

Natural history and treatment of disabilities

The theme of this year's annual meeting of the European Academy of Childhood Disability (EACD) is 'Treatment of Childhood Disabilities'. The meeting in Pisa (24–26 October) will examine, through lectures and workshops, the current state of the treatment of motor, perceptual, pervasive, and language disorders in children.

Our knowledge of these fields has certainly increased in recent years. DMCN (including the present issue) and other scientific journals regularly include studies and systematic reviews aimed at confirming the efficacy and safety of old and new treatments. Nevertheless, we must admit that published results are frequently inadequate or controversial, and that convincing evidence is still lacking for most treatments that have been in use for years, as well as for new therapeutic approaches.

The problem is that the panorama of childhood disabilities includes many factors that can disguise the positive effects of treatment or it can suggest positive results that are not truly a result of treatment. This situation needs to be corrected for two important reasons: first, the choice of the most appropriate treatment for each young patient must be suggested by evidence-based guidelines; second, data are needed to support our requests for more government and private funds for treating these children. So how can we improve matters?

In recent years, the quality and quantity of published research into various treatments have certainly increased. In particular, the treatments applied are better planned and described, the trials are better designed (more often controlled and randomized), outcome measurements are more often based on standardized scales or on instrumental tools, and the statistical methods used are increasingly sophisticated. But while the methods of research have improved, I have the impression that not enough attention has been given to the selection and description of the children studied. For example, sometimes participants are selected on the basis that they all display, apparently, the same symptoms (e.g. 'spasticity' or 'dystonia') or the same functional disability (e.g. in walking, feeding, speaking), irrespective of their disease or syndrome. In other cases, children are grouped according to internationally accepted definitions of a syndrome, such as cerebral palsy (CP), autism, specific language impairment (SLI), or other impairments, sometimes complemented by a description of the severity of their disability. However, these syndromes contain subtypes (often several) all sharing syndrome inclusion criteria, but quite different from each other in several aspects. Moreover, they are all 'developmental' syndromes which means that their signs and symptoms spontaneously change, both quantitatively and qualitatively, according to the age of the child and the phase of development of his/her syndrome.

Despite the several decades that have passed since the publication of Crothers and Paine's *Natural History of Cerebral Palsy*¹ fairly little is known about the natural history of

CP, autism, and other syndromes. Therefore, we must increase our knowledge on this subject and use all the data already available to group the study children and interpret the results more effectively.

What can we gain from this for our research into treatment? Firstly, we will be able to group index and control children not just according to the presence of similar symptoms or disabilities but by more homogeneous natural histories. This is probably the only way to disentangle the effects of the proposed treatment from spontaneous changes that occur over time. Some clinical improvement can be expected for almost all children, despite inappropriate or nonexistent treatment. Moreover, deterioration of existing disorders or the onset of new symptoms are also frequent in non-progressive neurological diseases. One must be aware of this in order to interpret the effects of treatment. For instance, we know that children with SLI usually greatly improve over time but they often show reading/writing disorders at school age. This kind of information on the developmental changes of a syndrome is essential to planning research on early treatment which is aimed at preventing later functional difficulties, and to evaluating the results.

Better understanding of the pathophysiological mechanisms behind symptoms and of their changes over time can lead to treatments that are 'tuned' to the age of the children and to the developmental phase of their disability.

Now is a particularly suitable time for further research in this field for a number of reasons. Simple and inexpensive methods, such as standardized video-recordings and validated scales, and sophisticated computerized analyses, are currently available to measure outcomes. Neuroimaging and other techniques can indicate infants at risk of developmental disabilities, and recent findings on the early signs of CP, autism, and other disorders show that an early diagnosis of these syndromes is possible. More than in the past, we are now able to identify biological and environmental factors that, in addition to the treatment, can influence the course of the disease. As a consequence, prospective, well documented studies of the natural histories of these syndromes are now within reach. This work requires the time and combined efforts of many researchers, but we can take advantage of European and international networks of research centres interested in childhood disabilities. Some of these networks already exist, or are about to be created in connection with the 6th Framework Programme of the European Community for Research. Other projects may be discussed in Pisa during the EACD meeting.

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Reference

1. Crothers B, Paine RS. (1988; first published 1959) *The Natural History of Cerebral Palsy. Classics in Developmental Medicine No. 2*. London: Mac Keith Press.