



## Invisible Disabilities

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Invisible conditions are more difficult to detect by medical doctors. Many such conditions go undiagnosed or are misdiagnosed. The stigma surrounding a chronic disease or disorder and the realisation that a seemingly healthy child is having a condition which affects functional efficiency throughout life, may in many cases compel parents to conceal the disability in social settings.

**W**hen we use the term “disability”, many people have a mental picture of persons with assistive devices such as wheelchairs, canes, hearing aids or using sign language—as also people with bodily features which appear different or distorted. However, disabilities also include a number of other conditions that are typically not apparent to onlookers. Quoting figures from the USA, it is estimated that 1

in every 18 persons has an invisible or hidden disability which prevents a person from adjusting to social roles and responsibilities. The statistics for developing countries may not be very different, if not worse. Hidden disabilities have some unique psychosocial issues which make conditions all the more complex and debilitating.

Consider this, a mother with autistic child having a meltdown

due to sensory reasons is told that she is not sufficiently competent as a mother since her child appears to be undisciplined and out of control. Similarly, children with learning disabilities are perpetually scolded for being lazy and not putting in their best efforts in academics.

Not only do people with invisible or less visible disabilities have to make day-to-day adjustments to exist in the world around them, but they

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*All images are for representational purpose only.*

must also navigate misconceptions about their condition—including the idea that they are incompetent, lazy or rude or disobedient or unresponsive. Thus the problem is that such people look normal and are thus expected to perform with the same competence and efficiency which is at par with their physique and appearance.

### Common Invisible Disabilities

Some of the most common invisible disabilities in which people appear healthy and in control of their lives and bodies are:

a. Minimal brain injury and developmental cognitive disorders which interfere with memory, motor skills planning, organisational abilities, cognition and communication. Children may find it difficult to perform higher level of academics, planning, and as adults they may make 'mistakes' in tasks which involve precision and multi-step processes such as digital transactions. Outwardly, they appear clumsy, distracted and disorganised.

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b. Learning Disabilities: Neurological disorders resulting in impairment in reading (dyslexia) writing (dysgraphia) or mathematics (dyscalculia), commonly associated with Attention Deficit and Hyperactivity disorder. Appearance: Lazy, distracted, intentionally avoiding work.

c. Autism Spectrum Disorders: Neurodevelopment disorders beginning early in childhood and severely affecting the ability to communicate, learn social skills and social interaction, associated with rigid and repetitive

behaviours. Appearance: Rude, undisciplined, fussy, stubborn, avoiding instructions, and not cooperating.

d. Chronic diseases such as certain renal disorders as also Fibromyalgia which is a chronic rheumatic condition that causes widespread pain and throughout the soft tissue in the body, accompanied by fatigue. Appearance: Lazy and constantly avoiding work.

e. Depression: Mental health and mood disorders involving persistent feelings of sadness, hopelessness and loss of interest strong enough to affect normal functioning; commonly associated with anxiety disorders causing persistent feelings of worry and fear. Outwardly appearance: Being unnecessarily sensitive, exerting oneself to become cheerful and trying to adjust.

f. Sensory Disorders: Children who have sensory issues may have an aversion to anything that triggers their senses, such



as light, sound, touch, taste, or smell. Common symptoms of sensory processing issues may include avoidance or hyperactivity. Appearance: Too fussy, not cooperating, need for stern discipline.

### Medical, Social and Psychological Challenges

#### Detection and Diagnosis

People might experience symptoms of conditions that qualify as disabilities, but they do not realise that they are experiencing something more than just normal variation. For example, a student who has a learning disability might experience high levels of frustration and poor performance in school, but parents and teachers assume that he or she is a low achiever (Licht, 1983). Someone who recently developed a hearing impairment might ask people to repeat sentences or to speak louder, but does not connect that experience to having a disability. That person might just avoid social settings and conversations or get frustrated thinking the environment was making hearing difficult.

Hidden disabilities are difficult to detect by parents, caregivers and teachers. Precious time during critical developmental period is wasted in trying to discipline and correct the child's apparent errant behaviour. Invisible conditions are also more difficult to detect by medical doctors. Many such conditions go undiagnosed or are misdiagnosed.

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Research has reported that the process of being diagnosed with a learning disability often involves collecting multiple conflicting diagnoses by healthcare providers over a long period of time. Also, the clinical criteria for some conditions generally also might change over time, as new research finding come in, making diagnosis difficult.

#### Stigma

The stigma surrounding a chronic disease or disorder and the realisation that a seemingly healthy child is having a condition which affects functional efficiency throughout life, may in many cases compel parents to conceal the disability in social settings. Research shows that the burden of concealing

a disability creates strain in social and work situations that might negatively affect health and well-being (Chaudoir & Quinn, 2010). Concealing also results in low self-esteem and related psychological personality problems. In contrast, disclosure relieves the strain of hiding the condition and increases the likelihood that the person will find and develop a social support network with others who might have similar conditions or experiences. However, social attitudes need to change to enable disclosure. There are a number of functional reasons why people with invisible disabilities might not tell others.

