

## The agenda for the autistic

THE TRADITIONAL VIEW of the professional as primarily responsible for generating awareness and understanding of disabilities is increasingly being challenged. This was evident at the second workshop of the Action for Autism (AEA) held for parents and professionals in Delhi between October 14 and 16. Twenty to 30 people in a population of 10,000 are affected by autism. By this estimate, over a million children and adults in India are autistic. However, there are just a handful of schools catering specifically to their needs.

Autism is a developmental disorder, manifesting in a range of behavioural characteristics typical of mildly to severely disturbed children. Those most common among them are communication and socialisation impairments and repetitive and ritualistic activities such as echoing whatever is said to them, repeating a word over and over again. There are no medical or genetic tests to diagnose autism. Rather, it takes the minute observation of both sensitive parents and doctors of the child's behaviour patterns. It is, therefore, not so surprising that the professional's role is after all limited in dealing with the autistic.

Appropriately, the workshop aimed at helping parents realise that they can teach their autistic children themselves. In a significant departure from convention, the thrust of the AEA's approach is that "parents are the real "professionals" when it comes to autism in India .. it will be the parents who educate the teachers who work with their children." In other words, "nobody knows a child better than their parents," is the AEA's avowed belief.

This underlying approach can potentially generate a sense of reassurance, and hope for the future among resourceful parents endowed with a degree of initiative. Indeed, demystifying claims to professional knowledge as it were, some parent participants in the workshop gave interesting examples of how to draw on the very same behaviour disorder to impart knowledge of new concepts to the child. A mother reportedly advised an utterly perplexed professional to apply pressure on the big toe to calm down her restless child during an outing. Another imaginative father had converted his son's obsession with cars (the only subject he would talk about) to teach him concepts like under and over and addition and multiplication.

Thus, the wider message flowing out of the AFA's approach for the professionals in the field of relief and rehabilitation in general is pretty clear. It tells teachers not to sneer at the simple cues originating in the parents' fund of experiential knowledge gained during the course of everyday life. The AFA's modus operandi is also not without an implicit message to parents. This is the importance of isolating the "parents know the child best" from the "parents know what is best for the child" attitude. In the face of poverty, illiteracy or even an inability to come to grips with the problem, the consequences of the latter can spell greater disaster than the disability with which they at any rate have to contend. It is in the delicate task of drawing the line between the two that both the parents' and the professional's skills are put to the test.

Now, the most urgent task as seen by the AFA is to persuade the Government of India to recognise autism as a disability. This would not only allow the autistic to take advantage of their legitimate privileges from the state, but more fundamentally to ensure that they receive the care and attention appropriate to their requirements. We hope that their efforts will bear fruit.