

THE PAEDIATRIC CONTINENCE FORUM AIMS FOR YEAR 2 (Oct 2009- Sept 2010)

Summary

Financial cutbacks to paediatric continence services across the UK have been a particular problem this year. Anecdotal reports of existing (often minimal) services being cut further, or merged with adult services, have been common. The political activities of the PCF have not been able to reverse this trend and the Department of Health has been powerless to intervene. However it is hoped that the two NICE Guidelines (with participation on the Guideline Development Groups by members of the PCF) will help to reverse this trend in the coming year. In addition, the PCF has succeeded in persuading NICE to publish a Commissioning Guide on paediatric continence, which should also add weight to the commissioning process.

The Election and a new government in May 2010 presented the PCF with the opportunity to lobby new MPs, but also limited political activities during the run up to the Election. For example, 6 months intensive work by the PCF in conjunction with ERIC, achieved a government review of the 1999 School Premises Regulations (water and toilets), but the amendments were not completed in time before the pre-Election “purdah” period to receive Ministerial “sign-off”. The full set of Regulations is currently being re-assessed by the new government.

During the year clinical members, Mary White and Dr Ursula Butler retired. Both had contributed greatly to the PCF since its beginnings in 2003 and will be missed. The company SCA Hygiene Products UK Ltd also stood down. However we have been fortunate to recruit four new clinical members, Susan Affleck, Charlotte Mawby, Christine Rhodes and Dr Sameena Shakoor (the latter representing the Royal College of Paediatrics and Child Health). We have also been delighted to recruit two new companies; Reckitt Benckiser Ltd and AstraTech Ltd

AIMS (The difference we want to make)

a) To increase awareness and understanding within the government and amongst service commissioners, managers and practitioners of:

- a. The need for integrated, community-based paediatric continence services to be available to children and parents nationally and on an equal basis
- b. The key elements in the design of such services
- c. The strategic changes needed to create such services
- d. Examples of integrated services that have been successfully delivered, demonstrating greater efficiency and better patient care.
- e. Evidence of services that are under pressure due to NHS cutbacks
- f. The need to drive forwards practical solutions that provide improved patient care through better efficiency.

Partly achieved. Through meetings with 11 MPs and Peers, the above messages have been conveyed; in excess of 30 Parliamentary Questions on paediatric continence issues have been tabled and answered, 5 letters to Ministers were answered and an Early Day Motion tabled on 29 June 2010 has so far received 34 of signatures. Six monthly meetings with key Department of Health officials have resulted in introduction to useful contacts eg Sir Ian Kennedy re an application for a National Quality Standard on paediatric continence; Sir Ian Carruthers, Chair of SW Regional Health Authority who helped to further ERIC’s educational work and who subsequently joined ERIC’s Board of

Trustees; introduction to Professor Stephenson, President of the Royal College of Paediatrics and Child Health to re-establish formal links and representation on the PCF from the College; dissemination of key messages via DH e-bulletins. The PCF also contributed to the new All Party Group on continence.

The PCF edited and arranged publication in September 2010 by the Department of Health of the second Exemplar on paediatric continence. This gives a step by step guide through treatment of a child with additional learning difficulties, using an integrated model. This Exemplar was written by two members of ERIC's Clinical Advisory Group.

b) To improve the level of integration of existing community-based, paediatric continence services nationally, and to establish new services where necessary in order to move towards a fully integrated service within each PCT.

Not achieved and with no real mechanism to improve the situation at PCT level, apart from 3 MPs who asked questions of senior PCT officials in their constituencies. A template to enable practitioners to easily document service disinvestment was circulated nationally by the PCF and produced some case examples to take up politically. We hope that the situation nationally (with a focus upon England and Wales) will improve over the coming year with the publication and dissemination, not only of the NICE clinical guidelines, but with the publication of a NICE Commissioning Guide and the NICE audit programme. The PCF is setting up a regional MP representative scheme to monitor what is happening on the ground (MPs to ask questions of the PCTs/ GP Commissioners) and the PCF will also be asking PCTs for their progress through Freedom of Information requests.

c) To achieve a short NICE Guideline covering daytime wetting and to support the dissemination and implementation of the full NICE Guidelines on bedwetting and constipation once they are published.

Our application for a short NICE Guideline on daytime wetting was turned down in September 2010. However, the PCF has been actively involved with the dissemination of the NICE Guidelines eg asking PQs on how far they are being implemented, asking MPs to investigate their uptake in their constituencies.

d) To ensure that the 1999 School Premises Regulations governing water and toilet provision and access for children in schools are updated to an acceptable standard and have an effective mechanism for enforcement.

Following a meeting with the government adviser to Ed Balls in August 2009, a green light was given to the Department of Education (Partnership for Schools) to carry out a six month review of the water and toilet elements of the 1999 School Premises Regulations. The PCF worked intensively with ERIC and Partnership for Schools in contributing to this process. Subsequent amendments to the SPRs were passed by the Department but were not in time prior to the Election "purdah" period to achieve Ministerial sign-off. The new Ministers team have been fully briefed and are currently reviewing the full set of regulations, although it is likely that they will be reduced rather than enhanced as a result of the government's "light touch" policy on the regulation front.

e) To respond to other issues as necessary.

The PCF responded to the government's consultation on the question of automatic generic substitution (25/3/2010). The PCF also contributed to the draft "Blueprint on Continence" issued by the All Party Group on Continence.

During a meeting with the Healthy School Programme, the PCF investigated the possibility of water and toilets being added to the ChiMat (Child and Maternal Health Observatory) website.

The PCF also added a section on continence to the revised book for schools “Managing Medicine in Schools”. This revision is currently “on hold” with the new government.

The PCF sent written evidence to the Health Committee’s review of commissioning (September 2010) and a consultation response to the government’s White Paper (September 2010 on paediatric continence services and commissioning).