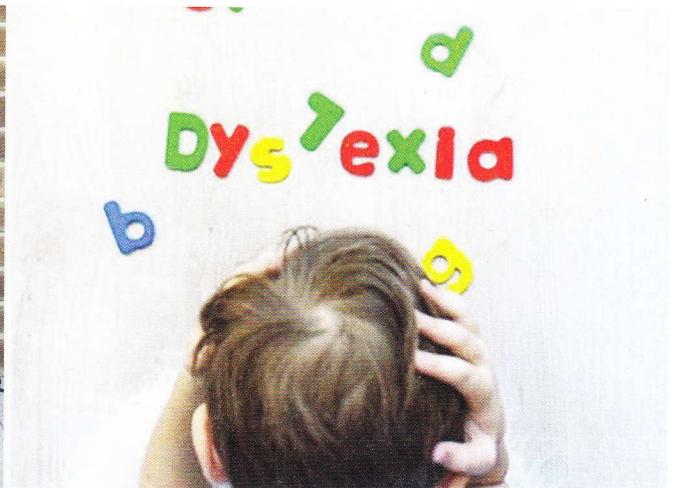
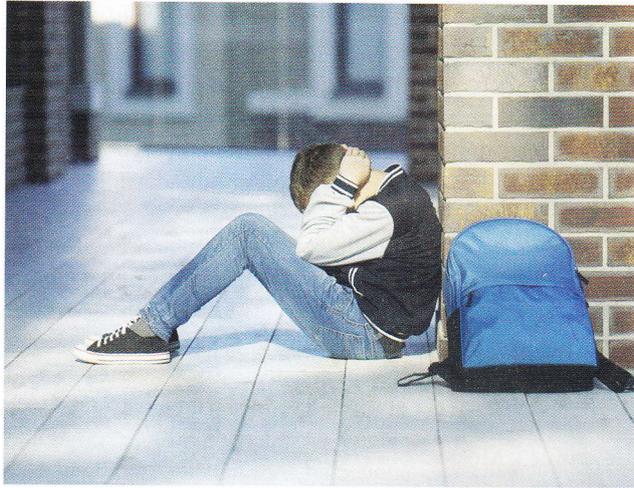
First, even if protected by law from overt discrimination, they still face potential prejudice or negative evaluations from others. Research suggests that there is a social stigma attached to having a disability, especially for psychological conditions (Stone & Colella, 1996). Some people with invisible disabilities might be willing to conceal their conditions and forego legal accommodations to avoid being treated differently or negatively by others.

Second, disclosure can raise questions about whether the disability actually exists or the individual is "faking it". When someone who "looks normal" claims to have a disability and requests special accommodations/provisions, observers might question whether a real disability is involved. Instead, others might assume the person is only trying to gain special privileges (Colella, 2008). In addition to dealing with the potential stigma associated with having a disability, persons with invisible disabilities risk the additional stigma of being viewed as someone who is falsely seeking personal gain.

#### Psychological Issues of Self-esteem and Self-confidence

Individuals who have (or think they have) invisible disabilities must carefully weigh the potential benefit of avoiding social stigma by not





disclosing against the costs to health, well-being, and performance. The current research cannot prescribe one clear way for persons with invisible disabilities to manage their identities and the disclosure process across all social and work situations. Some situations involve more risk of stigma than others. Some situations require more effortful ways to hide the disability than others. Also, some work and school tasks are more relevant to certain disabilities than others.

#### **Efforts toward Rehabilitation and Acceptance**

Today, India has more than 10 million children with autism, 10 million people with epilepsy, more than 150 million people with a need of intervention for mental illness, and many more with varied physical disabilities; living in relatively large cities. But 71% of children with disabilities are living in rural areas, which make getting intervention an even more difficult process for them. While the Indian healthcare infrastructure is no doubt growing year by year, there is still a lack of specialists to deal with mental and physical disorders. According to a World Economic Forum report, India currently needs 11,000 psychiatrists and 54,000 mental health professionals. Mental health workforce in India (per 100,000 population) include psychiatrists (0.3), nurses (0.12), psychologists (0.07) and social workers (0.07). According to

WHO, India spends around 0.06% of its health budget on mental health.

