



Submission to the Australian Government Department of Social Services consultation on the National Disability Employment Strategy

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The Continenence Foundation of Australia (the Foundation) welcomes the opportunity to respond to the Australian Government Department of Social Services consultation on the National Disability Employment Strategy.

The Foundation considers disability employment to be a key gauge of, and the gateway to, socio-economic, cultural participation and the wellbeing of all Australians with disability including people experiencing incontinence.

The Continenence Foundation of Australia

The Continenence Foundation of Australia is a not-for-profit organisation and the national peak body promoting bladder, bowel and pelvic floor health. Our vision is an Australian community free of the stigma and restrictions of incontinence.

The Foundation develops and delivers a range of initiatives in partnership with the Australian Government helping the Australian Government to achieve the objectives of the National Continenence Program which focuses on increasing education and awareness of bladder and bowel health in Australia to:

- Promote bladder and bowel health and prevention messages across the lifespan,
- Increase education and awareness of the treatment and management options available to people affected by incontinence, and
- Facilitate access to a range of information and support services.

The Foundation's membership broadly represents the specialist and non-specialist continence sector and workforce who provide care and services for, and raise awareness and advocate, on behalf of Australians with bladder and bowel control problems. The Foundation takes an integrated approach to the provision of education and professional development and plays an active role in supporting the upskilling of specialist and non-specialist continence health professionals including its contribution to evidenced-based documentation including national guidelines and policy reforms.

Summary

The Foundation holds significant reservations about the National Disability Employment Strategy's approach to addressing the barriers, challenges and stigma faced by people living with disability, including incontinence. The National Disability Employment Strategy (the Strategy) includes some key elements of what is required to promote the dignity, independence, accessibility and inclusivity of people living with disability within the disability employment sector. However, the Strategy will benefit from greater coordination with the new National Disability Strategy¹ so the focus shifts to achieving a person's potential through support for, and during, employment rather than simply providing access to meaningful employment opportunities. The Strategy will also be more effective for more people by extending priority area two from making only young people with disability job ready to all people with disability looking for work.

Loss of bladder and bowel function is recognised as a disability under the Disability Discrimination Act 1992, and can have an immense impact on the one in four Australians experiencing incontinence and the people who care for them.² An estimated one in three people with disability in Australia also experience incontinence.³ Altogether, this amounts to \$34 billion annually in productivity costs.² Ongoing stigma and discrimination also add significant barriers making it even more difficult for people living with incontinence to participate in the community and the disability employment sector.

Workforce participation is significantly impacted by incontinence. People with severe incontinence are more negatively affected in terms of employment compared to people without.⁴ This has adverse consequences for independence, confidence and workplace engagement. Further, self-managing incontinence or caring for others with incontinence places significant strain on individuals contributing to ongoing and perceived stigma and discrimination faced. For people with incontinence at work, it can reduce workplace productivity, job satisfaction and create stressful, inefficient self-management techniques highlighting the imperative for interventions in the workplace and across the disability employment sector.

To address these gaps within the Strategy, the Foundation has outlined four key areas to facilitate a person-centred and sector-wide approach to employment for people living with disability, including incontinence:

- The Continence Foundation of Australia's position as a national peak body be leveraged to develop a collaborative, multisector approach to support employment for people living with incontinence as part of the Strategy.
 - Develop continence-specific guidelines to support and enhance workforce participation of people living with incontinence, and their carers
 - Ensure economic security for all people living with disability, including incontinence
 - Foster coordination between workplaces and continence services to deliver comprehensive assessment, diagnosis and workplace specific management plans.
 - Implement inclusive projects and campaigns to promote acceptance and accessibility to the workplace of people living with incontinence.

An ambitious vision to drive progress

The National Disability Employment Strategy has some clear aims and guidelines to develop the disability employment sector in Australia. A multisector collaborative approach outlined in the Strategy will benefit many people living with disability, including incontinence, their supporters,

carers and employers. However, the Foundation believes significant changes must be made to the Strategy's vision and subsequently, its key focus areas to facilitate the necessary robust groundwork.

By adopting an ambitious vision, it will drive meaningful change across all aspects of the Strategy. It will encourage people with disability, and supporting organisations such as employers, to take confidence and build on this framework to boost workforce and community participation by people with disability. Only then will the Strategy enable holistic support that is individualised, dignified and considerate of the needs of all people in the disability community, including people living with incontinence.

