Management of physical disability

Editorial

The American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) and the European Academy of Childhood Disability (EACD) recently organized a workshop in Quebec to try and review the management of children with a physical disabilities.

The aim was not to produce any guidelines for specific treatment, but indicate something about what sort of service should be provided. But it was our intention to try and get an overall picture which might be applicable internationally. What should be available to families with a child with a physical disability? Although we wanted our discourse to deal with any child with a disability, there is inevitably a tendency to deal with the largest group of children, which is of course those with cerebral palsy. The group took it as a given that the service should be family-centred; the parents initially, and the children themselves, should be involved in determining what their needs were and how these needs should be met.

The meeting partially arose following the EACD's meeting which led to a journal supplement: 'Services for Children with Disabilities in European Countries'[1]. This document reviewed the present services for children throughout Europe and made a number of recommendations, some of which were particularly relevant to our discussion that 'Certain services or facilities should be available as a basic right in a caring society, rather than these having to meet a strict scientific test of effectiveness' (p5). And that services should be needs-led and avoid theoretical approaches favoured by professionals. There was also recognition that there should be a multidisciplinary team available to the family and child. Throughout our discussions we looked at the location where service was provided, and in this respect it was very helpful to be aware of Mary Law and her colleagues at CanChild's research on this[2].

Inevitably there was a tension in the meeting because of the awareness by many, if not all of the participants, of the lack of research into the efficacy of many treatments. We tackled the issue by looking at four different types of child. In the first session we assessed the issue of the younger child and the need for early stimulation; we discussed children who walked but experienced other problems; we then talked about children who are less able but who are attending school, thinking about some of the problems that they have; and finally we looked at those who are substantially dependent.

Inevitably, the young-child session was dominated by discussion of early intervention: a difficult topic in so far as early intervention means different things to different groups of specialists. Early intervention for educationalists often means thinking of children of two and three, whereas many physical therapists can of course start in the special-care baby unit. 'Stimulation', which was the heading we used for this topic, is the key note for what came out of the session. We avoided recommending any specific 'treatment' or therapy, but believed that children with delayed development, for whatever reason, could be helped with 'management' and 'stimulation'. The session on children who ambulated centred around a relatively new notion of health and fitness for this population and the continually strengthening evidence that physical exercise is good for people with disabilities just as it is for the normal population. There was some cultural difference between Europeans who walk around their cities, and North Americans who seem to exercise in artificial places called gymnasiums! This is key, a good service for this population of physically disabled children is needed and again they need appropriate advice and training about how they are to acquire this health and fitness.

The discussion on the group of children who are less able concentrated on doing things with them. We thought of augmentative movement with the use of motorized wheelchairs or trolleys from very early on and augmentative communication, which is sometimes denied by over-zealous professionals determined that their oral training will work. Discussion focussed on the social setting and incorporated WHO's ICF which emphasizes the importance of 'participation' and how the link therefore between function and environment can lead to the young person effectively participating in society.

For the most severely involved children with disabilities, the ineffectiveness of most of our treatments was emphasized, although it is probably in this group that the therapeutically minded clinician is most tempted to become involved, so again the emphasis on the adjustment of both the physical and the social environment at measurement was stressed; outcome measurement was another constant theme through the meeting.

We ended wishing for coordinated, well-organized services in countries around the world, and jealously reviewing the Swedes' programmes that seemed to have come nearest to this. Things can be done, as we all know for disabled children, and our aim in this meeting was to see that it should be done. These thoughts are my own and not those of my twenty colleagues at the meeting, but we hopefully will be putting together a handbook. I left feeling that our two organizations, the AACPDM and the EACD, can do much fruitful work together and that a proactive approach to administrators and politicians is much more likely to be helpful than the present situation in which academics and clinicians often respond to requests and pressure arising from parent groups, administrators, and politicians. We don't want to be leaders, but we do at least want to be ahead of the game.

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