ACT Health Directorate
Disability and Community Policy
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HCCA Submission: ACT Disablity Health Strategy

Thank you for the opportunity to provide feedback on the draft ACT Disability Health Strategy. The Health Care Consumers' Association is pleased to provide a consumer perspective on the needs and experiences of consumers with disability.

We hope that the Disability Health Strategy (the Strategy) will guide Government and health services in meeting the unique needs of people with disability accessing health care and managing their health.

HCCA looks forward to participating in the development and implementation of an Action Plan to begin working to meet the important goals of the Strategy.

Yours sincerely

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25 July 2023

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SUBMISSION

Draft Disability Health Strategy

25 July 2023

About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-profits Commission.

HCCA's approach to this submission

HCCA is a member-based organisation and we draw on the views and experiences of our membership and networks to advocate for consumers.

Consumers with disability can find accessing health care and having their specific health and support needs met more difficult. We strongly support the development of the ACT Disability Health Strategy to recognise and address the impediments to equity of care and access and to meet the unique needs of people with disability.

In preparing our response to this Inquiry we have drawn on the knowledge and experiences of our members, along with their specific feedback on the *Draft Disability Health Strategy.* We also consulted with HCCA's Health Policy and Research Advisory Committee (HPRAC). The feedback we received has been collated and contextualised below.

What do you think about the draft ACT Disability Health Strategy?

HCCA are supportive of the approach taken in the focus areas of the draft Strategy, but feel there is capacity to expand on the work. HCCA's priorities for outcomes from the Strategy centre on four key areas (these areas covered from p7 of this submission, under consultation question 2):

- Focus Area 1 – Health information and literacy
- Focus Area 2 – Service access, design, and delivery
- Focus Area 3 – Emergency planning and management
- Focus Area 5 – Data and research

We also have some more general feedback on the scope, as well as on the drafting of the Strategy, which we have included here below. This feedback covers:

- Implementation and Governance
- Process of Development of the Strategy
- Specific Drafting Suggestions

Implementation and Governance

We are pleased to see some detail around the plans for implementation and governance (page 7). We note that the ACT Health Directorate will take the lead to steer and monitor, as well as report to the community on progress. Closing the loop with the community, and particularly with those participating in consultations and in co-design, is essential.

It is difficult to assess the likely impact of the ACT Disability Health Strategy without understanding the actions proposed to be undertaken for each Focus Area.

These actions must be designed and executed with the full involvement of consumers. The Disability Health Reference Group sounds like a positive approach to partnering with consumers on the delivery of outcomes under the Strategy but we want to be sure that consumers are represented at every level of action. We also wonder why this group has not been involved in development of the first Action Plan?

In general, we find that people with disabilities are not appropriately considered in design processes, which can result in reducing the positive impact of measures meant to support them.

Once consumer shared with us their frustration with a system that does not understand the needs of people with disability:

> *'The system makes assumptions about what is possible for disabled people to do and places blame on people struggling rather than proactively support and accommodate.'*

People with disability are not a homogenous group. Ways in which a person with disability can be involved in decision making, and the level of support someone needs to participate or partner in decision making, depend on the type of disability they have. This may include requiring different levels of support to engage in co-design processes.

The Strategy does not speak to the support available for people to participate in committees and consultations related to implementation. It also does not specify a range of formats for consultation to ensure everyone who wants to participate can do so effectively. This support is essential to ensure representation from people with a range of different needs that must be reflected and supported by the Strategy and the actions which flow from it.

Consumers wondered about the relationship of the Strategy to other work going on in the disability sphere – for example; the Parents with Disabilities Project. How has the work of this project been connected with or harmonised with the Strategy? Have these sorts of projects been mapped to the Strategy?

HCCA members and staff have been involved in a range of related projects and recognise from experience that systems must look at people with disabilities (as well as the impediments they face) more holistically. This is true also for any actions which flow from the Strategy.

More broadly, how should this strategy align with other strategies and plans across Health, Community Services, Justice? We are aware this has been discussed by the steering group and would like to see these relationships explained within the Strategy.

How has the Strategy been developed?

This section talks about the significant consultation process undertaken in development of the Strategy. It would be good to see this section also address the principles of co-design as applied throughout this process. Many consultation processes inadvertently narrow consumer thinking around possibilities and reduce the diversity of thinking around issues and problem solving. Co-design means involving consumers or service users as equal partners in the planning or design of services, policies, programs and initiatives. You can see HCCA's co-design position statement here.

