



ACT Disability Health Strategy Roundtable: Listening Report

Phase Two of the ACT Disability Health Strategy Project

Draft

March 2023

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Introduction

Purpose of this document

This is a high-level capture of the key insights from the ACT Disability Health Strategy (DHS/the Strategy) Roundtable on 16 March 2023. These insights will inform the next draft of the DHS to be presented to the Minister for Health before being released for public consultation.

About the Roundtable

The roundtable was facilitated in person and online by ThinkPlace on 16 March 2023.

There were 33 participants, including people with disability, carers of people with disability, service providers, advocacy groups, and representatives from ACT Government Directorates.

Minister for Health, Ms Rachel Stephen-Smith, opened the roundtable, welcoming participants. Minister Stephen-Smith spoke about the ACT Government's commitment to the Strategy.

Participants of the roundtable provided feedback on the *Roundtable Draft DHS* through two conversations:

- Question 1: How satisfied are you with what is covered in the Strategy?
 - O What is missing from the Strategy?
 - Are there any focus areas, key issues or concerns that have been overlooked?
 - What would you like to change about the Strategy?
- Question 2: How do you feel about the overall structure of the Strategy?
 - O What do you think about the flow of the Strategy?
 - Are there any sections you feel need to move or change?
 - Do you have any concerns about language or terms used in the Strategy?

About the Disability Health Strategy

The DHS is a ten-year plan which aims to ensure people with disability have equitable and appropriate access to healthcare in the ACT. It is part of the ACT Government's vision for an inclusive society that gives everyone the chance to participate in community life and leaves no-one behind.

People with disability have inherent rights to life and access to equitable and tailored healthcare. However, while one in five people in the ACT reported as living with disability, they tend to have poorer health outcomes than those without disability. There are several issues that contribute to poorer health outcomes, which are outlined in the draft DHS. The intent of the Strategy is to help address these issues, and to improve health outcomes for people with disability.

The Strategy is the **overarching plan** to improve health outcomes for people with disability in the ACT. The Strategy will inform and guide the development of a subsequent **First Action Plan**.

The DHS development process

The development of the DHS is supported by a significant evidence base, including consultations, national and local legislation, policy, and research.

The DHS Project has been broken down into three phases:

| Phase One: | Phase Two: | Phase Three: |
|-------------------------|---|---------------------------------------|
| Scoping Study | DHS and First Action Plan (FAP) Development | DHS and FAP Launch and Implementation |
| Completed December 2021 | Underway | To be commenced |

Roundtable Agenda

The roundtable held on 16 March 2023 followed the agenda below.

| Time | Session | Who |
|------------------|---|---|
| 9:30 | Online Microsoft Teams meeting opens – tech support and troubleshooting available for online participants | ThinkPlace team |
| 9:45 | Arrival. Tea and coffee provided | |
| 10:00 | Welcome | Sarah Martin, ThinkPlace |
| 10:05 | Minister's opening remarks | ACT Minister for Health |
| 10:15 | The journey so far – how we have developed the strategy | Maria Travers, ACT Health Directorate / Co- Chair ACT Disability Health Strategy Steering Committee |
| 10:25 | Housekeeping and overview of the roundtable process | Sarah Martin, ThinkPlace |
| 10:30 | Question 1: How satisfied are you with what is covered by the Strategy? | Plenary discussion |
| 11:00 | Morning tea | All |
| 11:15 | Question 2: How do you feel about the overall structure of the Strategy? | Plenary discussion |
| 11:45 | Summary of what we have heard | Sarah Martin, ThinkPlace |
| 11:55 | Closing comments and next actions | Maria Travers, ACT Health Directorate / Co- Chair ACT Disability Health Strategy Steering Committee |
| 12:00 | Meeting close | Sarah Martin, ThinkPlace |
| 12:00 – 13:00 | Lunch provided in the café area | |
| | | |

Question 1: Strategy Content

Overview

The first question posed to roundtable participants addressed the **content** of the *Roundtable Draft DHS*.

The participants were asked "how satisfied are you with what is covered by the Strategy?". The aims of the discussion entailed addressing missing content and overlooked issues in the Strategy and allowing participants an opportunity to suggest changes to the Strategy.

Feedback

Connection to parallel strategies, frameworks, and the health reform agenda

Several participants reflected on the importance of connecting the DHS to other strategies, frameworks, and the overall health reform agenda. The following are specific references made by the participants.

