Submission to the *Productivity Commission report on Mental Health – Online Survey* consultation

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Rowan Cockerell, CEO, Continence Foundation of Australia
r.cockerell@continence.org.au

Background

The Productivity Commission (PC) inquiry into Mental Health (2020) was a comprehensive review of the mental health system and produced a final report which outlined 21 recommendations and 103 associated actions addressing prevention and early assistance, improving mental health and healthcare experiences of consumers, supporting mental health at workplaces and instilling incentives and accountability for improved outcomes. The Foundation provided feedback to the consultation via an online guided questionnaire.

This document provides the Foundation's responses to the online questionnaire on the final report; it does not include the Foundation's responses in relation to organisational details, demographics or respondent information.

Section 1: Critical recommendations

The recommendations of the PC Inquiry Report on Mental Health propose to set Australia on a path for sustainable, generational reform of its mental health system. While some recommendations can be addressed in the shorter-term, a large number will require implementation over longer time periods.

Q. Of the recommendations made, which do you see as critical for the Government to address in the short term and why?

Incontinence and mental health

Incontinence is a complex condition sharing many characteristics with mental health issues: there are no age, gender, or other demographic characteristics profiling a typical person with incontinence. It is stigmatised, affects quality of life and may lead to withdrawal from activities like exercise and work (Garcia et al, 2005; Avery et al, 2013). Incontinence for many is a chronic condition leading to greater risk of disability and mental health complications as a result.

The relationship between incontinence and mental health is not well understood or acknowledged within wider health and mental health sectors. An Australian study found a significantly higher rate of depressive disorders in people with urinary incontinence (21%) compared to those without (14%) (Avery et al, 2013). Likewise, a review of global studies found people with incontinence had a 6 to 43% likelihood of comorbid depression (Avery et al, 2016). While depression and incontinence both reduce quality of life independently, when they occur together, there appears to be an additive effect on both physical and mental health.

Incontinence and workforce participation

Evidence indicates incontinence appears to be a key contributor to low labour force participation. Only one in 5 (20.4%) people who always or sometimes needed assistance with managing their incontinence participate in the workforce compared to people who had difficulty but did not need assistance (42.3%) and people who had no difficulty at all (56.8%) (AIHW 2012). Even people who report no difficulty at all have a considerably lower level of employment compared to the general population. Productivity losses due to incontinence in Australia were estimated at $34 billion in 2010. Provision of adequate support for people with incontinence to stay in or get back to work must also be a key focus for improved economic participation.

Incontinence, mental health and data

Considering the issues outlined above, it is imperative the Australian Government agree upon and collect incontinence and mental health co-morbidity data nationally.

The Continence Foundation of Australia (the Foundation) advocates for the following critical recommendations to address in the short term:

- The National Mental Health Commission should have statutory authority. (Action 22.7)
- The National Mental Health Commission should develop and drive a National Stigma Reduction Strategy designed to reduce stigma towards people with mental illness and accompanying stigmatised conditions like incontinence. (Action 8.1)
- All Governments should implement all the actions in the Equally Well Consensus Statement and outline implementation statements, respective measures and timeframes (Action 14.1) and report annually on progress relating to incontinence and mental health issues.
- Workplace Health and Safety authorities should develop Codes of practice to assist employers to meet duty of care responsibilities in identifying and addressing risks to psychological health related to incontinence in the workplace (Action 7.2).
- Australian Governments to agree on a set of targets and timeframes that specify key mental health and suicide prevention outcomes, including continence-related data sets such as workforce participation and service provision which should be published regularly (Actions 24.4 & 24.5)

References:

- Garcia JA, Crocker J, Wyman JF. Breaking the cycle of stigmatization: managing the stigma of incontinence in social interactions. Journal of Wound Ostomy & Continence Nursing. 2005 Jan 1;32(1):38-52.
- Avery JC, Stocks NP, Duggan P, Braunack-Mayer AJ, Taylor AW, Goldney RD, MacLennan AH. Identifying the quality of life effects of urinary incontinence with depression in an Australian population. BMC urology. 2013 Dec;13(1):11.

