

## CHILDREN WITH DISABILITIES

*Education is one of the most effective ways to break the cycle of discrimination and poverty that children with disabilities often face.*

According to the World Report on Disability approximately one billion people in the world are living with a disability, with at least 1 in 10 being children and 80% living in developing countries. Among marginalized groups, children with disabilities remain the most excluded, discriminated not only because of their disability but also because of lack of understanding and knowledge about its causes, implications and stigma.

Children experiencing multiple forms of discrimination, particularly girls with disabilities, face a double disadvantage, because of their disability and gender. Girls with disabilities are not only confronted with stigma but are also constrained by traditional gender roles and cultural barriers.

Children with disabilities are less likely to start school and if they do, they are unlikely to transition to secondary school. Access to school for children with disabilities is often limited by a lack of understanding about their needs, lack of teacher training, unconducive school environment, classroom support and learning resources and facilities.

Denying children with disabilities their right to education has a lifelong impact on learning, achievement and employment opportunities, hence hindering their potential economic, social and human development.

To ensure that all children enjoy their basic human rights without discrimination, disability inclusion should be mainstreamed in all policies and plans. This applies to education systems, which need to promote inclusion by ensuring the presence, participation and achievement of all children, including children with disabilities.



National Centre for Promotion of Employment for Disabled Peoples Disability Law Unit (DLU) - North East in Shishu Sarothi, a leading N.G.O. working for children with cerebral palsy in Assam, has tried to assess the extent of implementation of the disability related laws in the North East region including Assam, Arunachal Pradesh, Manipur, Mizoram, Meghalaya, Nagaland and Tripura. Though responses were sought from Sikkim, none were forthcoming. So this state has not figured in this report. The assessment has been done through interactions, workshops and discussions with N.G.O.s, associations of people with disabilities and key stakeholders. The Report prepared by **Shishu Sarothi** throws light on the lack of implementation of the disability enactments in this region.

In the last twenty years, a number of statutes relating to the disability sector have been enacted. The major laws dealing with disability are The Mental Health Act, 1987, The Rehabilitation Council of India Act, 1992, The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, and The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

With the passing of these laws there are a plethora of provisions for protection, care, treatment, rehabilitation, security and empowerment for persons with different disabilities. These laws also help effect a change in the way society looks at disability.

But unfortunately, these laws are not being implemented properly in the North East region with even the awareness level remaining low, as the study reveals.

### **Discrepancy in Census figures**

To begin with, even the Census figures regarding the disabled population in the North East region are nowhere near the actual numbers as revealed by the C.B.R. Network (N.G.O.) figures. As per the Census there are 5, 30, 300 disabled people in Assam, whereas C.B.R. Network (N.G.O.) figures indicate 17, 79,968. In Arunachal Pradesh there are 33,315 persons with disabilities while there are 72,908 as per C.B.R. Network data. The same is the case with Manipur (28, 3756 persons with disabilities -Census 2000; 1,59,608 as per C.B.R. Network data), Mizoram (16,011 persons with disabilities - Census 2000; 59,540 as per C.B.R. Network), Meghalaya (28,803 disabled persons - Census 2000; 1,54,091 as per C.B.R. Network), Nagaland (2,26,499 persons with disabilities - Census; 1,32,880 as per C.B.R. Network) and Tripura (58,940 persons with disabilities - Census 2000; 2,13,233 as per C.B.R. Network).

## THE NATURE OF DISABILITIES

### PHYSICAL DISABILITIES

Children with Physical Disabilities can have

**Hearing impairment.** Depending on type of malfunction to the ear or nerves, impairment may range from mild to severe; temporary or permanent.

**Visual impairment.** Variation in range of impairment due to premature birth, injury, or medical causes.

**Motor impairment.** Variations range from physical restrictions of limbs, hand, trunk control, mobility, and strength.



### AT- RISK CHILDREN

- At-risk Children. Children's experience with **Biological** or **Environmental** factors that may result in developmental delays or disabilities.
- Biological Risk Factors
  - Children have biological history that can result in later developmental problems
  - Children at-risk include
    - a) Premature babies.
    - b) Children born to mothers who have German measles while pregnant or complications during labor.
    - c) Low birth weight babies.
    - d) Children who accidentally ingest toxic substance during infancy and toddlers years.
- Environmental Risk Factors
  - Can be at risk because of the environment in which they lived before and after birth.
  - These risk factors result from the mothers living in substandard or deprived environments.
  - Early identification of at-risk child is essential so that intervention earlier on can be provided.

