HOME BASED EDUCATION OF THE LEARNING DISABLED: A SOCIOLOGICAL STUDY IN DELHI

Every child is special and unique, right from a speck on the face to the toes! However, there are some children that needs extra care and attention, i.e., beyond the ordinary.

For parents this is often a source of conflict with the school system as they strive for a flexible curriculum that can cater to their child's special needs. This often leads the parents to ask themselves the one question, "Can't I homeschool my child?" And the answer to the question is "Yes".

Despite the progress, educational experts agree that at present, one of the major hurdles that the country is facing is providing access to quality-based education to all children. As per the national census held in 2011, it has been made known that 1.05% (2.13 million) of the children attending school suffered from disability out of which approx. 588,000 did not have access to education or schools.[1]

To be specific, roughly 44% population of children with special needs are restrained from obtaining education and institutions, thereby creating multiple and complex forms of limitations and hinderances and rendering it difficult for them to function and live life like an average child who has access to education and institutions. The census directly asks whether a person is suffering from disability and the answer is in the form of either a 'yes' or 'no'. Studies by experts have shown that direct questions regarding a person's disability always results in undermining of the disability itself.[2]

In Delhi alone, roughly 51.2% of children with intellectual disabilities have never been enrolled in any educational institution.

Before proceeding and analyzing the country's current progress in addressing the concerns of those with special needs and intellectual disabilities, it is necessary to examine the developments that have occurred within the country since earlier times. Studies on disability are still somewhat of recent origin (Johnstone, 2001)[3]. This research is in its early stages in India, with a long road

---

[1] Mont D. Measuring Health and Disability. Lancet, 2007; 369(9573):1658-63 https://doi.org/10.1016/S0140-6736(07)60752-1 PMID : 17499607

[2] Madans JH et al., Measuring Disability and Monitoring the UN Convention on the Rights of persons with Disabilities: The Work of the Washington Group on Disability Statistics. BMC Public Helath. 2011; 11. https://doi.org/10.1186/1471-2458-11-s4-s4 PMID: 21624190

[3] Johnstone, D. (2001). An Introduction to Disability Studies. David Fulton Publisher.

ahead; due to a lack of documents, researchers in the last 50 years have been ill informed about those in India with special needs and intellectual disability in the nineteenth century.

Attempts to investigate disabilities in India have always been made through scriptures, literature, films, and popular representations (Mehrotra, 2013, p. 120)[4].

However, as urban awareness of the rights of people with learning disabilities has grown over the last few decades, they are now being recognized as a separate category for their specialised needs. This recognition has also resulted in an effort to integrate them into mainstream society by promoting technical assistance in the form of institutions such as special schools and training centres, as well as ensuring that their rights are protected and accessible. On the other hand, the situation in rural areas is dire. (Mehrotra, 2013, p. 120)[5].

Since the 1970s, the Ministry of Education has worked to implement a scheme for inclusive education of children with special needs in schools, providing admission to education for children with special needs in regular schools in order to integrate them into the educational system.

According to Sue Stubbs, inclusive education helps to shape a more inclusive society (Sue Stubbs, 2001). Inclusive education is a type of schooling in which all students, regardless of special needs, learn together in the same class, same institution, and the teaching-learning is flexibly curated to meet the needs of the pupils, resulting in learning outcomes of comparable/satisfactory quality for all children[6].

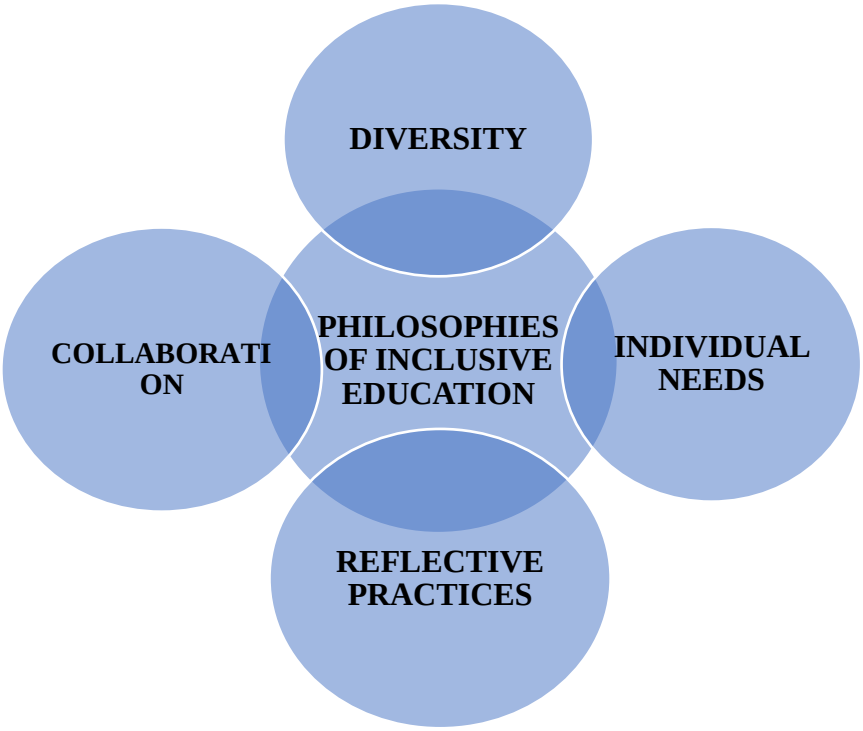
Inclusive education allows all children, including those with special needs, to attend more institutions. This type of education includes the following characteristics:

I. Recognizes that all children have the ability to learn.
II. Accepts and respects children's differences in terms of age, gender, ethnicity, language, disability, and so on.
III. Encourages children's education structures, systems, and methodologies to be flexible.
IV. It is a dynamic process that is constantly changing.

The terms 'integrated' and 'inclusive' are frequently used interchangeably, but they have distinct meanings. Integrated education aims to integrate children with special needs into the mainstream educational system, whereas inclusive learning aims to improve the quality of education provided to children with special needs after they have been integrated into the system.

According to Salend (2001), There are four essential principles that provide a framework and encapsulate the philosophies upon which inclusive education is based, namely:

[4] Mehrotra, N. (2013) Disability, gender and State Policy: Exploring Margins. Rawat Publications
[5] Mehrotra, N. (2013) Disability, gender and State Policy: Exploring Margins. Rawat Publications
[6] The Rights of Persons with Disabilities Bill, 2012.



