Department of Children and Youth Affairs Research Programme

Note No. 1 Research Briefing

The Child’s Right to be heard in the Healthcare Setting: Perspectives of children, parents and health professionals

1. What is the study’s background?
This study was funded by the Office of the Minister for Children and Youth Affairs (now the Department of Children and Youth Affairs) under the National Children’s Research Programme. The study was undertaken by Dr. Ursula Kilkelly and Dr. Mary Donnelly, both of University College, Cork.* The report was independently peer-reviewed and published in 2006.

2. What is the study’s purpose?
This study, undertaken at the Faculty of Law, University College, Cork, presents the experiences and perspectives of children, parents and health professionals on listening to children in the healthcare setting. Its objectives were:
» to consider the extent to which children are listened to by health professionals;
» to identify the obstacles to listening and communicating with children in the healthcare setting;
» to identify best practice in the area and to make proposals as to how it can be mainstreamed.

The research had three core elements: a literature review on the application of the child’s right to be heard in the healthcare setting; consultations with children and young people (aged 5-11), parents and family members, health professionals and voluntary groups active in the area; and an analysis of the educational and training curricula of the medical professionals who work with children.

This briefing note summarises the method of research, key findings, conclusions and recommendations of the study. The full report is available on www.dcyia.ie

3. How was the study undertaken?
The methods employed were designed to achieve the above objectives. The study was based on:
» A literature review comprising law, policy and practice relating to children’s treatment in the healthcare setting, including children’s rights and medical law.
» Empirical work to produce a ‘snapshot’ of the views, attitudes and experiences of children, parents and health professionals on whether children are listened to in the healthcare setting. In particular:
  » children between the ages of 5 and 11 were interviewed using a range of age-appropriate methodologies about their experiences and views on being listened to by health professionals;
  » parents and health professionals were interviewed, either individually or in focus groups, to identify their views on these issues.
» A review of the relevant education and training curricula of the medical professionals who work with children.

The key strength of the research is thus the combination of a range of stakeholders’ perspectives, together with a curriculum audit, to advance a unique and focused understanding of the issue addressed.

* The views expressed in this report are those of the authors and not necessarily those of the Department of Children and Youth Affairs.
4. What are the key findings?

4.1 The views and experiences of children

The children interviewed for this research varied in age, gender, background and their level of contact with the healthcare system. Yet despite these variables, they consistently identified the importance of being heard by health professionals and routinely explained the importance to them of being provided with age-appropriate explanations and information to help them cope with the consultation and treatment process. They articulated clearly a need to be understood and to be treated with empathy, kindness and good humour during illness, whether serious or not so serious. They appeared to have had better experiences with those who have had special training, notably in paediatrics.

Children also made valuable suggestions on how their interactions with health professionals could be improved. While many of the children referred specifically to their doctor in this regard, their recommendations – that training be undertaken for effective communication with children and that age-appropriate language and props be used – were directed at all health professionals. Furthermore, their recommendations – that waiting areas and hospitals be made more child-friendly, particularly for older children – are simple yet clearly important to improve the quality of the healthcare experience for all children. These findings are consistent with research carried out elsewhere.

4.3 The views and experiences of health professionals

The research found a clear difference between the approaches of some professionals, particularly those with specialist training in children’s healthcare and those who have specialised in other areas but nonetheless treat children. In addition to the need to address the training of all health professionals in this context, this also raises the need to adopt a common and a multidisciplinary approach to communicating with children throughout the healthcare system.

The different demands and challenges faced by health professionals must, however, be taken into account since all have different roles within the system, as well as different time and resources at their disposal.

Although the duty to listen to children is clearly placed on the shoulders of the health professional, the research confirms that the role of parents in the process is as influential in practice as in theory. Indeed, consistent with other research, interviews with health professionals confirm that the dynamic between them and parents is a hugely significant factor in how they communicate with their child patients. The fact that, for many health professionals, the influence of parents on the effectiveness of communication with children is decisive in either positive or negative terms means that any training of health professionals on listening to children must also address these tensions and how to deal with them.
4.4 Education and curriculum review

Education and training on communicating with children is not consistent across all health professionals and there is a notable difference between the education and training of nurses and therapists, on the one hand, and that of the medical and dentistry professions, on the other. The former group appears to have made good progress in the incorporation into their educational programmes of theoretical and practical approaches to listening to children. In contrast, analysis of educational curricula for the medical profession indicates a lack of detailed or structured focus on either the theoretical or practical framework within which the voice of the child can effectively be heard in the healthcare setting.

