Continence Foundation of Australia

BEYOND 'WAIT AND SEE' TACKLING CHILDHOOD INCONTINENCE

Policy Position Paper | May 2024

Purpose

This briefing has been prepared by the Continence Foundation of Australia for the Australian Government. The briefing outlines the evidence regarding delayed bladder and bowel control in children, its impact on children's health and development outcomes and identifies strategies to address these issues.

The Continence Foundation of Australia

The Continence Foundation of Australia (the Foundation) 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, health promotion, awareness, information and advocacy.

This expertise and extensive experience enable the Foundation to represent the interests of individuals, carers and health professionals in relation to continence, at national and state levels.

Contributors

The Foundation has consulted widely with members who work with children who are experiencing incontinence, and with their families, to prepare this briefing.

The condition

Continence is the ability to maintain bladder and bowel control until a socially appropriate time and place to urinate or defaecate has been reached. Full control is normally acquired in early childhood as the result of an active learning process. Toilet training often starts at 18 months – 2 years, but there is evidence that this is getting later, which causes problems at school entry and an associated increased risk of daytime wetting in primary school children (Christie, 2010; Joinson et al, 2009).

> *Continence difficulties include constipation, soiling (faecal incontinence), daytime wetting, bedwetting (enuresis) and problems or delay with toilet training. The majority of these are functional, that is they cannot be explained by anatomical, neurophysiological, radiological, or histological abnormalities.*

Instead, it is believed they are caused by a complex interrelationship of biological, developmental, genetic and environmental factors (Von Gontard, 2011). Structural (anatomical) or neuropathic causes are rare but need to be recognised early. Children with congenital conditions such as spina bifida or cerebral palsy have high rates of both urinary and faecal incontinence (Nijman, 2000; Von Gontard, 2013).

The negative impact for the children and their families of any continence difficulty should not be underestimated. Children and young people of all ages can be affected by continence difficulties. Children with additional needs and those with neurodevelopmental disorders, such as attention deficit hyperactivity disorder and autism are particularly affected, but often neglected in the mistaken assumption that incontinence is part of their wider condition (Von Gontard, 2013).

> *Children or young people who experience bedwetting may also have daytime wetting or symptoms such as hesitancy or urgency and/or constipation; children and young people with constipation/soiling may also have bedwetting/daytime wetting. There are causal links between these conditions, which require a holistic approach to treatment (Heron et al, 2018).*

The policy problem

Delayed bladder and bowel control is an important population health challenge in Australia. Failure to achieve toilet training milestones has far reaching impacts on health and developmental outcomes, learning and self-esteem. International evidence highlights the clear associations between childhood continence problems, children's mental health and parental intolerance/child punishment. Incontinence in childhood casts a long shadow forward, with potential long-term consequences for bladder and bowel health in adulthood, including recurrent urinary tract infections, kidney damage and both urinary and faecal incontinence (Proctor & Loader, 2003; Ashkenazi, 2003; Van Ginkel, 2013).

There is a lack of high-quality Australian data on prevalence or outcomes. There is, moreover, little information available to determine the full impact on the developmental and educational outcomes of Australian children. There is also a lack of evidence regarding the efficacy of prevention and early intervention programs which aim to address delayed independent toileting in children. Common strategies used by parents to overcome bedwetting are usually not effective, with some strategies, such as "lifting" and restricting drinks before bedtime, increasing the risk of bedwetting (Grzeda et al, 2017).

There are few guidelines and limited sources of support for early years services, schools, maternal and child health nurses and, critically, parents and families who are obliged to manage children with delayed bladder and bowel control on a case-by-case basis, when what is required is a strategic, evidence-based approach to reversing childhood incontinence at population level. There is substantial unmet need for information and integrated services to address this increasing public health problem.

Whilst the Foundation has welcomed the proposal to develop a national Early Years Strategy for Australia, there are concerns that the necessarily high-level focus of this strategic approach will not consider the impact of specific factors, including conditions such as incontinence, that may impact negatively on children in the early years. Incontinence in children is under-researched, under-reported and highly stigmatised though bladder and bowel dysfunction and consequent failure to achieve toileting milestones can have severely detrimental impacts on children and families including participation in education (Filce & LaVergne 2015).

