

Creating inclusive learning environments for persons with autism spectrum disorder

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Abstract:

Autism spectrum Disorder is the third most commonly found developmental disorder and occurs across cultures and socio-economic strata. Autism profoundly affects an individual's capacities for learning language, social interaction and imaginative faculties. Indeed, individuals presenting with its symptoms are often regarded as 'mad', and relegated to the margins of social existence, without access to appropriate intervention, education or training.

Although no large-scale epidemiological survey has yet been done in India, prevalence rates suggest that upto four million individuals are likely to have autism in India alone. This poses an enormous challenge as a public health and welfare issue as well as an educational one.

This paper engages with the issues pertaining to the educational needs of persons with disability in general and Autism in particular, in the context of a developing nation like India where endemic and structural poverty, malnutrition, child mortality etc dominate welfare agendas, and where disability tends to be relegated to the backstage, It is well documented that the majority of persons with autism do not receive a basic education. Few specialized schools exist to cater to their complex needs, and the majority of them are in urban areas. There is a dire need to absorb these children within the existing educational structures and put in place inclusive and accepting teaching practices and learning environments that will enable them to actualize their potential. 'Inclusion is very difficult idea to actualize in the context of a hierarchical, highly stratified society where caste, class gender and other axes of inequity conspire to mitigate against the marginalized.

ODL, due to its reach and flexibility is a potentially effective instrument in training teachers to create inclusive teaching –learning environments and imbibe the philosophy of inclusion in their ideology and practice. There is a pressing need to create and empower a cadre of sensitized, trained personnel to address the educational needs of persons with disability especially complex, little understood ones like Autism.

Introduction

This paper engages with some of the issues surrounding the 'inclusion' or 'integration' of children with disabilities into schooling system, specifically children with Autism Spectrum Disorder (referred to as 'Autism' in the paper). 'Inclusion' or 'inclusive schooling' is currently a 'fashionable' phrase, often used rather indiscriminately and without a deep understanding of its philosophical underpinnings which derive from the recognition that society is morally and ethically bound to help all individuals, irrespective of gender, caste, class and 'abilities' to achieve their fullest potential and contribute meaningfully to society.

In a hierarchical and highly stratified society like India the idea of inclusion flies in the face of long-standing socio-cultural beliefs that privilege ascriptive criteria like family, kin, caste gender etc. and render it doubly difficult for the marginalized sections (dalits, women, disabled etc) to avail of social resources. Against this backdrop, the issue of creating inclusive learning environments for children with disabilities becomes even more salient. By 'inclusive learning environments' I mean school settings that foster not just the academic, but also the social and cultural development of the child with disability. In this context, Singal et al's (2009) deployment of Bourdieu's concept of 'capital' is significant. The authors argue that schooling can not just improve an individual's access to economic capital resources, but also their social capital, by raising their ability to become part of a social group, develop new relationships and networks of influence and support) and their self-esteem, sense of worth and empowerment.

In the context of disorders such as Autism, the social component is of critical importance, as we shall see later. The nature of the disorder is such that it profoundly affects the child's ability to 'relate' meaningfully with the social world thereby increasing isolation and stigma. An inclusive learning environment provides opportunities not just for the disabled child but also his/her typically developing or 'normal' peers to engage with different subjectivities and develop attitudes and routines that foster accommodation, respect and acceptance of 'difference'. This is ultimately beneficial for community and society as a whole.

The paper begins with an overview of the concept of inclusion of persons with disabilities(PWD) in the Indian context with a special focus on the challenges therein. It then moves on to a discussion of Autism in India and the current scenario vis-à-vis the education and rehabilitation of persons with Autism. It outlines some interventions and practices that can help to bridge the gap and makes a case for teacher training and orientation that will enable teachers to view 'inclusion' and working with children with disabilities not as a 'problem' but rather an intrinsic part of their professional practice and value systems.

