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An Alphabet of Helpful Hints: H is for Honesty

Peter Limbrick

Though we would all accept that honesty is a virtue, in the world of childhood disability there can be discussion, not about the need for honesty, but about when it is appropriate and how much of it should be available to parents.

Parents are usually quite clear though. They want to know everything there is to know about their child. When their questions are not being answered they might suspect, rightly or wrongly, that information is being deliberately kept from them – and this can then stifle or erode their trust in their practitioners.

Professor Hilton Davis, who is interviewed in this issue of IQJ, is also clear about honesty. In his book, *Counselling parents of children with chronic illness or disability* (Davis, H. 1993), he describes the relationship that is essential between the parent and the helper as a partnership and discusses its necessary elements under the following headings:

a. Working closely
b. Common aims
c. Complementary expertise
d. Mutual respect
e. Negotiation
f. Communication
g. Honesty
h. Flexibility

About honesty he says:
Implicit in the characteristics of a partnership already mentioned, but worth making explicit, is the need for honesty. There must be an assumption on both sides that all ideas, feelings and information relevant to their joint endeavour will be shared accurately and openly, even when the information is not good.
(page 39)

In *Working in Partnership with Parents* (Davis, H. et al 2002), Davis again advocates open communication between parent and helper and says:
What is required here is not only accuracy, but honesty. Each partner needs to feel that they can be as open and honest as possible with the other and that this will be accepted as having positive or beneficial intentions for their mutual activity. The importance of this underlies the ability of the helper to challenge the ideas and actions when seen as unhelpful, but also the ability of the parents to challenge and question the helper, when they feel the need.
(page 53)

Davis goes on to discuss the qualities and skills the helper needs in order to develop a partnership with parents. One of these necessary qualities is genuineness which:
…involves honesty and sincerity, and implies valuing the truth, not deliberately misleading others, and reliability.
(page 60)

In my experience, as a teacher, keyworker and consultant, many parents have to face very serious issues and can have very difficult decisions to make. It is not an exaggeration to say that these decisions can have life and death consequences for the child and might impact on the family's ability to stay together. The stance that Interconnections takes is to respect, promote and protect a parent's right to have all information about their child and about relevant interventions. I would want such a family to have at least one familiar and trusted practitioner prepared to be honest with them as they weigh alternatives and decide on courses of action.

The topic of honesty often arises with practitioners and parents in my work in helping councils and health trusts develop their early childhood intervention systems. It is quite common for practitioners, new or experienced, to suggest there should be degrees of honesty depending on the situation. This almost always comes out of a professional desire to be caring and considerate and the rationales can typically be:

i. We have to wait until we feel the parent is ready to hear it.
ii. It would be cruel to tell them everything in one go.
iii. Some parents are not able to understand
– perhaps because they had learning difficulties at school
– or have a mental illness
– or have a different culture and/or language.
iv. We cannot always predict the child's future with any certainty.
v. We might have the information they need but not the authority to give it, or it is not our job to give it.

Practitioners, like parents, come in all shapes and sizes and there will be some who choose to duck an issue because they cannot deal with the consequences – perhaps a parent in tears or in a rage. While this means putting the practitioner's needs before the parent's, we can only criticise if the practitioner has access to regular emotional support and supervision herself, which very many do not.

In my consultancy work around the UK and Ireland, I try to counter these obstacles to honesty and open communication by inviting practitioners to put themselves into the shoes of parents. I do this by inviting practitioners to imagine arriving at work the next morning and being told that there has been a complaint against them and that the police are involved. Obviously this is not the same situation as parents face but for most of us it would be a traumatic time with serious implication perhaps for our career, our family and our mental state. Practitioners always agree that their immediate need would be for all available information – nothing held back, no drip-feed, no distortion and no softening of the facts. Full, uncensored information is essential so that the practitioner knows immediately what she is facing and can start planning her strategy to deal with it.