Salend goes on to say that there are several other major factors that contributed to the need for an inclusive education system, including:[7]:

1. Normalization
2. De-institutionalization
3. Early Intervention
4. Early Childhood Development Programs
5. Technological Progress
6. Civil Rights, advocacy organizations and subsequent litigation
7. Educational Changes

The community is mostly unaware of the possibility of special-needs children. Looking closer, parents are frequently unaware whether their children have learning disabilities because special needs are often recognised with low expectations.

Following the MHRD's implementation of the IEDC scheme[8], Following the NPE in 1986 and the Plan of Action in 1992, which emphasised providing integrated special education, awareness grew.

In the democratic system, the government's role in home-based education has been limited to encouragement, information, and support. Several statutes, including the RTE Act of 2009[9], the subsequent 2010 amendment did not include any specific provisions for 'home-based education' for children with special needs. The government did, however, launch a programme called Sarva Shiksha Abhiyan in order to universalize elementary education by 2010. This programme took a more practical approach to ensuring the inclusion of children with special needs, regardless of their kind, category, or degree of disability. Furthermore, this programme promoted a zero-rejection policy, ensuring that no child was excluded from the educational system.

[7] Salend, S.J., Whittaker, C.R., & Duhaney, D. (2001). Creating Instructional Rubrics for Inclusive Classrooms. Teaching Exceptional Children, 34(2), 8-13.
[8] The Ministry of Human Resource Development, Government of India
[9] The Right to Education Act, 2009

Home-based education is an important method of providing inclusive education, particularly for children with severe learning/physical disabilities, as it combines home-based and alternate educational settings, allowing them to master living skills. Home-based education seeks to educate and prepare individuals for life; alternative educational settings, on the other hand, seek to provide education and learning of social skills, vocational skills, and their application in life.

A child with severe intellectual disability may be unable to perform basic functions such as toileting, feeding, communication, motor skills, and self-grooming that an average child can. According to studies, inclusive education is the best form of education for such children with special needs, as it integrates them into regular schools and provides them with support resources, as well as a pre-integration programme in the form of home-based education to prepare them for school-based education later on.

With the pandemic, home-based education is still in its early stages, and while home-based learning has increased, it remains a contentious topic for many educators in the country. In a report released in July 2006[10], it was concluded that children with special needs should not be denied access to education and should be taught in an environment that accommodates their special needs.

While no formal impact assessment studies are available to assess the significance of home-based education, surveys and studies have revealed that it has the following advantages:

A. With the assistance of expert tutors, parents transform into teachers, resulting in mutual trust and providing the child and their family with access to inclusive and well-coordinated services that address the child and their family's concerns, thereby improving their quality of life.
B. Additionally, the progress of children with special needs can be assessed through a carefully curated individual programme that includes participation from both parents and children. Such a programme assesses the child's overall development and, along with cognitive and language skills, enables the extension of alternative services to regular educational establishments once they develop basic life skills.
C. Home-based education can also help children improve their communication skills, improve their expression, and improve their eye contact. Such services are provided while taking the child's linguistic needs, the socio-cultural norms in which they are raised, and the values and norms of their family into account; thus, there is no uniform programme for home-based education; rather, they are curated as per the needs of each child, individually, and thus aids in reducing disruptive behaviour amongst children with special needs.

However, there are some myths and stereotypes about home-based education, such as how it will reduce socialization and limit exposure to traditional forms of knowledge. However, there is evidence in India that contradicts this claim; advocates for home-based schooling have reported that there are no feelings of resentment, boredom, frustration, or any other bad habits that can be avoided through schooling.

With the new Education Policy (NEP 2020), the Indian education arena has been pushed even further into implementing inclusive forms of education in which children will not be denied admission under any circumstances, echoing the goal previously expressed in the Sarva Shiksha Abhiyan. The NEP aims to give children with special needs a foothold and encourage them to

[10] Discovery New Paths in Inclusion: A Documentation of Home Based Education Practices for CSWN in SSA: Elementary Education & Literacy Bureau-MHRD (2006)

enrol in school. While this is a significant step, the question remains whether we are truly prepared to deliver on what the policy promises. Are we as a society truly prepared to accept such a shift?

Prior to the NEP 2020, Samagra Shiksha was implemented between 2018 and 2019 with the primary goal of improving the nature of education provided to children with special and intellectual needs. The programme is designed to achieve the following goals:

A. Recognizing and evaluating children with special needs.
B. Providing assistive devices, appliances, large print books, uniforms, and so on.
C. Creating teaching and learning materials, as well as assistive devices and equipment.
D. Orientation programmes to promote positive thinking and raise awareness about children with special and intellectual needs.
E. To provide training to special educators and other teachers on how to modify the curriculum to accommodate children with learning disabilities.
F. Highlights free education under the RTE Act of 2009 for children with special needs.
G. Aims to establish a separate resource base for special educators/teachers working in educational institutions through financial assistance.

The RTE Act of 2009 addresses the needs of children with special needs. Section 3(2) of the RTE Act emphasizes elementary education for children with disabilities, and subsequent amendments in 2012 mandated that children with multiple and/or severe disabilities have the right to home-based education[11].

Furthermore, a new scheme, Inclusive Education for Disabled at Secondary Level (IEDSS), was implemented to address educational needs at the secondary and senior levels. This programme aims to provide students with disabilities with the opportunity to complete four years of secondary school in an inclusive environment within the general education system.

Children with various special needs require varying levels of attention and needs that can be met through homeschooling. Children with ADHD, for example, require smaller lessons and untimed tests, whereas children with Down Syndrome may require specific adjustments with testing, reading, and writing; Dyslexic children can be given an advantage by providing them with visual aids, assistive technology, and taped books. As a result, homeschooling can be beneficial for children with special needs. Fortunately, homeschooling does not necessitate the parents obtaining a degree in special education to teach them. The curriculum available for homeschooling is flexible enough to cater to the child's individual needs. When selecting a curriculum for a special needs child, keep the following considerations in mind:

- Determine your child's needs, as well as their strengths and weaknesses, by having them assessed before selecting a homeschooling curriculum.
- As a parent, you must prepare to receive reduced services while transitioning from school to homeschooling.
- It is also recommended that parents develop an individual plan for their child or a student educational plan.
- Make certain that the curriculum moves at the student's pace. Increase the child's already present reading, writing, and calculation skills.
- Give the child a new chance in a safe and encouraging environment.
- Encourages the child to participate actively in the learning process through exploration and discovery.
- Strikes the right balance between learning and enjoyment by relating the two.

