Adolescence and after

Editorial

Three articles in this journal report material on adolescents and young adults. Largo and colleagues' continuing work on neuromotor development from 5 through to 18 years of age [1, 2] examines the rapid progress of motor development in the early years through and up to puberty, followed by the much slower development and plateauing which is seen later on. The significant findings for the clinician are, of course, the wide variability on an individual level. It is perhaps surprising that very few gender differences are found. It is excellent though to have this standardized material on motor development in the later years of childhood and adolescence.

When we come to disability, one of our problems is the relative rarity of any one condition compared with the total population of disabled children. Within the major disability groupings such as cerebral palsy and general moderate-to-severe learning difficulties, we know that in time we shall be dividing these groups into smaller and smaller phenotypes When we take the known genetic conditions like Angelman syndrome (described by Jill Clayton-Smith in our current issue[3]) we are dealing with a rare (although less rare than originally thought) syndrome. Rare syndromes, however, make up the largest part of the whole group of disabled children and there is no way round us looking at these conditions on a one-off basis. Furthermore, the careful study of one well-defined phenotype provides us with an example of how we should be looking at all the other phenotypes when attempting to collect information.

There are a number of quite striking features in the young person with Angelman syndrome as they go through adolescence into adult life. First, the dysmorphology of the face with the open mouth and prominent chin becomes much more marked. I have often found it difficult to be certain that the face of the young child with Angelman syndrome is significantly different from the norm. The material in the Clayton-Smith article will help when looking back at those younger children as the salient points of the condition are emphasized. There are lots of satisfactory findings despite the condition, like growth and sexual development (although possibly decreased libido is mentioned). But equally there are some worrying features of the adolescent which will concern all who look after these children and will involve some of our colleagues who one would not immediately involve in an assessment team. I was particularly struck by the development of contractures and the rapid onset of scoliosis documented by Clayton-Smith; it appears that our orthopaedic colleagues are going to be involved in treating a number of these genetic conditions, one hopes, earlier rather than later. It may be too early to say whether early effective management of the developing motor condition would prevent later contractures and deteriorating scoliosis which has led to surgery reported in the paper. Angelman is not alone among the genetic syndromes in having consequences which may involve our orthopaedic colleagues.

Behavioural changes are noted and are significant too, such as the diminution of the hyperactivity seen in earlier years, meaning that the children have better concentration spans as they get older. Hopefully there is an implication that they may be more amenable to a program of learning which may help later development of some communication skills.

Clayton-Smith mentions that there is occasional aggression and anxiety. The early signs of 'happiness' which struck Angelman when he first wrote about the syndrome,[4] in noting an apparent cheerful disposition, have often seemed to me to be masking perhaps, even in the younger child, some quite different feeling. The combination of apparent cheerfulness with some underlying anxiety again is a feature which one may see in other conditions (for example, Down syndrome). Be that as it may, the changing pattern of the behaviour associated with this condition as the child grows into adolescence requires us to be aware of this and ready to produce an appropriate management response. The outcome of the study is to emphasize continuing management throughout adolescence and young adulthood. 'Communication therapy should still be pursued with adolescents and young adults' (p 479).[3] Equally, physiotherapy is indicated as a continuing process, hopefully to prevent the contractures and difficulties that may develop.

The need for continued services must be repeatedly emphasized with respect to all young people with neurological disorders. With managed care in the United States and fiscal problems in many countries, the need for continuing services for adolescents and young adults with disabilities cannot be overemphasized. Our financial and political masters must realize that a compassionate country has to provide services for these young people continuing through adolescence and into adult life: a policy which would have the strong support of this journal.

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References

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