

Early Identification and Early Intervention

The need of the hour for children with Developmental Disabilities

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Introduction

It took an Aamir Khan and a '*Taare Zameen Par*' to focus the attention of the '*aam admi*' on the plight of children with learning disabilities (LD) in this country. While it is heartening that LD is now getting long overdue attention, it is not the only developmental disability that we need to be concerned about. This is particularly important given the recent increase in the numbers of children diagnosed with developmental difficulties such as pervasive developmental disorders (PDD), Autism Spectrum Disorders (ASD), Attention Deficit Disorders (ADD) and Attention Deficit Hyperactivity Disorder (ADHD). Awareness of these other developmental disabilities is also crucial since early identification leads to early intervention. As of date, early intervention is considered to be the most important factor influencing long-term outcome in these children. Along with paediatricians and parents, it is the teachers and other educators, who can and must play a role in early identification.

Congenital developmental disabilities such as visual, motor, hearing and intellectual handicaps are now reasonably well acknowledged and recognised, with a concomitant awareness of what to do about it and where to seek help. The relatively invisible developmental disabilities such as ADD, ADHD, PDD, ASD and LD, on the other hand, are not so well known or identified. The fact that these are often seen in children who have an initial period of 'normal' development confounds the issue further. As in many newly developing disciplines the area of developmental disabilities in children, is fraught with terminological confusion. It does not help that the professionals themselves, often disagree on the label for a condition in an individual child.

While early identification is crucial, one must also take care not to label a child hastily. Paradoxically while the professionals themselves are uncertain, there are others who with passing acquaintance with these labels are generous in the application of the label to a child who might exhibit a characteristic or two associated with these conditions, without adequate investigation. Such indiscriminate labelling can have consequences that are as undesirable as a lack of awareness, particularly given the parents' propensity to access information on the Internet, from a variety of sources, whether authentic or not, and having to cope with a label without the necessary professional support that is mandatory when handing over such a diagnosis.

It is also true that as the presentation of symptoms change either as a consequence of clinical intervention or the lack of it, the diagnostic label too will change. Nevertheless whatever the label may or may not be, when a child is not developing as his peers, what is important is to recognise that fact and seek help at the earliest.

The importance of early identification

Early identification and intervention has assumed importance because several of these conditions are not fully well understood medically in terms of causation. Since there is no clear understanding of the biological cause as yet, there is no specific medication or medical cure as of now. Given this context, currently, early intervention is documented to be the best option in terms of measured long-term benefits. Early intervention has a dual effect – it not only helps the child to develop skills that are

expected at his age, but equally importantly prevents the child from developing negative behaviours consequent to the developmental issues faced by him or her.

An important social factor that impedes the detection and management of children with developmental disabilities is the widely prevalent attitude that since the child will sooner or later catch up; there is no cause for worry and therefore no need for intervention. Many parents who seek help from us have stories to tell about how they were told that it is quite common for some children to have a late start but that eventually, they more than make up for the initial delay – there is always an ‘uncle or grandfather who started late but look at him now – an IAS officer no less’ or a neurosurgeon or whatever the case may be. It is true that there are some ‘late bloomers’ among children. However, not every child with a developmental delay will ‘more than make up’ for an initial delay.

In fact, given the increasing societal pressure on performance, even late bloomers are subject to enormous pressure and at times develop behavioural issues. If on the other hand the child turns out to be with a genuine developmental delay/difficulty he has not only lost precious time in which, with intervention he could have made up for the delays, but in all likelihood has the additional baggage of negative behaviour.

Another important aspect of early intervention that is often overlooked is the fact that developmental skills including communication skills are not mastered only in early childhood but are built over several years, right up to adulthood. We do unconsciously and accurately modify our communicative levels when we address say a 3 year old as against a 6 year old. However many of us, including parents and teachers are not sensitive to the subtle differences in developmental skills between say a 12 year old and a 14 year old. Yet a teacher would not expect a 12 year old to cope in a classroom meant for 14 year olds. These subtle lags can also have a cumulative effect on subsequent skill development. The problem that a child with a developmental disability experiences, is often just that – not being able to cope with the requirements of his classroom and peers, because in any one or more aspects of his development, he is not quite on par with his peers and cannot process information with the same dexterity as his peers.

When this happens over a period of time, it is but natural that the child ‘acts up’ or starts showing behavioural patterns that are disruptive and unacceptable. Early identification sensitises the family, school and the child himself to his or her unique difficulties leading to an acknowledgement of his or her needs. Since early intervention addresses the specific issues of the developmental lags, it helps avoid the cumulative moss ball effect and reduces the building up of the behavioural consequences.

Screen

It is therefore important for parents and teachers to be sensitive to the characteristics that may be indicative of an underlying developmental disorder or delay. It has been my experience that many teachers given their experience with children, are able to pick out a child who is ‘different’ or ‘not quite like the others’, from among their many wards. Nevertheless it is useful to be familiar with some of the characteristics that could help identify a child with a developmental delay or disorder, in their early years. Given below are some of the characteristics that might help you identify a preschool child with a developmental delay or disorder

- Inconsistent response to being called by his or her name
- Inconsistent response to sounds and simple verbal commands
- Good response when instructions are given one on one, but poor response when a general instruction is given.