[11] https://samagra.education.gov.in/inclusive.html#:~:text=The%20provision%20for%20home%20based,with%20an%20outlay%20of%20Rs.

- Designate a specific area in your home for homeschooling. It does not have to be a replica of a school classroom; rather, it can be a colourful and informal space designed with your child's needs in mind. It can be decorated with colourful walls, a bean bag, sensory centres, and so on.
- Homeschooling does not imply being confined to the confines of your own home. Rather, as a parent, you must encourage your child to leave your home because homeschooling becomes more enjoyable when your child can explore the outside world and his/her surroundings, thereby practically applying the concepts that they learn. It can also promote socialization
- Plan your days to include ADLs (Activities of Daily Living), academics, therapies, playtime, outdoor physical activities, family time, and so on. However, take care not to overburden your child or yourself by making the day too hectic.

Homeschooling provides a completely unique educational experience! It gives the child the freedom and flexibility to study in a creative manner while also meeting the child's unique needs, allowing them to confidently develop the skills of any other child their age. It emphasises the importance of familial relationships as children acquire knowledge and skills based on the associations they form at home, real-life experiences they have, and the instructions provided by family members or tutors hired for them.

The education of children with special needs, specifically those diagnosed with Autism or Autism Spectrum Disorder (ASD), is still a developing field in India. However, when the comorbidity of intellectual disability coexists with autism, the task becomes even more difficult.

Autism, also known as Autism Spectrum Disorder (ASD), is a group of neurodevelopmental disorders characterized by social behaviors.

The research on children with autism in India is limited, and they are often referred to as having 'low functioning autism,' requiring specially curated content to meet their needs. The number of children diagnosed with autism and special schools serving children with special needs, including autism, has increased comparatively since the 1990s, but no research or studies have been conducted on the strategies used to educate children with autism or the quality of these programmes.

Autism, also known as ASD, is a group of neurodevelopmental disorders characterised by deficits in social behaviours and difficulty communicating with others, both verbally and nonverbally, during early childhood.[12]

According to Part A of the DSM-5 definition, ASD is characterised by persistent deficits in social communication and social interaction across multiple contexts, and it is manifested by[13]:

1. A lack of social-emotional reciprocity, which can manifest as an unusual social approach, a failure to maintain a normal back-and-forth conversation, a reduced sharing of interests and emotions, and a failure to initiate or respond back during social interactions.
2. Lack of nonverbal communication during social interaction, which can manifest as poor verbal and nonverbal communication, poor eye contact, a lack of body language, and a lack of facial expressions.
3. Shortcomings in developing and maintaining relationships, manifested as adjusting behavioural problems with changing social contexts, making and maintaining friendships, and lack of interest in their peers.

[12] Park et al., 2016; Charman et al., (1997) Infants with autism : An investigation of empathy, pretend play, joint attention and imitation. Developmental Psychology, 33(5), 781-789.
[13] American Psychiatric Association, 2013

Shortfalls in social functioning have been well documented in the form of studies as a prominently documented and identifying sign of ASD.[14] Some social skills deficiencies include difficulty initiating conversations, maintaining reciprocity, and considering another person's perspective and interest.[15]

Social skills can promote emotional, cognitive, and social development and are essential for developing meaningful relationships. A lack of such skills can impede the formation of meaningful relationships and lead to withdrawal from society. Furthermore, social withdrawal can lead to more serious problems, such as poor academic performance, inability to maintain social relationships and function in society, anxiety, depression, and other forms of psychopathology.[16]

Without any kind of positive intervention, such obstacles in social skills will persist throughout the child's lifetime, even in the later stages of their lives, causing a decline in their ability to carry out day-to-day activities and, in the worst-case scenario, impacting their ability to function.[17]

Autism is a developmental disability that lasts throughout a child's life and affects how the child communicates with, interacts with, and absorbs information from their surroundings. It has long-term consequences for the child's ability to socialise and participate in the community. The number of children diagnosed with ASD in India has increased significantly; according to the first ever survey of children with autism conducted by the International Clinical Epidemiology Network Trust (INCLEN) in 2013 for children aged 2 to 9 years, autism affects about 1%-1.5% of the children. They estimated that this amounted to roughly 10 million autistic children. This equates to approximately 1 in 66 children having autism, which is a higher estimate than the data provided by the Rehabilitation Council of India (RCI) in 2003, which stated that 1 in 500 children in India had ASD. As a result of the growing number of children being diagnosed with ASD, the need for specialised services has become critical..

Deficits in social communication and interaction across contexts, as well as repeated patterns of behaviour and activities, are the two determining criteria for ASD in the DSM 5[18] manual, allowing for a clear diagnosis.

Social and emotional reciprocity, a lack of verbal and nonverbal interaction, and difficulty maintaining social relationships are all indicators of a lack of social communication and interaction. Other types of behavioural concerns observed include inconsistent eye contact, social smile, response to name, and joint attention. [19]

Blenner, Reddy and Augystyn (2011) state that delayed language development is the most common parental concern for parents of autistic children.

---

[14] Attwood (1998) Aperger's Syndrome : A Guide for Parents and Professionals United Kingdom, Jessica Kingsley Publishers; Myles et al., 2005; Rogers (2000) Interventions that facilitate socialization in children with autism. Journal of Autism and Developmental Disorders, 30(5), 399-409.

[15] Baron-Cohen & Wheelwright (2004) The empathy quotient : an investigation of adults with asperger's syndrome or high functioning autism, normal sex differences. Journal of autism and developmental disorders, 34(2), 163-175; Koegel et al. (2016) Improving verbal empathetic communication for adults with Autism Spectrum Disorder.

[16] Bellini (2006) Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with Autism Spectrum Disorders and other social difficulties. Shawnee Mission, KS: Autism Asperger.

[17] Koegel et al. (2016) Improving verbal empathetic communication for adults with Autism Spectrum Disorder.