Here is a real situation about honesty I met as a keyworker but with some of the details altered for anonymity. This family had a child of eighteen months with four or five diagnostic labels and consequent health needs. The child's condition included significant sensory deficits, cerebral palsy, epilepsy, the need for a supply of oxygen and tube feeding. She died a few months after this time I am writing of. The parents were greatly confused by contradictory information. While hospital staff had told them after the birth that the prognosis was bleak, therapists and specialist teachers were continually praising the child's progress. Finding their courage at a routine consultation they asked the paediatrician (who had known the child since birth) to tell them just how disabled their child was in comparison to other infants he had known and worked with.

The paediatrician, who might perhaps have focused on more positive and encouraging feedback in this consultation had he not sensed the depth and sincerity of the question, said that this child was much more disabled than any he had known. He was open and honest. When I tell this story to audiences of practitioners, some wince visibly at the imagined pain of the parents. Yes, it was a painful reply, but it removed the confusion and contradictions and now the parents felt they could start to manage the real situation – just like the practitioner who had to manage the complaint against her. They knew at last what they were dealing with and felt now they could get on with planning their lives with their daughter.

But there are questions and there are questions. Some are light and conversational. Some come from somewhere deep – and it is the task of the practitioner to distinguish between the two. If not, then a passing thought by the parent can result in a bombardment of too much information, and a sincere question can fail to evoke the required honest response. When I am in doubt about the level of the question, a useful strategy is to ask question back to help me decide. Another is to give a short answer and then check if that is the information looked for.

As an example, a parent might ask if her child will go to school. Reassurance that all children go to school in the UK might be enough of an answer at that time or it might lead to a lengthy discussion of the pros and cons of special and mainstream education. I remember accompanying two parents to their consultation with their child's paediatrician during which he asked them if the child slept well. In response to their 'no' he spent ten minutes describing sleep problems he had known and all possible solutions. When he then asked

if that was useful, they said not because they were already being helped with their child's sleep. This helpful doctor would have saved time if he had checked what information was required – as it can be of benefit to all of us to spend a moment or two to explore what is really being asked.

Just as there are different levels of questions, so there can be different ways of answering. While parents are looking for honesty, they are not looking for cold brutality. Cold brutality sounds harsh and improbable – until you meet a number of parents who are willing to open their hearts to you about what they have experienced. This brings us back to Hilton Davis and the helping relationship. It seems logical to me that some news is best given by, and some very painful situations are best faced with the support of, a practitioner with whom a genuine partnership is already established. The paediatrician in the story above had known the family since birth and was respected and trusted. In the privileged position of keyworker, a mother confided in me that, while she was afraid her baby would die, she was equally afraid her baby would survive for a lonely life in a wheelchair being fed by tube. She could be honest about this because we had developed that sort of relationship.

While we hope all parents will have support from someone they trust at the most difficult times, no practitioner can expect to be in a position to offer that level of support unless they have worked on the relationship from the start – honesty, respect, genuineness, etc. Being honest with parents in the difficult times might not come naturally to all of us all of the time, but it is a part of the job and should be in our codes of practice, training, supervision and team discussions.

Honesty and openness might not always come naturally to parents either. Some parents, for a variety of valid reasons, will be reserved until they have decided the sort of person we are. It is worth considering that, when you meet a parent for the first time, they might have been let down by practitioners who have already come and gone. They might have grown to trust someone who is now on maternity leave or moved to another job. They might have spent time telling their story to a sequence of people with no practical outcome. They might already have been refused the support they know they need. Just as you might be making judgements about a new parent, the parent is likely to be assessing in the first minutes whether or not it is worth investing time in you, whether you are likely to be someone they can rely on to come up with the goods. This is not to suggest parents are cynical and grabbing – just that they are busy people engaged in a long struggle to get the best for their child and family.

Other parents, a minority, will not readily play their part in an equal partnership with mutual honesty no matter how skilled the practitioner. Obviously, this is not a reason for giving up on the child, but it does call for another strategy. Perhaps it is possible to achieve some useful work with the child without a partnership with parents. Perhaps in time you or another local practitioner can get a bit closer to the family.

References

Davis, H. (1993) *Counselling parents of children with chronic illness or disability*. Leicester: BPS Books.
Davis, H., Day, C. & Bidmead, C. (2002) *Working in partnership with parents: The Parent Adviser Model*. London: Harcourt Assessment.