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## DEVELOPEMENTAL DELAYS

- COGNITIVE DELAY

- Child with cognitive or mental retardation is unable to use thinking skills to the level that is characteristic of normal development.
- A child with Down's Syndrome experiences cognitive delays that result in mental retardation
- ADHD
- Language Delay
- Difficulty in articulating or expressing language. Speech deficit that limits verbalization, such as stuttering or inability to utter sounds correctly.
- Immature use of language.
- Limited vocabulary.

## Emotional and Behavioral Disorders

- Exhibit deviation from age appropriate behavior that can cause them to be very aggressive or very withdrawn. Leading to behavioral problems such as:
  - Aggression.
  - Academic disability.
  - Anxiety.
  - Depression.
  - Behavioral deviation can be caused by
    - Psychological causes – Bereavement due to loss of a parent through divorce or death.
    - Environmental causes – Parenting methods of child management, Teacher management strategies.
    - Psychological causes – Genetic factors.

A. Autism

B. Children with autism experience severe emotional disturbance. Noticeable as early as 2½ years of age.

C. More common in boys than girls and is believed to be a biological problem that occurs during prenatal stages of development.

D. Behavior exhibited includes

- a. Head banging.
- b. Extremely delayed expressive language.
- c. Echolalia speech.
- d. Stereotypical body movements.
- e. Children with Autism
- f. Can seem to be insensitive to sound and events around them.
- g. Have difficulty in socially interacting with others.
- h. Fail to recognize that outside world is different from self.
- i. Often experience mental retardation as well.

#### B) Abused & Neglected Children

- Children can be abused emotionally, physically, sexually, and through neglect. Frequently children who are abused experience more than one form of abuse.
- Abused children are aggressive and use inappropriate social behavior; they are equally likely to be withdrawn and passive.
- Aggressive children can be
  - Disruptive.
  - Antisocial.
- Children who have been sexually abused might use inappropriate sexual behavior in social interaction with peers.
- Physically abused children might wear clothing that is seasonally inappropriate to cover signs of abuse.
- Neglected children might be dressed inappropriately or in dirty clothes. Generally, because they have received minimal care and supervision.

#### Children with Multiple disabilities

- Children with disabilities frequently have combination of conditions.
  - Example. Children with visual impairments can also have hearing impairments, mental retardation with unusual and hearing impairments.
  - Cognitive delay or mental retardation can have language delay or communication disorder.
  - Behavior disorder can also experience language abnormalities or cognitive delay.

- It is important to understand the nature of disabilities in order to understand how these conditions and variations from normal development affect how children play.
- Easier to understand the limitation of children with physical disability and how their play is affected than children with behavior or mental disabilities.
- Providing play opportunity is more challenging in case of multiple disabilities.

## **Rights of the differently-abled child**

Disabled children are like all other children. In keeping to the Convention of the rights of the child (CRC), they are entitled to the same rights as any other child.

In addition to the right to non-discrimination which is mentioned above, it is necessary to highlight that disabled children are supposed to enjoy all rights guaranteed by the Convention as well as the rights mentioned below.



### **The right to proper treatment**

The second paragraph of article No. 23 CRC, dedicated to children with disabilities guarantees their right to get special care and to request the granting of state assistance, adapted to the child's country and to the financial standing of his parents or his guardian.

It is obvious that children with disabilities are entitled to special treatment, but in practice, most of these children are entirely deprived of even proper medical treatment. Their chance of recovering or in the least of living with less suffering are thus reduced to zero.

### **Right to education**



Due to the lack of infrastructure, of means, of knowledge and above all of goodwill, most of the disabled children do not receive education, not even primary education for that matter. In fact, international statistics point out that only 2% of disabled children enjoy the privilege of going to school. It is a serious violation of the CRC which guarantees the right of every child's going to school.