[18] American Psychiatric Association, 2013

[19] American Psychiatric Association, 2013

The second diagnostic criterion, restricted and repetitive behaviour, can be observed in the form of repeated motor movements, speech, and object use; insisting on sameness, highly restricted and fixated interests that are abnormal in focus.[20]

The term "spectrum" as used in the DSM 5 emphasises the fact that all of these behaviours exist on a continuum, i.e., autism affects children at varying levels of severity. The DSM 5 manual specifies how to score these behaviours in terms of the level of support[21]:

- Level 3: Requiring very substantial support
- Level 2: Requiring substantial support
- Level 1: Requiring support

Level 3 autism is defined as inflexible behaviour, a high level of difficulty coping with changes, and repetitive behaviour that interferes with day-to-day functioning. Kanner (1943) defines this as classic autism, as these are children with limited or non-functional language, heightened sensory responses, a strong desire to maintain sameness, and limited spontaneous activity.[22]

The term "autism" was first used in 1912. Prof. Eugen Bleuler, director of the Burgholzi Asylum in Zurich, coined the term to describe a schizophrenia symptom (Bleuler, 1912). In the late 1920s, Jean Piaget used it in his works, explaining it as a first form of thought during the phase of infancy, dominated by visual images and hallucinations that impact logical thought and social relations of the individual.

Dr. Kanner, was the first to distinguish between autism and schizophrenia. He conducted an experiment on 11 children who displayed monotonous repetitions, language deficits, and object preoccupations. Furthermore, autism was classified as a syndrome in 1943, and its symptoms were described in detail in an article titled "Autistic Disturbance of Affective Contact" in the journal Nervous Child, which was written by Dr. Kanner. In his article, he went on to describe the children's homelife, socioeconomic backgrounds, parents' backgrounds, and the major issues that their parents identified with their children. Kanner's observation aided other psychologists in making diagnoses.

Hans Asperger published an article in 1944 in which he described children with symptoms similar to those described by Dr. Kanner, but with higher levels of verbal and cognitive skills. As a result, the symptoms he described became known as 'Asperger's Syndrome’.

The importance of research in the development of autism as a disorder cannot be overstated. Kanner's work was validated by research that shed light on the impact of autism on children's lives as they grew into adults. The findings shed light on the role that IQ scores play in predicting clinical outcomes. Furthermore, research was instrumental in identifying neurological abnormalities and distinguishing between autism, mental retardation, and schizophrenia.

This understanding also aided in the development of therapies. While the initial belief that autism was caused by the environment persisted. Dr. Kanner, on the other hand, was convinced that the cause was internal and that nothing external had contributed to it. As a result, he was largely responsible for the disease's classification as a distinct disorder. Autism was classified as a "unusually early manifestation of schizophrenia, with its aetiology including the environmentally mediated effects of rearing by refrigerator parents" as a result of his research and study.[23]

---

[20] American Psychiatric Association, 2013

[21] America Psychiatric Association, 2013

[22] Kanner, l (1943). Autistic Disturbances of Affective Contact. Nervous Child, 2(3), 217-250.

[23] Rutter et al., 1999

This understanding influenced the therapies developed with the goal of undoing the harm done to ASD diagnosed children as a result of negative parenting styles.

More and more people began to study and thus became aware of autism, its impact on the lives of children as they grew into adulthood; the role of IQ scores in determining clinical outcomes; the impact of neurological abnormalities; the meaning behind the cognitive test score patterns of children; distinguishing autism from mental retardation, psychosis, and schizophrenia. Autism was said to impair social interaction, imagination, and communication in people. These impairments were identified and diagnosed using puzzles, games, family testimonies, and so on.

ASD was perceived as a biological disorder rather than a neurodevelopmental disorder in the 1970s, leading to the development of newer therapies.[24] The use of electric cattle prods was discarded, and ASD treatments were modified. This sparked another debate, whether to treat it as an illness, an impairment, or a naturally occurring difference that simply needed to be acknowledged by society.[25]

Thus, autism was reclassified as a neurodevelopmental disorder, and psychologists and neuroscientists began to treat it as such.

Researchers have claimed that people with ASD have many strengths.[26] People with Asperger's syndrome, for example, pay more attention to detail and perform the tasks assigned to them better than their peers.[27]

Neuroscientists believe that well-known prodigies and geniuses such as Mozart, Isaac Newton, Wittgenstein, Albert Einstein, and Charles Darwin had ASD.[28]

In general, there are four types of conditions that fall under the umbrella of ASD:

- Asperger's Syndrome: Children with this condition do not have a problem with language, but rather score in the average to above-average range on intelligence tests. They do, however, struggle with socialization and have a limited range of interests.
- Autistic Disorder: Children with this disorder struggle with social interaction and communication.
- Childhood Disintegrative Disorder: Children with this condition develop normally for at least two years, after which they gradually lose some or all of their communication and social skills.
- Pervasive Developmental Disorder: Children with this condition exhibit symptoms similar to autism, such as delayed social and communication skills, but they do not fit neatly into the category of autistic disorder.

The American Psychiatric Association recognizes the Diagnostic and Statistical Manual (DSM-5) as the authority for diagnosing autism. They suggest the following characteristics for diagnosis[29]:

- Unawareness of personal identity
- Pre-occupation with particular objects

---

[24] Courchesne et al. (2001) Unusual brain growth patterns in early life in patients with autistic disorder;
[25] Elliman, 2007
[26] Baron-Cohen, 2004
[27] Mayes & Calhoun (2002) Comparative and incremental validity of the Gordon Diagnostic System and WISC-III Freedom from Distractibility Index in identifying referred children with and without ADHD. Psychological Reports, 91, 575-587; Shah & Frith (1993) Why do autistic individuals show super performance on the block design task? Child psychology & psychiatry & allied disciplines, 34(8), 1351-1364.
[28] Wlassof, 2018; Fitzgerald, 2004; Ledgin, 2002
[29] DSM-5, 5th Edition. American Psychiatric Association

- Strive to maintain success
- Acute anxiety produced by change
- Abnormal perceptual experience (hearing and vision)
- Failure to develop speech beyond a limited level
- Distortion of movement
- Difficulty in learning, but some islets of particular skills or abilities of knowledge

Another factor not mentioned on the list is poor executive management. However, all of the factors need not be present for the diagnosis to be made. Behaviors differ from child to child, making diagnosis difficult, especially when the child's developmental age and language level are taken into account. Furthermore, not all symptoms indicate autism; symptoms can be deceptive because they can occur in other types of disorders.

There are numerous tools available for diagnosing ASD symptoms. The Autism Diagnostic Observational Schedule (ADOS) is strongly advised[30], some of the recognized tools used to diagnose ASD include the toddler version of the Autism Diagnostic Observational Schedule, the screening tool for Autism in Toddlers and Young (STAT), and the Communication and Symbolic Behavior Scales (CSBS).