Inclusive Education and Persons with Disabilities

The 'Social Model' of disability, which perceives disability not as a mere medical issue but one of social exclusion and marginalization, has heralded a 'Human Rights' perspective into our understanding of disability. Access to universal and appropriate education is a key indicator of the manner in which society views its disabled members. India is a signatory to the Salamanca Statement and Framework for Action on Special Needs Education (1994) that emphasizes access to quality education for all. The Statement endorses the need for fundamental policy shifts required to promote the

approach to inclusive education, namely, enabling schools to serve all children, particularly those with special education needs, by implementing appropriate strategies and changes. In keeping with the above, the Persons with Disabilities) Equal Opportunities and Full Participation) Act, 1995 (PWD Act) aims among other things, to provide access to free education in an appropriate environment to all learners with disabilities upto the age of 18.

The PWD Act has been hailed as a landmark legislation by authors like Baquer and Sharma (1997). They opine that in a country like India where the disabled population is so large and societal attitudes towards disability so negative, only legislation can ensure long-term change by increasing access to a barrier free environment, education and employment (p.274). However noble and enlightened the provisions of the Act, the issue of implementation is critical. Despite the efforts of Parent Support Organisations, Autism did not find a mention in the PWD Act, probably due to the faulty perception that it was a “rare” disorder and an upper-class concern. Autism was covered in the subsequent National Trust Act for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities (1999). The non-inclusion of these disability groups from the PWD Act reinforces the prevalent belief that persons with cognitive and intellectual disabilities or severe handicaps somehow fall out of the pale of the educational system.

Sharma and Deppeler (2005) maintain that if fully implemented, the PWD Act has the potential to change the educational status of more than 30 million disabled children who currently have no access to any kind of education. They identify the following challenges at the macro and micro levels that need to be addressed if the goal is to be achieved:

1. **The challenge of poverty associated with disability:** The mutually reinforcing links between poverty and disability result in a condition of “simultaneous deprivation” which creates barriers in the participation of persons with disability in the normal activities and routines of the community including schooling.
2. **The challenge of modifying deeply held attitudes:** The perception that disabilities (particularly the more profound and severe ones) are contagious, the Hindu belief in ‘Karma’ and the negative and exclusionary social construct of disability all mitigate against the inclusion and integration of disabled children in the educational system.
3. **The challenge of providing adequate levels of training to Key stakeholders:** It is observed that the majority of school personnel in India are not trained to design or implement educational programs for disabled children in regular schools. Where training in special education is imparted practical training in integrated settings is missing. ‘The member of trained special educators is also extremely small considering the large number of children that need their services. The problem is even more acute in the Autism Sector where, for a long time, a perception existed that no special teacher training programme was needed, and that teachers trained in the management of other cognitive disabilities would be adequately equipped to deal with Autism as well. This approach failed to take into account the unique difficulties of persons with autism and the pitfalls of adopting a “one size fits all” model.

Amongst the possible strategies to address these challenges, Sharma et al (2005) place teacher training at the top of the list. We shall return to this theme in a later section, however, it would be in place to discuss the Autism scenario in India at this stage

Autism in India: Issues and Challenges

Daley (2002) observes that Autism has fallen between the cracks of disability literature and mental illness studies. Historically, autism has been viewed more akin to mental disturbance or 'madness' than as a developmental disability like mental retardation or learning disability. However, half a century of research has established that it is in fact a neuro-developmental disability marked by impairments in the key areas of socialization, communication and imagination (Wing, 1988). In addition, children presenting with autism symptoms may also display a fondness for repetitive activities and stereotypical movements like rocking, finger-flicking, spinning the whole body etc., resistance to changes in the environment or to daily routine and unusual sensory modalities eg. over-sensitivity or under responsiveness to heat, light, noise, touch etc. (Powers, 1989). Autism may or may not be accompanied by mental retardation and a very small number of autistic people display 'savant' skills or areas of exceptional ability in some areas.

It is a 'spectrum' disorder and ranges from mild social impairments and eccentricities to profound difficulties in almost all areas of daily functioning. While some persons with Autism lead relatively 'normal' lives, working, raising families and participating in the community, others need life-long care and support. (www.autism-india.org). Given the complexity of the disorder, it is obvious that the educational needs of persons with autism remain largely unmet. Lal (2005) asserts that education for children with autism must foster the acquisition of not academic skills alone, but also socialization, adaptive skills, language and communication and reduction of problem behaviour. For this, she recommends among other things, an emphasis on functional activities and skills needed to be successful in the real world and social integration to the maximum possible extent. There has been debate among educators on whether children with autism would benefit more from inclusive/integrated school settings or special education ones, given the nature of disorder. While some opine that a general educational settings create a 'least restrictive environment', others are of the view that structured and intensive teaching in a specialized setting is more beneficial. However, I argue that in a situation like the Indian one, where the majority of children with disabilities including autism fail to get educational placements, the need of the hour is to work towards getting these children into school, special or 'regular', put in place systems and, above all help to foster attitudes amongst teachers, parents and all other stake-holders that education is a right, not a privilege.

