Consumers Health
Forum OF Australia

SUBMISSION

Australia's Disability Strategy Review

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P: 02 6273 5444
E: info@chf.org.au

twitter.com/CHFofAustralia
facebook.com/CHFofAustralia

Office Address
7B/17 Napier Close,
Deakin ACT 2600

Postal Address
PO Box 73
Deakin West ACT 2600

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CONTENTS

Contents

Introduction

Consumers Health Forum Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those interested in healthcare consumer affairs. CHF works to achieve safe, quality, and timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is consumer-centred care.

CHF supports a review of Australia's Disability Strategy (ADS), noting this was a recommendation of the recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission).

Achieving health equity for Australians requires health services and information to be accessible and inclusive for everyone – including people with disability.

People with disability are more likely to have poorer general and mental health than people without disability, have higher self-reported rates of use of mainstream health services (other than dental) and are more likely to face barriers accessing healthcare services.[1]

As outlined in the Discussion Paper for this review, the recent Disability Royal Commission found that many people with disability experience negative attitudes and discrimination that limit their access to healthcare, diagnosis, and decision-making about their own health. The disability community has consistently called for improved disability awareness and accessibility across the healthcare system.

The current ADS recognises that good health is a fundamental requirement of a good life and has included health and wellbeing as a key outcome area within the ADS. CHF's response primarily focuses on this outcome area.

Importantly, CHF would like to emphasise the need for a diversity of people with disability to be central to the design, implementation and evaluation of all aspects of the ADS. There is evidence that people with disability have poorer morbidity and mortality than the general population, and that this disadvantage is heightened even further for those with intersectional disadvantage. Recent reform in the disability space, particularly in relation to the NDIS, has not prioritised meaningful and genuine engagement and co-design processes. It is critical to ensure that the lived experience of people with disability is central to and reflected in all aspects of the ADS, including this review.

CHF Recommendations

CHF supports the proposed key recommendations:

- Refine ADS mechanisms to support a nationally coordinated approach to implementing ADS.
- Consider developing new Targeted Action Plans.
- Identify ways to support best practice approaches on accessible communications (including those related to health).
- Extend ADS data and reporting to improve visibility of intersectional experiences.
- Embed mechanisms that will support the early identification of delayed and undelivered TAPs actions.
- Develop and implement an ADS Community Engagement Plan, in addition to the existing ADS engagement commitments.

CHF also makes the following recommendations:

- Ensure that people with disability are at the centre of the design, development and implementation of all aspects of the ADS.
- Prioritise an integrated approach to action and initiatives related to the health and wellbeing of people with disability, including a focus on:
    - Improved coordination between the disability/NDIS, health care and aged care systems.
    - Building the capacity and capability of the workforce to respond to the diverse needs of all people with disability.
    - Ensuring national health prevention messaging and initiatives are accessible and inclusive.
    - Building the health literacy of all people with disability.
    - Coordinating action on the recommendations of the Disability Royal Commission.

Draft Findings and Recommendations

Draft Finding 1: More needs to be done to support a coordinated approach to ADS implementation across governments
Recommendation: Refine ADS mechanisms to support a nationally coordinated approach to implementing ADS.

CHF supports Finding 1 and the associated recommendation. A nationally coordinated approach is essential to ensure the ADS is effective. Further, the ADS should respond to and align with the significant reform work underway across the disability sector, both nationally and at a state/territory and local level.

Draft Finding 2: There is strong support for new Targeted Action Plans (TAPs)
Draft Recommendation: Consider developing new TAPs on: Inclusive Homes and Communities; Safety, Rights and Justice; Community Attitudes.

CHF supports the ADS Advisory Council advice that there is a need for more TAPs and an opportunity for the next round of TAPs to be more ambitious and directly linked to enabling and embedding system-wide change.

CHF welcomes the suggested TAP on Community Attitudes and suggests that this could incorporate a focus on addressing both conscious and unconscious stigma and discrimination, including within the healthcare system.

CHF also suggests there may be opportunities for additional TAPS that focus on health –see the section below on **Outcome Area: Health and Wellbeing** for further details.

Draft Finding 3: Accessible information and communications are vital for safe and inclusive communities
Recommendation: Identify ways to support best practice approaches on accessible communications.

CHF agrees that accessible communications should be a priority for long-term action within the ADS. This should include a particular focus on health information.

Accessible health information and communications are central to the safety, wellbeing, independence, and inclusion of people with disability. Ensuring that appropriate public health information is available in a variety of formats, supports and equips people with disability to make their own choices about the health services and supports that best suit them.

As indicated in the Discussion Paper, there are currently no clear requirements or standards related to accessible information and communications and this is an oversight that should be remedied.