Diagnostic tests and evaluations are extremely beneficial because they provide parents with answers and potential solutions in the form of confirmation as to whether their child has autism or not.[31] Subsequent testing allows parents to provide more support based on the additional information provided about the child's strengths and challenges.[32]

Parents are an essential part of the process and should be included in all discussions about what to expect and how to benefit from the evaluation. Pediatricians are also an important part of the process. These doctors are heavily involved in assessing the needs of children with ASD.[33]

According to studies and research, behavioral signs of developmental delay can be identified as early as 6 to 12 months; however, for an accurate diagnosis, where the symptoms are consistent and not fading or emerging, most professionals wait until the child is at least 18 months.

In 1938, Hans Asperger appears to have borrowed the term "autistic" from Bleuler, who was the first to use it. Asperger conducted a study in which he observed four boys who were not interacting with their peer groups, failed to understand the meaning of certain words such as "respect" and "polite," and had complete disregard for an adult's authority. Their habits and movements revealed unnaturalism and stereotypism patterns.

Rutter et al. (1999) investigated the relationship between research and clinical practise, citing the Maudsley Hospital study to develop diagnostic criteria based on empirical findings. The study's criteria have been established as an important element, and they also include an onset 30 months prior.

The Maudsley study was critical in that it provided a better understanding of ASD and improved how professionals diagnosed the disorder. Furthermore, it resulted in the evolution of diagnostic measures, such as general developmental screening, screening for ASD symptoms, and rating scales for autistic behaviour, using measures such as questionnaires, interviews, and observations.[34]

[30] Lord et al., 1999
[31] Midence & O'Neill, 1999
[32] Braiden et al., 2010
[33] Huerta & lord, 2012
[34] Rutter et al., 1999

Constant research and review provided the professionals with much-needed clarifications and effective tools. Several studies have found that ASD can be detected as early as 18 months.[35]

The DSM-III differentiated between autism and childhood schizophrenia in the 1980s. By 1987, the manual had provided a checklist of criteria/factors for diagnosing autism. The DMS-IV manual revised the definition of autism and added Asperger's syndrome between 1994 and 2000. In the 2013 edition of the said manual, i.e., DSM-V, all kinds of sub-categories were included in the main diagnosis of ASD, as well as two groups, namely, impaired social communication and/or interaction and/or repetitive behaviours.[36]

Initially, there was no way to recognise the biological markers for ASD, and screening was entirely based on the child's behaviour. However, researchers from the Weizmann Institute of Science, in collaboration with colleagues from Carnegie Mellon University and the University of California, were successful in identifying biological markers of autism in children.[37] Their research method included scanning the brain activity of sleeping children. They discovered that the autistic brain has weaker synchronisation between language and communication than the non-autistic brain. Furthermore, as this synchronisation began to decline, the symptoms of ASD increased. The scientists were able to identify nearly 70% of autistic children between the ages of 1-3 using only scans, allowing for early diagnosis.

Studies comparing 109 autistic children to 33 typically developing children revealed difficulties with maintaining eye contact, joint attention, imitation, difficulty with nonverbal communication, ortend play, and language development by 18 months of age.[38]

The range of symptoms, deficit symptoms, similarity between autistic and age-related behaviours, similarity of symptoms to other disorders, age of the child, and cognitive functioning all contribute to the difficulty in diagnosing ASD.[39] Further along the autism spectrum, one child may be both verbal and echolalic, while another may be nonverbal but scream at the same time.

The symptoms can be so diverse that one person cannot conduct the diagnosis alone; rather, a team comprised of several members specialised in assessing multiple areas of functioning is required to carry out an accurate diagnosis of ASD. The first step toward a diagnosis can be taken in the pediatrician's office, where the doctor can request that the child be screened if the doctor believes the child is exhibiting concerning behaviours or if the care-giver reports such behaviour. Furthermore, if a follow-up screening is required following the screening, the child must undergo a formal diagnostic evaluation.[40]

According to the American Psychological Association, surveillance for the onset of ASD symptoms should begin at the paediatrician’s office and continue even during routine visits. Despite all of these precautions, despite all of the monitoring, there are many cases of people slipping through the cracks and only being diagnosed later in life; and remaining undiagnosed throughout their lives.

---

[35] Landa & Garrett-Mayer, 2006

[36] American Psychiatric Association, 2013

[37] Siegel-Itzkovich, 2011

[38] Charman et al. (1997) Infants with autism : An investigation of empathy, pretend play, joint attention, and imitation. Developmental Psychology, 33(5), 781-789.

[39] Richler et al. (2007) Restricted and repetitive behaviors in young children with autism spectrum disorders. Journal of Autism and Developmental Disorders, 37(1), 73-85; Sigman & McGovern (2005) Improvements in cognitive and language skills from preschool to adolescence in autism. Journal of Autism and Developmental Disorders, 35(1), 15-23.

[40] Johnson & Myers (2007) Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics, 120(5), 1183.

There is no known cure for autism; rather, there can only be a significant reduction in symptoms to the point where people lose their ASD diagnosis; however, this occurs only after intensive treatments and sometimes not. Furthermore, most autistic children learn to speak by the age of four or five. However, many autistic children lack social support, employment opportunities, and self-determination. While the core issues persist, the severity of the symptoms decreases with age.

Autism symptoms range from highly visible to subtle, making diagnosis difficult. ASD can manifest in a variety of ways, ranging from nonverbal to fluent; from highly intelligent and answering to one's name to speaking prior memorised scripts; from being unaware of others' presence to individuals touching things of interest. Autism is known as Autism Spectrum Disorder (ASD) because of its wide range of symptoms. Profound autism can occur in conjunction with prominent symptoms as well as additional disabilities or retardation. Asperger's syndrome, for example, is characterised by normal or high intelligence, language development, autistic-like behaviour, and a lack of social and communication skills.

Aversion to physical contact, minimised eye contact, speech deficit, and facial expressions during early childhood are a few of these behaviours and nonverbal interactions. The inability to recognise social situations and facial expressions that are part of communication is a well-documented symptom of autism. People with autism, for example, frequently openly observe other people with keen interest, oblivious to the fact that their staring makes the other person uncomfortable.[41]

It is also common for people with ASD to avoid making eye contact with the person who is addressing them, preferring to look off to the side of the individual. Furthermore, sensory overload can occur in such people; visual stimuli such as sunlight streaming into a room, photographs, and lights can all lead to a meltdown. Others may find satisfaction in observing visual stimuli for longer periods of time, such as light streaming through glass or lines in a glass-stained window. Furthermore, their acute hearing allows them to hear sounds that are normally barely audible and to attend to conversations that are taking place at a distance.[42]

Everyday sounds in the environment, such as the sound of a blender in the kitchen, the sound of an electric shaver, or the sound of a fan, can all cause an overload in an autistic child. Although noises in a normal classroom can be distracting, studies have found that people with autism are more likely than the general population to have absolute pitch.