The ACT Detainee Health and Wellbeing Strategy, the Disability Justice Strategy, Offender Frameworks

The Strategy is missing an explicit mention to people in prison. The participants suggested recognising relevant documents to ensure people have access to the best quality healthcare on equal terms. If acknowledging these documents is not feasible, a participant suggested reflecting on how the DHS interacts with other strategies.

Disability Justice Strategy

Several participants agreed that the Strategy needs to address the legal factors that impact people with disability. This is to ensure that people can express their needs and wishes in relation to the care and assistance they receive. Some of the factors mentioned were:

- Treatment and assessment orders that don't require an individual's consent;
 and
- Guardianship arrangements.

The participants noted that page 11 of the *Roundtable Draft DHS* addresses informed decision-making about healthcare and suggested that the language could be refined with the help of ACT Government Guardianship Unit due to their

specialised skillset. Doing so would allow to develop clarity on the topics of quardianship reforms and legislation and their consequent impacts.

Health Workforce Strategy

A participant suggested connecting the DHS to the *ACT Health Workforce Strategy* (under development), as the DHS does not address the supply of health workforce to meet the needs of people with disability. The participant noted that this is especially relevant for allied health professionals, as many of professionals with disability expertise work for the NDIS in the private sector.

Health Reform Agenda

A participant suggested the Strategy should clearly articulate how it connects to the health reform and where it is positioned within the ACT Government's health reform agenda. The participant also raised considerations around the potential economic benefits of an accessible healthcare system and why an accessible healthcare system is a modern and fit-for-purpose healthcare system for the ACT.

Prioritisation of Strategy and performance indicators

Identifying priority areas of change

A participant suggested that the Strategy should indicate what the ACT Government perceives to be priority areas of change. They noted that these areas could be those requiring immediate attention, such as diagnostic overshadowing, poor infrastructure, inaccessible equipment in acute settings, accessibility, and access to information.

The participant also suggested integrating more detail on evaluation and monitoring of the Strategy, especially in relation to the development of the First Action Plan and the timetable for the implementation of the measures. They commended the *ACT Housing Strategy Implementation Plan* as a model for doing so.

Performance indicators

While acknowledging that this may belong in the action plan, one participant suggested the need to establish measurable targets for the Strategy. They expressed a concern that the Strategy may be difficult to implement in practice unless it embedded measurable key performance indicators (KPIs).

Mechanism for government accountability

A participant suggested that the Strategy is missing a framework that contextualises how the ACT Government will be held accountable to the Strategy over the course of the next ten years.

Improvement of definitions

Blending of social and medical models of disability

A participant noted the social and medical models of disability are contrary to each other and suggested that the Strategy must explicitly clarify the change of direction from the medical model to a social model.

Holistic definition of 'good health'

Several participants agreed that the Strategy does not sufficiently define the concept of 'good health' and suggested that there needs to be more clarity about how the Strategy interacts with people's lifestyles, such as having a job, as well as detail reasonable adjustments, such as access to online medical appointments.

Explicit reference to all elements of healthcare

A participant suggested that the Strategy should be explicit about what elements of healthcare it covers. For example – preventative health, hospital care, and care in the community.

Program integration and eligibility

A participant raised that as NDIS plans focus on primary disability and may not account for other disability, the Strategy needs to integrate an overview of eligibility criteria for programs, particularly if they are siloed.

Suggested additions to the Strategy

Integration of carers

Participants suggested the Strategy lacks reference to people who cannot speak for themselves, even though there is content around informed decision-making and inclusion of formal and informal care advocates.

One participant noted that it is not the responsibility of the Strategy to address these nuances but to ensure that a mechanism is in place for people whose perspectives are not heard to be informed and involved.

Ensuring diverse engagement of people with disability

A participant raised that there is already great discussion about co-design and engagement with people with disability in relation to the development of healthcare services and infrastructure, and in the development of disability awareness training for health professionals.

Given high prevalence of disability in the Aboriginal and Torres Strait Islander communities, the participant made a practical suggestion to extend this content to involve people with disability that represent diverse parts of the community to ensure diverse engagement.

Inclusion of animal therapy

One participant suggested integrating animal therapy into the Strategy. They noted that the Strategy could outline positive and negative parameters of animal inclusion and develop guidelines for areas that want to start including animals or want to start being more inclusive of people who have therapy animals.