The Strategy's vision should be better coordinated across the disability sector

The Foundation believes the vision outlined in the National Disability Employment Strategy Consultation Paper has considerable room for improvement. In short, the National Disability Employment Strategy's current vision is not ambitious enough. Instead of a vision aiming for 'An inclusive Australian society where all people have access to meaningful work opportunities', it should complement and add to the vision outlined in the new National Disability Strategy position paper¹: 'An inclusive Australian society that enables people with disability to fulfil their potential as equal members of the community [and in the workplace]'.

Access to meaningful work opportunities on its own does not automatically translate into employment. What is also required is assistance to become employed, ongoing support while working and professional development, all of which must be relevant and meaningful. Also, acknowledgement and planning of programs for intervention should consider and complement individual status relating to participation in existing disability programs such as whether they are an NDIS, prospective NDIS or non-NDIS participant. To deliver the most effective interventions, the Strategy must focus on delivering holistic support and development through employment for people living with a disability, including incontinence, for the Strategy to remain cohesive and in line with the new National Disability Strategy.

A National Disability Employment Strategy for all people with disability

While the Foundation generally supports the four priority areas, there is considerable concern over the second priority area – 'Building employment skills, experience and confidence of young people with disability'. The focus only on young people with disability precludes much of the disability population who experience barriers to appropriate and meaningful workplace employment, engagement and relevant supports. While the focus of priority area two appears to be on young people with disability who are transitioning between study and work according to the Strategy's consultation paper, there are many other opportunities to target people with disability of all ages, including people who acquire a disability during their working life and older people.

The Australian Human Rights Commission (AHRC) found that employment discrimination against older people and people with disability is systemic, acts as a significant barrier to workforce participation and requires a multifaceted response.⁵ The AHRC report clearly states that 'employment discrimination is also a huge waste of human capital'. In addition, poor health was found to be a leading cause of premature and involuntary retirement and imposes a great cost to the economy due to loss of work productivity.⁵

The Strategy should also proactively attend to barriers faced by people living with disability within specific demographic groups including by age, gender, sexuality, employment status, NDIS and non-NDIS participants, COVID-19 and bushfire affected communities, Aboriginal and Torres Strait Islander communities and experience of incontinence. It is important for the focus of this priority area to be

on people with disability of all ages because it is only in this way that the central priority area of the Strategy 'Changing community attitudes' can be upheld for all. The Foundation believes the Australian Government must fulfil its responsibilities under the UN Convention on the Rights of Persons with Disabilities (CRPD) by using all available opportunities to demonstrate leadership in improving employment prospects, support and professional development for all people living with disability.

Furthermore, the Foundation believes the Strategy should borrow from the National Disability Strategy position paper on its guiding principles of 'involve and engage', 'design universally', 'engage the broader community', 'address barriers faced by priority populations' and 'support carers and supporters'. This way, the Strategy would be cognisant of the broader key issues being faced and deliver significant positive flow on effects for people living with disability, including incontinence, their employers and the wider community.

The impact of incontinence

Incontinence is a multifaceted and complex condition that is under recognised and under-served across the Australian population, including within the disability community. Incontinence, or loss of bladder and/or bowel function, is recognised as a disability under the Disability Discrimination Act 1992 but this has not translated into an adequate approach to support, manage and treat incontinence within the disability sector. Likewise, incontinence has not been recognised for its impact on employment nor the needs of people experiencing incontinence and the supports they require.

Incontinence has a significant burden on Australians across the life course yet its impact largely remains obscured at a national level:

- One in four Australians above the age of 15 experience incontinence.²
- Approximately one in three Australians with a disability currently experience incontinence.³ 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.²
- Incontinence costs Australians \$67 billion annually including health system expenditure, productivity losses, cost of care and burden of disease.²
- 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.²
- People experiencing incontinence (urinary and faecal) are significantly more likely to report lower quality of life.⁶⁻⁸
- People aged 15 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).⁴
- Incontinence is a common co-morbidity with other disabilities including autism, down syndrome, stroke, multiple sclerosis, cerebral palsy and spina bifida.⁹⁻¹⁴
- It is also a key risk factor for other chronic conditions¹⁵ including cancer, diabetes, asthma and heart/cardiovascular disease.³

For people with incontinence, the complexity of their incontinence symptoms and management can affect multiple aspects of their lives. People living with incontinence are stigmatised which can lead to withdrawal from work, social, physical and sexual activities¹⁶, or concealment of their incontinence, all of which adds to mental health issues.¹⁷⁻¹⁸ 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.