The key facts

- In 2009, 51% of Australian children were toilet trained by 36 months old, a decrease from 97% during the mid-twentieth century (Christie. 2010).
- 19% of children beginning primary school in Sydney had experienced at least one episode of daytime wetting in the past six months, with 2% having two or more episodes per week (Sureshkumar et al. 2000).
- Toilet training after the age of 24 months is associated with persistent daytime urinary incontinence, whereas toilet training between 1-24 months led to more favourable outcomes (Joinson et al. 2008; Joinson et al. 2019).
- There is a rise in urinary tract infections in children, with researchers linking it to delayed toilet training over the previous half century (Bakker & Wyndaele 2000).
- The ability to independently toilet is a key milestone in a child's development. A lack of bladder and bowel control, beyond the expected developmental period, can negatively impact a child's physical and mental health, as well as their learning and development (Education and Resources for Improving Childhood Continence (ERIC) 2016). Postponement in toilet training can also have health, economic, environmental and social impacts (Kaerts et al, 2012).
- Incontinence can seriously undermine a child's quality of life, educational attainment and mental health outcomes (Cox, 2002). In Australia it is acknowledged that a lack of bowel control at four years of age and lack of bladder control at five years requires assessment and intervention (Austin, et al., 2016). While it is acknowledged that bladder control maturity may take longer in some children, the lack of monitoring and assessment to identify underlying issues that would benefit from early treatment can result in long term health and wellbeing issues for the child. Incontinence is considered a chronic condition when it continues to affect an individual for longer than six months.

The need for a proactive approach

- Early identification of bladder or bowel dysfunction can mitigate the risk of poor health and wellbeing outcomes, including psychological wellbeing, for children who experience delayed bladder or bowel control.
- Failure to identify and treat continence problems at an early stage can give rise to chronic changes in the bladder or bowel. For example, there is recent evidence that experiencing hard stools in early childhood is a risk factor for later problems with constipation and faecal incontinence at school age, unrecognised congenital, structural, or neuropathic bladder or bowel dysfunction may result in renal (kidney) deterioration or acute bowel crises, with significant consequences for the child's health. Without treatment problems, this may persist into adolescence and adulthood (Heron et al, 2018; Koppen et al, 2016)
- The risk of unrecognised constipation and other underlying pathologies, including undiagnosed urinary tract infections and, more rarely, congenital bladder or bowel problems is greater for those with moderate to severe learning disabilities, cerebral palsy, and Down's syndrome. If present and untreated, these conditions may result in renal deterioration or chronic bowel problems (Rogers & Patricolo, 2014).

Groups at particular risk

- Whilst data on the prevalence of incontinence in First Nations communities is limited, it is known that Indigenous populations experience chronic conditions (including renal disease) at a higher rate than non-Indigenous populations, some of which places them at higher risk of experiencing incontinence (AIHW 2012).
- Families in high-risk groups face additional barriers to accessing information and appropriate continence support and care for children who are experiencing difficulties. This necessitates targeted supports, including information around proper nutrition and fluid intake to support children to achieve healthy bladder and bowel function.
- Children with autism spectrum disorder and other disabilities experience significant effects on health and developmental outcomes because of their incontinence, including physical and mental health disorders, and high rates of school absenteeism. Compared to typically developing children, children with additional needs have a higher likelihood of experiencing incontinence and this incontinence is more likely to persist into adulthood. The impacts of incontinence must inform strategies designed to improve health equity for children with disabilities (von Gontard et al. 2015).

- Children from rural and remote areas are at higher risk of not receiving the necessary support to address their needs. Improving access to specialist primary care services for children with additional needs, including those who require a continence assessment or support for underlying conditions is warranted to ensure that all children receive the care they need to achieve positive health outcomes.

Impacts on children's development, education and life chances

There are a variety of physical, social, emotional and familial risk factors for incontinence in children and adolescents.

- An Australian study found that moderate to severe daytime incontinence is strongly associated with a frightening or stressful event in the past six months (Sureshkumar et al. 2000).

- Another study showed faecal incontinence is highly prevalent in children who experience sexual and physical abuse, as well as those with behavioural disorders (von Gontard et al. 2017).

- Data from the Avon Longitudinal Study of Parents and their Children (ALSPAC) study showed that adolescents (aged 13-14 years) who experienced urinary incontinence since childhood reported greater psychosocial problems compared to their peers who had developed greater bladder control. Adolescents who experienced a lack of bladder control were more likely to experience depressive symptoms, poor self-image, problems with peer relationships at school and negative perception of school and teachers (Grzeda et al. 2017).