There has so far been no community based epidemiological study in India to assess the prevalence of autism. However, based on prevalence rates in the West, it is estimated that anywhere between 2 to 4 million persons are likely to have autism. The overwhelming majority remain undiagnosed or misdiagnosed and lack access to education and rehabilitation. The scarce facilities that exist are usually run by N.G.O's and parent support organizations (Narayan et al, 2005). Moreover, these special schools are usually located in urban centres whereas the majority of disabled population is in the rural areas. Autism was recognized as a disorder by the G.O.I only in 1999 and included in the National Trust Act. The Diploma in Special Education (ASD) certified by the Rehabilitation Council of India took off in 2003. However, there is a huge gap between

the trained educators available and the children that need their services, as earlier mentioned. In this scenario, there is no option but to get these children into schools, special and inclusive, and train teachers to address their special needs. In their analysis of educational support systems for children with autism spectrum disorders and mental retardation, Narayan et al (2005) report that the preferred mode of instruction for these children was home-based training, even through this entailed a high level of parental stress. They report that nearly 3/4ths of the parents interviewed by them were eager to send their child to a suitable school but dissatisfied with existing facilities. They also opine that the inclusion of Autism as a disability in the PWD Act (1995) will strengthen and promote the education of these children.

As the foregoing discussion has indicated, the educational scenario vis-à-vis autism in India is worrying and in need of urgent remedial measures. The key input is preparing a cadre of sensitive and adequately trained teachers working in both specialized and regular settings and interacting with each other, the family and the communality to foster the social and educational development of autistic children. In the following section, we highlight some of the issues and strategies with regard to preparing both pre-service and in-service teachers to making inclusion a part of their philosophy and practice.

Training Teachers to Create Inclusive Learning Environments

Discussing their experience of inclusion of children with autism and other developmental disabilities in the Alice H. Hayden Preschool at the University of Washington's Experimental Education Centre, Schwartz et al (1996) identify five strategies or "tricks of the trade" to help autistic children achieve important objectives such as acquisition of skills, developing relationships and participating as full members in the class. They include

1) Teaching communicative and Social Competence: In order to ensure that an inclusive program does not become parallel instruction it is important to teach autistic children how to initiate spontaneous communication within natural contexts and respond appropriately to the communications of others. Communication can be both verbal and through system like the Picture Exchange Communication System (PECS).

The program also stresses upon developing imitation skills (a key deficit area) to help autistic children improve and increase social interactions with their typically developing peers.

2) Using Instructional Strategies that maintain the flow of Classroom Activities: Rather than isolating children with autism from their peers to provide individualized instruction, teaching takes place within the context of developmentally appropriate activities eliciting the participation of peers as well.

3) Teaching and Providing Opportunities for Independence: By providing clear cut visual and auditory cues, children learn to participate in a routine. While receiving close support and supervision from adults, they are also given the freedom to explore and learn.

4) Proactively and systematically building a classroom community that includes all children: The program is based upon participatory learning and meticulous planning

and preparation goes into ensuring that children with a diverse range of abilities can engage in activities independently and meaningfully.

5) Promoting generalization and maintenance of skills: In order to ensure that skills are demonstrated across a variety of non training situation and across time, strategies that promote generalization and maintenance of skills are thoughtfully implemented.

The above strategies are apt examples of good teaching practices in themselves which are likely to be as effective with disabled children as typically developing ones. It must be emphasized that training teachers to adopt child-centric practices which are based on a sound understanding of child development will equip them to deal with students of diverse abilities and backgrounds. Given the complex social-economic diversities that characterize Indian society, such training is bound to stand teachers in good stead.

Lacunae in teacher Education:

The standard of teacher training courses across India varies greatly and the inclusion of children with disabilities is usually approached from a 'deficit' perspective. Optional 'special needs' papers are offered to train teachers to deal with diverse abilities. This reinforces the "difference" of children with disabilities and stigmatizes them further.

