Helping hard-to-reach families to manage their children’s continence problems

Research assessed parent and child understanding of the continence issues affecting them and the response of the family and healthcare professionals.

Research was a necessary part of this project to: establish a baseline of actions and reactions in year 1; provide interim assessments on new initiatives; and, in year 3, assess their impact.

In conjunction with the project and over the same period, ERIC evaluated clinic services in the UK with a view to pushing forward the implications of the paediatric national service framework (Department of Health, 2004), helping to get childhood continence problems onto the radar of child health mapping and to support appropriate PCT-level commissioning of paediatric continence services.

Some findings from this research help to fill out the background and provide comment on likely future needs and improvements for not only disadvantaged families but also all children who have continence problems.

AIMS
The research aimed to inform new initiatives from ERIC by assessing parent and child understanding of the continence issues, their actions and reactions in response to these, how they approached seeking help and their unmet needs. Specialist healthcare professional opinions were also included.

Over time, the research aimed to provide a snapshot of how changes were being implemented, evaluating mismatches between help available and what was needed, how help was accessed, and how any materials (such as leaflets and booklets) and ERIC initiatives might help to address these problems.

This article discusses the research but does not describe the materials developed for the project in detail. For the purposes of this article, ERIC’s overall task is referred to as ‘the project’ and the study that supported it as ‘the research’.

LITERATURE REVIEW
Little research has been published on the impact of continence problems on disadvantaged families. Children with daytime wetting were found to have more parent-reported psychological problems than their peers (Joinson et al, 2006) and twice the normal rate of issues such as attention and activity problems and oppositional behaviour. Nocturnal enuresis has been linked to high levels of child distress and parental concern (Butler, 1998). Parents have degrees of action and reaction to children with problems, from understanding to annoyance and intolerance, to outright anger (Haque et al, 1981).


METHOD
Design
A number of approaches were used for collecting data. For parental interviews, a comprehensive semi-qualitative questionnaire was accessed, and how any materials (such as leaflets and booklets) and ERIC initiatives might help to address these problems.

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METHOD
Design
A number of approaches were used for collecting data. For parental interviews, a comprehensive semi-qualitative questionnaire was used. For child interviews, a semi-qualitative structured interview was used. For parent child pairs, a semi-structured focus group interview was used. For children who had not been interviewed, a semi-structured focus group interview was used.

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was developed. A second, shorter version was also drafted for self-completion. This allowed parents to be interviewed face to face or by telephone. The self-completion questionnaire allowed respondents to remain anonymous.

In the first wave (year 1), interviews were done face to face or by telephone (respondent choice) or by assisted self-completion questionnaire; child interviews were undertaken face to face by an experienced interviewer with parental supervision. In the third wave, interviewing was either by self-completion questionnaire or by telephone. Interim assessments of ERIC materials were made using self-completion forms.

In year 1, healthcare professionals took part in an initial focus group in one of the pilot areas. A group of them also made interim assessments of materials using self-completion forms. They provided a final assessment of materials and initiative during individual interviews conducted over the telephone.

**Sample**

The intention was to obtain 100 representative in-depth, semi-structured interviews with parents in the following ‘disadvantaged’ groups: social disadvantage (economic vulnerability, minority ethnic groups); physiological disadvantage (concomitant contributing illness); psychological disadvantage (such as autistic spectrum disorder, learning difficulties); emotional problems (contributing factors). Sample numbers are shown in Box 1.

One in two of the original 45 families provided follow-ups; 13% of these were from minority ethnic groups. The remaining 30 families were either impossible to follow-up (15) or had provided anonymous interviews or refused to be re-contacted (15).

Eight new interviews were completed to provide a comparator to the information from the first wave of interviews. Three of the new eight interviewees were from minority ethnic groups. The children were 3–15 years of age.

**Recruitment**

Parents were initially recruited from two pilot areas (Bristol and South Wales). A variety of sources and resources were used to recruit interviewees during the first 6–7 months of the project, including referral from healthcare professionals, posters, flyers, direct invitations via waiting rooms, newspaper adverts, word of mouth and calls into the ERIC helpline.

The majority of interviewees were recruited after contact with healthcare professionals. The team experienced significant difficulties in contacting and recruiting target-group families. A higher proportion of children with physical and mental disabilities than in the general population were recruited.