### **Right to leisure**

Sometimes, being totally engrossed in the special care given to disabled children, people around them forget that they are, before anything else, children who need to enjoy themselves, who need to play, express artistically, engage in sports, etc. Yet, the right to leisure is a right included in the Convention of the Rights of the Child (art. 31 CRC) and this naturally applies to the differently-abled child as well.

### **Right to participation**

This is one of the fundamental needs of a disabled child, but unfortunately the one which is most often ignored. Like in the case of any other child, the handicapped child must be given the opportunity to be heard in any proceedings affecting him according to article 12 of the CRC.

His right to participation equally extends to all aspects of social life, on which subject the child, disabled or not, should be given the opportunity of expressing his opinion, of getting connected, of keeping himself informed and of taking part. Yet, because of their disabilities, one often thinks that they do not have the capacity of expressing a coherent idea, and the decision is taken without listening to their opinion.

Children suffering from a disability, by their vulnerability, are particularly sensitive to the act of giving voice to their opinion, even though sometimes, communication with them would present numerous obstacles (difficulties in communicating with them, slow thinking, lack of understanding). Thus, handicapped children should be considered an integral part of decision making when it comes to issues which matters to them. Eliminating obstacles, which block their way to social integration, should be therefore identified as an immediate necessity.

### **A great room for improvement**



The word “handicapped” often contains a pejorative connotation: a handicapped suffers from incapacities, so the temptation to treat them as incompetent is widely

felt. But, a disabled child is capable of





engaging himself in constructive things, and above all they are capable of progress. Unfortunately they are seldom provided with an opportunity to progress.

Globally speaking, there is great room for progress in the field of the rights of the disabled child. One such progress has been their being called “differently-abled children” in place of “disabled children”.

In fact, what is needed to guarantee the rights of the differently-abled child is a change of mentality. In addition to this, authorities all over the world should take necessary steps to introduce a juridical and an institutional structure which would assure the protection of disabled children, allowing them to come out of their dark dwellings and which would most necessarily let them enjoy proper living conditions they are worthy of and opportunities that they very well deserve.

## How to interact with people who have disabilities

It's not uncommon to feel a bit uncertain talking to or interacting with someone who has a physical, sensory, or intellectual disability. Socializing with people with disabilities should be no different from any other socialization. However, if you're not familiar with a given disability, you might fear either saying something offensive or doing the wrong thing by offering assistance.

### Be respectful above all else

Someone who has a disability should be afforded the same amount of respect as anyone else. View others as people, not impairments. Focus on the person at hand and her individual personality. If you must put a "label" on the disability, it's best to ask what terminology she prefers and stick with the terms she chooses. In general, you should follow the "golden rule": treat others as you would like to be treated.

- Many, but not all, people with disabilities prefer "people first" language, which puts the name or person before the disability. For example, you would say "his sister, who has Down syndrome" rather than "his Down's sister".
- More examples of appropriate people first language include, "Robert has cerebral palsy," "Leslie is partially sighted," or "Sarah uses a wheelchair," rather than saying someone "is mentally/physically challenged/handicapped" (both of which are often seen as patronizing terms) or referring to "the blind girl" or "the girl in the wheelchair." If possible avoid these blanket terms when referring to people. While some people find the word "disabled" unpleasant, others use it to describe themselves because they feel erased by treating it like a "bad word", and their disability is part of who they are. Take your lead from the person you are interacting with. If they refer to themselves as "disabled", ask if they are comfortable being described that way or why they choose to describe themselves like this. It will help you gain insight into their perspective.
- It's worth noting that labeling norms vary a great deal between people and groups. In particular, many deaf, blind, and autistic individuals have rejected people-first language and prefer "identify-first" language (for example, "Anisha is autistic"). As another example, it's common within the deaf world to see the terms deaf or hard of hearing used to describe their disability, but the term Deaf (with an uppercase D) to refer to their culture or someone who is part of it. If in doubt, just politely ask the individual you're talking to what they prefer.

**Never talk down to someone with a disability.** Regardless of being their abilities, no one wants to be treated like a child or patronized. When you're speaking to someone with a disability, don't use child-like vocabulary, pet names, or a louder-than-average talking voice. Do not use patronizing gestures such as patting her on the back or head. These habits communicate that you don't think the person with a disability is capable of understanding you

and that you equate her to a child. Use a regular speaking voice and vocabulary, and talk to her just like you would talk to someone without a disability.

