Addressing continence in children with disabilities

Keywords: Continence/Children with disabilities/Bladder dysfunction

This article has been double-blind peer reviewed

Renal anomalies have been found in up to 21% of children with Down’s syndrome

Children and young people with physical and learning difficulties frequently experience bladder and bowel dysfunction. Improving outcomes for this group of children can present substantial challenges to health professionals, who need to be aware of the systemic and localised comorbidities, including psychological issues that might contribute to bladder and bowel problems.

Current literature on this subject is limited. However, there is evidence that underlying comorbidities influencing bladder and bowel function are often either missed or not recognised (De Waal et al, 2009; Ersoz et al, 2009; Kupferman et al, 2009; Hicks et al, 2007).

There are many factors that might influence bladder and bowel function in children and young people with disabilities, which are listed in Box 1. In addition to these, children might be late in being diagnosed due to difficulty verbalising their needs and the assumption that their urinary or faecal problems are simply part of the disability picture.

There is a frequent misconception that, if children with learning disabilities present with wetting and soiling problems, the cause is related to some sort of developmental delay rather than an underlying bladder or bowel problem. As a result, many of these children do not undergo a comprehensive bladder and bowel assessment. Instead, they have a simple “pad assessment” and are issued with nappies in the mistaken belief that they are not ready to be toilet trained. This is a potentially dangerous situation, particularly as untreated problems can lead to long-term bladder or intestinal damage.

Health professionals in primary care may lack clinical knowledge and experience in this area, and there may be a shortage of trained home care and school nurses.

The scale of the problem

Studies have identified a higher incidence of lower urinary tract symptoms in children with physical and learning difficulties (Hicks et al, 2007; Duel et al, 2003; Handel et al, 2003; Roijen et al, 2001; van Laecke et al, 2001). A study by de Waal et al (2009) identified that individuals with...
Genitourinary problems associated with Down’s syndrome

Down’s syndrome is a chromosomal abnormality, individuals are at increased risk of congenital conditions, including cardiac and gastrointestinal defects, as well as metabolic and renal diseases. However, renal and urinary tract anomalies have received less attention than other congenital malformations.

The comorbidities influencing both bowel and bladder function in children with Down’s syndrome are listed in Box 1. An issue for this group of children is that others may have a low expectation of their ability to be toilet trained and achieve full continence. As a result, wetting problems are often attributed to an inability to achieve normal milestones rather than as a symptom of an underlying pathology.

In 1960, Berg et al first noted the link between renal anomalies and Down’s syndrome, with 3.5% of autopsy cases having renal malformations, and a later study has shown a higher incidence of up to 21% (Ariel et al, 1991). Hypospadias, where the urethra opens on the underside of the penis, and urethral abnormalities, such as posterior urethral valves (PUV) – a condition that only affects boys when there is a blockage in the urethra near to the bladder – have also been noted in this population. Hypospadias has been calculated to occur in approximately 0.3% of all live-births, with the incidence in boys with Down’s syndrome being approximately 6.5%, an almost 20-fold increased risk (Lang et al, 1987).

The overall prevalence of renal and urinary tract anomalies in the Down’s syndrome population, including posterior urethral valves, is four to five times higher than in the general population (Kupferman et al, 2009).

Dysfunctional voiding of urine is more common in Down's syndrome than in the general population and can lead to functional bladder outlet obstruction, with associated urinary retention and increased bladder pressures, which can result in renal damage. The reasons for this dysfunctional voiding are not clear, but it may be related to overtraining of the pelvic floor in an attempt to encourage the individual to stay dry. Another contributing factor is the presence of abnormalities such as undiagnosed posterior urethral valves (Seki and Shahab, 2011).

Hicks et al (2007) carried out a study to explore whether boys with Down’s syndrome might have bladder outflow obstruction secondary to detrusor sphincter dyssynergia (DSD). DSD occurs when the sphincter muscle of the urethra contracts at the same time as the detrusor muscle of the bladder is contracting, resulting in obstruction of normal urinary outflow. They identified that these children were at increased risk of renal injury and found that 50% of boys studied required urinary diversion for dilated upper urinary tracts following bladder outflow obstruction, while 77% had bladder dysfunction and 68% had a history of wetting. They concluded that the risk is not fully appreciated and it is important that all children and young people with Down’s syndrome, particularly those with wetting problems, have detailed history and a bladder scan. DSD has also been reported in adult patients, and while most common in boys, it has been reported in a female with Down’s syndrome (Kai et al, 2007; Culley et al, 2006).

The relatively high incidence of urinary problems in individuals with Down’s syndrome indicates the need for assessment, regular reviews and investigations if required. This will facilitate early diagnosis, prompt treatment intervention and help to prevent upper urinary tract deterioration.

Gastrointestinal function

Gastrointestinal abnormalities, both structural and functional, affect up to 77% of all individuals with Down’s syndrome (Moore, 2008). Hirschsprung’s disease (congenital megacolon) and anorectal malformations, including imperforate anus (partial or complete obstruction of the anal opening), are more common in Down’s syndrome than in the general population, and if these are not well managed and treated in early childhood, they can lead to chronic problems in adulthood.

An audit of 57 adults with Down’s syndrome attending a hospital clinic identified a range of gastrointestinal problems (Wallace, 2007). These included coeliac disease (12%), constipation (19%) and unexplained diarrhoea (19%). Wallace recommended that specially designed protocols should be developed to help identify and manage these problems.

Constipation

Constipation may also be a particular problem in those with learning and physical difficulties for a number of reasons, including poor mobility and altered muscle tone. As the onset of constipation can be quite insidious and difficult to detect, it may not be recognised by individuals who have reduced ability to perceive and report their symptoms. Often the first sign of constipation is that the child or young person starts to soil due to underlying faecal impaction. It is important not to presume that the development of faecal soiling is due to the person developing a behavioural issue or “incontinence”, and to ensure that they are fully investigated for the presence of underlying constipation.

Implications for practice

Currently in the UK there do not appear to be specific integrated care pathways for children and young people with disabilities who have comorbidities influencing bladder and/or bowel function, especially with regard to transition from paediatric to adult care.

In many cases, families and healthcare providers will need to work together to ensure that the child or young person is able to achieve the best possible outcomes and support them in achieving their full potential.
Comorbidities influencing bladder and bowel function found in individuals with Down’s syndrome:

- Gastrointestinal comorbidities including Hirschsprung’s disease (congenital abnormalities of the bowel resulting in sections of the bowel being permanently narrowed)
- Duodenal anomalies
- Renal anomalies
- Bladder outlet functional obstruction
- Cognitive impairment

Children and young people’s understanding of the need for regular medication to manage problems such as constipation may be reduced as a consequence of communication issues, depression and autism and management may be difficult. Procedures such as clean intermittent catheterisation and clean self-intermittent catheterisation, bowel wash-out, rectal washouts or enemas, and laxative use may also be difficult with this patient group; parents and carers will need specialist advice on managing these problems.

Simple measures such as correcting fluid intake, regular toileting and introducing medication as necessary, can make a huge difference in terms of improving bladder and bowel problems.

Conclusion

All children presenting with bladder and/or bowel problems should have equal access to bladder and bowel (continence) services regardless of any associated learning or physical disability. Presumptions should not be made as to the cause of the bladder and/or bowel problems and all children should undergo appropriate assessment to exclude any underlying pathology. The risk is that untreated bladder and bowel problems, including incontinence, will persist into adulthood. A transition plan should be put into place for those young people, with specific tailoring for their age and their disability.

References