Many health professionals who had not experienced any training on communicating with children had developed their own methodologies through emulation of senior colleagues, on-the-job training and reflection on specific case histories with clinical colleagues. Those who had experienced training took a more structured and perhaps formalised approach in their communication with children.

In light of the mixed progress towards incorporating communicating with children into the education and training curricula of health professionals, it is important that awareness of the need for such training is on the increase. The current state of change of the medical curriculum in particular means that the time is opportune for cooperation within the healthcare setting on this issue. While different approaches will be required in different areas, considerable good practice, which is equally relevant and appropriate to all professions, can be shared widely. The mainstreaming of theoretical and practical knowledge on how to communicate effectively with children is to be strongly encouraged.

5. What are the conclusions?

The study draws conclusions on best practice in communicating with children and identifies both positive initiatives and obstacles with regard to listening to children in the healthcare setting. In these three areas, the following conclusions were reached:

1. Best practice in communicating with children:
   Best practice in this area was identified by children, parents and health professionals as follows:
   - the child must be involved in treatment decisions as far as possible, bearing in mind his or her capacity to understand and willingness to be involved;
   - the patient’s parents or carers must be involved in treatment decisions;
   - the views of children must be sought and taken into account;
   - the relationship between health professional and child should be based on truthfulness, clarity and awareness of the child's age and maturity;
   - children must be listened to and their questions responded to, clearly and truthfully;
   - communication with children must be an ongoing process.

2. Positive initiatives: The research identified the following positive examples of best practice:
   - addressing children directly during the consultation process;
   - adopting an age-appropriate approach to treating children, which takes into account their development and capacity to understand;
   - chatting with the child to make him or her feel relaxed, while also respecting personal boundaries;
   - preparing children adequately for what is about to happen in a treatment or procedure, and giving them the opportunity to ask questions and to prepare themselves;
   - empathising with children, being light-hearted and good-humoured where appropriate;
   - using age-appropriate language and props to explain things to children, including their condition, the prescribed treatment or the procedure about to be undertaken;
   - giving children choices as to how they want to proceed;
   - being honest with children in order to build a relationship of trust;
   - creating an environment in which children are encouraged to ask questions;
   - making the healthcare environment, including waiting rooms and treatment areas, child-friendly for children of all ages.
3. Obstacles to communicating with children:
Common obstacles to communication were identified by all three study groups – children themselves, their parents and their health professionals:
» Training and experience: Both are necessary in order to improve the skill of health professionals in communicating with children.
» The role of parents: Parents can act either as a barrier or an enabler to children’s communication with their health professional.
» Time: Health professionals do not always have as long as they need to communicate effectively with children.
» Physical environment: This can hinder efforts to communicate in a meaningful way with children about their healthcare.
» Personality of the health professional: The personality or attitude of individual health professionals often plays a significant role as to whether or not they listen to children.

4. Training in communication skills with children is an essential component of appropriate professional education: This needs to include theoretical approaches in addition to clinical experience.

6. What are the recommendations?
This section presents the recommendations emerging from the study.

1. Public information campaign
A public information campaign aimed at children and adults needs to take place to raise awareness of the right of the child to be heard.

2. Training
Child development, children’s rights and appropriate ways to communicate with children of all ages and stages of development should be incorporated into the training of all health professionals. This should also address the role of parents in the process.

3. Protocols and best practice
Protocols need to be developed between all health professionals, establishing best practice and shared approaches to communicating with children.

4. Research
Further research should be undertaken into the extent to which children are listened to in the healthcare setting. In particular, the experiences of teenagers and children and young people with disabilities should be taken into account.

7. What are the benefits of the study?
The benefits of this study arise from its application of children’s rights to the practice of listening to children in the healthcare setting. The merit of the approach taken is that it not only listens to children about their experiences and views, but it discusses the perspectives of parents and health professionals to see what common ground exists between all three parties central to the healthcare of children. It also draws important conclusions about the training and education of health professionals in this area.