- It is appropriate to slow down your speech for someone who is hard of hearing or has a cognitive disability. Equally, it may be acceptable to talk to people who have hearing loss in a louder than average voice, so that they are able to hear you. Usually, someone will mention it to you if you are speaking too quietly. You may also ask whether you are speaking too quickly, or ask her to tell you if you need to slow down or speak more clearly if necessary.
- Don't feel like you have to reduce your vocabulary to the most basic words. The only time you may be asked to simplify your language, is if you are talking to someone who has a severe intellectual or communication difficulty. Baffling your conversational partner is unlikely to be viewed as good mannered and neither is talking at somebody who is unable to follow what you are talking about. However, if in doubt, speak casually and ask about their language needs.

**Don't use labels or offensive terms, especially in a casual way.** Labels and derogatory names are not appropriate and should be avoided in conversation with someone who has a disability. Identifying someone by her disability or assigning a label that is offensive (such as crippled or handicapped) is both hurtful and disrespectful. Always be careful of the things you say, censoring your language if necessary. Avoid names like moron, retard, cripple, spastic, midget, etc, at all times. Be careful not to identify someone by her disability instead of her name or role.

- If you introduce someone with a disability, you don't need to introduce the disability as well. You can say "this is my co-worker, Susan" without saying "this is my co-worker, Susan, who is deaf."
- If you use a common phrase like "I gotta run!" to someone in a wheelchair, don't apologize. These types of phrases are not intended to be hurtful, and by apologizing you'll simply be drawing attention to your awareness of her disability.

**Speak directly to the person, not to an aide or translator.** It's frustrating for someone with a disability to have to deal with people never talking directly to her if she has an assistant or a translator present. Equally, talk to a person in a wheelchair, rather than the person standing next to them. Their body may not be working fully, but it doesn't mean their brains aren't! If you're speaking with someone who has a nurse to help or someone who is deaf and has a sign language interpreter, you should still always speak directly to the person who is disabled.

- Even if the person doesn't have typical listening body language (e.g. an autistic person who doesn't look at you), don't assume that they can't hear you. Speak to them.

**Be patient and ask questions, if necessary.** It can be tempting to speed along a conversation or to finish the sentences of someone with a disability, but doing so can be disrespectful. Always let her speak and work at her own pace, without you egging her to talk, think, or move faster. Additionally, if you don't understand something someone says because they're speaking too slowly or too quickly, don't be afraid to ask questions. Assuming you know what someone said can be detrimental and embarrassing if you mishear her, so always double-check.

- Someone with a speech impediment might be particularly difficult to understand, so don't rush her to talk faster and ask her to repeat herself if necessary.
- Some people need extra time to process speech or turn their thoughts into spoken words (regardless of intellectual ability). It's okay if there are long pauses in the conversation.

**Don't be afraid of asking about a person's disability.** It may not be appropriate to ask about someone's disability out of curiosity, but if you feel this might help you make a situation easier for her (like asking a person if she would prefer to take the elevator with you instead of the stairs if you see she has trouble walking), it is appropriate to ask questions. Chances are, she has been asked about her disability repeatedly over her life and knows how to explain it in a few sentences. If the disability resulted from an accident or the person finds the information too personal, she will most likely answer that she prefers not to discuss it.

- Assuming you know what her disability is can be offensive; it is better to ask than to presume knowledge.

**Recognize that some disabilities are not visible.** If you see someone who appears able-bodied parking in a handicapped spot, don't confront her and accuse her of lacking a disability; she may have a disability you cannot see. Sometimes called "invisible disabilities," disabilities that cannot be immediately seen are still disabilities.

- A good habit to be in is to act kindly and considerately towards everyone; you can't know someone's situation by just looking at her.
- Some disabilities vary from day to day: someone who needed a wheelchair yesterday might only need a cane today. This doesn't mean they're faking it or "getting better," just that they have good days and bad days like everyone else.

**Put yourself in the position of someone with a disability.** It may be easier to understand how to interact with people who have disabilities if you imagine having a disability yourself. Think about how you would want people to talk to or treat you. It's likely that you wanted to be treated just as you are now.

