

**REVIEW OF PAEDIATRIC HEALTHCARE SERVICES IN NORTHERN IRELAND (PHASE 1 AND 2):**

**CONSULTATION RESPONSE QUESTIONNAIRE ON A DRAFT REVIEW OF PAEDIATRIC HEALTHCARE SERVICES PROVIDED IN HOSPITALS AND THE COMMUNITY**

You can respond to the consultation document by e-mail, letter or fax.

Before you submit your response, please read Appendix 1 about the effect of the Freedom of Information Act 2000 on the confidentiality of responses to public consultation exercises.

Responses should be sent to:

E-mail: [secondary.care@dhsspsni.gov.uk](mailto:secondary.care@dhsspsni.gov.uk)

Written: Secondary Care Directorate  
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Castle Buildings  
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**Responses must be received no later than 31<sup>st</sup> January 2014**

I am responding:

on behalf of an organisation

(please tick a box)

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## Recommendations within the draft Review of Paediatric Healthcare Services Provided in Hospitals and the Community

**Q1. Does the scope of the information detailed in the review provide a comprehensive assessment of the needs for paediatric healthcare services provided in hospitals and the community over the next 10 years? YES/NO**

If NO please explain

While the Paediatric Continence Forum (PCF) welcomes the review and the focus the NI Government is placing on paediatric health services, the review does not recognise the specific need for attention to be given to paediatric continence services. Around one in twelve children are affected by continence problems, causing them significant difficulties, physically and psychologically and causing problems with education and family relationships.

Continence problems, such as bedwetting, daytime wetting and constipation and soiling, occur at a sensitive time in a child's emotional and physical development, often causing feelings of low self-esteem and social isolation. They also contribute to family stress and to the very real risk of bullying by siblings and peers. These difficulties, in turn, can prevent children from taking full advantage of social and educational opportunities at school.

The PCF believes that dedicated children's continence services should be commissioned. We wish to note that referral pathways need to exist between paediatric continence services and mental health services for children and young people, despite mental health services being outside the scope of this review.

In particular, child incontinence is not the child's "fault", and it is essential that children are not punished for wetting accidents, which can result in a "vicious cycle" of increased stress and more accidents, potentially leading to harsher chastisement and a risk of child abuse. Issues of safeguarding need to be addressed, and this is best done in an integrated manner.

**Q2. Are the enablers for change detailed for paediatric services appropriate or do you feel there are others? YES/NO**

If NO please explain

The PCF believes a key enabler for change which is omitted is integrated/team working and joined-up commissioning, which may include across organisational boundaries. Poor quality paediatric continence services can lead to children being hospitalised for problems such as faecal impaction and urinary and kidney problems – which not only reduce health outcomes and the quality of life for children and their parents, but are more expensive for health services.

The PCF defines an integrated paediatric continence service as a single service for children with all wetting and constipation/soiling problems. It should

also treat children from 0-19 years, be run by a multidisciplinary team, led by a paediatric continence nurse specialist, and have clear and effective referral and care pathways to secondary care; education; child and adolescent mental health services; and social services.

**Q.3 Are the 23 recommendations detailed in the Executive Summary of the review appropriate or do you wish to add or remove any? YES/NO**

If NO please explain

There should be additional recommendations which set out the need for integrated paediatric continence services, as defined in response to Q2.

There is strong evidence to support integrated services, including the 2010 National Audit of Continence Care by the Royal College of Physicians which concluded that clinical outcomes are higher when a service is integrated. Conversely, gaps in service provision lead to inappropriate referrals and wasted resources, as recognised by the (English) Department of Health's National Service Framework for Children, Young People and Maternity Services, published in 2004.

NICE's paediatric continence service commissioning guide (published in December 2010) states that an effective integrated paediatric continence service could "lead to up to an 80% reduction in the number of emergency admissions to secondary care, by providing assessment and management of continence problems (constipation and urinary tract infections which often present as acute abdominal pain) in primary and community settings".

Effective integrated paediatric services lead to fewer outpatient appointments (for UTIs and constipation).

The Paediatric Continence Forum is currently developing a commissioning guide for paediatric continence services, with the view that this will be accredited by NICE.

**Q.4 Taking account of the context and content of this document are there any other important issues not addressed? YES/NO**

If NO please explain

The key issue that needs to be addressed is the need for joined-up commissioning for paediatric continence services, as noted in the response to Q3.

**Please use space below to address any issues not asked in above questions**

The PCF is a national group of patient representatives and healthcare professionals which campaigns for improved services for children with continence problems. It was established in 2003, and works closely with the

national charities ERIC (Education and Resources for Improving Childhood Continence) and PromoCon (Promoting Continence through Product Awareness). One of the key goals of the PCF is for every area in the UK to have a proper community-based integrated paediatric continence treatment service, led by an expert paediatric continence professional, with a clear system of referral and care pathways across primary and secondary NHS care, education and social services.

### **Equality implications**

Q5. Do you think the proposals are likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the Northern Ireland Act 1998? If yes, please state the group or groups and provide comment on how these adverse impacts could be reduced or alleviated in the proposals

Yes  No

Response:

Q6. Are you aware of any evidence, qualitative or quantitative, that the proposals may have an adverse impact on equality of opportunity or on good relations? If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact.

Yes  No

Response:

Q7. Could the proposals better promote equality of opportunity or good relations? If yes, please give details as to how.

Yes  No

Response:

THANK YOU FOR YOUR COMMENTS.

### FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation. However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Lord Chancellor's Code of Practice on the Freedom of Information Act provides that:

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- the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature

- acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner

For further information about confidentiality of responses please contact the Information Commissioner's Office at

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