In a study involving musical abilities, Dr. Stanutz discovered that children with ASD outperformed typically developing children in musical games that tested pitch discrimination and musical memory.[43] In this study, children aged 7 to 13 were asked whether two tones were identical or slightly different, and whether they were solo or part of a melody. Over the course of a week, the children were also required to memorise melodies. It was discovered that children with autism had a remarkable ability to recall melodies.[44]

Autism can also cause sensitivity to smells, as well as waves of nausea or disgust, leading them to insist on their own pace, reject physical proximity, and sniff everything. Temperatures that are comfortable for some may cause discomfort in people with autism. The touch of a fabric can cause discomfort or pleasure; sitting still for extended periods of time can also cause discomfort. Repetitive behaviours can include banging the head, rocking back and forth, running in circles, repeating phrases, spinning or flicking fingers, and eating the same food. While the smell. Taste

[41] Schoen, 2003
[42] Wallis & Cray, 2006
[43] Sarris, M. (2015) Perfect Pitch: Autism's rare gift
[44] Stanutz S., Wapnick, J. & Burack, J.A. (2014). Pitch Discrimination and Melodic Memory in Children with Autism Spectrum Disorders. Autism, 18(2), 137-147

and texture of food may be difficult, and resistance to change may be another form of emphasis on repetition.

Communication can be difficult for children with ASD. Babbling is a common activity that all infants engage in before they begin talking; however, some autistic children do not engage in babbling. Idioms, figurative language, and metaphors can often cause confusion in the minds of children with ASD, which can lead to unpredictable outcomes, because ASD diagnosed children have literal thought processes or are unresponsive. For example, telling someone with ASD to "go fly a kite" may lead to the individual actually going and flying a kite rather than leaving. However, some people are geniuses or savants who can solve complex mathematical equations on their own or play a piece of music that they have only heard once.[45]

Self-management, which includes the ability to recognise a goal, plan, organise, and execute a plan, be oblivious to distractions, respond to change, solve problems, develop effective strategies, manage one's time and self, and put forth all necessary effort to achieve one's goal, is an accepted part of life. These functions are classified and referred to as Executive Functions (EF), a critical ability that an individual possesses when performing new tasks or adapting to a programme change.[46] ASD can impair EF functioning; two symptoms of impaired EF are failure to focus on a single task and failure to perform multi-step tasks. At two different levels, the level of fluency in task performance by ASD-diagnosed children and clinically controlled subjects was studied and analysed. The findings revealed a deficiency in traits such as self-management, implying impaired intentional thought and action.[47]

Autism is still a widely studied disorder, but its cause remains unknown. ASD is thought to be caused by the following factors:

- Anomalies in the brain's structure[48]
- Typical genetic variants[49]
- Prenatal complications[50]
- Increased serotonin levels in the blood, as well as a lack of affection on the part of the parents, are some of the factors that have been proposed as possible contributing factors to ASD at various times.[51]

Many factors, including genetic, environmental, toxic, and metabolic factors, have been identified as having contributed to the disorder, according to research.[52]

Later studies on the nature of autism indicate that the social deficiencies prevalent in ASD are due to a lack of awareness that their associates do not have thoughts and emotions, or a lack of 'theory of mind'.

While discussing the causes of ASD, Nguyet et al. (2010) discover epigenetic contributions to ASD and a novel autistic candidate gene, RORA, whose protein product is reduced in an autistic brain, indicating that autism is now regarded as a multigene disorder with epigenetic influence.

---

[45] American Psychiatric Association, 2013

[46] Frith, U. (2003). Explaining the enigma. 2nd Ed. Oxford, England: Basil Blackwell

[47] Turner, M. (1999) Annotation: Repetitive Behavior in Autism: A review of psychological research. Journal of Child Psychology, 40(6), 839-849.

[48] Ha et al., 2015; Rutter, 1967; Bauman & Kemper, 1985

[49] Gaughler et al. (2014) Most genetic risk for autism resides within common variations. Nature Genetics.

[50] Lobascher et al. (1970) Childhood autism: An investigation of aetiological factors in twenty-five cases. The British Journal of Psychiatry, 117(540), 525-529

[51] Eisenberg, L. & Kanner, L. (1956). Childhood Schizophrenia: Symposium, 1955: 6. Early Infantile Autism, 1943-55. American Journal of Orthopsychiatry, 26(3), 556.

[52] Abruzzo et al., 2015; Karimi et al., 2017

Gene mutations have been identified as a major barrier to neurodevelopment in children by studies.

Genetic factors play a significant role in the development of autism in individuals. Studies on twins and families show that some people are genetically predisposed to ASD, and this conclusion was reached by looking at a pattern of ASD/psychiatric disorders in families. Thus, if one twin has autism, the other twin has a 36%-95% chance of being affected.[53]

While ASD is largely thought to be genetic in origin, as evidenced by the above-mentioned studies, evidence also points to the presence of epigenetic regulatory mechanisms in the pathogenesis of ASD. Currently, epigenetic modifications and their complex mechanisms are regarded as the most important moderator of environment-genome interactions.[54]

The researchers concluded that epigenetic modifications are a critical regulatory mechanism for keeping gene expression under control by excluding the involvement of DNA mutations or polymorphisms in a study that examined altered expression of micro RNA's (miRNA) and their target genes in the brains of mouse offspring.[55] This allows gene expression to be passed down to the next cellular generation or organism generation.[56]

Epigenetic regulation, including DNA methylation and histone modification, is critical for normal brain development, and dysregulation of the epigenetic machinery has been linked to a variety of neurodevelopmental and neuropsychiatric disorders, including ASD.[57]

However, because no single genetic variation or mutation can account for a large number of ASD cases, the converging actions of ASD-related genes on common pathways, as well as interactions with non-genetic factors, are regarded as likely explanations for ASD pathophysiology.[58] Using epigenetic mechanisms, environmental factors can influence the quality and quantity of gene expression without changing the DNA sequence. Some of these mechanisms include DNA methylation, histone protein changes, and non-coding RNA expression.[59]