Intersectionality

Several participants suggested recognising larger cohorts for the purpose of developing the First Action Plan. A participant expressed that while it may be difficult to capture as many intersections as possible, they suggested defining what specific intersections are crucial to ensure there is adequate detail to support the development of the First Action Plan.

Another participant suggested articulating the vision for what intersectional healthcare looks like. The participant also asked to consider what good intersectional healthcare looks like in practice.

Including women with disability as a key cohort

A participant suggested that women with disability be considered a key cohort within the Strategy. They acknowledged that while the removal of a list of cohorts was to enable the conversation about intersectionality, identifying key cohorts is essential for the development of priority actions from the Strategy. This is because the Strategy could be leveraged to identify the issues that will need to be addressed in the First Action Plan.

Acknowledging the needs of trans and gender diverse populations

A participant noted that 68% of the LGBTIQA+ community in the ACT indicated that they have a disability, and that most queer people with disabilities are trans and gender diverse.

The participant suggested that the Strategy should acknowledge the specific healthcare needs of trans and gender-diverse people in the ACT.

Including diverse bodies

A participant suggested that the Strategy acknowledges the needs of people with diverse bodies. The participant specifically talked to recognising people who are born

with intersex variations or variations of sex characteristics, whereby a significant proportion of those people will either have congenital or acquired disability.

Question 2: Strategy Structure

Overview

The second question posed to the roundtable participants addressed the **structure** of the Strategy.

The participants were asked "how do you feel about the overall structure of the Strategy?". The aims of the discussion entailed addressing content progression and section structure of the Strategy, as well as raising any concerns relating to the language or terms used in the Strategy.

Feedback

Document format

Document length

A participant suggested that the Easy English version of the Strategy is shortened for accessibility, as it is currently 48 pages long. They suggested the shorter document to be similar to a quick guide.

Sections requiring change

A participant suggested that the Strategy should better describe what the interface between healthcare navigation and integration looks like in practice, as discussed under the *People with disability are afforded healthcare navigation and integration* section on page 9 of the *Roundtable Draft DHS*.

Concerns about language or terms

Acknowledging support workers

A participant noted that it is important to acknowledge the disability support workforce who deliver crucial services to ensure that their role is supported by the Strategy.

Definition of 'integrated'

Several participants agreed that the word 'integrated' in relation to healthcare provision is an ambiguous term. They agreed that words such as 'holistic', 'joined', and 'collaborative' are better suited to ensure clarity on the meanings in the Strategy.

Another participant noted that the Strategy needs to establish more clarity about the interface between health and disability to ensure continuity of care between, often disjointed, specialists and establish good handover practices between healthcare professionals.

Another participant stated that it is also essential to use language consistently throughout all the ACT Government's documents.

'People with disability' vs 'people with disabilities'

Participants discussed the correct method for referencing disability.

A participant raised that their organisation tends to say 'people with disabilities' to acknowledge that some people have multiple disabilities that can intersect in many ways. Another participant noted that 'disability' is a collective noun and should be used as such in reference to people with one or multiple disabilities.

Another participant suggested involving representative organisations in establishing an appropriate convention for the Strategy.

Defining 'trauma-informed'

A participant noted that the Strategy does not provide a clear definition for what 'trauma-informed' means.

Improving wording for the blended model of disability

A participant suggested that further work needs to be done to clearly articulate what the blended model of disability means to distance it from the medical model of disability. They noted that the context and definition of the blended model is unclear, requiring more work in the *Principles* section.

Possible actions

The following are suggestions raised at the roundtable.

- A participant suggested healthcare staff should have a human rights awareness KPI. For example, staff could be asked how they demonstrated upholding a human right within their service delivery (at their performance reviews). This could also extend to trauma informed care in practice, for example how they demonstrated Trauma Informed Care in Practice with a patient.
- A participant suggested providing individuals who rely on family members for interpretation with an independent interpreter to ensure no occurrence of bias.
- A participant suggested thinking about what is required from health
 professionals when delivering integrated care in practice, especially given that
 many healthcare professionals are specialists who often operate in silos.
- A participant suggested only a person with disability should chair the to-beestablished Disability Health Reference Group.

What's next?

Feedback gathered through the roundtable has been captured in this listening report and will be considered by the ACT Health Directorate. While all feedback will be considered, not all feedback will be applied to the next draft of the strategy.

The next draft of the strategy, incorporating feedback from the roundtable, will be presented to the ACT Minister for Health.

When approved by the Minister, the next draft of the Disability Health Strategy will be released for public consultation.