Incontinence and workforce participation

Incontinence can have a significant impact on workforce participation. This effect often increases according to the severity and level of assistance required to manage incontinence. Evidence indicates that for people of working age with severe incontinence, labour force participation was less than half that of people without severe incontinence (26.1% compared to 55.8%)⁴ meaning they are more likely to be under greater financial stress and have lower economic independence. This trend is mirrored in people with incontinence who require assistance. For people aged 15-64 who always or sometimes needed assistance with managing bladder or bowel control, only 20.4% participated in the workforce, compared to 42.3% who had difficulty but did not need assistance and 56.8% who had no difficulty at all.⁴ It should be noted that even people without severe incontinence or who had no difficulty with their incontinence still had a significantly lower workforce participation rate compared to the general population. In fact, it is directly comparable with the 53.4% of the Australian disability population currently in the workforce.¹⁹ For NDIS and prospective NDIS participants who are employed or wish to take up employment, the rate of incontinence will likely be much higher and must therefore be considered an important barrier to address as part of the Strategy.

Continence care and incontinence management can also have additional consequences on the workforce participation of carers. Carers may take time off work to accompany people living with incontinence to medical appointments, provide care at home or assist with other unpaid tasks for the person living with incontinence.² The Australian Institute of Health and Welfare found three in four carers spent 40 hours or more per week caring for someone with incontinence.⁴ Primary carers who assisted with managing incontinence reported feeling weary and lacking energy or being worried or depressed at significantly higher rates compared with carers who did not usually assist with managing incontinence.²⁰ It is likely these factors impact workforce participation with primary carers aged 15 to 64 who help manage incontinence having lower levels of employment than carers who did not (44.3% vs 55.4%). It also translates to lower levels of full-time employment where only 15.2% of people who care for a person with incontinence are in full time employment compared to 26.7% of carers who did not.⁴

Given the higher levels of both formal and informal care provided for many NDIS participants, the time required of unpaid carers to manage the participant's incontinence can create further barriers to employment for themselves. By providing adequate support for both people with incontinence and their carers, this additional stress - financial, physical and emotional, will be eased to a significant extent.

Economic impact of incontinence

The combined economic impacts of incontinence can be keenly felt on an individual, household as well as a national level. The average annual cost of productivity losses for a person living with incontinence is \$7165, which translates into a national cost of \$34.1 billion.² A greater proportion of this cost burden is carried by individuals at \$23.5 billion compared to \$10.6 billion incurred by the Australian Government.² For people with multiple disabilities including incontinence, it is highly

probable the cost of productivity losses is greater and so constitutes a significant proportion of this amount.

Productivity losses of carers of people experiencing incontinence add another \$2.7 billion reflecting the opportunity cost of informal care.² This is also in addition to the cost of formal care and aids at \$1.96 billion. However, these huge numbers alone do not tell us the full picture. Given the figures were current as of 2010 and that the number of people in Australia experiencing incontinence is projected to rise from 4.6 million in 2010 to 6.2 million by 2030², it is expected the overall costs of incontinence have increased significantly in the interim. This collective cost can be significantly reduced through effective and adequate support for people experiencing incontinence, and must be addressed to lift employer engagement, capability and demand.

Incontinence management, support and health promotion

Many of the consequences of incontinence on workforce participation and in the workplace can be addressed or avoided. Fear of involuntary or unexpected urine or faecal loss and subsequent odour can lead to people living with incontinence to give up work, social, sexual and physical activities to avoid embarrassment.¹⁶ Substantial reorganisation of daily activities may be needed to anticipate situations when leakage might occur.¹⁶ Addressing this in the workplace requires organised and coordinated planning to maximise work productivity, worker confidence and co-worker and community attitudes.

Workplace discrimination

People living with incontinence are subject to both direct and indirect discrimination including at the workplace. Many who are employed will try to hide their incontinence. One study examining the qualitative aspects of faecal incontinence and employment found work was the most complicated situation to manage faecal incontinence outside of the home.²¹ There was a perceived belief that faecal incontinence and its symptoms such as odour were not considered socially and professionally acceptable. Participants lived in fear of humiliation due to an accident at work and most found the daily stress and anxiety of struggling with symptoms and managing the stress exhausting. People with multiple conditions and/or disabilities, including incontinence, will likely face additional barriers to employment, including greater levels of discrimination, that must be considered. It is clear that negative perceptions of incontinence and fear of discrimination, rather than an employee's productivity and capability, may present greater risk to health and safety compared to incontinence itself.

