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Commentary

A quarter of a century after the Sheldon report was published, we learn that in South East Thames, one of the most densely populated parts of Britain, four out of 14 health districts still lack an identifiable base from which to care for their disabled children. This is a depressing statistic. Of course, the absence of a child development centre does not necessarily mean that the disabled child receives second rate care, any more than the existence of a beautiful purpose built centre guarantees that care will be excellent. This study did not attempt to assess whether the absence of a child development centre made any difference to the quality of care, but the need for a 'single front door', a place where all the necessary professional help can be found, is repeatedly emphasised by individual parents and voluntary organisations.

The authors have not told us much about the operational policies of the child development centres in their study, but for me one point stood out – the extraordinary finding that just two teams regularly copy their reports to parents. Two out of 14! I wonder what reasons would be given by the remaining 12 for not following this practice. Perhaps they have forgotten that parents may in any case exercise their right to read their child's notes? Perhaps the members of these teams have not read the evidence that parents want and value the information contained in assessment reports. 1,2 How can a team claim to regard parents as partners (as doubtless they all do) if they copy their reports to all the relevant professionals but not to the people with the greatest need and right to know? Evidently, these teams have not considered the implications of social sciences research on the relationships between professional and family within child development centre structures. 3,4

The evaluation described in this paper addresses only the first two of the three stages of audit; it focuses on structure and looks briefly at process, but ignores outcome. Although the authors presumably feel that the standard of service for disabled children in many districts leaves much to be desired, they do not provide any direct evidence for this. The assessment of long term outcomes in the management of disabled children is of course very difficult, because severely disabled children rarely show a dramatic gain in development or function and very few can ever be said to have been 'cured'.

Nevertheless, there are short term outcomes such as parental adjustment and satisfaction, and effective service utilisation, which could be assessed by each child development centre team. After all, the aim of the child development centre is not merely to accelerate developmental progress. An equally important role is helping the parents to comprehend what it means to have a handicapped child and to deal with their grief and anger. The extent to which parents and professionals are able to collaborate to help the child is itself a measure of good care.

Districts where the professionals have learnt to work as a child development team and are based in a child development centre will probably fulfil this wider role more effectively than those which are not. Nevertheless, parents cannot be expected to be any more interested in concepts like 'multidisciplinary working' or 'district handicap team' than in who holds the contract for cleaning the child development centre toilets! The key question is not whether we have a particular structure in our child development team or centre, but how the service looks to the consumer – 'what is the experience like, for a parent in our district, who is concerned about a suspected disability in their child?'

In our own district audit, which will be reported in detail elsewhere, we asked parents this question. Three main themes emerged in their answers. Firstly, the way in which the news breaking process was handled was immensely important, as so many other authors have found. 5 Secondly, problems with 'boundary disputes' and poor information transfer between health, education, and social services caused considerable irritation (in spite of our immense efforts, which we believed had been successful, to overcome these problems). Clearly we had not yet achieved the single front door as effectively as we had thought. Thirdly, we learnt that our notion of the multidisciplinary team was a somewhat artificial construct, as every family had built their own particular and unique team of professionals to cater for their child's needs. Sometimes this team did not include any of the 'core members' of the child development centre. Indeed, it did not always include health professionals at all. The parents were interested in their whole network of support and how it had worked from the beginning, not just in the child development centre.

We called our audit 'Can we do better?'. There can be few child development teams who could not do better, even without additional resources. The first task is for the parents to consider its mission operandi – it is perhaps surprising that in the Zahir and Bennett study very few teams had 'awaydays'. Secondly, clinicians must be involved in management within their provider unit. If we have already clarified our own objectives in the care of the disabled child, it
will be much easier to ensure that managers and clinicians are striving for the same goals. Thirdly, it is no good blaming the purchasers or fundholders for underfunding the care of disabled children. We must first ensure that our purchasers understand the experience of having a handicapped child, what it is like to be a consumer of our services in our particular district, and how the situation could be improved. Describing the shortcomings of a child development team in terms of inadequate buildings or insufficient staff simply will not do.

Purchasers are (or should be) much more interested in quality than in structure. We must explain what we believe can be achieved for the disabled child and how a high quality service should work. My personal experience of the purchaser/provider system is that it can be put to work for the benefit of disabled children.

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1 Jolly H. Have parents the right to see their child’s records? Arch Dis Child 1984; 59: 601–2.