ACT Disability Health Strategy Roundtable: Listening Report

Phase One of the ACT Disability Health Strategy Project

Final Report

November 2021

Contents

Introduction

Purpose of the document

This is a high-level capture of the key themes and insights from the ACT Disability Health Strategy Roundtable on 16 November 2021. These themes and insights will inform ACT Health Directorate's (ACTHD) understanding of how to work with the disability community to co-design the ACT Disability Health Strategy.

About the workshop

The workshop was facilitated online by ThinkPlace, with the help of Dougie Herd, on the 16 November 2021.

There were 30 participants at the workshop, including:
- People with Disability (PwD)
- Carers (C)
- Service providers (SP)

Minister for Health, Ms Rachel Stephen-Smith, opened the workshop, welcoming participants. Minister Stephen-Smith spoke about the ACT Government's commitment to the ACT Disability Health Strategy and the importance of developing the strategy with the disability community; including people with disability, carers and service providers.

The purpose of the workshop was to inform Phase One of the ACT Disability Health Strategy Project: Scoping Study so that the disability community could advise the ACTHD on how they should be involved in the strategy design, including: the roles, membership, and characteristics of the Steering Committee and how the department should best engage with the disability community.

The roundtable included three conversations:

1. **Learnings from the COVID-19 response – what worked best?**
   Key learnings from the ACT Government's response for people with disability to inform the approach to the ACT Disability Health Strategy

2. **What is the role of the steering committee for Phase Two?**
   Role, membership and characteristics

3. **How best do we engage with the community?**
   To decide what is critical to inform the ACT Disability Health Strategy

Agenda

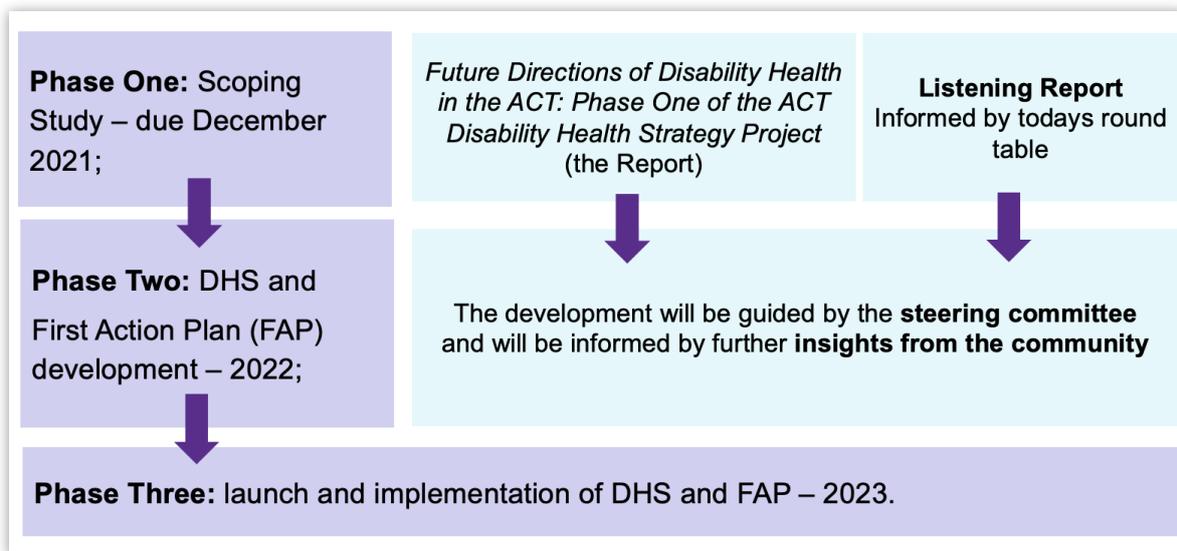|	
Overview of the roundtable	*Cate Shaw ThinkPlace*
Welcome Acknowledgement of country	*Rachel Stephen-Smith, ACT Minister for Health*
Overview of the ACT Disability Health (DHS) Strategy Project and *Future Directions of Disability Health in the ACT*	*Maria Travers, ACT Health Directorate*
COVID-19 Response – what worked best? Key learnings from the ACT Government's response for people with disability to inform the approach to the ACT Disability Health Strategy	*Conversation*
What is the role of the steering committee for Phase Two? Role, membership and characteristics	*Conversation*
How best do we engage with the community? To decide what is critical to inform the ACT Disability Health Strategy	*Conversation*
Next steps	*Maria Travers, ACT Health Directorate*
Close	

Context of the workshop

The ACT Disability Health Strategy is a high priority for the ACT Government.

