

Disclosure

Can there ever be an optimal approach to the 'disclosure' to the family of the disabling condition from which their child suffers? There should be an ideal plan in one's head about disclosure (see e.g. *Right From the Start*¹). One can update this from time to time.² In shorthand, my template is something like this: see the parents together with the child in a good private space without junior staff, but maybe with a colleague such as a therapist or psychologist; have plenty of time; and have a written report available. Remember the parents' recognition of that first consultation is often a blur and all they'll retain is the 'fatal' diagnostic word. So you give them the written report and you aim to see them again within the week so that they can have time to put together all the questions that they want to ask you, providing them, if available, with an information sheet about the diagnosis and arrange to have a third consultation within a week or two of the second.

Remember too the highly desirable measures: information, which is easily understandable and easy to remember; and the manner of the teller (this puts a lot of burden on one). Be sympathetic, understanding, a good communicator, direct, approachable, and open (see Table III, Sloper and Turner).³ If everybody behaves like this, all should go well with this process. But sadly one's only too aware it doesn't. Baird and colleagues² show that nearly 50% of parents of children with cerebral palsy that they saw had been dissatisfied or very dissatisfied with the way they received information about their child's condition.

Looking back at disclosures that I've made in the last few years, they never seem to fit neatly into that clear-cut pattern.

The diagnostic process and the confirmation that something is wrong emerge slowly over months. Why was the health professional reassuring in the early months? Well of course the health professional wanted to reassure her/himself. So now the parents are for a month or two having troubles with the baby – difficult feeding, poor sleeping – but think all is basically well.

What the health professional feels but doesn't know how to communicate to the parents at that point, is often her/his own uncertainty about what is going to happen with this baby. We get into the diagnostic process: there's waiting to hear the results, the delayed report, the MR scan not available on the session when you were going to look at it together.

What of the groups of children with other disabilities, those who have a fairly normal first year and then don't talk or develop or seem to have some odd communication problems or who begin to display antisocial behaviour? Again, when the family reach the health professional with labels like autism picked up from friends or the internet ringing in their minds, what does the health professional do? The health professional feels uncertain again, wants to see the child for longer, and wants lots of reports but is left again with uncertainty and the difficulty of communicating that to the parents. So at the end of the day, the health professional may well feel that there's a botched situation. My first paradigm of how to disclose needs a

preface as to what is to happen when things are not clear-cut.

Parents need a continual flow of information about what is happening to their child. As soon as a family turns up with a child about whom they're anxious and anxious in a way which makes the health professional anxious, the health professional must share that anxiety with them so that the family and the health professionals can move forward in perplexity together. Explain why you don't know and what you're going to do about it.

Have we really conveyed the information that means the family understands and appreciates their child's situation? A father told me he still had his son down for one of the top English private schools, although the child with severe learning disability had no hope of attending the institution – information which I thought I'd been putting over to the family for the previous five years. But I'd failed.

In developed countries there are now immense sources of information from parent groups through to professional bodies concerned with particular disabilities. One needs now a little hand-out with a suggestion about some of the best websites to contact on child development, disability and behaviour and so on. All this expertise is not going to work if the family has not understood something of the nature of their child's disability and what the future holds for him or her. One parent whom I questioned about the difficulties of these early years of understanding said it was as if 'I had to do a three-year course crammed into 6 weeks'.

The disclosure I've been thinking about has been to the family with the young child, whereas as the child gets older he or she also wants to know what's going on and it is never too early to start seeing that the child is in a good position to listen to what the health professional is saying to him/her and the family. All the time they want new information, and there are new facts about their condition which they want the health professional to get right. Disclosure then is a lifetime task for health professionals. Disability is not a tidy subject and untidiness and muddle is not just something the parents suffer but it's something that professionals suffer too as they struggle to try and form a satisfactory information network throughout the child's early life and into adolescence and adult life. Disclosure is not a task over and done with. It continues.

(Some of the thoughts expressed here were developed for the EACD/ICPS conference on parents and professionals working together and I'm grateful to the participants for discussing them with me.)

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References

1. Leonard A. (1999) *Right From the Start*. London: Scope.
2. Baird G, McConachie H, Scrutton D. (2000) Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood* **83**: 475–80.
3. Sloper P, Turner S. (1993) Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine & Child Neurology* **35**: 816–25.