- Avery, JC, & Stocks, N. Urinary incontinence, depression and psychological factors-A review of population studies. European Medical Journal Urology 2016;1(1): 58–67.
- Australian Institute of Health and Welfare 2012. Incontinence in Australia: prevalence, experience and cost 2009. Bulletin no. 112. Cat. no. AUS 167. Canberra: AIHW
- Deloitte Access Economics. The economic impact of incontinence in Australia. The Continence Foundation of Australia; 2011.

Q. Of the recommendations made, which do you see as critical for the Government to address in the longer term and why?

Person-centred mental health system

A person-centred mental health system means access to high quality care that is relevant and does not stigmatise or discriminate. The care provided must fill in gaps by coordinating with relevant and qualified personnel including Nurse Continence Specialists.

A review of literature on continence care in the dementia community found health professionals were lacking in continence knowledge, advice and support (Gove et al, 2016). It was suggested that some health professional advice and support was not considered helpful, appropriate, effective or acceptable by people with dementia and caregivers (Drennan et al, 2011). A common narrative was general health professionals failed to understand the impact and consequences of the issue and referred them to another professional who was similarly unable to help (Drennan et al, 2011). This evidence points to the risk of untrained health professionals being similarly ineffective in providing care to people living with mental health conditions and incontinence.

Differences between safe and effective care against usual and ineffective care is stark. 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 and higher health-related quality of life compared to the usual care group. The usual care group experienced significantly higher mental health deterioration and the intervention group did not experience any, highlighting the mental health protective effect of specialist continence care (Chin et al, 2016).

From the perspective of consumers and carers, input from continence specialists into mental health should be integrated into service provision as necessary.

Care coordination approach

Incontinence affects 1 in 4 adults in Australia. The number of people affected is projected to increase to 6.2 million in 2030 (Deloitte, 2011). The high prevalence and comorbidity rate of incontinence and mental health conditions points to the need for greater care coordination services to provide access to higher quality care.

Whole of government approach

Care coordination at the service level should be complemented by an overarching National Mental Health Strategy aligning health and mental health sectors including continence care.

The Foundation advocates for the following critical recommendations to address in the long term:

- Governments should work towards improving coordination and integration between health and other services and create systems and processes that bring together a range of treatments and supports needed (Recommendation 4).

- Governments and regional commissioning bodies should assess the need for care coordination services and ensure coordination programs are available for those living with incontinence and mental health issues at a local level (Action 15.4).
- A whole of government National Mental Health Strategy which aligns continence care with mental health and other sectors (Action 22.1)

References:

- Gove D, Scerri A, Georges J, van Houten P, Huige N, Hayder-Beichel D, Leichsenring K, Morris VC. Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges. Journal of Clinical Nursing. 2016. 26(3-4):356-365.
- Drennan VM, Cole L, Iliffe S. A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. BMC Geriatrics. 2011. 11(1):75.
- Chin WY, Choi EPH, Wan EYF, Chan AKC, Chan KHY, Lam CLK. Evaluation of the outcomes of care of nurse-led continence care clinics for Chinese patients with lower urinary tract symptoms, a 2-year prospective longitudinal study. Journal of Advanced Nursing. 2016. 73(5):1158-1171.

Section 2. Implementation issues

Q. Of the critical recommendations identified in the previous questions, are there any significant implementation issues or costs you believe would need to be considered and addressed?

The relationship between incontinence and mental health is not well understood within the wider health and mental health sectors. Without significant expertise, appropriate, timely and mental health-informed continence care will not be available to a significant proportion of the affected population. This need must be addressed by Australian Governments.

Government role in continence and mental health care intervention

The role of Australian Governments in planning, implementing and monitoring any integration of continence and mental health care in Australia would be limited without expertise contributed by relevant health bodies. This would affect interventions by Australian Governments on multiple fronts from:

- Coordination and integration of continence and mental health services
- Capacity to assess continence and mental health needs at a local level
- Developing a holistic National Mental Health Strategy which is inclusive of safe and effective continence-related interventions
- Adequately incorporating continence care into the operationalisation of the Equally Well Consensus Statement
- Capturing appropriate data sets relating to continence and mental health and responding to issues and trends efficiently and effectively

Work Health Safety Authorities

Without urgent Government intervention, the Foundation believes any implementation of assistance programs and codes of practice by Work Health Safety Authorities to better support people living with incontinence and mental health conditions in the workforce will be limited and implemented in a piecemeal manner.

