



**Continenence  
Foundation  
of Australia**

# **A New Disability Services Act**

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## Introduction

The Continence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the consultation on the New Disability Services Act. We see this development as an important step to ensuring that the voices of people with disability are reflected in Australia's strategies and services that aim to enable people with disability to enjoy their human rights and full participation in their communities.

The Continence Foundation of Australia is the peak body for promoting continence (bladder and bowel control) health. The expertise of the Foundation includes policy and advice to support reform, education, awareness, information, advocacy, continence service provision, and more importantly, experience of putting people at the centre of program design. This expertise and extensive experience enables the Foundation to be best placed to represent the interests of individuals, carers and health professionals in relation to continence, at national and state levels.

## Disability and Incontinence

Incontinence has a significant burden on Australians across the life course, yet its impact largely remains unrecognised:

- One in four Australians above the age of 15 experience incontinence.<sup>1</sup>
- Approximately one in three Australians with a disability currently experience incontinence.<sup>2</sup> For NDIS participants, who usually have a greater level of functional impairment, this will likely mean a higher proportion require safe and effective continence supports.
- Occurrence of incontinence is not inevitable with age. Over half of women and more than one in three men living in the community with incontinence are under 50 years of age.<sup>1</sup>
- Incontinence costs Australians \$67 billion annually including health system expenditure, productivity losses, cost of care and burden of disease.<sup>1</sup>
- The burden of disease of incontinence is associated with almost 140,108 Disability Adjusted Life Years (DALYs) or years of life lived with disability annually.<sup>1</sup>
- People experiencing incontinence (urinary and faecal) are significantly more likely to report lower quality of life.<sup>3-5</sup>
- People aged 15 years and over with severe incontinence are more likely to report being in fair (34%) or poor (22.2%) general health than people without severe incontinence (24.8% and 10.4% respectively).<sup>6</sup>
- Incontinence is a common co-morbidity with other disabilities including autism, down syndrome, stroke, multiple sclerosis, cerebral palsy and spina bifida.<sup>7-12</sup> There is also an increased risk of experiencing incontinence as a direct result of other chronic conditions including cancer, diabetes, asthma and heart/cardiovascular disease.<sup>13</sup>

For people with incontinence, the complexity of their incontinence symptoms and management can affect multiple aspects of their lives. People living with incontinence can be stigmatised which can lead to withdrawal from work, social, physical and sexual activities<sup>14</sup>, or concealment of their incontinence, all of which can impact negatively on a person's mental health.<sup>15-16</sup> The stigma of incontinence must be addressed to protect the rights of people living with it, so they feel accepted and treated with dignity and respect.

Workforce participation is significantly impacted by incontinence and people with severe incontinence are more negatively affected in terms of employment than those without<sup>1</sup>.

Disability associated urinary incontinence is defined by the International Continence Society (ICS)<sup>17</sup> as *urinary incontinence in the presence of a functional inability to reach a toilet in time*. This may occur in those living with a physical, sensory, psychological or intellectual disability and can impact their capacity to maintain continence.

Disability associated incontinence is when a person:

- has altered physiology or bodily functions as a direct part of their disability;
- has no ability to sense or control their bladder and bowel as a result of their disability;
- has not had the ability to develop bladder and bowel management due to features of their disability;
- is unable to access the required supports to access toileting/hygiene facilities in a timely manner, or to self-manage their clothing; and/or
- is unable to process the sensory demands of toileting or has experienced trauma that impedes on their function.

### **Recommendations:**

- 1. The Foundation recommends that in addition to points (i), (ii) and (iii) in object c), health care and services be incorporated into the objects and be subject to the planning, development, implementation and review in conjunction with people with disability as per object d).**
- 2. The Foundation recommends the adoption of a social model of disability in the new Act.**
- 3. The Foundation recommends the adoption of the definition of disability contained in the UN Convention on Rights of People with Disability.**
- 4. As per our position in relation to the objects of the Act, we recommend that health care and services (inclusive of continence care and support) be included in the supports and services covered by the Act.**

## The Foundation's Response to Consultation Questions

### 1. Do you agree with the proposed objects for the new Act? What other objects should be included in the new Act?

The Foundation welcomes the proposed objects for the new Act and agrees that they underpin the intention of the review.

