team to provide holistic care. As a result, healthcare is often fragmented and/or delayed, which can result in missed opportunities to prevent needs from escalating.

Accessible, inclusive, and enabling healthcare at home, in the community, and at the hospital is relational as opposed to transactional, where healthcare is done 'for' or 'to' a disabled person. Healthcare is planned around the person to meet all their needs, across home, community, and specialist care settings. Coordinating services around the whole of a person's needs enables them to have more choice and control over their healthcare needs.

Recommendations

The recommendations in this report are specific to improving access to 3DHB services for disabled people. Many of the issues identified in this project relate to systemic problems within the healthcare 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 people and their whānau. We recommend the 3DHB do the following:

1.   Resource and run ongoing EGL and disability rights training for all healthcare services working across primary and secondary care in the 3DHB region. EGL training should be delivered by suitably qualified disabled people and whānau of disabled people.

2.   Promote social and human right model thinking to encourage local healthcare services to address the wider determinants of health. Thinking about health and

wellbeing beyond narrow medical understandings will help address disabled people's poor health outcomes.

3.   Support and invest in the establishment of local disability leadership groups across the 3DHB region to help create and oversee the development of local healthcare services. Local disability leadership groups would work closely with and inform the work of the Sub-Regional Disability Advisory Group.

4.   Promote greater collaboration between primary and secondary care. This would include a particular focus on ensuring the responsibility for transferring care between services, such as specialist hospital care and care in the community, is clearly delineated as being the responsibility of the healthcare provider, and not the person.

5.   Commission an audit of all telehealth services and invest in supporting primary and secondary healthcare services within the 3DHB region to provide accessible telehealth communication

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