Recommendation 6.1 of the Disability Royal Commission called for a national plan to promote accessible information and communications focusing, in the first instance, on information and communications about preparing for and responding to emergencies and natural disasters, and public health.[2]

In response, the Australian government has committed $12.3 million for a national approach to accessible information and communications for people with disability, including the development of an Associated Plan under Australia's Disability Strategy 2021–2031.

CHF calls for this Associated Plan to incorporate a focus on public health information and to align with current national work on health literacy, including the development of a National Health Literacy Strategy.

Importantly, people with disability must guide and be meaningfully involved in the development of accessible information and communication to ensure that it is fit for purpose and responds to the diverse needs of all people with disability.

Draft Finding 4: ADS reporting does not support government accountability, implementation compliance, or recognising intersectional experiences of people with disability
Draft Recommendations: Extend ADS data and reporting to improve visibility of intersectional experiences; Embed mechanisms that will support the early identification of delayed and undelivered TAPs actions.

CHF supports the disability community's call for greater transparency in ADS reporting and representation of intersectional experiences through collection of, and reporting on, data for intersectional cohorts.

There is evidence that people with disability have poorer health outcomes and experience greater barriers to healthcare than the general population, and that this disadvantage can be heightened even further for those with intersectional disadvantage. For example, data shows that there are more experiences of discrimination from health staff (such as a doctor or a nurse) amongst people with disability in outer regional and remote locations (8%) compared to inner regional (3.9%) and major cities (2.7%).[3] Further, people who are homebound due to the severity of their disability are an identifiable and often overlooked cohort with intersectional disadvantage within the disability sector. Improving the visibility of intersectional experience in data and reporting is critical to accurately capture and reflect the diverse, complex needs and experiences of people with disability, to promote equity and to drive informed, inclusive advocacy.

CHF also supports greater identification of delayed and undelivered TAP actions through more robust reporting mechanisms.

Draft Finding 5: For ADS to achieve is goals, it is critical that people with disability are genuinely involved in the design, implementation, and governance of ADS
Draft Recommendation: Develop and implement an ADS Community Engagement Plan, in addition to the existing ADS engagement commitments

It is essential that people with disability are not only involved in, but **lead** the design, implementation and governance of ADS. Priorities for reform must informed by lived experience. There are recent concerning examples of disability reform that have occurred without genuine and meaningful co-design with the disability community, including the recent passing of the NDIS Amendment Bill.[4] Further, the lack of government commitment to act on recommendations of the Disability Royal Commission has left the community disheartened and angry.

The current ADS commitment to one public forum or consultation every year is simply inadequate – particularly given the fact that significant disability reform has been occurring recently within very short and often inadequate time periods that are not conducive to meaningful engagement and consultation.

While the suggestion of a community engagement plan sounds positive, this must be informed by the needs and preferences of people with disability to ensure it is effective.

Further, there is a need to ensure that engagement is inclusive of and responsive to the very diverse needs and intersectional experiences of people with disability. For example, engagement opportunities should enable online engagement for people who are homebound, translators for people with disability from a CALD background, access to Auslan translators for those who require them, Easy Read materials for those with intellectual disability, and so on. The only way to ensure inclusivity and accessibility is to actively and meaningfully involve people with disability from the outset.

Outcome Area: Health and wellbeing

Do you agree that the health, allied health, and mental health services should be a priority for future work under ADS?

CHF strongly agrees that health, allied health, and mental health services should be a priority for future work under ADS.

While the relationship between disability and health is complex, generally people with disability have poorer health and higher levels of psychological stress than people without disability.[5]

Access to quality health care is a fundamental human right. However, data has shown that people with disability are more likely than the general population to face barriers to accessing healthcare services. In 2018, for example 7.6% of people with disability under 65 delayed or did not see a GP when they needed to because of cost and 1 in 4 (24%) people aged 15–64 with disability waited longer than acceptable to get an appointment with a GP.[6]

As noted within the Discussion Paper for this consultation, "the disability community has told us that disability awareness and accessibility need to improve across the healthcare system."

It is well recognised that people with intellectual disability face significant barriers to healthcare access and use.[7] Action to improve the health of people with intellectual disability is welcome and currently being progressed through the National Roadmap for Improving the Health of People with Intellectual Disability (as well as the Intellectual Disability Health Capability Framework and the Primary Care Enhancement Program for People with Intellectual Disability). However, there remains a lack of coordinated national action that responds to the diverse health and wellbeing needs and experiences of all people with disability.

People with disability often have complex comorbidities that require individualised, coordinated, multidisciplinary approaches for safe delivery of health care. While our health system acknowledges this, it does not currently deliver on it.

For example, people with disability who are homebound face systematic exclusion from the primary healthcare system. Many of these people currently have no access to Medicare-subsidised telehealth, due to the annual face-to-face consultation telehealth eligibility rule.[8] Without access to primary health care, these people cannot get the reports they need to access disability supports, income support, education adjustments, and so on.