Service integration

Without mental health professional knowledge, education or training in continence care and the steps that should be taken for referral between mental health and continence services, a consumer

must navigate a complex system by themselves. Given the lack of understanding by general health professionals of continence needs, and the similar situation for mental health professionals, the dual challenge of incontinence and mental health may be left to the individual or their carers to address by themselves.

Formal and informal supports

Additionally, one of the biggest challenges in providing continence assessment and management recommendations is not having an adequate support system around the consumer with a significant mental health issue. Care managers, support workers and family carers with an understanding and focus on the importance of continence care and dignity would better facilitate holistic, quality care provision.

Funding

Appropriate funding for the above actions should involve significant consultation with different bodies, services, experts, health professionals and consumers and carers affected by incontinence and mental conditions. It would also involve planning, producing accessible resources reviewed by experts for the public and health professionals and education of the mental health and continence workforce.

Q. What do you believe is required for practical implementation of these recommendations? What do you feel are the key barriers and enablers?

Health peak body representation

The Continence Foundation of Australia is the peak body for promoting bladder, bowel and pelvic floor health. The expertise of the Foundation in education, awareness, information and advocacy alongside representation in each state and territory means that we are best placed to represent the interests of individuals, carers and health professionals in relation to continence and mental health care.

Services offered by the Foundation include clinical services for people with incontinence and mental health conditions, the National Continence Helpline, the National Public Toilet Map, education tools and online courses for health professionals. These services provide a basis for information and resource sharing, training and upskilling the continence and mental health workforce as part of a holistic integration of the mental health and continence health sectors.

Practically, the involvement of the Foundation will lead to better:

- Integration of continence and mental health services to provide safe and effective mental health appropriate continence care
- Greater capacity for Government bodies to assess continence and mental health needs at a local level
- Incorporating appropriate continence-related interventions into the National Mental Health Strategy
- Effectively including continence care into Equally Well Consensus Statement action implementation
- Capturing relevant data related to continence and mental health status nationally

Consultation on a national and local level

As a health peak body, the Foundation represents consumers and health professionals from around Australia. The latter includes nurse continence specialists, pelvic floor physiotherapists and medical specialists. Where appropriate, the Foundation can act as a conduit and representative for these groups to better enable recognition, improvement and guidance on continence and mental health care issues.

Building capacity to facilitate better quality continence and mental health care

The Foundation supports practical implementation of the following recommendations:

- The Australian Government should fund separate representative peak bodies, including the Continence Foundation of Australia, to represent the views, at the national level, of people with incontinence and mental illness, and of families and carers. (Action 22.4)
- The appropriate implementation of all actions proposed by the Equally Well Consensus Statement by Australian Governments will not only recognise but enhance the care provided for people with a mental health condition and incontinence (Action 14.1).
    - All mental health professionals (including peer workers) to receive role-appropriate physical health assessment training as part of ongoing mandatory training which includes safe and effective continence care. Nurses working in mental health services should be trained to carry out physical health checks including continence assessments (Equally Well, 2018) and be trained to make additional referrals as appropriate.

Reference:

- National Mental Health Commission. Equally Well: Improving the physical health and wellbeing of people living with mental illness in Australia. Australian Government. 2018.

Q. Are there clear steps you believe need to be taken to ensure the recommendations are successfully implemented?

Incontinence is a complex issue that needs to be addressed through a coordinated effort which includes governments, health peak bodies, continence services and advocacy groups, health professionals, consumers and carers.

The Foundation, as highlighted in previous responses, has the expertise and capacity to develop the recommendations outlined. We outline the following steps that the Australian Government can take to implement them below:

- The Australian Government to consult with the Continence Foundation of Australia to leverage its expertise on continence care and how to better integrate it with mental health care.
    - Develop or update guidelines and resources for use by health and mental health services to improve the mental health and continence care of affected individuals.
    - Collect data on the prevalence, physical and mental health and financial impacts of incontinence through the Intergenerational Health and Mental Health Study as part of the Long-Term National Health Plan.
    - Inclusion of continence-related care and interventions in the National Mental Health and Suicide Prevention Plan, National Standards for Mental Health Services as well as the National Stigma Reduction Strategy

- Provide guidance for assessment of need for mental health and continence care coordination services and ensure coordination programs are available for those living with incontinence and mental health issues.

