



**COMHAD NEWS LETTER**  
**COMMONWEALTH ASSOCIATION**  
**FOR HEALTH & DISABILITY**



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## **EDITORIAL**

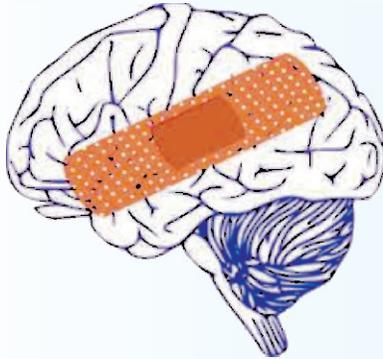
As I write this editorial, my mind goes back to ponder over some glimpses of the past. I sat in the genetic clinic of a large public general hospital and medical college, to see a beautiful adolescent girl walking along with her proud parents. She was a child of Down Syndrome and had just passed her S.S.C. examination. She had also graduated in Bharatnatyam dancing! Probably, the idea of inclusive education was not formally conceptualized three decades ago. However, the credit must go to the school authorities who accepted the child in their school and the parents who left no stone unturned to see that their daughter gets the best.

Times have changed now. Through this issue of our bulletin, we get for you four articles written by experts. They give a different perspective of inclusive education. 'Divyang' children are no more disabled, they are differently abled with so many skills that can potentially transform them into becoming better than the best!

Surely, that is what the aim of COMHAD is. We hope, the readers find each of the well researched and lucidly written articles an academic treat and an educative experience.

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## Emotional and behavior disorders in childhood epilepsy – A case for Mental Health First Aid in a Pediatric office in India



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Rajesh (name changed to protect identity), an eleven year old bright and somewhat sensitive boy. He was diagnosed with epilepsy at the age of three years and has been on Phenytoin since. He does not like to make friends. He seems occupied with his own work. He has low self-esteem and gets bullied by his brother and friends. Rajesh's father is very unhappy about Rajesh's school performance and openly criticizes Rajesh while praising Rajesh's brother. Only Rajesh's mother supports him but feels helpless and wonders how to help her son.

Sameera (name changed to protect identity) is a seven year old delightful girl who got diagnosed with epilepsy at one year of age. She has difficulty in concentrating on task, is quite forgetful and is always on the move as if running on a motor. She is unable to finish her work in class. She does not sit still and moves constantly in the entire class. She loses her things often. And sometimes becomes extremely angry for seemingly trivial issues.

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Sameera (name changed to protect identity) is a seven year old delightful girl who got diagnosed with epilepsy at one year of age. She has difficulty in concentrating on task, is quite forgetful and is always on the move as if running on a motor. She is unable to finish her work in class. She does not sit still and moves constantly in the entire class. She loses her things often. And sometimes becomes extremely angry for seemingly trivial issues.

Epilepsy is a worldwide problem that affects between 2% and 3% of the population. 75% of the cases begin before adolescence. Children with epilepsy are 3 to 6 times more likely to develop psychopathology than the general population<sup>1</sup>. The Isle of Wight study<sup>2</sup> found that 28% of children with epilepsy had psychiatric disorders. Table 1 indicates how mental health difficulties are commoner in population with pediatric epilepsy than the general pediatric population

**Table 1. Prevalence of mental health difficulties in population with pediatric epilepsy as compared to that in the general population<sup>3,4</sup>.**

Medication	Indication	Dose	Comments
Methylphenidate	ADHD	Uptitrate to 1mg/kg	Caution with untreated/uncontrolled epilepsy
Atomoxetine	ADHD	Uptitrate to 0.8-1.2mg/kg	Hepatic monitoring
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Risperidone	Severe disruptive/explosive behaviour, psychosis	0.25-2mg	Extrapyramidal and metabolic side-effect monitoring
Fluoxetine	Depression and anxiety	5mg to 20mg	Can remain in the body up to two weeks; good for adolescents
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\*Comorbidity of multiple mental health difficulties in one child is more of a rule than an exception.

Following are some real world observations regarding mental health concerns in children with epilepsy in India shared between experienced clinicians –

- Learning disorders more common in children with epilepsy, especially the ones who're on anti-epileptic medications longer.
- The children are tagged as 'dumb' by their peers or even teachers which leads to low self esteem, loss of confidence and social withdrawal.
- Family support is very important. The children whose parents aren't supportive feel more lonely and more depressed.
- Behavioral disorders- attention deficit and attention deficit hyperactivity disorders are more frequently associated in these children.
- Emotional issues in children with epilepsy are not addressed properly as the parents appear to not recognize it as a serious problem. Education and counseling in this direction is lacking



