

The paediatric clinic: disability and the family

Only about sixty years ago, hospitals were more concerned with the illness of the child than the child itself, and the family was regarded as merely an appendage to the child. Gradually the child was seen to be a person and was consequently treated with something bordering upon respect (of the sort appropriate at that time for someone of their age), though visits from their parents were still regarded as a privilege. Later, parents (preferably mothers) were accepted as legitimate contributors to their child's care, and the phrase 'the family' was incorporated into the paediatric vocabulary, as part of the solution, not the problem. But even today, 'the family' is thought of and created as a single entity, when of course it is anything but that. All new babies change family relationships and such change is compounded by disability. Whether the baby is a grandchild, child, or sibling will mean a different perspective and degree of responsibility for each relative, but what is certain is that they will all be affected by this change.

The family environment can be a resource for coping or an additional source of stress¹. Where the baby has a disability, there is evidence that mothers and fathers differ fundamentally in their coping strategies²; all family members have to find their own way of coping with the change, which may be differently understood. The father is most often the working partner and cannot always attend hospital. He may hear everything from the mother and on occasions vent his immediate feelings, which might otherwise have been discussed with a nurse or doctor, towards his wife instead. The mother, meanwhile, is organising her own thoughts, facing the strain of hospital visits, caring for and perhaps treating her child, and coping with the demands of other family members. Mutual grieving is not always supportive; mismatched views can set 'Why *can't* you accept this situation?' against 'How *can* you just accept it?'

Grandparents may have a different understanding of the situation and, far from being supportive (as they intend), can become an additional burden. Often an early response to the inevitable question of 'Why our family?' can be 'We've never had a problem like this', implying that the disability is not from their side of the family. Unsupportive grandparents may criticise their son's/daughter's spouse more directly.

Carr noted that 45% of mothers of children with spina bifida reported that their other children had suffered from less attention and fewer holidays and outings than their friends³. She subsequently reported that the siblings of children with Down syndrome showed no ill-effects⁴. However, in a recent article⁵, the brother of a girl with Down syndrome wrote lovingly of his childhood with her but added, '...so we must never ever complain...and we must tell others that having a disabled member of the family is an enriching, life-enhancing experience', indicating that his

family expected a level of tolerance that we would not even expect about a sibling who did not have a disability.

Clinical experience leads me to consider that siblings can be extremely upset by their new situation; they may be concerned about the loss of their 'happy family' image and how their friends will perceive them. Many siblings, as they adjust to the change that a new family member brings, 'may find unexpected levels of parental preoccupation, sadness, irritability and anger to which they have neither access nor explanation'⁶. 'Will things ever be the same?' seems to sum up their most commonly expressed thoughts. Their dismay at the family's plight can lead the child to blame their parents for bringing this insecurity into their life. It is important that siblings understand what is going on; but there is a risk that all conversation may circle around this one child who dominates every family decision and all parental attention. All this can be difficult for children to bear and even harder to talk about. Most parents are prepared to take on the challenge that this new child presents, whatever this may mean for their own lives, but they do not wish this to become a burdensome legacy for their children. They may say as much at home too, but what can be the proper response within the family? 'Thanks Mum, that's a great relief, we'll just put him in a home'? Hardly. The family is more likely to take on the responsibility of caring for the child gladly and with love, although this is not always the case.

Every reader will be aware of these stresses and many more. But how many of those in health care have the time to explore fully the changed relationships one child has caused? How many have the chance to see more than the 'face' that one stressed family member chooses to show? It is 'the family' that we hear about. But who can really consider its many aspects? If we truly wish each member of the family to be considered, let it be by people who have the time and the expertise.

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References

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