**DATA ANALYSIS**

The research was largely attitudinal in nature, based on awareness and experience. As such, it was largely discussion based, lending itself to standard qualitative analytical techniques.

During in-depth analysis, a search for keywords enabled an overview of emotional resonances to be developed. Numerical rating and scoring scales were used where appropriate.

The data presented shows the results represented as a percentage of the base, but the year 3 follow-up base is lower. Nevertheless, as a point of comparison and using percentage-based analysis, this shows differences over time.

**RESULTS**

This summary provides an overview of information generated in the first wave of baseline interviews plus the follow-up of families over the life of the project.

All continence problems were represented, including soiling, constipation, daytime wetting and combinations of these, with nocturnal enuresis the most common problem experienced in line with the findings of other research (Butler et al, 2005a; Bakker et al, 2002; Sureshkumar et al, 2000).

By year 3, three children (out of the 15 families followed up) had had no resolution of their continence issues (20%); five had partial resolution (33%) and seven (47%) had complete resolution. All had tried external help.

**IMPACT OF CONTINENCE PROBLEMS**

Throughout the project, we found that:
- Parents lacked self-identification, had low awareness of options and might also lack motivation to seek help;
- Healthcare professionals sometimes failed to identify continence issues;
- Those with associated physical or mental disabilities may be under the care of healthcare professionals but the continence issues may not be dealt with appropriately;
- In some cases, inappropriate referrals had been made (usually by GPs) or promised referrals were not forthcoming.

Fig 1 shows the impact of continence problems on family life at the baseline research (n=45) and the improvement over a three-year period (n=15). The findings confirmed that continence problems have a major impact on families, but also that a degree of acceptance can develop. This can result in parents not seeking help at the right time.

Parents admitted that they suffered significant extra stress because they felt isolated and were unable to find appropriate advice or were unsure where and when to seek help.

One in three parents admitted to annoyance and one in four to expressions of anger in response to their children’s continence problems. These were removed when the problem was resolved or even partially resolved.

Parents identified a group of children more likely to be unconcerned about their continence problems. Mostly, these children had underlying psychological issues, including autism spectrum disorder.

The data confirmed a significant emotional impact on all children including stress, loss of...
confidence, defensiveness, embarrassment, anger and guilt. Although parents believed a
degree of lack of confidence and anger
remained after three years, where resolution
had been achieved, these parents were
happier, less concerned about the past and
able to forget about previous problems.

This was a parental/carer interpretation of
the child’s response and therefore it has
inherent limitations. However, the three
in-depth interviews with children confirmed a
range of emotional reactions, including stress,
anger, guilt, defensiveness and loss of
confidence. Children also reported difficulties
in school life and social outings.

When issues were not resolved, the emotions
of the parent or child were further complicated
by a range of associated factors including:
- Where people lived and poor social
situations;
- Lack of holidays or respite;
- Embarrassment for the child and concern
over bullying/teasing;
- Lack of support from healthcare staff;
- Money/financial issues;
- Lack of time to deal with outcomes;
- Inability to discuss issue with the child.

ACHIEVING CHANGE

It is clear that disadvantaged parents have
barriers that prevent them from seeking help
(although it is likely that such barriers exist
across the board to some extent).

Barriers fall into six main categories:
- **Language/understanding:** Parents had a
  low awareness of causes and effects of
  continence problems; inability to understand
  the psychology of continence problems and
discuss things with their child; and possible
  language difficulties.
- **Motivation:** Parents had: disillusion with
  the NHS ‘system’; stigma; difficulty in talking
  about problems; a general belief that after
  years of dealing with the problems ‘nothing
  will help’; and had been told their child would
  grow out of it naturally.
- **Knowledge:** Parents do not know how to
  access help; there is insufficient accessible
  information; healthcare professionals may not
  be proactive in offering what is available; and
  there is insufficient outreach by healthcare
  professionals to those who most need help.
- **Cost:** Parents are afraid that help will cost
  them more money; they do not know what is
  free; and they may not claim benefits to which
  they are entitled because they do not know
  they are available.
- **Time:** Accessing help takes time and energy.
  Many of the parents have more than one child
  and often more than one child with continence
  problems. Inappropriate referrals and long
delays meant that some parents waited two
  years or more before seeing the right person.
- **Stress:** Parents become depressed and
  stressed and they may ask for medical help for
  themselves rather than the child. Depression
  also results in demotivation and lack of action.