It is heartening to see that in recent years awareness is somewhat increasing regarding mental health difficulties faced by children with epilepsy. Gulati et al.<sup>5</sup>, in the Indian Journal of Pediatrics (2014) identified that epileptic patients have intellectual disability and behavioral co-morbidities to the tune of up to 25 and 75% respectively. Khanna et al.<sup>6</sup> explored the social, psychological and financial burden on caregivers of chronically diseased children. They found that caregivers reported moderate depressive symptoms and mild to moderate anxiety symptoms. Rana et al.<sup>7</sup> indicated in 2015 that the Quality of Life of unaffected siblings of children with chronic neurological disorders (including epilepsy) was significantly impaired. Health-workers need to consider including older siblings of neurologically affected children during family-counseling sessions, to provide information and suggest coping strategies. This intervention is likely to improve the functioning of the family unit as a whole which would be most beneficial for the child. At the 15th National Conference of the Neurology Chapter of Indian Academy of Pediatrics which concurred with the annual pediatric conference of Nagpur branch of Indian Academy of Pediatrics (NAPCON XI) at Nagpur, India (October 16-18, 2015), it was officially recognized by Dr. RG Patil in his chairperson's address that Pediatric Neurological disorders affect not only the physical and mental health of the children but also cause psychological injury to the parents (personal communication).

### **Need for Mental Health First aid in the Pediatric office – A Stich in Time Saves Nine!**

When it comes to a busy Pediatric practice in India, it is not hard to acknowledge the limited opportunities for training in developmental and behavioral pediatrics. While grappling with a high case load of physical morbidity and risk of mortality, it is neither uncommon nor unnatural to under-recognize mental health concerns OR feel helpless, frustrated, angry or even judgmental when emotional and behavior concerns are brought up by the parents.

There is an inherent genuine recognition on the part of the clinicians that such families need help. At the same time, there is a dearth of specialist child and adolescent mental health clinicians who are found practicing mostly in metropolitan cities in India; access to them may be limited.

The issue of referral to mental health clinicians can also be a bit tricky. Stigma can be a major barrier in such referrals. When the parents might be struggling already with their child's epilepsy, the added emotional and behavior disorders is like a "double blow" for them and parents in such a crisis may find it hard to reach out for the appropriate support. Families look up to the Pediatrician as "THE doctor" for their child – this is a crucial and unparalleled therapeutic alliance. The Pediatrician is in a better position than perhaps anyone to help the family feel listened to, that their concerns are valid and that help is possible. There is a good argument for at least some "first aid" to occur in the pediatric office for such families (Table 2).

## **Table 2. Concept of Mental health first aid in a Pediatrician's office.**

- ▶ Early detection of emotional and behavior disorders in children with (or without) medical/neurological disorders
- ▶ Initiation of treatments that do not require the exclusive expertise of specialist child and adolescent mental health clinicians
- ▶ Aims to empower parents and help them feel more in control of the situation
- ▶ Reduces the stigma that could have occurred and could have led to a lost opportunity to help the child
- ▶ If first aid not enough and if a referral needs to be made to a psychiatrist, parents are more likely to accept the need for the referral – “at least we tried!”

### **Providing mental health first aid to children with epilepsy and their families in a pediatric office**

1. Early detection of emotional and behavior disorders: Psychiatric comorbidities are strongly associated with long-term Quality of Life in childhood-onset epilepsy, which suggests that comprehensive epilepsy care must include screening and treatment for these conditions, even if seizures remit<sup>8</sup>. “Nature and nurture” play important roles in development of emotional and behavior disorders in children with epilepsy (see Figure 1, Table 3 and Table 4). Screening for neurobehavioral comorbidities should be an integral part of management in children with “active” epilepsy<sup>9,10</sup>. Screening tools and rating scales (see Table 5) can be very useful in not only time-efficient early detection but also in ongoing monitoring of response to treatment. Familiarizing self with the psychiatric nosology from ICD 1011 and/or DSM 512 would be helpful. Referrals to Psychologists, Speech pathologists, Occupational therapists need to be considered to aid the assessment (e.g. IQ and academic testing, Language assessment, Sensory Profile). It is also helpful to conceptualize or formulate the child's and family's predicament on a multi-axial diagnostic statement (see Table 6) which aligns with the ILAE multi-axial classification of epilepsy.

