

Telling is not always answering

'John - ny's broth - ther's ma - ad!' may sound like no more than a schoolchild's unkind taunt to a boy whose brother has cerebral palsy, dribbles and is mildly developmentally delayed. Years later, aged nineteen and faced with a life-insurance form, Johnny asked his parents how to answer the question 'Is there a history of insanity in your family?'. The real tragedy was that the parents did not know the answer either.

Outside of academic philosophy, answering well-formed questions is usually easy; but to answer an ill-formed amorphous question is to court confusion.

When I first joined the motor industry, I went to my department manager with a problem. Being busy he asked me to write down the question in not more than twenty-five words, putting underneath all the possible solutions and ticking the one I liked best. If I still had a problem I was to bring him the piece of paper. However, having formed the question there was no need to write the list of solutions as the answer was obvious once the question had been clearly stated.

Those of us who have worked within the community rather than only in a hospital setting have had the opportunity, denied many others, to see the impact of childhood disability on families within their homes. One consequence of this has been that when discussing family needs with more clinically based colleagues our priorities can differ somewhat: one example of this is how to answer questions related to the prognosis. For cerebral palsy, after causation and all that can arise from that, the first questions usually relate to life expectancy, walking ability, intellectual (or school) ability and the catch-all - 'Will he/she have a normal family life?'

We each do our best to answer such questions, often to get the response 'Nobody ever told me that before'. More often than not we know this to be untrue either because we have confidence in our clinical team or have been present when the question was originally answered. Of course it is flattering to be told one has responded not only brilliantly, but uniquely; however there may be a little more to it than that. It is not easy to accept or fully understand the answer to a question that you have not yet reached the point of needing to ask.

Not infrequently it is obvious that an answer has been fully accepted by one parent (perhaps confirming what they already suspected) while their partner is totally overcome by this 'new' information. Although they jointly asked the same question, they had not reached the same understanding of their situation. For example when asking 'Will he walk?' one family member may want to know 'Just how bad is he?'. To another, however, the question asks 'Will he be wheelchair-bound?'; 'Is he crippled?'; or 'How will he play with other kids and make friends?'; or 'Does this mean he will have to attend a special school? Is there one near here? Is it any good?

What are the other children like there? I want him to have a good education because he is bright you know'; or more straightforwardly 'Have we got to take a wheelchair everywhere for the rest of our lives? Have you any idea what that is like?'. And perhaps to a brother or sister: 'Are we never going to be like my friends' families?'

The individual's perspective within the family gives him or her a continuing but differential interpretation of the information they receive so that the same verbal question may be used by the family to seek out answers to many different questions. This can make even simple discussion of their predicament almost fruitless. Even when the question asked has the same meaning for all the family, the answer may be interpreted quite differently.

Gradual realisation about the child's prognosis is not the only hurdle. There is also the realisation of the limitations of therapy for these children and the very different uses of words like 'success'. Parents can be driven towards the more exotic therapy regimes (some of which require immense family disruption and commitment) and expectations are naturally high at the start. It is unfortunate, in my experience, that usually these high expectations are lost by one partner some time before the other; and the joint aims of the family fragment and become ever more difficult to discuss. To attempt to answer questions then can be to take sides in a serious and fundamental family row.

It is for these reasons that I often suggest to parents that together they *write down* their questions and discuss them within the family before bringing them to the outpatient clinic. Not infrequently I am asked if I would join in these discussions and having started with only two or three basic questions, find they are reinterpreted by different members of the family and we end up with a list which is rather different and a bit longer, particularly if grandparents or older siblings are there too. Not infrequently the family have the resources to answer each other's questions during the discussion and, perhaps more importantly, they arrive at some mutually agreed problems.

So this is really a simple plea to those in a position to answer families' questions. Try to avoid the situation where the parents think you have not listened to them and they seem not to have listened to you, by uncovering the questions the family are really asking rather than those you immediately hear.

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