#### **Creating Awareness and Infrastructure**

The first step towards rehabilitation is to create awareness; that there indeed exist certain lifelong debilitating disorders which require special assistance and provisions from the community. The Rights for Persons with Disabilities Act, 2016 is a step toward such awareness. Apart from covering 21 categories of disabilities from the previous 7 categories under the 1995 Act, this new Act also includes some of the seemingly invisible conditions such as autism and learning disabilities within its ambit. A visionary plan of action at the State level is important to give a sense of direction to professionals, planners and field level workers. This is no easy task since each disorder has its own unique problems and unique means of

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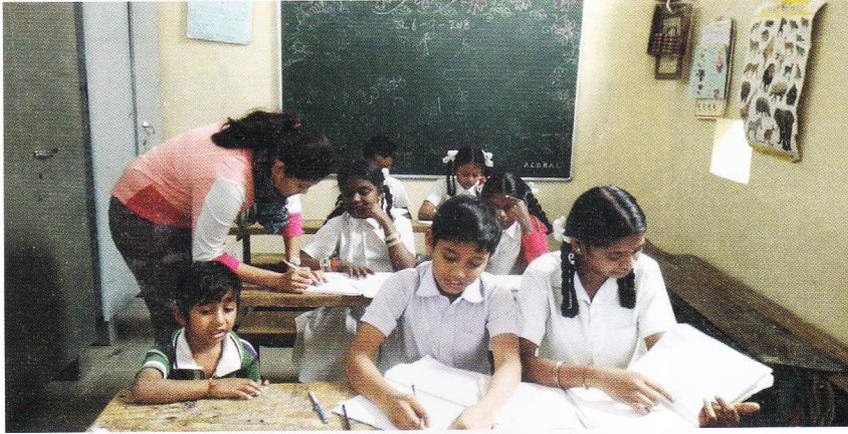
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capacity building and training needs for therapist and parents. The need to create a trained human resource of professionals, special educators and therapists cannot be undermined. The Rehabilitation Council of India has an important and difficult task to implement considering the non-uniformity in training requirements of each category of disorders.

#### **The Special Needs of Childhood Developmental Disabilities**

There are some universal rules which can be followed in rehabilitation of childhood developmental disorders—early detection, early intervention, and training and empowering parents/caregivers. Early intervention can work wonders, when brain and body cells are most malleable and receptive to training and therapy. Hence the need for early detection at the primary health centre level, and continuous monitoring through home visits by trained healthcare workers. There is a need to provide parents with professional counselling when their child is diagnosed with a disability. The sooner we help a parent bridge the gap between denial and acceptance of a child's disability, the better they will be able to help their child in the future. Counselling of parents in the potential strengths of a special needs child at an early age can go a long way in maximising functional adjustment to educational and vocational development required to fulfil adult



social responsibilities. Networking and connecting parents has been found to be extremely beneficial.

### Special Education and Vocational Training - Focus on the Strengths

Once diagnosed, and accepted, there is no looking back. The person with disability thereafter can be trained and rehabilitated in many ways by following the golden rule of focusing on the person's strengths. Children with learning disabilities make amazing progress with alternative teaching practices. Similarly, children with autism move ahead in life using alternative and augmented communication techniques. These techniques not only help in life skills, but also help reduce behavior-related issues such as meltdowns and temper tantrums, since the child is able to communicate his or her needs, requirements, feelings and fears. A confident and accepted child who can convey his problems can fit in very well in any kind of social situation.

### Need for Innovation, Use of Technology and AI

The application of Artificial Intelligence tools and technology in detecting disabilities which are not apparent to onlookers, can be a game changer in the case of early detection. Medical professionals are increasingly looking to articulate intelligence tools in providing a clearer diagnosis at a very early age. Not only that, applications based on AI are changing the way therapy can be provided to

certain disorders and disabilities. Most used in the case of autistic children, apps and devices are being tailored to suit the special and unique needs of a young child. Applications in handheld smartphones are assisting parents in providing, augmenting and assisting the communication requirements of a child by providing visuals, sounds and situations. Not only that, such apps are reducing the expense and resource burden on the family to undergo expensive and exclusive therapies on a daily basis.

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## Inclusion and Social Acceptance

There has to be a conscious effort made by the government sector and society together to become more inclusive towards everyone living with a disorder or disability. The process starts with the family and the classroom, both building blocks of society. With the advent of global information in every household and best practices being shared through online mechanisms, prejudices and stigma are surely on their way out. Once parents are accepting, empowered and connected, they will be able to help their child in the future. Most importantly, people living with disorders and disabilities need to be encouraged to share their story with those around them so that people can better understand how to support them. India has a great vibrant culture. It already has the necessary social compassion towards the deserving. Awareness and sensitisation of disabilities which are not apparent will most certainly result in acceptance and social inclusion. Once minds are open and accepting, and are geared toward achieving educational and life skill goals, the necessary innovations, techniques and therapies will also come forth. It is imperative to start a movement of being consciously inclusive, and looking for solutions, starting today. □

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