### **2. Practical tips in treatment of mental health concerns as a part of first aid in pediatric office:**

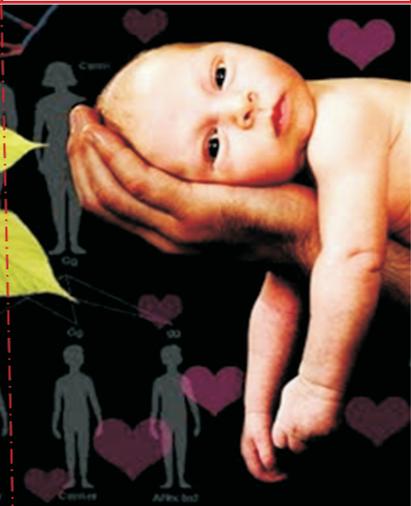
- a. Medications and simple behavior strategies can be initiated in the pediatric office
- b. Medications have a definite role in emotional and behavior disorders, but expect no miracles (Tables 7 and 8).
- c. Simple behavior modification techniques can be easily learnt at workshops and/or using books (Tables 9 and 10). Workshops can be organized by trained local developmental Pediatricians, Psychologists or Psychiatrists. These behavior modification techniques and the books can be shared with the parents. Parents can continue to use these techniques and attend Pediatric office weekly or fortnightly, as practicable, for a quick review of how they are going and the challenges they've faced in using the techniques. Ongoing encouragement and corrective feedback to parents usually does not take more than 20-30min.

If in 4-6 such sessions parents are unable to modify their way of managing behaviors and their relationship with their child, or if there are more complexities in the form of multiple psychosocial social difficulties or diagnostic issues, they may be referred on to child and adolescent mental health specialists.

d. It is important to be aware of various risks in the childr – risk of harm to self or others, or risk of abuse, neglect, vulnerability, school refusal or expulsion from school. If in complex/high-risk scenarios the risks escalate before a referral to a child and adolescent mental health professional, appropriate liaison with agencies, like school, child welfare, NGOs, etc. needs to be considered, preferably after collaborative discussions with the parents. In case of dilemmas, at least an opinion can be sought anonymously from welfare agencies. Documentation helps for medico-legal purpose. Secondary consultation from Psychiatry colleagues can be sought via collegiate discussions.

e. Encouraging parents to join support groups is helpful. Parents in these groups support each other and learn from each other’s struggles with daily tribulations.

**Figure 1. Understanding “nature and nurture” when emotional and behavior disorders develop in pediatric epilepsy**

NATURE	NURTURE
	
<ol style="list-style-type: none"> <li>1. Genetic predisposition to develop mental health disorder (triggered by epilepsy)</li> <li>2. Underlying common dysfunction – eg. Tuberous Sclerosis as a common diathesis for autism features and infantile spasms.</li> </ol>	<ol style="list-style-type: none"> <li>1. Direct adverse effects of epilepsy on neuro-cognitive function especially if epilepsy is uncontrolled</li> <li>2. Psychosocial difficulties in adapting to epilepsy and developmental disorder</li> <li>3. Role of Anti-Epileptic Drugs</li> </ol>

**Table 3. Commonly noted association between  
Anti-epileptic drugs and emotional/behavior concerns in children**

<b>Common Anti-epileptic drug</b>	<b>Associated mental health concerns</b>
phenobarbital, clobazam	ADHD, paradoxical activation/agitation
levetiracetam	Aggression, anger, apathy, depersonalization, depression, psychosis
topiramate	Difficulty in concentrating, dizziness, memory difficulties, sleep disturbances

**Table 4. Psychosocial difficulties in adapting to epilepsy**

<p><u>Potential adverse experiences for the child with epilepsy:</u></p> <ul style="list-style-type: none"> <li>• Stigma of having epilepsy</li> <li>• Physical/cognitive side-effects of medications</li> <li>• Learning difficulties</li> <li>• Developmental delay</li> <li>• Bullying at school</li> <li>• Expressed emotions of either over involvement or even criticism/hostility from parents, family members or teachers based if they themselves are struggling to find the right way to support the child</li> </ul>
<p><u>Potential adverse experiences for the parents of the child with epilepsy<sup>25</sup>:</u></p> <ul style="list-style-type: none"> <li>• Stigma</li> <li>• Major adjustment to chronic illness/ disability/ developmental delay in their child</li> <li>• Emotionally overwhelmed and fearful</li> <li>• Post-traumatic stress symptoms and major depressive disorder, anxiety and decreased quality of life</li> <li>• Increased stress levels, especially if multiple mental health comorbidities were present in the child (e.g. depression and learning disorder, in addition to epilepsy)</li> <li>• Multiple children may suffer from epilepsy in the family</li> </ul>

**Table 5. Some useful screening tools and rating scales for emotional and behavior disorders in a pediatric office. (Administering scales and questionnaires to multiple informants is recommended)**