- Continence problems occur at a formative time for children and influence their health, wellbeing and emotional development. They are associated with reduced quality of life, constructive peer relationships (Ring et al, 2017) and cause social isolation and feelings of difference (Joinson et al, 2018). They are also a cause of reduced self-esteem (Ring et al, 2017), a sense of social stigma (Joinson et al, 2007), distress and behavioural disorders (Von Gontard 2011). Ching et al (2015) and Zhao et al (2015) found that bullying, either as victim or perpetrator, is associated with increased lower urinary tract symptoms. Most families are concerned and positively involved. However, lack of understanding and frustration causes some to respond by punishing their children. This can result in a 'vicious cycle' of increased stress, more incontinence, potentially harsher punishment and the risk of child abuse (Sa et al, 2016, Schlomer et al, 2013).

- Trauma and stress in childhood including sexual and physical abuse is not only strongly correlated with childhood incontinence, but there is also evidence that some adverse childhood experiences are associated with lower urinary tract symptoms in adult women and men. (Geynisman-Tan et al, 2021; Warne et al, 2024).

Impacts on families

- Parents play an essential role in helping their child learn to independently toilet, however they often lack access to information, services and support when their child is experiencing delayed bladder or bowel control, which can contribute to stress for parents of children with enuresis (day- or night-wetting) who are characterised as being more stressed than average (Von Gontard et al. 2017).
- Almost 74% of mothers expressed abusive maternal attitudes towards children and adolescents with elimination disorders and bedwetting (Alpaslan et al. 2016). The rate of abusive maternal attitudes increased for children and adolescents who lived with poorly educated parents or from large, chaotic, divorced families and families who were of lower socio-economic status, suggesting that the existing stressors of parenting are amplified when caring for a child with additional continence needs (Alpaslan et al. 2016).
- A study of 104 families of children with faecal incontinence found that 23 had severe and widespread difficulties, including sexual abuse (Silver, 1996). Equipping parents with the tools and knowledge to help their child manage their bladder or bowel dysfunction may reduce stress for both the affected child and the parents, having a positive effect on family dynamics.

What works: the evidence

Early identification of bladder or bowel dysfunction can mitigate the risk of poor health and wellbeing outcomes, including psychological wellbeing, for children who experience delayed bladder or bowel control.

The evidence suggests that an effective response to childhood incontinence would ensure that all children, from birth to 19, with continence difficulties (bladder and/or bowel problems and/or delayed toilet training), should have access to a specialist, community-based paediatric treatment and support that can provide individualised, evidence-based care in line with evidence and national guidance (United Kingdom Continence Society, 2019). Children with these problems cannot be treated as ‘little adults’. These services should work within pathways of integrated primary and secondary health care as well as linking to other services including education.

International evidence suggests that well-resourced, integrated community children’s continence services reduce cost to health care systems by

- Reducing accident and emergency attendances for abdominal pain related to constipation
- Fewer referrals to secondary care for consultant assessment or treatments
- Fewer unnecessary investigations

- Reduced admissions to hospital for constipation or treatment of urinary tract infection
- Reduced need for disposable continence products which has beneficial impacts on family budgets, particularly on those with low incomes and on the environment (ERIC 2019).

Addressing the Gaps

1. Federal, state and territory governments should commit to establishing integrated, multidisciplinary health and development checks for all children through Maternal and Child Health (MCH) services at three years old. These should include assessment of independent toileting, bladder and bowel dysfunction and referral to paediatric continence health care professionals, as required.
2. The universal approach of the Early Years Strategy should be accompanied by targeted approaches to support toilet training and independent toileting which address the higher needs and multiple disadvantages experienced by many children and families in rural and remote communities, and of children with disabilities.
3. The Federal Government should work with Aboriginal and Torres Strait Islander communities to ensure that children in remote communities have full access to the proposed multidisciplinary health and developmental check at three years of age, and to identify and address delayed bladder and bowel control as a barrier to achieving all five developmental milestones in the Australian Early Development Census. This would assist in achieving Closing the Gap health and wellbeing targets.
4. The Federal Government should commit to investment in, and development of, the continence specialist workforce and MCH services to support early childhood services, schools and health professionals in building their capacity to identify issues related to bladder and bowel control in children and provide them with support on toilet training. This could include outreach from continence specialists and expansion of existing programs such as the School Readiness Program, currently operating in Victoria.
5. The Federal Government should consult with the Continence Foundation of Australia as the national peak body, and the Foundation's network of front line clinicians and health promotion experts with specific expertise in continence health, to develop evidence-based information, support and advice about toilet training and bladder and bowel health, and to disseminate these resources to early years providers, family support services, schools, primary care and community health services to help them with toilet training and bladder and bowel health.
6. Ensure that the Early Years Strategy achieves significant improvement in the collection of data, particularly in relation to the incidence and impacts of incontinence. This is essential to contribute to the overall health and development in children to achieve to bladder and bowel control.