The ACT Government is committed to co-designing this strategy with the disability community, including people with disability, carers, and service providers.

The ACT Government want to ensure they are starting this conversation not with a blank page but with what they have already heard from people over the years and with an evidence base having looked at the literature.

The ACT Disability Health Strategy project has been broken down into three phases.

Phase One: Scoping Study – due December 2021;

Phase Two: DHS and First Action Plan (FAP) development – 2022;

Phase Three: launch and implementation of DHS and FAP – 2023.

Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project (the Report)

Listening Report Informed by todays round table

The development will be guided by the **steering committee** and will be informed by further **insights from the community**

COVID-19 response – what worked best?

Strong partnerships between Government and the disability community to be collaborative and mutually supportive	**Clear and consistent two-way communication with the disability community**	**Inclusive processes** and communications channels

Key learnings from the ACT Government's response for people with disability to inform the approach to the ACT Disability Health Strategy

Theme 1: Co-design of the access and sensory centre with the disability community

Things that contributed to its success include:

1. **Co-design** of the model with people with disability and their carers from the beginning
2. **Feedback loop** response to feedback about things that were not working (e.g. signage)

   - *'The access and sensory centre (while not perfect) is a world class model for an accessible health space and contrasts significantly with the current experience of mainstream health services.' (PwD)*
   - *'The success of the access and sensory centre was down to the fact that it was designed with the disability community.' (PwD)*
   - *'The sensory clinic was good, but nowhere near enough and not responsive to feedback quickly enough. No clear signage, all written or verbal communications only (needed visuals & sign language) difficult to understand options of support even once there.' (C)*
   - *'We did not get everything right the first time but, the ACT Government was listening and continues to make improvements.' (PwD)*
   - *'Particular learning that should be taken forward is the flexibility of the staff. We could ask for adjustments, and they would go above and beyond. It would be great to get the staff to speak about their experience too.' (PwD)*

Theme 2: Two-way communication

Listening to the disability community and keeping the community informed.
- *'Generally, ACT Government was really responsive. Really appreciated the ongoing opportunities for engagement and that continued through the COVID-19 response. A lot of those community updates and opportunities to raise issues as we became aware of them was very beneficial.' (SP)*
- *'What worked well was feedback loops between Government and community.' (SP)*

Theme 3: Consideration of the role of carers

The disability community appreciated that the ACT Government was mindful of carers and their needs were accounted for.
- '*Recognition of role of informal carers in relation to people with disabilities is very important.' (SP)*

Theme 4: Building trust with the disability community.

The disability community gradually built trust in ACTHD over the period of the pandemic which meant they felt safe and empowered to communicate their needs.
- *'2021 was very different from 2020, there was definitely more trust.' (PwD)*
- *'Using trusted community members made people feel safe.' (SP)*
- *'Ensuring that there was consent for vaccines. The disability community made sure that it was absolutely people's choice.' (PwD)*
- *'Also, level of trust with the ACT Government - when things didn't work, people were respectful but fearless and frank - and this was listened to by the ACT Government.' (SP)*

Opportunities for improvement

Increased inclusion of older adults with disability
- '*The response towards older people with disability was quite patronising.' (SP)*
- *'50% of people over 65 have a disability, people above the age of 65 make up 40% of people with disability. There is need to make sure we are reaching all the people with disability, including older people.' (SP)*
- *'Reliance on social media – good but need to make sure that older people with disability aren't being left behind.' (PwD)*

Need for more inclusive design and process
- *'Young carers need to be considered in future strategies.' (C)*
- *'Need recognition of specific needs of people with dementia - report from Dementia Australia on how to meet these.' (SP)*
- *'People with mental illness in the forensic system were overlooked.' (SP)*

Clear and consistent sources of communication from a single source of authority

- '*There is work to be done to maintain progress we've been making in communication - need some consistent communication protocols across government. E.g., when changing mask mandates, they didn't outline disability context and only in complicated formal documents.*' (PwD)
- '*Clear, accessible information from an authoritative source (so sharable) was biggest challenge.*' (SP)

Begin by considering inclusion and accessibility from the start of the process

- '*If a bit more of a disability perspective was included when structuring these responses these issues could have been easy to address. These problems were occurring whilst community was raising them and being responded to later down the line.*' (SP)

What is the role of the steering committee for Phase Two?