Facilitating information generation, education and guidance

The Foundation can provide multiple benefits by generating relevant information to develop national data sets as well as facilitating pilot programs to produce guidance and training to deliver mental health-informed continence care. The National Continence Helpline, which received more than 25,000+ calls in the 2019/20 despite decreased traffic due to COVID-19 (Continence Foundation of Australia, 2020) for assistance can be utilised to capture data on needs, trends and population characteristics that can facilitate development of a minimum national data set on mental health and incontinence. The National Continence Helpline clinicians participated in a study by Movember of telehealth services for men post-prostatectomy. Outcomes included significant decreases in the number of men experiencing worry, fatigue and distress with a corresponding increase in improved self-care and usual living activities. This program can be adapted for people with mental health conditions and the outcomes can be utilised to develop training and guidelines for the mental health and continence specialist workforce.

The Foundation recommends the following steps be taken to best utilise the National Continence Helpline:

- Governments to fund and utilise data from the National Continence Helpline to:
  - Develop, in consultation with the Foundation, a minimum national data set to report on and monitor relating to mental health and incontinence.
  - Set up and deliver a pilot program on comorbid mental health and continence issues to develop education and guidance for the mental health and specialist continence workforce on integration and referrals of service.

Reference:

- Continence Foundation of Australia. Bladder Bowel Collaborative: Final Annual Report. 2020. Department of Health.

Section 3. Critical gaps

Q. Do you believe there are any critical gaps or areas of concern in what is recommended by the PC?

The recommendations by the Productivity Commission have not recognised incontinence as a key comorbidity of mental health conditions. Incontinence must be recognised as a chronic condition leading to a greater risk of disability and mental health issues. Its consequences and effects across mental health and all other aspects of life are ignored to the detriment of consumers, carers and the mental health system.

Quality of care related to incontinence should be an important aspect of the mental health system. The Victorian Mental Health Complaints Commissioner provided evidence of incontinence-related complaints to the Foundation which outline the need for safe and effective continence care within the sector. The complaints involved humiliating and undignifying experiences which are not reflective of person-centred care. For the former, examples included the use of restrictive interventions such as seclusion rooms in inpatient units with no toilet or use of mechanical restraints in emergency rooms which forced consumers to urinate or defecate on the floor or on their bed. For the latter, the complaints related to unresponsive services when concerns about incontinence as a

side-effect of mental health medications were raised, a lack of management for existing incontinence with services not providing continence pads or products and consumers experiencing incontinence due to an unmanaged physical health issue (Email from Emma L, Victorian Mental Health Complaints Commission, July 21 2020). The severity and variety of issues outlined are a key concern as they impede upon an individual's human rights, dignity and choice as well as their physical and mental health concerns.

Another important concern is the lack of data within the NDIS on the prevalence of participants with mental health conditions and incontinence. As of 2019, the number of people with a primary psychosocial disability in the NDIS was approximately 28,000 (9.1% of participants). The number of participants with any psychosocial disability is approximately 51,000 or 16.7% of all active participants (NDIS, 2019). However, despite the high level of co-morbidity between mental health and incontinence, no incontinence-specific information is provided. This is a critical gap in the data that the NDIS should be obliged to collect.

Given the breadth of issues highlighted and the key role of incontinence for people living with mental health conditions, its importance must be recognised and addressed in ongoing mental health system reforms. These reforms must incorporate the need for coordination between the mental health and continence health sectors including developing relevant data sets to report and monitor, improved guidance on assessment and service provision, resources, and a greater emphasis on work health and safety for individuals affected by mental health conditions and incontinence to better support quality of care and inclusion within the community.

Reference

- NDIS. People with a psychosocial disability in the NDIS. 2019. Available from: https://data.ndis.gov.au/reports-and-analyses/participant-groups/people-psychosocial-disability. [Accessed 2021 February 10].