<b>SDQ</b> – Strengths and Difficulties Questionnaire <sup>13</sup>	Brief, self-administered behavioural screening questionnaire (25 questions) for 4-17 year olds. It exists in several versions and languages including Hindi. Freely available online.
<b>PSC</b> – Pediatric symptom checklist <sup>14</sup>	35 items self-administered screening questionnaire for 3-18 year olds. Has a Hindi version. Freely available online.
<b>DBC</b> – Developmental Behavior Checklist <sup>15</sup>	Tool for assessment of behavioural and emotional problems of children, adolescents and adults with developmental and intellectual disabilities. Can be bought at a fairly reasonable price.
<b>CGAS</b> – Childhood Global Assessment (of functioning) Scale <sup>16</sup>	A quick rating scale that provides a good measure of baseline/improvement in/decline in child’s functioning on the background of emotional and behavior difficulties. Freely available online.
<b>DD-CGAS</b> – Developmental Disorder CGAS <sup>17</sup>	CGAS modified for children with developmental disabilities like intellectual disability and autism spectrum disorder. Freely available online.
<b>ADHD Rating scale 5</b> <sup>18</sup>	Takes just 5 minutes to complete and comes in both a child (5-10) and adolescent (11-17) version, with developmentally appropriate symptom descriptions.
<b>ISAA</b> – Indian Scale for Assessment of Autism <sup>19</sup>	Can be used by clinicians experienced in management of autism
<b>M-CHAT-R</b> – Modified Checklist for Autism in Toddlers Revised <sup>20</sup>	20 questions screening for autism in children between 18 months and 30 months of age
<b>SNAP IV</b> – Swanson Nolan and Pelham questionnaire <sup>21</sup>	Teacher and parent rating scale for ADHD and other externalizing symptoms
<b>K 10</b> – Kessler Psychological distress scale <sup>22</sup>	Self-rated, very brief, widely used scale in adolescents for internalizing symptoms and to screen for depression and anxiety

**Table 6. Multi-axial classification in child and adolescent psychiatry<sup>24</sup>**

<p>Axis 1 – Major psychiatric disorder (eg. Depression, ADHD, ASD)          Axis 2 – Specific developmental delay (eg. Expressive Language Delay, Specific Learning Disorder)          Axis 3 – IQ level (Intellectual Disability, Borderline IQ, Average intelligence etc.)          Axis 4 – Medical/neurological disorder          Axis 5 – Family history/genetic predisposition, psychosocial difficulties (ref to table 4)          Axis 6 – CGAS score (ref to Table 5)</p>
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**Table 7. General principles regarding medications for emotional and behavior disorders**

- Ideally, psychotherapy/psychosocial interventions need to be tried before considering medications
- It is wise to avoid medications unless extremely severe behaviour, significant distress and/or high risk situations
- Start low, go slow

- Medication in child mental health is ALWAYS a trial
- Parents need to know effects, side-effects and possibility of no effects. They need to be completely on “our side” before starting the trial
- 4-6 weeks trial good enough for effects to be distinct. Weekly follow-ups important during this phase

**Table 8. Common medications for emotional and behavior disorders in children**

Medication	Indication	Dose	Comments
Methylphenidate	ADHD	Uptitrate to 1mg/kg	Caution with untreated/uncontrolled epilepsy
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**Table 9. Suggested skills that can be inculcated by busy practitioners via workshops to address emotional and behavior concerns**

1. Active, empathic listening to validate concerns of patients/families
2. Functional analysis of behaviour and behavior modification
3. Positive parenting strategies
4. Tuning-into-Kids Parenting program
5. Basic Cognitive Behaviour Therapy techniques

**Table 10. Suggested books and useful resources that can be shared with parents**

1. **Where There Is No Child Psychiatrist: A mental healthcare manual.** Authors: Valsamma Eapen, Philip Graham And Shoba Srinath. Publisher: Royal College of Psychiatrists, UK. October 2012.
2. Freely available Online textbook - Rey JM (editor). **IACAPAP e-Textbook of Child and Adolescent Mental Health.** Geneva. International Association for Child and Adolescent Psychiatry and Allied Professions 2015.
3. Inexpensive and useful books on home based training for children with developmental disabilities by the **National Institute for the Empowerment of Persons with Intellectual Disabilities** (formerly, National Institute for the Mentally Handicapped) - [http://www.nimhindia.gov.in/pub\\_list\\_Nov\\_t2016.pdf](http://www.nimhindia.gov.in/pub_list_Nov_t2016.pdf)
4. **The Whole Brain Child: 12 Revolutionary strategies...** Authors: Daniel Siegel and Tina Payne Bryson. Publisher: Delacorte Press. 2011.
5. **Your Defiant Child: Eight steps to better behavior.** Authors: Russell Barkley and Christine Benton. Publisher: Guilford Press. 2013.
6. **Making a Difference: Behavioral Intervention for Autism.** Authors: Catherine Maurice, Richard Foxx, Gina Green. Publisher: PRO-ED, Incorporated (May 1, 2002)
7. **Cognitive Behavioral Therapy for the Busy Child Psychiatrist and Other Mental Health Professionals: Rubrics and Rudiments.** Authors: Robert D. Friedberg, Angela A. Goman, Laura Hollar Wilt, Adam Biuckians, Michael Murray. Publisher: Routledge (26 January 2012).

**To conclude:**

Epilepsy in a child is a life changing adversity for everyone in the family. So is a mental disorder. The combination obviously is worse. So in such life-changing scenarios, it only makes sense to make long-lasting changes to approach to life to cope with the stress.