- Therefore, you should talk to people with disabilities as you would anyone else. Welcome a new co-worker with a disability as you would anyone else new to your workplace. Never stare at someone with a disability or act condescending or patronizing.
- Don't focus on the disability. It is not important that you figure out the nature of someone's disability. It is only important that you treat her equally, talk to her as you would to anyone else, and act as you would normally act if a new person entered into your life.

**Offer genuine help.** Some people are hesitant to offer to help someone with a disability for fear of offending her. Indeed, if you are offering help because of an assumption that someone cannot do something herself, your offer could be offensive. However, very few people would be offended by a genuine, specific offer of assistance.

- Many people with disabilities are hesitant to ask for help, but may be grateful for an offer.
- For example, if you go shopping with a friend who uses a wheelchair, you could ask if she needs assistance carrying her bags or attaching them to her wheelchair. Offering to help a friend is not usually offensive.
- If you are not sure of a specific way to help, you can ask, "Is there anything that I can do to help you right now?"
- Never "help" someone without asking first; for example, do not grab someone's wheelchair and try to push her up a steep ramp. Instead, ask if she needs a push or if you can do anything else to make it easier for her to navigate the terrain.

**Acknowledge that most people with disabilities have adapted.** Some disabilities are present from birth, and others come later in life due to development, accident, or illness. However the disability developed, most people learn how to adapt and take care of themselves independently. Most are independent in everyday living, requiring little help from others. As a result, it can be offensive or annoying to assume that someone with a disability cannot do many things, or to constantly try to do things for her. Work under the assumption that the person can accomplish whatever task is at hand by herself.

- A person who gets a disability as a result of an accident later in life may require more help than someone with a life-long disability, but you should always wait until they ask for your help before assuming they need it.
- Don't avoid asking someone with a disability to do a certain task because you worry they can't accomplish it.
- If you do offer help, make the offer genuine and specific. If you are offering from a place of genuine kindness, and not an assumption that the person cannot do something, you're less likely to offend.

## **Editorial:**

The term “disability” encompasses a wide range of situations, from minor disabilities, like diminished vision or hearing, to severe disabilities, such as inability to move around or brain dysfunctions. Children with disabilities are one of the most marginalized and excluded groups in society. Facing daily discrimination in the form of negative attitudes, lack of adequate policies and legislation, they are effectively barred from realizing their rights to healthcare, education, and even survival.

Estimates suggest that there are at least 93 million children with disabilities in the world, but numbers could be much higher. They are often likely to be among the poorest members of the population. They are less likely to attend school, access medical services, or have their voices heard in society. Their disabilities also place them at a higher risk of physical abuse, and often exclude them from receiving proper nutrition or humanitarian assistance in emergencies.

Education is one of the most effective ways to break the cycle of discrimination and poverty that children with disabilities often face.

However, children with disabilities are less likely to start school and if they do, they are unlikely to transition to secondary school.

Their access to school is often limited by stigma, lack of understanding of their needs, lack of teacher training, uncondusive school environment, lack of classroom support and learning resources.

But denying children with disabilities their right to education has a lifelong impact on learning, achievement and employment opportunities, hence hindering their potential economic, social and human development.

This month’s news bulletin is all about differently-abled children who require some different kind of attention and training. As they are special they also need some special kind of attention. They should be treated equally with a feeling of empathy.

(Quotes need to be given at the end of 1<sup>st</sup> 3 pages)

***"If we are to teach real peace in this world, and if we are to carry on a real war against war, we shall have to begin with the children."***

*— Mahatma Gandhi, Indian political and spiritual leader*

***"While we try to teach our children all about life, our children teach us what life is all about."***

— Angela Schwindt, home schooling mom

***"It's the greatest poverty to decide that a child must die so that you may live as you wish."***

— Mother Teresa, Roman Catholic nun

***"Pretty much all the honest truth telling there is in the world is done by children."***

— Oliver Wendell Holmes, author and poet



*Capacity Building for Caregivers of Children Homes & Observation Homes held on 16<sup>th</sup> & 17<sup>th</sup> December 2016 conducted by Mind India at hotel Alankar.....*



*Workshop on Reporting of Child Care Institutions under ICPS held on 23<sup>rd</sup> December 2016 at Hotel Nakshatra, Guwahati.*