7. Health surveys, including biometric health measurement surveys, should routinely collect data and evaluate and report on
   - Data on the association between incontinence and a child's health and development
   - Data on the efficacy of prevention programs and interventions for delayed independent toileting
   - Data on number of children commencing school before learning independent toileting and the impacts this has on their education
   - Data on longitudinal health studies on continence issues across the life span.

Conclusion

Children with urinary and faecal incontinence need high quality, evidence-based information, and support to address the roots of the problem and seek solutions. Accompanying pathologies in detected cases can be determined in the early period by means of multidisciplinary pre-school screenings at three years of age and the provision of expert support, including referral for evaluation by a paediatric continence specialist when necessary.

> *A proactive approach to addressing childhood incontinence can prevent adverse effects on children's long-term psychosocial, educational and personality development and overall life chances, reduce the stress on families, reduce inappropriate demand on school and on primary care services and reduce costs to health services. This is preventative health care.*

To address the significant, yet often misunderstood, impacts which incontinence has on a child's health and development, the Foundation recommends that the Australian Government works collaboratively with childhood experts and frontline workers to address the gaps in health policies and services, and achieve its goal of addressing inequities and improving health outcomes in children.

References

Alpaslan, A. H., Koçak, U., Avci, K., & Güzel, H. I. (2016). Association between elimination disorders and abusive maternal attitudes. Journal of forensic and legal medicine, 40, 22-27.

Aschkenazi S, Botros S, Miller J. (2007) Does the bladder have a memory? Is childhood dysfunctional voiding related to bladder and pelvic floor dysfunction in adult women? Neurourol Urodyn2007;26:(Abstract 61):679-80.

Austin, P.F., Bauer, S.B., Bower, W., Chase, J., Franco, I., Hoebeke, P., Rittig, S., Walle, J.V., von Gontard, A., Wright, A. and Yang, S.S., 2016. The standardization of terminology of lower urinary tract function in children and adolescents: Update report from the standardization committee of the International Children's Continence Society. Neurourology and urodynamics, 35(4), pp.471-481.

Australian Institute of Health and Welfare 2012. Incontinence in Australia: prevalence, experience and cost 2009. Bulletin no. 112. Cat. no. AUS 167. Canberra: AIHW

Bakker, E, and JJ Wyndaele. "Changes in the Toilet Training of Children During the Last 60 Years: The Cause of an Increase in Lower Urinary Tract Dysfunction?" BJU Int 86 (2000): 248-52

Christie, A. (2010). Toilet training of infants and children in Australia: 2010. The Restraint Project.

Cox DJ, Morris JB, Borrowitz SM, Sutphen JL. Psychological differences between children with and without chronic faecal incontinence. Journal of Pediatric Psychology, 2002; 27: 585- 591

Education and Resources for Improving Childhood Continence (ERIC) Why are children potty training later?

Retrieved from: https://eric.org.uk/why-are-children-potty-training-later/

Filce, H. G., & LaVergne, L. (2015). Absenteeism, educational plans, and anxiety among children with incontinence and their parents. Journal of School Health, 85(4), 241-250.

Geynisman-Tan, J., Helmuth, M., Smith, A.R., Lai, H.H., Amundsen, C.L., Bradley, C.S., Mueller, M.G., Lewicky-Gaupp, C., Harte, S.E., Jelovsek, J.E. and Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN) Study Group, 2021. Prevalence of childhood trauma and its association with lower urinary tract symptoms in women and men in the LURN study. Neurourology and urodynamics, 40(2), pp.632-641

Grzeda, M. T., Heron, J., von Gontard, A., & Joinson, C. (2017). Effects of urinary incontinence on psychosocial outcomes in adolescence. European child & adolescent psychiatry, 26, 649-658.

Heron, J., Grzeda, M. T., von Gontard, A. et al.: Trajectories of urinary incontinence in childhood and bladder and bowel symptoms in adolescence: prospective cohort study. BMJ Open, 7: e014238, 2017

Jönson Ring, I., Nevéus, T., Markström, A., Arnrup, K., & Bazargani, F. (2017). Nocturnal enuresis impaired children's quality of life and friendships. Acta Paediatrica, 106(5), 806-811.