Anecdotal evidence suggests that many teachers feel helpless and inadequate in teaching children with disabilities especially given the poor facilities and large numbers of students of all backgrounds that they have to deal with. They are often reluctant to attend special training programs if these coincide with their holidays and free time (Lal, 2005).

Sharma and Deppeler (2005) recommend that a policy of training one teacher from each school or cluster of schools be adopted. The teacher could be provided intensive training to work with various disabilities and could then act as an inclusion or integration specialists for a group of schools in their locality.

They also raises the important question of the identification of the specific content that should be included in teacher training programs given the tremendous socio-cultural, linguistic and economic diversity in India.

Other recommendations include

1. Designing innovative systems of training specifically Open and Distance Learning.
2. Collaboration between different ministries and integration and pooling of scare resources.
3. Involving NGOs in implementing integrated/inclusive education programs.
4. Establishing an alterative system of examination for students with disabilities so that they can demonstrate their abilities rather than be penalized for their disabilities.
5. School-University partnership in order to explore local and regional specific strategies that work on the ground.

ODL: Training for Inclusion

There is a pressing need for training school educators on a mass scale in order to implement inclusive educational services. Conventional training methods simply cannot match up to the challenge of training such large members. ODL therefore is a viable medicine.

In this context, we may cite the role played by the Indira Gandhi National Open University (IGNOU). IGNOU established the National centre for Disability Studies (NCDS) to develop human resources for the creation of a disabled-friendly society, to promote interdisciplinary study of disability and remove barriers to empowerment of PWD. The mission of the centre is “to provide and promote teaching, research and extension activities in the area of disability studies through distance mode of learning blended with conventional facilities through the convergence scheme thereby facilitating the educational empowerment of persons with disabilities.” (IGNOU Profile 2010).

The programmes offered by the NCDS include:

PG Diploma in Disability Management (PGDMD)

This is a collaborative programme of IGNOU and the Rehabilitation Council of India (RCI), focusing on preventive aspects of disabilities and early intervention services.

B.Ed. (Special Education)

The B.Ed. (Special Education) is a collaborative programme of IGNOU and the Rehabilitation Council of India (RCI). It aims to develop professionals for special and inclusive education within a broad perspective of education. The programme allows for specialization in one out of the areas of hearing impairment, mental retardation and visual impairment. As yet, there is no specialization offered in Autism.

Foundation Course on Education of Children with Disabilities

This course has been developed in collaboration with RCI. It aims to develop basic knowledge and skills in teachers to enable them to cater to the specific educational needs of children with disabilities in integrated classes. It focuses on:

- Introduction to disability and inclusive education;
- Early identification, assessment and intervention;
- Education of children with disabilities;
- Assistive devices and therapies;
- Practical training in inclusive education.

Mention must be made of IGNOU’s vast regional services network essentially comprising 61 regional centre and over 3000 learners support centres. It is through this network that the support services viz. admission counseling etc. are provided to the learners of the various academic programmes. For IGNOU to succeed in meeting the vast human resources requirements in the area of inclusive education, the R.C.s, LS.Cs and the NCDS need to work in tandem. As mentioned earlier, it is also important to elicit the cooperation and expertise of N.G.Os working in the disability sector. Lack of formal

qualifications or specialized training must not be an impediment in recognizing and utilizing the vast experience of hands-on work that many N.G.O functionaries have accumulated in the area of teaching and rehabilitation of PWD. The opinions, expertise and experiences of parents, caregivers and other persons intimately associated with PWD must also be given due recognition and respect. Last but not the least, the voices of persons with disability must also be heard and their needs and requirements given the consideration and respect they deserve. Using these various experiences as inputs and feedback can only strengthen the process of curriculum development.

Concluding Remarks

The education of persons with disabilities has posed immense new challenges to the existing educational system impelling practitioners and policy makers to revisit and review long held attitudes, beliefs and practices. The burgeoning of the disability movement has also contributed much to our understanding of what constitutes an 'inclusive' system of education. Complex and often intractable disabilities like autism complicate 'received wisdom' and conventional practices and force us to think of ways of doing that are universally valid and yet accommodative of the diversity that characterizes the human race.

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