

Welsh Government – Parliamentary Review of Health and Social Care

Response from the Paediatric Continence Forum, 08/05/2017

- 1. What matters most to you about health and social care services, and what should we concentrate on to make things better?** The Paediatric Continence Forum (PCF) is an independent group of healthcare professionals and parents that engages with the Government and healthcare organisations, with the aim of improving paediatric continence services across the UK. About one in 10 children and young people are affected by continence problems – covering bedwetting, daytime wetting, constipation and soiling and toilet training issues – often causing significant social and psychological pressures, including being bullied at school. The PCF campaigns for all children to have access to an integrated, well-resourced community based paediatric continence service, led by a specialist paediatric continence adviser, to alleviate these problems in a timely and appropriate way. Early intervention prevents later and more expensive treatment in secondary care.
- 2. What do you see as working well?** Wales and the other devolved nations have historically had stronger paediatric continence service provision than England: in 2014, 57% of Welsh Health Boards commissioned the four paediatric continence services, and two of these covered all areas of continence under an integrated service. As this covers nearly 30% of Wales, this was an encouraging sign – in England only 39% of CCGs commissioned the four services, and only 26% had integrated services. However, data for 2017 shows that only four of the Health Boards now have paediatric continence service provision, and none of these are under an integrated service. It is disappointing that paediatric continence provision seems to be taking a retrograde step in Wales.
- 3. Can you think of any new ideas and good practice you have seen, that could be copied more widely?** The best example of paediatric continence services the PCF has come across in Wales are those provided through Cardiff & Vale University Health Board, which offers provision for all four areas of continence and product supply, albeit not through an integrated service. The Health Board also has four nurses with specific training in paediatric continence management and children's nursing involved in these services, and makes use of the PCF's NICE-accredited Paediatric Continence Commissioning Guide in designing its services. This guide provides a blueprint to enable service providers, clinicians and managers to deliver integrated community paediatric continence services, and we hope that it could be used across Wales to spread good practice. This guide can be accessed at <http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf>.
- 4. What problems are there in the current systems, and how do they show through in the services people get?** The lack of widespread provision of integrated, well-resourced paediatric continence services across Wales is a serious concern. Without these services, the parents and carers of children and young people with bladder and bowel problems often go to their GP for assistance. GPs are unfortunately not given detailed training on this area of child health and so often cannot give appropriate advice to parents – for example, a common issue is parents being told their child will “grow out of” bedwetting – and so the child's continence issues remain unsolved, and could worsen. Differing provision between Health Boards also results in a “postcode lottery” for whether a child has access to these services – for example, Powys Teaching Health Board informed the PCF that children have sometimes been referred out of county by a Powys paediatrician for consultation and treatment for a urology problem.
- 5. What do you understand by integration of health and social care and what do you think a fully integrated service looks like in practice?** The integration of health and social care services

is not an area which the PCF is qualified to comment on, but we would like to highlight the need to ensure health services themselves are integrated where necessary, with continence being a key example. There are clear causal links between different bladder and bowel problems among children – children or young people who experience bedwetting may also have daytime wetting; and children with constipation or soiling may also have bedwetting or daytime wetting. Each local Health Board should therefore provide a single integrated paediatric continence service, rather than separating it into specific services, which could prevent appropriate diagnosis and treatments from being provided.

- 6. What do you think stops improvement from happening and how could this be overcome?** There is a lack of understanding of the nature of paediatric continence among many healthcare professionals, which prevents professionals from pressuring for suitable services to be provided. Financial pressures also inevitably provide a barrier in improvements to services, especially if it is not understood why services are needed or their cost, and the PCF would question whether this has impacted upon service provision over time (as outlined in our answer to question 2).
- 7. What more can people do to look after their own health and wellbeing?** It is crucial for parents to be fully informed – by health visitors, school nurses or GPs – of what is considered “normal” for childhood continence. If a parent understands when their child’s toileting behaviour should be of concern to them, they can take further action to receive an appropriate diagnosis and treatment to prevent a worsening of symptoms.
- 8. What improvements can be made to information and advice to help you make decisions with professionals about your care?** GPs, school nurses and health visitors should be made aware of their local paediatric continence service to ensure that any parents or carers with concerns about their children can be directed to the most appropriate service. These services are then best placed to provide further information and advice to assist families.
- 9. Please tell us about any ideas you may have that you think could deliver real improvements to services?** As we hope we have made clear in the answers to previous questions, the PCF believes that every area in Wales should have access to an integrated, well-resourced paediatric continence service to provide appropriate and timely treatment for bladder and bowel issues. The provision of these services can reduce expenditure in other areas of the NHS, such as in A&E/secondary care. The PCF estimates that (based on 2014/15 NHS England tariff costs) following an appropriate care pathway for bladder and bowel conditions – underpinned by a community paediatric continence service, and avoiding referral to secondary care services – could cost an average of £318, compared with an inappropriate care pathway costing in excess of £2,000. Following an optimal care pathway not only reduces expenditure for the NHS, but also improves the quality of service and positive outcomes for the child and family.
- 10. What do you think should be covered by national rules and what should be left for local managers and professionals to decide?** It is ultimately a local decision as to what community health services should be provided, but this should be driven by a national aim for these services to prioritise the health and wellbeing of children and young people.

For further information, please visit www.paediatriccontinenceforum.org or email paediatriccontinenceforum@whitehouseconsulting.co.uk.