Impact while at work

Incontinence at the workplace can have a substantial impact on worker productivity. A national US survey found 88% of employed women aged 18-60 with severe symptoms of incontinence reported at least some impact on concentration, performance of physical activities, self-confidence and ability to complete tasks without interruption.²² Furthermore, increased severity of incontinence was linked to a more severe impact on these activities.²² Incontinence has also been shown to impact attitudes towards work as well as pushing employees into leaving the workplace. An Australian study on nurses and midwives found experience of severe urinary incontinence was associated with significantly lower job satisfaction and greater intention to leave their current job than those without severe symptoms.²³ In another study, this came to fruition with two participants retiring early due to their faecal incontinence.²¹ Just as workplaces make arrangements for people with disability from interview to long-term employment, so should employers support people living with incontinence at the workplace to reduce its impact and create a cohesive working environment. Incontinence that is not supported appropriately in the workplace can drive people affected to leave

earlier than intended which can have long-term impacts on both individual's economic security and employer's workforce planning.

Person-centred support

Incontinence is a highly personal experience. It is therefore essential that workplaces take the required steps to ensure appropriate planning, management and care is implemented, in line with the affected employee's wishes, to deliver optimal outcomes. As an example, stress urinary incontinence can occur during activities such as coughing, sneezing, walking and lifting while urge urinary incontinence is associated with a sudden and strong need to urinate. Both of these, which make up only two of the many types of urinary and faecal incontinence, will require adequate but distinct forms of support in the workplace. Further, the level and complexity of support required is complicated by the stigma, individual health, experience and needs of people living with incontinence and other health conditions and person-centred processes must be put in place to address these. Given the highly individualised nature of incontinence, person-centred continence care and incontinence management must be a key aspect of the Strategy's approach to be able to build the confidence of people living with disability, including incontinence, to obtain meaningful work and be supported while employed.

Incontinence should be a National Disability Employment Strategy priority

Addressing incontinence as part of the National Disability Employment Strategy must involve a multifaceted approach. The Strategy should provide individual and sector-wide support to enable economic security, greater social acceptance and participation, better work-specific management and guidelines, appropriate referrals for care. This needs to be underpinned by a coordinated approach between government, employers, non-government organisations, advocacy groups, health services and the community. Supporting people with incontinence, especially people who require greater levels of assistance, to gain employment will also likely reduce the impact on carers.

Continence Foundation of Australia leadership

As a national peak body representing Australians with or at risk of incontinence, their carers and health professionals, the Foundation can provide significant leadership to coordinate, develop and act on a continence-specific approach for the Strategy. Involvement of people living with incontinence, their carers, health professionals with expertise in continence, Australian Governments, and other advocacy groups can lead to effective evidence-based work practices informed by industry expertise. The Foundation's expertise includes years of experience working with people in the disability sector and more recently, NDIS participants which can be drawn upon to develop programs and supports for employment. These work practices can be expanded across the disability employment sector with a consistent and coordinated support from continence health services (see below).

Greater awareness, acceptance and engagement from employers can have a meaningful impact on the level of direct and indirect discrimination in the workplace. This will improve workplace-employee relations, including enhancement of trust between employee and employer, and boost workplace participation and engagement for people with incontinence. In turn, this means they will become more independent, self-confident and can make a greater contribution to the community. Consequently, the Foundation proposes the following measure to be assessed as part of the Strategy to determine its success:

- Measuring workforce participation by people with severe incontinence.

Economic security for all

It is vital that the Strategy promote the economic security of all people living with disability, including incontinence, to help sustain quality of life, independence and reduce financial pressures. To address this, appropriate funding arrangements to protect individuals against financial stress, in times of emergency and to maintain economic participation and independence are vital to maintain quality of life. This should be incorporated into the NDIS for participants with incontinence and other relevant programs such as the Continence Aids Payment Scheme. For instance, where continence products have been funded within an NDIS plan, funding for a continence assessment is necessary to promote, establish and maintain continence and any requisite capacity building supports. Removal of the eligibility requirement to hold a pension card, aligned to the Stoma Appliance Scheme, increasing access to the Continence Aids Payment Scheme (CAPS) for people in the workforce or seeking employment will also enable greater economic security for a larger proportion of people living with incontinence. Considering this, the following targets should be reported on as part of the Strategy:

- Access to sufficient funds to cover the costs of continence aids and equipment for all people with disability regardless of employment status or NDIS participation.
- Incidences of funding for specialist continence assessments where continence products are part of an NDIS plan.
- Increasing access to the Continence Aids Payment Scheme (CAPS) for people in the workforce or seeking employment by removing the eligibility requirement to hold a pension card or have a certain neurological condition, aligned to the Stoma Appliance Scheme