Mental Health First Aid in Pediatric office, especially in the context of pediatric epilepsy (and other medical disorders) would be a sensible and patient-centered approach. It would help if clinicians develop their own First Aid Kits based on their resources to support children and families with mental health concerns.

**Acknowledgments:**

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Some of the real world observations at the beginning of this write-up, including the two case vignettes, were kindly contributed by Dr. Mounica Reddy and Dr. Dipty Jain based on their experience in different cities in India. Both are consultant Pediatricians at the Dept. of Pediatrics, Indira Gandhi Government Medical College and Hospital, Nagpur, India.

## INCLUSIVE EDUCATION-PHILOSOPHY

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"My path may be tough & the journey may be different....

But I know...

I do not walk alone!"

How beautifully these lines depict the thoughts of a person with disability, when he is assured of his or her acceptance, inclusion & appreciation by the society!

The concept of inclusive education exactly embodies this philosophy of helping all children with or without disabilities to participate & learn together in the same classes which makes learning more effective for both.

For a long time, children with disabilities were educated in separate classes or in separate schools. People got used to the idea that special education meant separate education. But we now know that when children are educated together, positive academic and social outcomes occur for all the children involved.

A sizable body of Research shows, that when a child with disabilities attends classes alongside peers who do not have disabilities, good things do happen. This has not only generated a lot of interest in finding out meaningful ways of inclusion of children with disability but has also paved ways in sensitizing policy makers towards framing laws for implementation of inclusive education for all.

We have reached the tipping point where it is no longer educationally or morally defensible to continue to segregate students with disabilities.

In fact, we shouldn't be striving to educate children in the least restrictive environment but rather in the most inclusive one!

The achievement of students without disabilities is not compromised by the presence of students with disabilities in their classrooms. Some studies even show that implementing inclusion on a school wide basis improves achievement for all students. And just as important as academic outcomes, the attitudes and values that all students learn when they are educated together are!

How children are treated in schools often mirrors how they will be treated in later life.

As with other minorities, segregated school placements lead to a segregated society, whereas inclusion in the earliest years promotes increased opportunity and greater understanding of differences for all involved.

A society that separates its children (during their school years) is likely to maintain those separations indefinitely, reinforcing attitudinal barriers to disability in all aspects of life! Inclusion, on the other hand, is founded on social justice principles in which all students are presumed competent and welcomed as valued members of all general education classes and extracurricular activities in their local schools – participating and learning alongside their same-age peers in general education instruction based on the general curriculum, and experiencing meaningful social relationships.

Disability is to be considered to be a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.

Improving educational results for children with disabilities should be an essential element of any national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

When students with disabilities spent more time in a general education classroom they were more likely to score higher on standardized tests of reading and math; have fewer absences from school; experience fewer referrals for disruptive behavior; and achieve more positive post-school outcomes such as a paying job, not living in segregated housing, and with having a broad and supportive social network. These results were true regardless of student's disability, severity of disability, gender or socioeconomic status.

We now know that inclusion works, but we also know that simply placing children with and without disabilities together does not produce positive outcomes.

Inclusive education occurs when there is ongoing advocacy, planning, support and commitment to this philosophy!

Not only do we know inclusion works, we know how to make it work. There are resources for teachers and administrators from large, urban schools on how to implement inclusive education. One can find hundreds of books, research articles, guidelines for inclusive practice, testimonials from students with and without disabilities, teaching strategies, and strategies for designing instruction and assessment for all learners to help guide the students & teachers.

There are certain guiding principles that qualify inclusive education:

\*All children belong!\*

\*Every child and family is valued equally and deserves the same opportunities and experiences.\*

\*Inclusive education is about children with disabilities – whether the disability is mild or severe, hidden or obvious – participating in everyday activities, just like they would, if their disability were not present.

\*It's about building friendships, membership and having opportunities just like everyone else. \*All children learn in different ways.\*

\*Inclusion is about providing the help children need to learn and participate in meaningful ways.

Sometimes, help from friends or teachers works best. Other times, specially designed materials or technology can help.

\*The key is to give only as much help as needed. \*It is every child's right to be included.\* \*Inclusive education is a child's right, not a privilege.\* The Disabilities Education Act clearly states that all children with disabilities should be educated with normal children of their own age and should have access to the general education curriculum.

### **Inclusion as a holistic vision :**

Any child may experience a special need during the course of educational years (UNESCO).

Some children feel 'left-outs' and never enter school or enter only for a few years and, as repeaters, become 'drop-outs' or, more correctly 'pushed-outs', without their needs having been met.

These children are a vivid illustration of the failure of schools to teach rather than the pupils' failure to learn.

A school system emphasising 'Education for All' should ensure the right of all children to a meaningful education based on individual needs and abilities.