Some consumers hold concerns about consultation processes that may also impact their willingness to be involved. We heard from one consumer about their frustration with consumers not being brought in early enough in the process, and not being given the scope to participate in exploring innovative approaches:

> *'[The] Government wants to move straight to solutions and not exploring potential. They hire consultants that work to their assumed rules and result in biased consultation documents'.*

Another consumer felt that decisions and actions are too often led by what government chooses to share with consultation participants:

> *'Decisions are always shaped by what govt has put out for consultation.'*

For these reasons it is valuable to have the process explicitly detailed in the Strategy, including explanations of how consumers have been included as equal partners - in both decisions around consultation groups and explanatory documents.

Specific Drafting Suggestions

- On page 2, at the third dot point under 'who is this strategy for', it talks about 'responses to people with disability'. We believe it would be better to talk about the responsiveness of services or systems to people with disability.
- The third dot point further down page 2, which talks about poor attitudes, could perhaps say 'poor attitudes from staff'?
- The goals on page 8 are difficult to read – there are too many dot points under the main headings. We would like to see this structured in a way that is more accessible to readers. Overall, we support the three main goals, but think the structure here impacts negatively on ease of understanding for consumer readers.
- We support the intent of the Principles on page 9. To strengthen these we would like to see the removal of equivocating language. For example; under Diagnostic Overshadowing the Strategy says 'The health care system in the ACT will *work towards* lowering instances of diagnostic overshadowing'. We would like to see a stronger commitment here such as 'The health care system in the ACT *will reduce* instances of diagnostic overshadowing'. We would like to see this level of confidence in the Strategy for the Social Determinants of Health and Trauma Informed Practice also.
- We would like to see more referencing of evidence for a range of points in the Strategy. For example, on page 11 in the paragraph about financial barriers it states that 'people with disability are less likely than people without disability to have a high level of income and more likely to rely on government income support payments'. We believe claims like this, which underpin the approach of the Strategy, would ideally be referenced within the text.

Do you think anything is missing from the draft ACT Disability Health Strategy? (Responses to four of the proposed Focus Areas)

Focus Area 1 – Health information and literacy

HCCA has two areas of primary concern for Focus Area 1

- Digital health accessibility and support for consumers
- The health literacy environment – and the activities that could improve health literacy (individual and environmental) for people with disabilities.

Digital health solutions, such as telehealth, hold great potential to enhance accessibility for people with disabilities but these innovations must be accessible to everyone.

As one consumer noted:

> *'A lot of people are on the wrong side of the digital divide and these people should not be ignored.'*

Currently these innovations are hampered by a lack of commitment to accessibility from the outset. Yes, there are the known issues with access to internet, smart devices and computers but, significantly, there are also built in exclusions to programs, and models of care. One example of this exclusionary design is the Digital Health Record (DHR). The DHR holds great potential to benefit people in managing their health care. This benefit is not currently available to many due to the limited accessibility features of MyDHR (the consumer portal to access the DHR). Accessibility features for MyDHR could and should include access to the portal in a range of languages and compatibility with screen readers.

The Strategy's focus on health literacy is important and consumers are supportive of building health literacy as a vital part of improving health access and outcomes for people with disability. We would like to see a greater focus placed on environmental health literacy – to reflect the central role of facility, service and model of care design in facilitating higher levels of health literacy for people accessing care. HCCA's position statement on health literacy is available here.

Focus Area 2 – Service access, design, and delivery

Consumers raised with us a range of issues relating to service access, design and delivery. These are covered below, under the following headings:

- Accessibility
- Diagnostic Overshadowing
- Equity and Assumptions

Accessibility

Accessibility of services for people with disability is a matter not only of facility and service design but also staff skills and attitudes.

Consumers shared with us their experiences of encountering negative attitudes to disability within health care services:

> *‘Some of the most hurtful and damaging things that people have spoken to me about arise because of these attitudes and their expression’.*

Consumers would like to see the Strategy address a range of assumptions that have a negative impact on people with disability, including the assumption that clinical and administrative staff do not need training or experience to meet the unique needs of patients with disability.

Consumers made it clear that:

> *‘Even teaching people to ask “how to help” is necessary - eg “I need to do an internal examination - how are we best to do this? What would work best for you?”’*

One of the consumers shared a case study about the experience she had supporting her daughter with disability to access the health care she needs. They found that staff did not have the requisite skills to meet their needs and ultimately sought treatment privately. While this worked for them, this redress is not available for everyone and it is important that consumers can access the care they need, delivered in a way that meets their needs, within the public system. Every area of the system must be equipped to deal with disability and differing needs around communication, consent and treatment.