Continence health workplace guidelines

Appropriate workplace Codes of Practice and corresponding supports should be developed by Workplace Health and Safety authorities to assist employers to meet duty of care responsibilities by identifying and addressing risks to physical and mental health related to incontinence in the workplace. This includes implementation of BINS4Blokes (a Foundation-led campaign to install incontinence bins in all toilet facilities) in office spaces to facilitate greater workforce participation and decrease inappropriate disposal in toilets or general waste bins. For NDIS and prospective NDIS participants, coordination of workplace engagement and support for incontinence should be addressed alongside appropriate therapists including continence specialists. These guidelines should be developed in consultation with the Continence Foundation of Australia to create a rounded set of guidelines to provide person-centred support. Consequently, the following targets should be reported against as part of the Strategy:

- Development of continence health workplace guidelines by both Workplace Health Authorities and the Continence Foundation of Australia.
- Number of instances of the implementation of the continence health workplace guidelines.
- Instances of incontinence bins being installed in workplace toilet facilities.

Workplace-continance service coordination is required for person-centred continence support

Workplace supports must also include specialist continence service providers to enable comprehensive assessment and adequate supports, where appropriate, to be implemented at work. The Foundation believes that the expertise of continence specialists, including nurse continence specialists and pelvic floor physiotherapists, and the complexity of the continence assessments they undertake for people with disability is being overlooked. In their work with people with disability, continence specialists are highly knowledgeable in many areas including neurological conditions, physical disabilities, intellectual disabilities, spinal cord injury, the autism spectrum and psychosocial disability. Access to comprehensive assessment, appropriate diagnosis and development of individualised management plans delivers better outcomes for people living with incontinence and their carers. It would be appropriate therefore to have a referral system in place for continence specialists to provide a comprehensive and tailored management plan to optimise workplace engagement.

Safe and effective continence care and incontinence management can translate into better health and mental health outcomes, and consequently work productivity and participation. A Hong Kong study found a continence nurse-led care programme for people with lower urinary tract symptoms (LUTS) resulted in significantly lower LUTS severity, higher health-related quality of life and no deterioration of mental health as compared to the group which received usual care.²⁴ Physical equipment must also be considered to provide adequate support for people living with incontinence. An Australian study found comprehensive continence assessment for people with an acquired brain injury by a qualified expert to deliver tailored management plans and assistive products had the following results²⁵:

- Reduced toileting care hours by 4.3 hours per study participant per week, which represented a reduction in average weekly care costs of \$633.29 per person.
- Reduced average yearly costs of consumable products for continence (e.g., continence pads) by \$3614.80 per person per year.
- Improved participant independence in activities of daily living, three months after implementation.

Pathways for safe and effective continence care for employed people with incontinence must also be developed to ensure they can make informed decisions on their wellbeing at work. For NDIS participants, there is little information about appropriate pathways to specialist continence services who can assess, diagnose and provide support plans for participants. Following the major policy change to include some disability-related continence supports in 2019, it is estimated 40-60,000 participants require re-assessment in light of the change. The Foundation is well placed to support any project funded by the NDIA to provide specialist expertise and guidance to create a continence support participant pathway to address real concerns about participant health and wellbeing in the workplace.

Expertise in management of incontinence can be applied in the workplace for greater quality of life outcomes as highlighted above. In light of these facts, the following targets should be reported on as part of the Strategy:

- Development of an appropriate referral process, in consultation with the Foundation, for employed individuals living with incontinence.

- Development of training for employers with existing staff living with incontinence, in consultation with the Foundation, on how to engage with people experiencing incontinence, develop ‘continence in the workplace’ plans and implement them effectively.
- Employers should advise employees living with incontinence of the availability of the National Continence Helpline which will contribute to greater rates of referral for specialist continence assessment, early intervention and better workplace management.

Changing community attitudes

The Foundation supports ‘Changing community attitudes’ as a central aspect of the Strategy. Supporting this priority area by promoting inclusivity of all disabilities, including incontinence, across the community will be key to enabling a more cohesive and productive society. The Foundation encourages the adoption of several initiatives, as relevant for employers, which can help people with disability get back into the workplace including the implementation of Changing Places and Adult Change facilities, BINS4Blokes and Stoma changing facilities. Removing these barriers to participation for people with disabilities will help to facilitate greater inclusion and access and change community attitudes thereby promoting economic, socio-cultural participation, independence and successful implementation of the National Disability Employment Strategy. Measurement of the number of instances where the following initiatives are implemented will help to change community attitudes related to disability and incontinence:

- Changing Places
- Adult Change facilities
- BINS4Blokes
- Stoma changing facilities

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