- Speech is not clear or is understood only by parents
- Over activity or hyperactivity – inability to pay attention, sit at a place; sustain an activity as compared to peers
- Disruptive behaviour in the classroom – screaming, pinching, pushing, running around without apparent cause
- Underactive or hypoactive – does not participate in classroom activities like his peers.
- Does not show interest in or interact and play with peers
- Does not initiate activities or conversation spontaneously
- Reacts inappropriately to touch, movement, sound or light
- Is poor in imitating actions and words
- Seems to be in a world of his own and talks or laughs to himself

Rule out any major causative factor

In the event of your identifying a child with a few or more of the above characteristics, one of the first steps to be taken is to rule out, at least at a cursory level the presence of a gross sensory disability such as poor vision or poor hearing that might be the cause of the difficulties experienced by the child.

While a severe motor, visual or hearing deficit is often identified easily by the parent and/or teacher, partial disorders in these areas are more difficult to identify and require more careful and consistent observations to be made of the child's behaviour – for instance does he consistently respond better to questions when he can see the speaker's face or does he consistently read better when he is seated in the front row. Again when in doubt, it is best to rule out any such sensory impairment with a referral to the concerned professional. Apart from the physical factors in the child, it might also be worthwhile to rule out any serious difficulties that the child might be facing at home including the environment at home.

Provide additional input and monitor

When a basic sensory or motor difficulty is not the root cause of a child's immature behaviour it is important to provide him or her with some additional support and monitor the effect. For instance some children with communication difficulties do well when they are addressed 'one on one' but have great difficulty in following general instructions given to the class as a whole. Others may perform well in routine structured activities but have difficulty in coping with an unexpected change. Some others may do well when given printed or written material but have difficulty in following verbal instructions. In such cases it is important for the teacher to identify these patterns, provide the necessary modifications and monitor the changes. If no positive changes are seen in about 3 months it is for the teacher to take a more proactive role. Seek professional help if no progress is seen in 3 months despite the additional input.

These are easier said than done, given the many difficulties that teachers face in providing additional input. Among the most common factors in countries like ours are – low student teacher ratio, inadequate numbers of teachers, absence of resource teachers in schools, and finally the additional needs in terms of finance and space for resource room facilities. It is regrettable that despite the increasing number of programmes in 'special education' and the subsequent numbers of 'special educators', most of them either continue to find employment only in 'special schools' or establish 'clinics' which provide one on one training, with hardly any employed in mainstream schools to provide support to the many children in mainstream schools, who need their service. This, despite our official educational policy being supportive, nay mandatory, of inclusion.

The picture is further compounded by family factors - both parents are working, with the primary caregiver of the child being either paid help or aged grandparents who lack the sensitivity and/ or

energy to stimulate the child adequately and note developmental discrepancies, if any. In such situations it is often the teacher who has to sensitise the parents to the need for investigations as well as to the importance of early intervention and the long-term cost of such neglect.

Issues and attitudes specific to the Indian context

On a final note I would like to briefly address some of the issues and attitudes that are specific to the Indian context that need to be considered. A major confounding factor that we face is the issue of multilingualism. Most urban children in India are faced with an environment in which they are exposed to at least 2-3 languages, often within their homes. It is also our official educational policy that a child learns at least three languages at school, with some recent exceptions being given to the child with LD.

The given Western wisdom until recently was that exposure to more than one language for a child (or for that matter for an adult too!) is detrimental to their overall erudition/intellect. Professionals such as SLPs in this country have often taken this dictum as given. At the same time practical realities in our country are far from conducive to the practice of such a dictum. Fortunately, there is a changing perception of bilingualism as both a practical phenomenon in most parts of the world and also as possibly having some positive features. Nevertheless the issue of what is best for a child with a developmental disability remains. Theoretically speaking, for the child with a developmental disability exposure to a single language may be ideal. However, the practice of it on ground in India is well nigh impossible. We therefore have to learn to take a judicious decision keeping in mind the realities of the child's environment, the nature of his difficulty, the nature of the languages that he is exposed to and required to learn and how all of these interact – no simple issue this, but until such time that we have clear answers grounded in scientific research carried out in our context, there will be no clear guidelines for best practices.

A second important issue that needs to be considered is parental aspirations, rather societal aspirations, regarding educational outcomes. As a society we have increasingly moved away from the broad goals of education as one of maximising every individual's potential. Instead the aim is to obtain for one's child, admission into an educational system, which will at the end of it provide him with employment that is maximally lucrative. To compound the issue further this straightjacketing begins right at the preschool level.

The plight of most typically developing children in such a system, let alone the ones with developmental disabilities is unenviable at best. Paradoxically even the few educators who have attempted to break this stranglehold are pressurised to fall in step with the others, by the time their wards reach school leaving age, given the lack of opportunities for furthering their education within the alternative moulds at higher levels. It is time that we as a society rethink these issues and put our expectations of education and the educational process within the larger framework of the good of all, each with his or her strengths and weaknesses, leading to a more wholesome integrated society.

Suggestions

There is much to be done before we can reach such an equitable society. As far as children with developmental disabilities are concerned the larger society not only has a moral obligation but also an economic concern. These large numbers of children with developmental disabilities have to be cared for by the society if their conditions are not ameliorated early and adequately. A first step towards enabling them to be self-sufficient is of course to increase awareness not only among educators but in the society as a whole. A second step would be to provide training for early identification, providing referral sources for formal evaluation and intervention. On the part of the service providers it is important to extend intervention to schools and homes, taking into consideration the resource crunch

and the acute shortage of trained professionals. Newer models of service delivery and monitoring of their efficacy, that take into consideration our existing drawbacks, have to be developed, tested and advocated.