The regular schools should increasingly play a major role in making provision for children with special educational needs available nation-wide.

Making the school system flexible and adopting an inclusive approach may, however, prove the most challenging task of all, a task calling for deep reflection and discussion of the two fundamental questions:

**"What is the overall role of education", &  
"What is it we want children to learn in school?"**

It might lead to the need of reforming the school system as a whole from a traditional, examination-oriented to an inclusive, child-oriented approach.

### **Policy & Reality**

Though many educational experts now increasingly vouch for inclusive education, in reality, there are many obstacles in its effective implementation in schools. To open up the regular school system to disabled children is not an easy task. The policy on inclusion and mainstreaming can easily become "main dumping" if not implemented carefully.

In fact, a big gap exists between the ideal situation and the present reality.

There is an urgent need for interventions for equipping general teachers with special skills & making general curricula, teaching methods, Evaluation procedures & learning material more "disability-sensitive."

Addressing the attitudes /needs of other children in the school to ensure such interventions benefits all children, is also equally imperative.

There are certain long standing myths about inclusion, which have been busted by many studies, world over.

**Myth 1 :** Separate is better.

**Reality :** Segregation doesn't work. Whether children are separated based on race, ability, or any other characteristic, a separate education is not an equal education. Research shows that typical children and children with disabilities learn as much or more in inclusive classes.

**Myth 2 :** Children must be "ready" to be included.

**Myth 3 :** Parents don't support inclusive education.

**Reality :** Parents have been and continue to be the driving force for inclusive education. The best outcomes occur when parents of children with disabilities and professionals work together. Effective partnerships happen when there is collaboration, communication and, most of all, TRUST between parents and professional is the key.

Thus, it is important to have a holistic, comprehensive and inter-sectoral approach where all pieces are put together. It is not enough to present and implement one part only. An inclusion policy cannot stand-alone and cannot be a substitute for careful planning of interventions and systematic capacity-building for the implementers of these interventions. Thus, the curriculum for "ALL" needs to be:

**Children centred :**

Children with disabilities need child-centred curriculum, which takes into account the individual needs of children. The curriculum needs to set specific, observable, measurable and achievable learning outcomes (SOMA).

**Flexible :**

A flexible, locally relevant curriculum, teaching and learning strategies are intrinsically important for children with special needs to participate in the educational process.

**Participatory :**

Children with special needs require a learning environment in which they can actively participate in learning in small groups learning settings. To make such opportunities available to them, requires a positive outlook on the part of the school authority.

**Partnership with parents**

is a key factor as children learn not only in the classrooms but also at home. So proper sensitization of parents & bringing them into the loop of a humane approach is essential. Finally, it should be envisage a

**Holistic vision :**

Whereby the inclusion is not treated as a problem but as a path towards an increasingly sensitive & open minded approach by society towards disability as a whole!

The starting point of any discussion on inclusion should always be what is best for the particular child. Another point to remember is, emphasising inclusive education does not rule out special schools or centres. They would still be required to cater to children with profound and complex difficulties in need of more specialised and extensive help, for e.g. many deaf children. This alternative should, however, not be considered, unless classroom placement cannot meet their needs.

In line with the new policy of inclusive education, special schools will begin to function more and more as resource centres. They involve in outreach programmes, where they draw on their vast experience and knowledge. They link their activities with those of the regular schools, the families, and the communities.

Inclusive education services allow children with disabilities to stay with their family and to go to the nearest school, just like all other children. This circumstance is of vital importance to their personal development. Interrupting a disabled child's normal development may have far more severe consequences than the disability itself.

In this context, it is important to stress the role parents have. They have a right to be involved in all decision-making concerning their child. They should be seen as partners in the education process. Where there is such co-operation, parents have been found to be very important resources for the teachers and the schools.

As a rule, there are a number of practical problems that have to be solved before a child with special educational needs can go to school or take part in school activities. The arrangements it takes are fairly simple, provided coordinated local and unconventional initiatives are stimulated. One should also remember that the child's schoolmates represent a valuable potential partner who is ready and able to help in overcoming some of these problems. Finally, let's understand the difference between the two approaches in the following overview:

**Traditional Approach :**

Education for some

Static

Collective teaching

Learning in segregated areas

Emphasis on teaching is subject-orientated

Opportunities are limited by exclusion

Diagnostic / prescriptive

Labels children disability wise

Disability approach

**Inclusive Education Approach :**

Education for all

Approach is Flexible

Individualised Teaching

Learning in Integrated areas

Emphasis on learning is child-centred

Holistic

Equalisation of opportunities for all

Planning is made on ability levels and opposes all kinds of labelling Inclusive Approach

**Conclusion**

Inclusive education responds to all pupils as individuals, recognizing individuality as something to be appreciated & respected.