The third wave of the research confirmed
that all barriers could be overcome or
ameliorated with new strategies. All those
involved need to take some responsibility,
including healthcare professionals in primary
care. For these strategies to be successful,
parents need to be able to access them.

When parents sought help, they did so for
several reasons. While there was the need for
diagnosis and hope for a ‘cure’, parents often
consulted at a point of desperation, out of
worry and fear, or because self-initiated
strategies had proved ineffective. There was
concern about starting school.

When parents did not seek help, it was
because they were unaware of the help
available. They thought or may even have been
told (sometimes by GPs or health visitors) that
the child would ‘grow out of it’ and that there
was no need to think of interventions until the
child was seven years old.

This research found that asking for help
from the wrong person, at the wrong time, for
the wrong reasons increases social isolation
and affects child confidence. Only parents who
had received appropriate help felt ‘better’
emotionally. In this context, appropriate help
meant timely referral to relevant healthcare
professionals and receiving an appointment.

Parents had tried wide-ranging approaches
to self-help (Fig 2) and external help (Fig 3).

Parents had successful interventions as a
result of appropriate specialist referral and
from contact with ERIC.

Broadly, parents confirmed a need for three
main areas of help:
- Better healthcare professional involvement;
- Help to be given at the right time and by the
  right person. Parents admitted that they had
  little awareness and knowledge of who they
  should contact or how to approach them.
- More information and advice and for this
to be appropriate, targeted and available.

Discussions with healthcare professionals
confirmed the belief that parents need help in:
- Overcoming the inertia and frustration
  resulting from a lack of effective interventions;
- Consulting earlier – parents can wait for a
  long time before asking for help and they
  ‘learn to live with it’;
- Developing a willingness to try new ideas
  because they often show a lack of belief in
effective interventions.
DISCUSSION

Parents identified two overriding needs. They wanted to understand what was happening to their child and why, and to facilitate a change.

All respondents acknowledged there were three main ways in which such change could be brought about: through information and proactive support, as early as possible, by using clearer pathways and ensuring interventions hinge on practical solutions. Suggestions from parents and healthcare professionals included:

- Improving education and knowledge by providing: new printed materials; helplines; good internet sites; personal advice; and new child-orientated materials;
- Healthcare professionals should: raise awareness; be proactive; provide ongoing education in primary care; facilitate childhood continence training; increase PCT involvement; and ensure appropriate referrals;
- Clear pathways for families to access, with better outreach for the disadvantaged, better planning and good guidelines;
- A menu book of help; good, accessible, affordable products; outreach to communities by all involved in continence care; and more school involvement.

As a result of this study, ERIC has developed initiatives including new printed materials such as a picture and text booklet for children on soiling, a menu book of help for parents, and a leaflet for parents of reception-aged children. All received positive feedback from parents and healthcare professionals.

In addition, ERIC has been campaigning for increasing PCT involvement, addressing commissioning issues and improving business plans to facilitate a better service without it costing significantly more.

This research plus other research undertaken to support the paediatric national service framework and child mapping highlights that the system that should support parents and children has problems doing so because:

- There are commissioning issues for PCTs and continence is not a priority;
- Schools themselves cannot or do not address the problem, especially in areas of social disadvantage;
- Waiting lists for specialist continence advisers are very long;
- There are inappropriate hospital referrals, which also affect budgets;
- There is an over-reliance on products and less reliance on intervention.

In associated research, where all continence services in the UK were sent a questionnaire (270 clinics responded), analysis confirmed that staff are often committed and ‘doing their best’ with the resources available.

However, issues of ownership and getting the best out of budgets need to be resolved if services are to improve. Childhood continence should also feature more on the PCT radar.

CONCLUSION

We need an inclusive approach to paediatric continence. For those with social disadvantage, the issue is not just one of appropriate intervention but also getting parents to acknowledge the problem and to access care.

When new ERIC initiatives have been put in place, findings indicate beneficial outcomes. Disadvantaged families need increased and targeted solution-based approaches, which will require the support of local PCTs.

See p29 for the Continence Journal