Submission to the Australian Government Department of Social Services consultation on a new National Disability Strategy – Stage 2 Consultations

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Background

The Continence Foundation of Australia (the Foundation) made a written submission to the Australian Government Department of Social Services consultation on a New National Disability Strategy – Stage 2 Consultations. The consultation asked for feedback on the elements proposed to create the architecture, rather than any specific interventions, of the 2020-2030 National Disability Strategy (the Strategy). The Foundation provided feedback via an online guided questionnaire.

1. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

The Continence Foundation of Australia (the Foundation) supports the vision and agrees the six outcome areas of: economic security; inclusive and accessible communities; rights protection, justice and legislation; personal and community support; learning and skills; health and wellbeing are still the right ones to focus on to achieve the vision. These outcome areas address the major barriers identified by people with disability, their carers and supporters in the *Shut Out* report of 2009: 'Excluded and ignored'; 'Broke and broken'; 'Can't get a job'; 'Can't get there, can't get in, can't get it'; 'The wasted years'; and 'Isolated and alone'.

2. What do you think about the guiding principles proposed here?

Guiding principle: Universal design

The Foundation supports implementing **Universal design**, raising basic standards for people with disability. Changing Places and Adult Change facilities are examples of removing barriers to participation for people with complex disability.[1-2] The *Review of Implementation of the National Disability Strategy 2010-2020's* highlighted Changing Places as a positive implementation example due to:

- cooperation across governments

- partnerships with advocates and community organisers
- engagement with people with disability, and
- learning from good practice.

The Foundation supports other universal design initiatives including:

- BINS4Blokes – disposal bins for incontinence products in all toilet facilities
- Stoma changing facilities

Guiding principle: Support carers and supporters

Universal design will provide greater support and/or decrease requirements for assistance from **carers and supporters**. The Foundation supports recognition and inclusion of carers throughout the Strategy in accordance with the Carer Recognition Act 2010. Given the time-consuming nature and physical and emotional impact of caring for someone with incontinence compared to caring for someone without incontinence[3] the Strategy should address carers and supporters needs to sustain their important roles and support improved socio-economic outcomes for both carers and people receiving care.

Guiding principle: Involve and engage

The Strategy must ensure individuals and disability organisations are consulted, informed, and listened to. Implementation must be appropriately resourced to **involve and engage** people with a wide of range of abilities so the Strategy can be genuinely co-produced.

3. What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

The new Strategy should have a stronger focus on improving community attitudes. This is, and has always been, a key part of the advocacy strategy for the Continence Foundation of Australia. As set out in The Foundation’s vision statement, we aspire to an Australian community free of the stigma and restrictions of incontinence.[4] Community attitudes must be improved; towards disability in general and towards incontinence as both a chronic health condition and disability, given a significant part of our consumer base have a lived experience of disability.

Having active campaigns in the public eye will help to achieve acceptance from and improve community attitudes. These include the Changing Places, Adult Change and BINS4Blokes initiatives as mentioned previously. They comprise important steps to transforming community attitudes and behaviours towards people with disability. Implementation of these campaigns should not be the exception but part of mainstream expectations and infrastructure. It is by creating inclusive environments that people within the community can become acclimatised to, learn about and more easily accept changes.

The Foundation’s focus on disability is founded upon the need to deliver positive systemic change across all outcomes by:

- Creating greater community awareness and understanding around the issue
- Facilitating higher quality service provision, and
- Advocating at a policy level.

4. How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

The Foundation recognises difficulties experienced by many consumers navigating complex government systems to get the assistance they need. This is especially the case at the interface of health care and disability support contained in the NDIS Price Guide and Support Catalogue.[5-6] Eligibility to claim disability-related health supports is limited to ongoing needs, directly related to a significant and permanent functional impairment and must not be the usual responsibility of the health system. For example, people with incontinence who are NDIS participants must firstly access appropriate health professional care to ensure optimal continence management (Assessment, Planning and Provision of Disability-Related Health Supports). They must then ensure their NDIS plan is funded to provide their individualised continence product requirements (Low-Cost or High Cost Disability Related Health Consumables).

People who are not eligible for the NDIS must navigate their condition and financial eligibility for the Commonwealth Continence Aids Payment Scheme (CAPS)[7] as well as various state and territory assistance schemes.

Clearly outlining government responsibilities is necessary but not sufficient. It should be complemented by recurrent program funding for system navigators[8], assisting people with disability, their carers and supporters to successfully address their needs across the six outcome areas of the Strategy.

5. How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability? (Examples of the non-government sector include big, medium and small businesses, community organisations, employees of these businesses, private research, investment organisations and individuals.)

The Foundation believes NGOs have a vital role to play in improving outcomes for people with disability. A greater focus should be placed on the role of health peak bodies, such as the Continence Foundation of Australia, due to their collective capacity to promote and deliver a wide range of specialised activities. A peak body is a ‘representative organisation that provides information dissemination services, membership support, coordination, advocacy and representation, and research and policy development services for its members and other interested parties’.[9]

Health peak bodies provide significant services to the disability sector. As an example, the Foundation provides services for people living with disability through:

- NDIS services
- National Continence Helpline
- National Public Toilet Map
- Health promotion activities, and
- Education work advocating for better person-centred care and upskilling of the workforce.

Health peak bodies are therefore well placed to promote the rights and needs of people living with disability, not only in the health and well-being outcome area. Having evidence-based practices informed by industry expertise, including health peak bodies such as the Foundation, also aligns with government priorities to ensure a high quality, person-centred workforce is available across the disability, aged care, health and mental health care sectors.

6. What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

The *Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities* report acknowledges the current reporting mechanisms of the Strategy have been ineffective in ensuring action or accountability due to a lack of measurable goals. Additionally, it stated measurable goals that are qualitative and quantitative should be included. The Foundation agrees with these statements but also recommends the outcome measures should be validated.

Both incontinence and disability have a measurable impact on quality of life. One study found that a higher degree of moderate or severe disability is observed in populations (women) with incontinence compared to those without.[10] From research the Foundation has conducted, we know the incidence of incontinence is high across a wide range of disabilities including stroke, autism and down syndrome. Furthermore, these studies recommended attention for continence issues should be provided in the form of screening, assessment and treatment.[11-13]

Examples of information that should be recorded to measure progress and included in information made available to the public include use of validated tools, measuring key indicators such as quality of life, incidence of incontinence, and implementation of appropriate continence plans. Annual reporting would ensure the Strategy remains relevant and can be continuously evaluated.

7. How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

The new Strategy needs to have representation from a wide range of parties across all stages of the strategy. This should include people living with disability and incontinence, their carers and supporters, membership based organisations especially peak bodies, which have strong representation from disability community members, health consumers, LGBTI groups, culturally and linguistically diverse and Aboriginal and Torres Strait Islander communities.

For the Strategy to be open to continuous improvement and continuous feedback from these individuals and groups, the Foundation recommends the National Disability and Carers Advisory Council be resourced to have oversight of delivery and monitoring throughout the life of the Strategy. This should include at a minimum, annual check-ins with the community about successes and challenges in addressing the six outcome areas.

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