Such education responding to special needs will thus have positive returns for all pupils. All children and young people of the world, with their individual strengths and weaknesses, with their hopes and expectations, have the right to education. It is not our education systems that have a right to a certain type of children. Therefore, it is the school system of a country that must be adjusted to meet the needs of all its children. Though this is a daunting and difficult task, but as it is rightly said "where there is a will there is a way!"

## INCLUSIVE EDUCATION: DISABILITIES LAWS & IMPLEMENTATION : INDIAN SCENARIO

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Education is a powerful instrument of social change, and often initiates upward movement in the social structure. Thereby helping to bridge the gap between the different sections of society. Education is the right of every child because it equips him to meet the challenges of life. The children with disabilities (CWD) need this all the more, to supplement their differential talents so that they can prepare themselves for a happy productive and useful life.

The educational scene India has undergone major change over the years, resulting in better provision of education and better educational practices. Efforts to educate children with disabilities began soon after independence in India. In 1944, the **Central Advisory Board of Education (CABE)** published a comprehensive report called the Sergeant Report on the post-war educational development of the country. **District Primary Education Programme (DPEP)** document defined child with various disability and classified disabilities, namely, visual, hearing, locomotor, and intellectual (DPEP, 2001). In the 1970s, the government launched the Centrally Sponsored Scheme of **Integrated Education for Disabled Children (IEDC)**. The scheme aimed at providing educational opportunities to learners with disabilities in regular schools, and to facilitate their achievement and retention. The objective was to integrate children with disabilities in the general community at all levels as equal partners to prepare them for normal development and to enable them to face life with courage and confidence. A cardinal feature of the scheme was the liaison between regular and special schools to reinforce the integration process.

UNICEF's Report on the Status of Disability in India 2000 states that there are around 30 million children in India suffering from some form of disability. The Sixth All-India Educational Survey (NCERT,1998) reports that out of India's 200 million school-aged children (6–14 years), 20 million require special needs education. While the national average for gross enrolment in school is over 90 per cent, less than five per cent of children with disabilities are in schools. According to the Census 2001, there are 2.19 crore persons with disabilities in India who constitute 2.13 percent of the total population. This includes persons with visual, hearing, speech, loco-motor and mental disabilities. According to **the Education for All (EFA) Global Monitoring Report 2010**: reaching the marginalized, children with disabilities remain one of the main groups being widely excluded from quality education. Disability is recognized as one of the least visible yet most potent factors in educational marginalization.

**The United Nation's Convention on the Rights of Persons with Disabilities (UNCRPD)**, which was entered into force in 2008, was ratified by India in October, 2008. Despite this, the change has been slow, with segregation in special schools dominating the scene until recently. Let's have a brief look on various Inclusive Education Policies and their implementation in India.

The 1995 **Persons with Disability Act (PDA)** states that disabled children should be educated in integrated settings where possible, although it seems that the lack of implementation may be due to there being no enforcement agency for this legislation. Despite the promotion of inclusive education, government documents focus on inclusive education as being about including children with disabilities in the education system, but not specifically the mainstream (Singal, 2005a).

In India, **National Council of Educational Research and Training (NCERT)** joined hands with UNICEF and launched **Project Integrated Education for Disabled Children (PIED)** in the year 1987, to strengthen the integration of learners with disabilities into regular schools. In 1997, IEDC was amalgamated with other major basic education projects like the DPEP (Chadha, 2002) and the Sarva Shiksha Abhiyan (SSA) (Department of Elementary Education, 2000). The Persons with Disability Act, 1995 has a provision of providing education to children with special needs in the most appropriate environment. The SSA launched by the Govt. of India, in 2001, underlines the prerogative of a child with disability to be included in the mainstream of education.

Ministry of Human Resource Development (MHRD) in its **Sarva Shiksha Abhiyan (SSA)** framework (2006) clearly states, "SSA will ensure that every child with special needs, irrespective of the kind, category and degree of disability, is provided education in an appropriate environment. SSA will adopt zero rejection policy so that no child is left out of the education system. It will also support a wide range of approaches, options and strategies for education of children with special needs." Inclusive Education for Disabled at Secondary Stage (IEDSS) was approved in India in September, 2008 to replace IEDC Scheme from 2009-10. The Scheme is 100% centrally funded.

The Rehabilitation Council of India (RCI) is mainly responsible for education and rehabilitation of CWSN. The Rehabilitation Council of India (RCI) was set up as a registered society in 1986. On September, 1992 the **RCI Act** was enacted by Parliament and it became a Statutory Body on 22 June 1993. The Act was amended by Parliament in 2000 to make it more broad based. The mandate given to RCI is to regulate and monitor services given to persons with disability, to standardise syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education. The Act also prescribes punitive action against unqualified persons delivering services to persons with disability.