<u>Case study</u>

The consumer wanted to access a physio service in CHS for her daughter with a disability. She rang and asked for a practitioner with experience in disability. The service set up a longer appointment because she was assertive about her daughter’s needs. However, when they attended the appointment, the health professionals did not have the appropriate background or experience in working with people with disability, particularly intellectual disability. The appointment was a bit difficult, but they did have some thoughts about an individual treatment plan that could be set up. They have now chosen to go private for this service instead, and this has met their specific needs more appropriately.

Since then, they have needed to call the Community Health Intake line to follow up and found this a significant barrier. It took a long wait to get through and when they did, the staff could not address her query, and did not understand what she wanted or needed.

The consumer reflected that it would have been useful for the service to ask her initially about individual needs of the patient, rather than her having to ask for someone who would have the skills for this appointment.

She talked about it being best practice to have staff in health services who specialise in disabilities (ensuring this is wide ranging, considering physical, mental, mixed etc.) The consumer/carer experience is so much better when every area of a service, including intake staff, have people equipped and trained.

The consumer explained that the intake line is a real disincentive, she believes there is probably a much higher demand for services but she hears from others in the community that many people give up with the long wait times, as well as the difficulty communicating your needs with the staff once you get through.

Even when you leave your number for call back, it doesn't always happen, and if you do get a call back but can't answer, they don't follow up again and you are back to square one. The needs of consumers around the intake line seem to be so much more than what is able to be provided. Better patient navigation and support to access and coordinate services would be helpful, perhaps a disability gateway service (similar to the carer's gateway - https://www.carergateway.gov.au/).

Diagnostic overshadowing

While the Strategy explicitly commits to (working towards) addressing diagnostic overshadowing, consumers have said this does not go far enough. We know that there are personal financial and health costs to diagnostic overshadowing but there are also systemic costs to people with disability being misdiagnosed or ending up accessing multiple services seeking appropriate health care.

Some of our consumer feedback queried if there are there common diagnostic overshadowing errors that are known and can be expressly addressed with relevant clinicians and other staff. While this is likely better addressed in an Action Plan, it is useful to understand that it is a priority area for consumers.

Equity and Assumptions

Consumers also told us about their experiences of assumptions being made about their quality of life. They also told us about the way these erroneous assumptions about what they as an individual need or value impact on the health investigations and treatment options offered and thus the health decisions available to them.

Consumers are concerned that assumptions made about quality of life by clinicians and others have the potential to impact their fair access to appropriate health care. This concern has grown over the course of the COVID-19 pandemic as public discussions around risk and mortality focussed on underlying conditions implying acceptance of greater mortality among those who have chronic illnesses and disabilities. This was reinforced through formal consideration of triaging access to high level care should hospitals become overrun. When looking at competing resource uses - who will be treated and who will not - what are the assumptions authorities are making about survival and quality of life for people with disability?

Consumers are aware of this often unspoken tension and would like to see these issues illuminated and refuted by the Strategy:

> *'I feel there needs to be a lot more direct and clear attention to this in the Disability Health Strategy – it's like the elephant in the room, that no one really talks about, but it affects the health of people with disabilities.*

Both of these issues, arising from erroneous, ableist assumptions, contribute to the early death of and failure to treat people with disabilities.

Some consumers with disabilities are concerned that their lives are not valued by the health system in the same way:

> *'There are people in health care and our community more broadly who believe that people with disabilities cannot possibly have a good quality of life. In rare cases these people hold overtly eugenic beliefs, but more often, they view it as unkind to prolong the presumed suffering of the person with the disability, because they believe that they would find a life with disability unacceptable.'*

These assumptions and their impact on clinical decision making remain a serious issue. HCCA would like to see acknowledgement of these issues and a specific commitment to counter the biases continuing to impact on quality of care in the ACT Disability Health Strategy.

One consumer said they felt that:

> *'Clinicians view disabled people through negative lens.'*

The Strategy should act explicitly to counter this impression and to provide health service staff with the skills and understanding to respond supportively and compassionately to the needs and values of the individual with a disability in front of them.

We believe it is important for the Strategy to address the education of health staff, including education about stigmatising judgments and how they impact negatively on the lives and safety of people with disabilities.