Joinson, C., Heron, J., Von Gontard, A., Butler, U., Emond, A., & Golding, J. (2009). A prospective study of age at initiation of toilet training and subsequent daytime bladder control in school-age children. Journal of Developmental & Behavioral Pediatrics, 30(5), 385-393.

Joinson, C., Grzeda, M. T., von Gontard, A., & Heron, J. (2019). A prospective cohort study of biopsychosocial factors associated with childhood urinary incontinence. European child & adolescent psychiatry, 28, 123-130.

Joinson, C., Heron, J., Emond, A., & Butler, R. (2007). Psychological problems in children with bedwetting and combined (day and night) wetting: A UK population-based study. Journal of Pediatric Psychology, 32(5), 605-616.

Joinson, C., Heron, J., von Gontard, A., Butler, U., Golding, J., & Emond, A. (2008). Early childhood risk factors associated with daytime wetting and soiling in school-age children. Journal of pediatric psychology, 33(7), 739-750.

Joinson, C., Whale, K., & Randall, J. (2018). Young people with continence problems need better support at secondary school. Bristol: University of Bristol.

Kaerts, N., Van Hal, G., Vermandel, A., & Wyndaele, J. J. (2012). Readiness signs used to define the proper moment to start toilet training: a review of the literature. Neurourology and urodynamics, 31(4), 437-440.

Koppen, I. J. N., Von Gontard, A., Chase, J., Cooper, C. S., Rittig, C. S., Bauer, S. B., ... & Benninga, M. A. (2016). Management of functional nonretentive fecal incontinence in children: Recommendations from the International Children's Continence Society. Journal of pediatric urology, 12(1), 56-64.

Nijman, R.J.M., (2000). Classification and treatment of functional incontinence in children. BJU international, 85(S3), pp.37-42.

Proctor E, Loader P. (2003) A 6-year follow-up study of chronic constipation and soiling in a specialist paediatric service. Child: Care, Health and Development2003;29(2):103-9.

Rogers, J., & Patricolo, M. (2014). Addressing continence in children with disabilities. Nursing times, 110(43), 22-24.

Schlomer, B., Rodriguez, E., Weiss, D., & Copp, H. (2013). Parental beliefs about nocturnal enuresis causes, treatments, and the need to seek professional medical care. Journal of pediatric urology, 9(6), 1043-1048.

Silver, E. (1996). Family therapy and soiling. Journal of family therapy, 18(4), 415-432.

Sureshkumar, P., Craig, J. C., Roy, L. P., & Knight, J. F. (2000). Daytime urinary incontinence in primary school children: a population-based survey. The Journal of pediatrics, 137(6), 814-818.

United Kingdom Continence Society (2019). Children's Continence Commissioning Guide. Retrieved from: [https://www.bbuk.org.uk/wp-content/uploads/2019/12/PCF-Childrens-Continence-Commissioning-Guide-Dec-2019.pdf.](https://www.bbuk.org.uk/wp-content/uploads/2019/12/PCF-Childrens-Continence-Commissioning-Guide-Dec-2019.pdf)

Van Ginkel R, Reitsma JB, Büller HA, van Wijk MP, Taminiau JAJM, Benninga MA. (2003) Childhood constipation: Longitudinal follow-up beyond puberty. Gastroenterology;125(2):357–63.

Von Gontard, A. (2013). Urinary incontinence in children with special needs. Nature Reviews Urology, 10(11), 667-674.

Von Gontard, A., Baeyens, D., Van Hoecke, E., Warzak, W. J., & Bachmann, C. (2011). Psychological and psychiatric issues in urinary and fecal incontinence. The Journal of urology, 185(4), 1432-1437.

Von Gontard, A., De Jong, T. P., Badawi, J. K., O'Connell, K. A., Hanna-Mitchell, A. T., Nieuwhof-Leppink, A., & Cardozo, L. (2017). Psychological and physical environmental factors in the development of incontinence in adults and children. Journal of Wound, Ostomy and Continence Nursing, 44(2), 181-187.

Warne, N., Heron, J., von Gontard, A. and Joinson, C., 2024. Mental health problems, stressful life events and new-onset urinary incontinence in primary school-age children: a prospective cohort study. European Child & Adolescent Psychiatry, 33(3), pp.871-879.