The proposed objects recognises that people with disability are more likely to live in poverty, have poor-quality or insecure housing, low levels of participation in workforce and education, and be socially excluded or marginalised. However, by omission the proposed changes to the Act fail to address the importance of equitable access to health care and services, despite health and wellbeing being one of the priority areas of Australia's Disability Strategy 2021-31.

Incontinence is a common health condition, affecting one in four Australians above the age of 15<sup>1</sup> and approximately one in three Australians with a disability,<sup>2</sup> and is capable of early recognition, potentially preventable and always manageable. Nonetheless, incontinence has not been accorded priority focus in health policy and services as a manageable chronic health condition, impacting on the health, wellbeing, social and economic participation of people living with it, including people with disability associated incontinence. People with incontinence require support to manage their incontinence and optimise their bladder and bowel control. Achieving this through better planned and implemented health services will help them in maintaining independence and to be able to participate in society fully and meaningfully.

- **The Foundation recommends that in addition to points (i), (ii) and (iii) in object c), health care and services be incorporated into the objects and be subject to the planning, development, implementation and review in conjunction with people with disability as per object d).**

### 2. Do you agree with the proposed approach to the target group? How do you think the target group should be defined?

The recognition of the multiple barriers people with disability face is essential to ensure there is a multi-faceted approach to addressing the discrimination and stigma faced by people with disability, as is the recognition of the common shared characteristics, and intersectionality that may contribute to greater disadvantage for some individuals and communities.

The Foundation believes the social model of disability will enable this, and will contribute to recognition of incontinence as a barrier to full participation, due to the complex ways in which it interacts with other impairments and barriers people with disability face.

- **The Foundation recommends the adoption of a social model of disability in the new Act.**

### **3. Do you think the new Act should include a definition for disability? Do you have any additional comments?**

- **The Foundation recommends the adoption of the definition of disability contained in the UN Convention on Rights of People with Disability.**

This definition will give greater recognition to Australia's responsibilities as a signatory to the UN Convention on the Rights of Persons with Disability (UN CRPD), and to strengthen Australia's response to the discrimination and stigma experienced by people with disability.

Incontinence, or loss of bladder and/or bowel function, is recognised as a disability under the Disability Discrimination Act 1992. However, this has not translated into an adequate approach to assess, manage incontinence, and support people living with it, through the implementation of disability and health strategies. The Foundation believes that the adoption of UN CRPD definition and an approach in line with the social model of disability, will provide a broader and more nuanced understanding of disability and the stigma and other barriers to full participation faced by people with disability, including those who experience incontinence.

### **4. Do you agree with the supports and services listed? What other kinds of supports and services should be included in the new Act?**

The Foundation agrees that supports and services included in the new Act should be broad and should include flexibility to respond to emerging needs and changing circumstances, as well as future developments in disability services and provision of supports.

Projections from the 2010 Deloitte report *The Economic Impact of Incontinence in Australia* found that the total number of Australians with urinary or faecal incontinence or both is projected to be 6,217,663 by 2030.<sup>1</sup> The increasing prevalence of incontinence, and the needs emerging from it must be addressed by the Disability Services Act through provision of supports and services to people with disability.

Supports and services under the Act should also address continence needs the person living with disability faces to support their participation in the community including work, education, social and recreational activities.

- **As per our position in relation to the objects of the Act, we recommend that health care and services (inclusive of continence care and support) be included in the supports and services covered by the Act.**

## **Conclusion**

The Continence Foundation of Australia welcomes this review of the Disability Services Act. It provides the opportunity to ensure Australia upholds its obligations as signatory to the UN Convention on the Rights of People with Disability, and to promote the equal and active participation of all people with disability.

We look forward to working with the Government and the disability sector to ensure supports and services provided to people with disability also recognise the impact of incontinence on participation and wellbeing.

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