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To understand and represent the complex diversity of the disability community
- *'We are seeking to get outcomes for people with disability across the enormous diversity, disability sector and autism sector. We need to identify the problems.' (PwD)*

Respect
- *'We need to educate our clinicians about how to work with people and partnership with people with disability - we need to be respected by clinicians.'*

Co-Design
- *'Design the strategy with people living with disability.'*

Who should the member representation be?

Whole of Government
- *'The whole of Government needs to be involved, this change needs to be deeply embedded within the design and delivered across the whole the ACT health system.' (C)*

Senior executive buy-in
- *'We need really senior buy in so that this gets woven into core business, not set along the side as a discrete project.' (PwD)*
- *'There needs to be buy-in from ACTHD at the highest level, so this becomes core business. We need to ensure this is not a side project but, a best practice transformation of the whole disability community.' (PwD)*
- *'This won't happen unless there's senior agency driving it through. It is significant cultural and operational change.' (PwD)*

People with lived experience
- *'There needs to be diverse representation of people with disability.' (PwD)*
- *'I would love to have someone like my son, who doesn't speak - make the information in that session accessible to people with disability.' (C)*
- *'Include people who don't have visible disability.' (PwD)*

Knowledge, expertise and insight
- *'People are going to need to have some knowledge and insight about how health services are constructed, what levers you need to pull to meaningfully change.' (PwD)*
- *'We need people with ability for reach and who can see the bigger picture as well as people with lived experience.' (SP)*
- *'The gap is experts. I know of some academics interstate who have been working on accessibility in health. They could be invited to be part of this.'(PwD)*

Organisational representation
- *'Disability is diverse. I would very much be open to having representative groups here. Representative groups should be seen as capable of representing those it does.' (PwD)*

Other considerations

Clarity of roles and expectations
- *'There needs to be a sense of clarity of roles in the group, what are they accountable for, part of the connectedness is connected to groups and communities outside of the steering committee.' (SP)*

Renumeration for participation

- *'People with disability and carers on the steering committee need to be resourced to do it, we are all so time poor and having to do oversight of multiple strategies, this is going to require people to get into the detail, attending lots of meetings, needs to be carved out on top of the work that people are already doing who are already under stress and capacity issues.' (PwD)*
- *'We need people with lived experience, someone who has lived with a disability for a while. Could we turn it into a paid position for people with lived experience?' (SP)*

Ensure a process that has rigor, is robust and rights based

- *'I would support an accessible, widely open EOI (expression of interest) that is well advertised to get in new people. Also, would love to love to see knowledge of the area, experience, knowledge and commitment to the area.' (SP)*
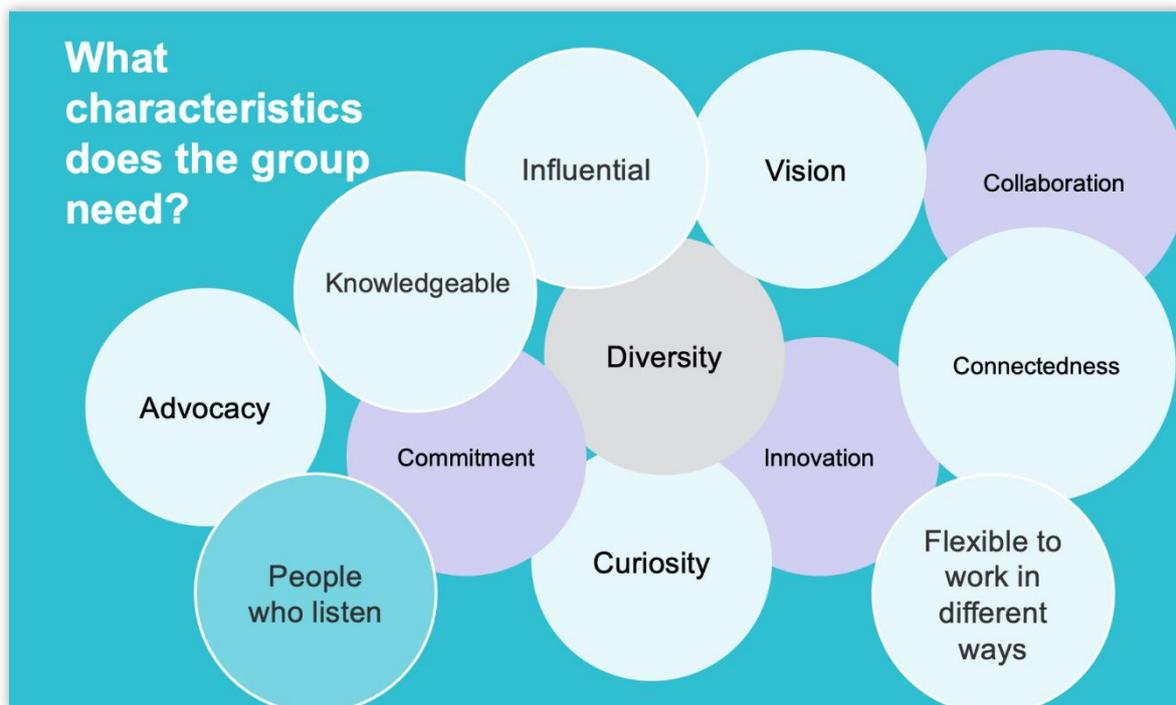
Characteristics of the steering committee

