

**East Sussex Parent
and Carers' Council
(ESPaCC)**



**Our Children,
Their Voice, Their Future**

Tuesday, 03 December 2013

Dear Anne and Pari,

I am writing to you on behalf of East Sussex Parent and Carers' Council.

ESPaCC represent East Sussex Parents, Carers and families of children and young people aged 0-25 years with any additional need, and we have recently been contacted by a number of our membership with regards to the forthcoming changes in the children's continence service.

ESPaCC have not been made aware of or involved in any consultation regarding either the new service provision or the products to be supplied, and we would welcome further information about and clarification of the "*best practise offer in line with NICE guidance*" to which you refer.

As I am sure you are aware, this change in practice is likely to cause significant distress to many families, and we would like to understand better how you reached your decision.

- How many children and young people were involved in trialling the new products
- How many families were consulted prior to changes in service provision
- How many families will benefit from the changes
- How many families will be adversely affected
- What are the projected financial savings per child or young person per annum

Please note:

NHS bodies have a duty to make arrangements to ensure that users of services are, directly or through representatives, involved in:

- a. Planning of the provision of services;
- b. The development and consideration of proposals for changes in the way those services are provided, if implementation of the proposals would have an impact on the manner in which services are provided or the range of services available; and

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- c. Decisions to be made by the NHS body affecting the operation of those services, if the decision would have an impact on the manner services are provided or the range of services available.

The views of disabled children, young people and their families are therefore expected to inform local design and delivery of continence services, and provision should be decided based on an individual's clinical need.

Please could we have sight of all consultations and additional research that has been undertaken to inform the implementation of your service provision and the products to be provided.

We would welcome a written response, and would be willing to undertake the collation of views and concerns for your attention.

In the meantime however, we will place a link on our website so that families can contact you directly.

Please find attached additional documents for your consideration.

Best regards,

Michelle Nice

ESPaCC Co-Chair

MichelleNice@eastsussexpacc.org