Consumers shared with us that the stigmatising attitudes people with disabilities experience from health service staff has wide ranging impacts on their quality of life and decision making:

> *'The strategy does not really talk much about these stigmatising attitudes and how they reduce the life quantity and quality of people with disabilities as well as*

> *their life choices, such as whether to have children or not., and how the health professionals perceive their capacity to do various things, without actually trying things out'.*

This issue can present in two ways, as this consumer describes:

> *'I feel it works both ways to the disadvantage of people with disabilities - the health professional's own discomfort with disability may mean that they act as if the person doesn't have a disability, and so do not provide advice with reasonable adjustment in mind. Equally, they may assume the person has no strengths or abilities and so does not talk to them about choices (with or without an advocate present)'.*

Focus Area 3 – Emergency planning and management

HCCA's research on consumers' communication and information needs in the early stages of the COVID-19 pandemic showed that people with disabilities had unique information needs that were not always met by standard official pandemic communications channels. Our research showed that a greater proportion of people with a disability (31%) were accessing information from specific health professions or disease specific organisations and community organisations. This shows us that it is important that a range of non-government organisations must be involved in the design and implementation of effective emergency planning and management.

While the Strategy adequately reflects the need to involve the disability sector in development and provision of information, it neglects the role these organisations must play in supporting people with disability in times of crisis.

The ACT has historically struggled with disability conscious emergency planning. This was evident in the delayed implementation if disability specific interventions for the COVID-19 pandemic. For example, Women with Disabilities ACT report that they found it difficult to get transparent, relevant, and timely advice from governments for people with disabilities during both the 2019-2020 bushfire crisis and COVID-19. We hear anecdotally that other community organisations had similar issues. But we also saw how effective the later coordinated response between Community Services Directorate, Health Directorate, and non-government/community organisations was. Genuine collaboration can meet a wider range of needs in a more targeted way.

The Sendai Framework on Disaster Risk Reduction (2015-2030) provides a useful model for 'inclusive economic, structural, legal, social, health, cultural, educational, environmental, technological, political and institutional measures that prevent and reduce hazard exposure and vulnerability to disaster, increase preparedness for response and recovery, and strengthen resilience'[1].

We are aware that people with disabilities are likely to experience the worst consequences of climate change earlier and more significantly due to higher rates of poverty, poor quality or inappropriate housing and social isolation from the community[2]. For this reason it is important to prepare and plan for the expected increase in climate related emergencies with an appropriately inclusive framework that addresses the unique needs of this cohort.

Focus Area 5 – Data and research

Consumer participation in research

Consumer participation in research is fundamental to achieving research outcomes that can be readily applied to improved experiences and health outcomes for consumers in areas that matter most to those the research aims to benefit. The ACT Health Directorate strategic plan for research has specific actions on engaging with and increasing consumer involvement in research[3], it would be good for the Strategy to discuss what good consumer involvement in research looks like – how will consumers be involved, what will their role be and how will they be supported to participate?

Consumers shared with us a range of issues which they believe impact negatively on the availability of quality, actionable data. This included the lack of recognition that disability is not always static. Capacity and symptom severity can fluctuate and this needs to be recognised in the development of appropriate interventions that meet the needs of people with disability.

Currently data collection tends to classify people by diagnosis not the impacts the diagnosis currently has on the individual – this more nuanced information is often not available on a medical record. Assumptions and interventions are made based on a narrow subset of the experiences of people with a specific disability.

One consumer said:

> *With my rheumatoid arthritis my disability will fluctuate. It isn't always an acute presentation. Because of this I have no access to help because I am not permanently disabled. This impacts on my health.*

We strongly support the Strategy's emphasis on the need for data and research as evidence for prioritising areas of quality improvement for improving services and health outcomes for people with disability seems solid. And we caution that a breadth of data is essential for this focus to pay off in terms of appropriately targeted services.

The strategy should build on the Canberra Health Services research strategy[4] and build research collaborations and community research hubs that ensure participating in research is accessible and equitable to all consumers. equitable access to research participation and involvement helps ensure the data collected is representative of the whole population and minimises data skewing.

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[1] Sendai Framework | UNECE

[2] Women with Disabilities ACT Submission to the Disability Royal Commission on the Issues Paper on Emergency Planning and Response July 16th 2020 Publications – Women With Disabilities ACT (wwdact.org.au)

[3] Better together: A strategic plan for research in the ACT Health system 2022-2030

[4] Canberra Health Services: Research Strategy 2021-2025