Consumers also face challenges in the interaction between disability services/NDIS and the health system. For example, CHF has heard reports of hospitals commonly not catering for the needs of people with disability, resulting in significant safety issues:

> *"One simple example is meal trays being removed untouched because the inpatient either does not even know the meal tray was delivered or because they know the meal tray is there, but they cannot feed themselves. There must be a way to identify needs and then to meet them." – healthcare consumer advocate*

Currently, the NDIS will not pay for support workers while a person is in hospital, on the grounds that it is assumed the hospital staff will assume care for the patient.[9] As demonstrated above, this can be an inaccurate assumption that may ultimately lead to neglect and poor health outcomes.

Stigma and discrimination across the healthcare system can also impact significantly on the wellbeing and safety of people with disability. As outlined in the Disability Royal Commission Report, attitudes and practices that deny or limit people with disability's access to quality health care can include:

- Devaluing of their lives and both conscious and unconscious bias
- Attributing symptoms or behaviours to a person's disability rather than considering they may be signs of a health problem or condition unrelated to disability.
- Failing to listen to people with disability and their families.
- Failing to provide necessary adaptations and supports.[10]

How should ADS take action towards improving health, allied health, and mental health? In what other ways could we improve this Outcome Area?

To date there has been a lack of clear actions/progress within the Health and Wellbeing Outcome Area, reflected in the lack of reported outcomes.[11]

For example, the Health and Wellbeing Outcome Area includes a key policy priority of 'All health service providers have the capabilities to meet the needs of people with disability' – yet there are no clear goals or actions against this priority, which limits the potential for progress. The practical actions reported against the Health and Wellbeing area in the ADS Implementation Report[12], while positive, are siloed and do not represent a coordinated or nationally driven approach to systemic change.

CHF recommends that the ADS priorities integrated and coordinated action focused on improving the health and wellbeing of people with disability. This could be achieved through the development of an Associated Plan specifically focused on health and wellbeing, or through a series of Targeted Action Plans. Importantly, people with disability must be at the centre of the design, development and implementation of an Associated Plan and/or Targeted Action Plans.

The ACT has recently released a Disability Health Strategy and Action Plan, that aims to make sure people with disability have equitable and appropriate access to healthcare in the ACT. A similar approach at a national level would allow for this critical area to receive the attention and funding it requires and foster a coordinated, national commitment to improving access to high quality healthcare for all people with disability. It would provide an opportunity to build on and align work already underway (including the National Roadmap for Improving the Health of People with Intellectual Disability) and move towards a more integrated model and approach.

Action towards improving the health and wellbeing of people with disability must incorporate a focus on improving coordination between NDIS/disability services, health services and aged care services. This would support more integrated and appropriate care for people with disability and reduce challenges navigating each system. The siloing of funding streams for these three interrelated service systems and the lack of coordination between them leads to poor outcomes and low navigability. The onus on being able to navigate the system should not sit with the consumer, but rather the system should be built so that people can easily engage with it.

For example, recent research has demonstrated that emergency departments and NDIS providers working more collaboratively would better support people with psychosocial disability presenting to emergency departments.[13] Currently, ED clinicians appear to be unclear about what the NDIS provides and communication between the two systems is fragmented and inconsistent.

Further, the ADS should support targeted action on building the capability and capacity of the workforce to respond effectively and appropriately to the diverse needs of people with disability, including reducing both conscious and unconscious biases, stigma and discrimination.

The ADS should also prioritise action on prevention and building health literacy. National health prevention messaging and initiatives must be inclusive and accessible to people with disability to be effective. For example, women with intellectual disability are less likely to participate in breast screening, but recent research has identified 52 key strategies that could be taken up by health services to address this issue, including ensuring accessible information is available and the use of peer mentors.[14]

Health literacy is critical to enable people with disability to become informed consumers and to advocate for their needs. Research shows that many people with intellectual disability have low health literacy, making it more difficult for them to understand how and when to access health services, and to know which services will meet their needs.[15] The National Health Literacy Strategy (currently in development), should address this and include a focus on accessibility, which action under the ADS could then build on and align with.

The ADS should also ensure oversight of and advocacy for recommendations made by the Disability Royal Commission, including (but not limited to):

- Review of national health agreements, strategies and plans that affect people with disability, including the National Health Reform Agreement and Mental Health and Suicide Prevention Agreement.
- Embedding the right to equitable access to health services in key policy instruments.

- Increasing capacity to provide supports and adaptations through improved guidance, funding and accessible information.
- Introducing disability health navigators to support navigation of health care for people with disability.[16]

Prioritising and supporting a coordinated approach to health reform that improves the lives of people with disability should be a central goal of the ADS, driven and led by the needs, experiences and insights of people with disability themselves.

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