Another way the environment can have an impact is through exposure to harmful environmental factors during the pregnancy phase. If such exposures occur during critical stages of embryo development, the expression of developmental genes may change, increasing the risk of genomic imprinting diseases such as autism.[60]

Neuroimaging studies have provided crucial insights into the changes that occur in the brains of people with ASD. The amygdala is an important component of the limbic system, and the affective loop of the cortico-striatothalamo-cortical also plays a role in autism, as does the nucleus accumbens, which influences social reward in ASD.[61]

Researchers believe that ASD is the result of complex interactions between genetic and environmental risk factors.[62] As a result, understanding the interaction of these factors in the

---

[53] https://www.ninds.nih.gov/health-information/patient-caregiver-education/fact-sheets/autism-spectrum-disorder-fact-sheet

[54] Karimi et al. (2017) Environmental Factors influencing the risk of autism. Journal of Research in Medical Sciences, 22(27)

[55] Sunwoo et al., (2018) Maternal immune activation alters brain Micro RNA expression in mouse offspring. Annals of Clinical and Translational Neurology, 5(10), 1264-1276

[56] Bollati & Baccarelli, 2010

[57] Jaenisch & Bird, 2003

[58] Kim & Leventhal, 2015

[59] Karimi et al., 2017

[60] Foley et al., 2009

[61] Park et al., 2016

[62] Kim & Leventhal, 2015

pathogenesis of ASD is critical for developing an effective treatment strategy. Some of these risk factors can be divided into three categories: prenatal, perinatal, and postnatal. Each class represents a stage of neonatal development.

It is believed that altered neuroimmune mechanisms play a role in the development of schizophrenia and related psychotic illness during the prenatal stage.[63] Furthermore, prenatal infection has been linked to a neurodevelopmental primer that can lead to a variety of mental illnesses. According to a study that used seven epidemiological studies, prenatal traits associated with an increased risk of autism and ASD include advanced maternal age, advanced paternal age, and maternal place of birth outside of Europe and North America.

Birth weight, gestational duration, and intrapartum hypoxia, i.e., oxygen levels in the tissue, are all factors to consider during the Perinatal stage. Although these factors have not been confirmed as independent risk factors for autism, experts have suggested that they be taken into account and thoroughly investigated for future purposes. Furthermore, Caesarean Sections have been identified as a possible risk factor for autism. Based on the combined results of 61 studies conducted in 19 countries, experts concluded that a child has a 33% chance of being diagnosed with autism if the mother gave birth via Caesarean section; on the other hand, children born via vaginal delivery had an autism rate of 0.8%. Although it has not been proven that C-section babies directly cause autism, a study found that 17 of the 29 study populations examined had a higher risk.[64]

Another study discovered a higher prevalence of prenatal, perinatal, and postnatal factors in children with ASD when compared to typically developing siblings, with postnatal factors primarily represented by respiratory functions.[65] The study presented a link between perinatal and postnatal factors and ASD, with perinatal traits identified primarily in the form of acute foetal distress (26% of cases), long duration of delivery, and prematurity (18% of cases for each factor). Respiratory infections (24%) were observed as postnatal factors. However, no correlation was found between advanced age of parents at the time of conception and ASD in terms of parental factors. Furthermore, no correlation was discovered between the severity of ASD and various traits. The risk factors retained in the final decided model after logistic regression were male gender, prenatal urinary tract infection, acute foetal distress, difficulty in labour, and respiratory infections. As a result, the study confirms the presence of perinatal, perinatal, and postnatal factors in children with ASD and suggests that some or all of these factors may interact as determining variables for the genesis of ASD.

As a result, the precise cause of autism is still unknown. In their review titled 'Characteristics of Brains in Autism Spectrum Disorder,' Ha et al. (2015) shared findings from brain imaging studies. This review found dysfunctional activation in critical areas of social communication. Neuroimaging studies have provided insight into the changes that occur in the brains of people with ASD.

Inclusion is based on the fundamental human right to education for all, which was established in the 1948 Universal Declaration of Human Rights.[66] Article 24 of the UN Convention on the Rights of Persons with Disabilities (CPRD) has encouraged inclusion by requiring States parties to the convention to implement changes in their education systems and take steps to ensure that children with disabilities have access to quality education.

---

[63] Meyer, 2014

[64] https://www.reuters.com/article/us-health-csection-brain/possible-link-between-c-section-and-autism-adhd-idUSKCN1VI1VS

[65] Hadjkacem et al., 2016

[66] United Nations, Universal Declaration of Human Rights, 1948.

Despite the UN's success in increasing global access to education, children with disabilities continue to be a marginalised group. According to data collected in 2018, approximately 29 million children in South Asia were not attending school.[67]

As the world's largest democracy, India faces numerous challenges in ensuring access to education for children with learning disabilities. It is undeniably true that the country has made significant progress in improving access to education for children with learning disabilities. Between 2002 and 2003, the number of students who dropped out of school was estimated to be 32 million, but by 2010-2011, the number had dropped to 2.7 million.[68]

Iovanonne et al. (2003) investigated educational programmes designed specifically for children with autism, such as TEACCH[69], The LEAP programme and the UCLA behavioural intervention programme have identified six core traits that they believe should be included in any educational programme for autistic children, namely:

- Individual student and parent support and services
- Step-by-step instructions
- An understandable/structured environment
- Curriculum content that is specialised
- Using a functional approach to behavioural issues
- Involvement of family members

The National Research Council (2001) outlined the skills that must be included in the specialised curriculum, which are as follows:

- Verbal, nonverbal, and expressive communication
- Social abilities
- Symbolic and functional communication
- Being aware of the environment and responding to motivational systems
- Fine & gross motor abilities
- Replacement of problem behaviours with appropriate behavioural skills
- Cognitive abilities
- Competencies required to function in a regular classroom

The delivery of service to children with autism can be categorized into various criteria. According to Cerveza et al (2011), there are two criterias when looking at models of service delivery, i.e., setting and age. Programs that are setting based may range from home based to centre based or school based, whereas programs that are based on the age of the child may range from early intervention programs to school based and adult based programs.