Highlight intersectionality of multiple marginalised individuals

People who listen

Shifting the power

- *'I want to see a shift in power to those that need help from the people in power.' (C)*

Flexibility

- *'The group can work in multiple modes and different ways using different technology, to include diverse voices.' (PwD)*

People of Influence

- *'Capable of supporting the transformation of the health system into the future, over a couple of budget cycles. This is not a one-off strategy, transforming the system is going to take a couple of goes and a couple of years.' (PwD)*

Consistency

- *'We need consistency of representation; we can't have people dropping in and out.' (PwD)*

Transparency and accountability

- *'Through community organisations being at the forefront of the committee with a transparent process regularly engaging with their communities to remain accountable.' (SP)*

How do we best engage with the community?

To decide what is critical to inform the ACT Disability Health Strategy

Thinking through engagement through YourSay
- *'YourSay has value in creating awareness for the whole community and engagement needs to be really targeted.' (PwD)*
- *'Most vulnerable people aren't going to connect here.' (SP)*

Engage with complexity and diversity
- *'Understand diversity and complexity about whom this conversation is centred around, finding ways to assist them and engage with them. Finding ways to engage with them, the responsibility is on the system because that is where the power lies.' (SP)*

Design inclusive communication channels
- *'Understanding that social media, internet etc is not always accessible.' (C)*
- *'Develop a multipronged approach where you accept feedback through many channels and formats (voice memo, video, etc.)' (PwD)*

Include Indigenous organisations
- *'Indigenous organisations that can give information. That covers diversity and inclusion.' (C)*

We should leverage previous learnings. We already know so much!
- *'We must draw on the huge amount of research that has all-ready been done, e.g. "Imagining Better" and mental health research. We know so much.' (PwD)*

Recruit communication expertise
- *'Communicating takes resources which goes back to funding - people on the steering community needs to know how to access funding.' (PwD)*

Be mindful about repeat engagement
- *'We need to be careful not to re-traumatise people by repeating research that has already been done.' (PwD)*

Listen to people with disability who have been patients in the health system
- *'There needs to be a deliberate reach to people with disability who have been patients in the health system.' (PwD)*

Ability News
- *'is providing immediate information to people with disability, empowering and informing the sector.'*

Include a mainstream audience
- *'Start communicating in general communications we will meet more people - mothers, children, artists, first nations, organisations - diverse - put our communications into mainstream communications.'* (SP)

Have ongoing feedback loops and opportunities to input across the entire project
- *'If there's no time delay then people can feed back into strategy at any point in time. We just need to ensure that people are clear about touchpoints where they can feed information in.'* (SP)
- *'A health strategy needs to be a "living document" than changes with (and keeps up with) continuous input.'* (PwD)

Ensure that you have accounted for enough time to engage with the sector
- *'We have a great network of voices to involve, but it's the matter of whether we have time and opportunities to support people to be involved. We need enough notice that we can get in touch with people and them in the space where they are ready to talk. It could really help if we had that lead time.'* (SP)

Further points

Let's not wait! Build confidence by acting early on known quick wins
- *'Things need to happen now to create confidence. To make it known the intent is serious. There is a level of corroded trust because conversations have been happening for so long. We need to create confidence that the transformation of health care for the disability community is serious. We need to see some action. Are there some quick wins that could be actioned early? What can we do now? Let's not wait.'* (PwD)

Be mindful that people in this space are exhausted and overworked
- *'Working in this sector is difficult. People are exhausted and overworked. Need to be very clear about reimbursement and what outcomes you're expecting from their involvement.'* (SP)

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