

BRIEFING PAPER FOR– Bowel and Bladder Services for Children & Young People in Warwickshire

1. Context

- 1.1 Bladder and bowel (continence) problems affect more than 900,000, 6.4% children and young people in the UK (NHS England, 2018), with a negative impact on their health, wellbeing, and emotional and psychological development.
- 1.2 National 'Children's Continence Commissioning Guide' (2019) recommends a fully integrated 'Children's Community Continence Service' that provides support for children from birth to 19, with continence difficulties (bladder and/or bowel problems and/or delayed toilet training).
- 1.3 2017/18 the Department for Health and Social Care moved commissioning responsibilities for health visiting and school nursing services from clinical commissioning groups into public health divisions within local councils. The move transferred commissioning duties under a new national service specification. At this time the new specification did not consider the fact that many school nursing services co-delivered bowel and bladder services alongside a very small, dedicated specialist nursing contingent, and removing the school nursing capacity to this service and the implications and impact of these changes.
- 1.4 Historically, different continence services for children had been in place across Coventry and Warwickshire as part of services commissioned by the three former Clinical Commissioning Groups. These services were disrupted by the recommissioning of school nursing services and more recently by challenges with health visiting services.
- 1.5 Feedback from Warwickshire parents and carers shows how the lack of continence services have impacted children and in particular autistic children. The quotes are taken from the feedback collated by Warwickshire Parent Carer Voice in 2022:
 - *"No-one else I could go to for advice"*
 - *"She didn't seem to have any understanding of the issue of continence in someone with autism and basically told me that my son is autistic "and that is just what they are like"."*
 - *"I wish there was a discount for nappies for my ASD boy he's nearly 5 and there expensive he can't have cheap ones he comes out in a rash and uses at least 6 in one day that being a good day"*

- *“No continence service that’s accessible for autistic young people”*

- 1.6 A business case received from South Warwickshire Foundation Trust to the Coventry and Warwickshire Integrated Care Board and the context outlined above prompted a rapid review of bowel and bladder services for both Coventry and Warwickshire including an interim two-year award to deliver the Bowel and Bladder service for Warwickshire.
- 1.7 This briefing paper outlines the development of the bladder and bowel services for Warwickshire, ensuring that children with continence issues are supported and cared for, to help them maintain their dignity and improve their emotional wellbeing, and to prevent stress and financial hardship on parents who have been left trying to manage by themselves.

2. Current service provision

- 2.1 The interim two-year award was made to Coventry and Warwickshire Partnership Trust (CWPT) as the lead provider working in partnership with South Warwickshire University Foundation Trust (SWFT), to deliver the following:
- Fully scope the needs of the population for a tiered approach using existing capacity.
 - Consider opportunities for efficiency of working across the footprint.
 - Co-produce a new set of clinical pathways with the parent carer forums across each area of clinical need.
 - Define a set of outcome measures.
 - Review the services following the two year period to identify and outline the ongoing business case to the ICB
- 2.2 CWPT has been working in partnership with SWFT recruiting to the new team and working with partners including parent carer forums to develop clinical pathways. There will be access to continence assessments for CYP across Coventry and Warwickshire from April.
- 2.3 This is a new service for Warwickshire and the initial priority will be for those with the highest clinical need. This first year will help define the unmet need and identify the future service delivery model.
- 2.4 The Warwickshire service will be rolled out from May to special schools and when fully staffed will extend across CYP in Warwickshire.
- 2.5 In the interim families can access support via the following
- Liaison with health visiting or school nursing (age dependent) for general continence advice and support.
 - Make an appointment with their GP should their continence issues change or worsen.
 - Ask their GP for a referral to a community paediatrician if their continence issues are severe and linked to an underlying health diagnosis / suspected diagnosis.

- ERIC the children's bowel and bladder charity can be reached at [Home - ERIC](#) they have an advice line and a significant range of resources.
- Working families is a charity which can direct families to what benefits they are entitled to apply for [A Guide to Benefits if you Care for a Disabled Child - Working Families](#) some families are eligible for benefits which they may use to purchase containment products.

- 2.6 The continence assessment will give an indication of a child or young person's ability to control their bladder and bowel. The majority of children will be able to manage this with support from the nurses. Support will take the form of proven strategies for parents to work through with their children for e.g. alarms, education materials and medication. For those children and young people who have physical health conditions preventing them controlling their bladder and bowel (neurological, congenital or anatomical), containment products can be prescribed.
- 2.7 To support this service, free on-line training for universal services of health visiting, school health nursing, nurseries and special school nursing is being provided from April onwards.
- 2.8 The next two years are part of a pilot project and will be evaluated throughout this phase before further decisions are made about the sustainability and future delivery of service.

3. Conclusions

- 3.1 Coventry and Warwickshire ICB recognise their commissioning duties in relation to children and young people's bowel and bladder care and will spend the next 2 years funding the service with aim of evaluating the outcomes to inform the future service delivery.
- 3.2 The ICB will continue to work in its arrangement with CWPT as the lead provider working in partnership with SWFT to fully scope need, enhance and coordinate existing resource and co-produce specialist pathways.
- 3.3 The ICB is committed to reviewing the outcomes of the pilot programme and evaluating the future service delivery model.

End of Report