In India, there are four models for delivery of service that are available to the parents of children diagnosed with autism, these include:

- Mainstream schools
- Special schools
- Centre-based instruction and home-based training
- Initiatives by parents

[67] UNESCO Institute for Statistics Database

[68] Social and Rural Research Institute. National Sample Survey of Estimation of Out-of-School Children in the Age 6-13 in India. New Delhi: Social and Rural Research Institute, 2014.

[69] Treatment and Education of Children with Autism and Communication Handicaps

Understanding the ability level is used to enrol children with autism in school, and the choice of education model is based on the child's ability level and parental aspiration.

According to the Rehabilitation Council of India, the quality of education provided to autistic children in schools varies. They also claim that there is no system in place to monitor standards and ensure that autistic children receive quality education. Furthermore, most schools lack specialised staff to care for autistic children within the school setting.

According to Narayan et al. (2005), most autistic students dropped out of school because their needs were not met, and they were unable to cope with the academic life of a regular school.

According to Bhargava (2009), most children with special needs in India are educated in special schools. According to Action for Autism, an advocacy and training organisation based in India, there are only about 79 schools/establishments in the country that specifically educate children with ASD. They differ from special schools in that they use autism-specific strategies, which contrast with the strategies used by special schools, which take a more generic approach. However, with the growing emphasis on mainstream, regular schools adopting an inclusive style of teaching under the Right to Education Act of 2009, the number of children enrolling in mainstream schools is on the rise.

Despite the positive outcome, an article in the Hindustan Times dated 02.04.2018 revealed a disturbing fact: children with autism tend to change schools at least four to seven times before graduating from high school at the age of 18. According to Dr. Subharati Ghosh, parents of autistic children must exert considerable effort in order to ensure that their children have access to inclusive education.[70]

However, studies on home-schooled children have revealed that a small percentage of parents believe in the concept of 'unschooling,' which is defined by self-directed learning without the presence of formal teachers or any kind of textbooks and instructions.[71]

To date, only one study has attempted to systematically quantify the home-school education provided to children with ASD. Five of the nine home-schooling programmes described by Simmons (2014) have parents who have allegedly used the educational philosophy of unschooling to varying degrees. It ranged from the entire educational programme to a method used on one or two days per week.

Simmons classified the level of structure in the home-school environment as low to high. The following indicators were used to define these structures:

- Direct provision of instruction
- Instructional workspace
- Expectations presented with clarity
- A schedule that’s predictable
- Numerous chances to respond
- Feedback on the performance

The following indicators were used to determine the level of structure:

- 0-2: Low
- 3-4: Moderate
- 5-6: High

[70] Pratap, A. Children with autism go through 4-7 schools in Mumbai before the age of 18, says study. Hindustan Times

[71] Martin Chang, Gould & Meuse, 2011; Ray, 2010; Taylor-Hough, 2010)

Six of the nine subjects' home-school environments were described by parents as having low to moderate structure (Simmons, 2014).

In terms of instruction delivery, Simmons (2014) discovered that home-schooled children with ASD received instructions for an average of 4 hours per day, according to parent reports. Furthermore, it was discovered that six of the nine children did not receive instruction in all required content areas as required by the state's education law. In addition, eight of the nine families relied on independent individuals with teaching credentials to carry out some aspect of the home-schooling programme.

Furthermore, research has discovered high levels of stress in parents of autistic children, including those who have implemented home-based behavioural interventions for young children. Six of the nine parents interviewed by Simmons (2014) stated that they do not expect their child to return to traditional schools. In this study, two parents indicated that they might consider sending their children back to traditional school, while one parent indicated that they would be sending their child back to traditional school in the near future; this parent stated that the reason for her sending her child back to traditional school is that she was unable to continue providing home-schooling to her child due to financial constraints.

Parents of ASD home-schooled children, on the other hand, have reported tremendous benefits to the entire family from home-schooling. These advantages are directly related to five essential factors that parents consider when deciding to homeschool their children: intellectual stimulation, individual instruction, social and emotional growth, reduced negative peer interaction, and, finally, less stress on the child and family (Simmons, 2014).

At the same time, parents have highlighted the various challenges they face while home-schooling their autistic children. One common challenge mentioned by almost all parents was difficulty in completing their own work because they had to keep ensuring that their child stayed on task. This was a major concern, particularly for parents who worked from home and required their child to work independently for a set period of time.

However, treating and homeschooling autistic children remains a difficult task and a challenge. Stigma is a problem because some communities continue to be in the dark about autism. Another challenge is the financial burden and cost of raising a child with autism. Handling the disorder through diet is also a difficult task for parents and carers. Other challenges include locating appropriate services such as transportation, therapy, and treatment; adequate placements that reflect the child's level of functioning; and adhering to the proper procedures when necessary.

The number of children diagnosed with autism is increasing, but many are unaware as they have never heard of it or seen a person diagnosed with ASD unless they have seen them in movies such as Rain Man, which is insufficient to educate them about autism or ASD.

Another issue is the financial burden. Parents who choose to stay at home and care for their autistic children face financial difficulties. According to studies, mothers of children with ASD work 7 hours less per week and are 6% less likely to have a job than mothers of children with no health concerns. Children with ASD are more likely to have at least one parent living at home, resulting in a 21% loss of income when compared to families with children with other health-limiting conditions. A lower income has an impact on the family's socioeconomic status and also limits the children's access to healthcare and therapy options.

Aside from that, ASD-diagnosed children and their families face additional challenges. The above is just a sampling; from the disorder's stigma to the challenges of bringing about change through the legislative process, childcare, the economic burden of caring for the child and medical costs, therapies, loss of income, and the life-long care that autistic children require. Managing the

disorder with diet or supplements is an added challenge for the diagnosed individuals' parents and carers. Furthermore, parents and carers face the challenge of providing educational jargon and intimidating processes while attempting to access services and placements for their children. This results in restrictions and limitations being imposed while attempting to follow the proper procedure when necessary.

REFERENCES

1. Christina Ann Simons (2014), Evidence-Based Practice for Home-schooled Children with ASD: Group Comparison and Parent-Implemented Intervention
2. Giselle Lobo and Madhura Joshi, A survey of Strategies Used to Educate Chidlren with Autism in Goa.
3. https://leverageedu.com/blog/homeschooling-in-india/
4. https://a2zhomeschooling.com/regional/asia_homeschooling/india_homeschooling/
5. https://www.webmd.com/brain/autism/symptoms-of-autism
6. https://disabilityinsider.com/2021/07/13/education-and-employment/teachers-learn-how-students-with-learning-disabilities-might-solve-problems/