

Endeavours of parents

Most health professionals who work with disabled children probably feel that they have competencies in relating to both disabled children and their families who care for them. Medical training has for many years emphasized the importance of communication with all families. Acutely ill adults or those with a significant medical problem expect doctors and their colleagues to advise on what should be done, and patients want to understand the quality of that advice. Given the stresses of the patient's condition, he or she is motivated to accept it. As we all know, in the situation of chronic disability or illness we have a totally different state of affairs, particularly when, as is the case with the disabled child, treatments and management are not going to be curative. Hence the complication of the relationship between the family and the advisers.

Robards¹ has usefully discussed under the heading of 'Style of Consultation' four different ways in which partnership with parents may be established and these approaches are based on the descriptions of Appleton and Minchen.² They describe four patterns of communication between parents and practitioners: the expert model, the transplant model, the consumer rights model, and the social networks model. They then talk about the fifth emerging model of 'empowerment'. There is an implication of moving from the expert model when 'there is little negotiation between the parties, and parents may be reluctant to question the professionals'¹ (p 63), to the empowerment model which is seen as moving in the right direction. The empowerment model actively promotes parents' sense of control over decisions affecting their child, is sensitive to the parents' right to opt into the professional system at any level they chose, and encourages the unique adaptive styles that each family and social network will employ. There is, however, an inherent implication that, provided parents accept advice which has been given in one form or another the activities thus induced will benefit the child.

From the time of Bowlby (if not from the time of Freud) enormous numbers of studies have been done on relationships between parents and their 'normal' children. The importance of attachment and the consequences of failed attachment indeed underlie child psychiatry. 'Good enough' parenting is regarded as essential for children, and professionals have some ideas about what categorizes satisfactory parenting as opposed to unsatisfactory parenting. However, when we encourage parents to play such a major role in caring for and nurturing their child with a disability, suggesting that this 'will do the child good', we are actually asking parents to play a role for which we have very little evidence. Can good nurturing for the child with a disability alleviate the effects of his or her biological disadvantage? Compliance or non-compliance by the family may affect the outcome for that child of his or her biological disadvantage. Otero and Hodes³ investigated the effects of maternal, emotional, and treatment compliance on

the control of their patients' epilepsy. In summarizing they stated that where there had been good levels of compliance, more children had recovered from epilepsy at follow-up. Good treatment compliance was also found to be associated with less maternal hostility and criticism of the child. There was perhaps a slightly alarming implication in their final sentence of the summary: 'Poor treatment compliance and the associated psychological disturbances suggests that assertive paediatric and psychosocial interventions may be needed for some children with epilepsy' (p 604). This finding leads us back to the belief that 'the expert knows best' and that empowerment models might not work.

In the current issue of the journal Laucht and colleagues⁴ from Germany investigate children at risk and maternal responsiveness. Their analysis indicates that children of responsive mothers had lower total scores in all behaviour domains than children of non-responsive mothers. I was particularly interested to look at those aspects of development where there is known to be a strong neurological component such as attention-deficit-hyperactivity disorders, where there were birthweight effects. These problems showed more significant outcomes than conduct disorders, which suggests that the intervention was important and the finding was that the responsive mothers had lower rates of these problems than non-responsive mothers. They suggest that the combined effect of biological and psychosocial risks on child adjustment are additive and their data remain ambivalent to the role that social environment plays in modifying the effect of perinatal complications on child behavioural outcome. This sounds complicated; it is, this type of research is not easy.

However, one can draw from the authors' conclusions the importance of 'good' early parenting in the behavioural development of biologically 'at risk' children. The message for parents clearly is that their labours will help the biologically disadvantaged child just as they would if they adopted or were looking after a psychosocially deprived child.

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References

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