Article 24 of the Convention (UNCRPD, 2008) on education states that:

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

c) Reasonable accommodation of the individual's requirements is provided;

d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;

c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf-blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

**National Policy for Persons with Disabilities (2006)** states that: "Education is the most effective vehicle of social and economic empowerment. In keeping with the spirit of the Article 21A of the Constitution guaranteeing education as a fundamental right and Section 26 of the Persons with Disabilities Act, 1995, free and compulsory education has to be provided to all children with disabilities up to the minimum age of 18 years.

According to the Census, 2001, fifty-one percent persons with disabilities are illiterate. This is a very large percentage. There is a need for mainstreaming of the persons with disabilities in the general education system through Inclusive education.”

**The proposed Rights of Persons with Disabilities Bill, 2014**, introduced in the Rajya Sabha (Parliament) on February 7, 2013 by then Minister of Social Justice and Empowerment, repeals the Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act, 1995. The Bill provides for the access to inclusive education, vocational training and self-employment of disabled persons.

Thus, the government of India promises inclusive education to be implemented in all educational institutions, at all levels. Evaluation of IEDSS has shown an increase in student enrolment in 11 states from 2010 to 2012. In 2010, ‘India implemented the Right to Education Act (RTE) to legally support inclusive education’ (Bhan and Rodricks, 2012, p. 367). In addition, a working draft of the PWD Act 2011 was prepared by the Centre for Disability Studies, University of Hyderabad. Although the amended law has not yet been passed by the Indian parliament, it shows the government’s commitment regarding the implementation of policy initiatives for PWD emphasizing inclusive education.

However, the literature review yielded a dismal picture of the outcomes that the policy initiatives had aimed to achieve. For example, Mani (2003) argued that not even 5% of children with disabilities have been provided with educational services in inclusive classrooms, although the implementation of an integrated system of education began in 1975. Gopinathan (2003) contended that the percentage of students with disabilities attending regular schools is even lower: only 750,000 students with disabilities receive educational services in regular schools, and the total population of students with disabilities stands at 30–35 million nationwide (Mitchell and Desai, 2005; Singh, 2001). According to data provided by the Ministry of Human Resource Development (2007), the number of students with disabilities served under various inclusive education schemes/programmes is 5,800 through PIED; 203,146 through IEDC; 621,760 through DPEP; and 1.6 million through SSA. It is clear from these figures that the number of students with disabilities receiving services under inclusive education has been constantly growing. However, it can also be said that the efforts made by the government have only been able to touch the fringe of the problem, considering the number of students with disabilities in the country.

## Conclusion

It is important to remember that Inclusive education is at a very early stage of conceptualization and implementation in India. It can be assumed that achieving the Education for All (EFA) targets and Millennium Development Goals will be impossible without improving access to and quality of education for children with disabilities. The absence of accountability mechanisms, which results in poor policy implementation, suggests that in order to ensure implementation of 1995’s Persons with Disabilities Act, some kind of legal enforcement mechanism needs to be created by the government.

## CAREER OPTIONS FOR PERSONS WITH DISABILITY

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Career, job, business, employment and work are the important aspect of adult life. It is no different in case of persons with disability. All individuals, irrespective of their level and type of disability should be given an opportunity to prepare themselves for some or the other career option. With increasing awareness, provisions and facilities as well advanced technology, the chances of getting employment for persons with disability are definitely better. Preparing students with disability for workplace needs a comprehensive trans disciplinary vocational assessment with emphasis on post school planning. If the person with some variety of disability is able to recognize his strongest abilities and skill, definitely he / she will be able to find a suitable career. As well, with increasing awareness, even the society is willing to accommodate PWD in variety of job settings. In fact many corporate sectors are offering special jobs for PWD.

Persons with disability needs to empower himself with certain specific vocational / academic skills to fit into the right kind of job. As we can see, there are different types of disabilities resulting in limitation of activities, capacities and functions. Hence it is equally important for the individual to be aware of his skills as well as his limitations.

The following areas need to be considered, before actual employment is planned. This will help in better acceptance and adjustment .

- \*awareness of interest / aptitude
- \*exposure to career options
- \*assessing and building skills
- \*extensive and individualized support from society
- \*comprehensive vocational assessment
- \*academic skills
- \*daily living skills
- \*personal and social skills
- \*occupational and vocational skills
- \*career maturity
- \*adoption of the principals of inclusion, non-discrimination and accomodation

Here are certain work areas which are suitable for specific disabilities. It is important to note that, these professions are just the ideas where PWD can work. But, if the PWD decides to work up upon his /her abilities, then they can definitely expand their horizons to find vocation in variety of fields.

Persons with physical disability- these individuals are really fit to work in areas of administration, accountancy, pharmacy, work from home jobs. Computer technology is a real boon for these individuals, where they can have variety of options like graphic designing, DTP, web designing and related with social media as well.

Persons with ID / cognitive disability-These individuals can work in sheltered workshops / units like file, chalk ,phenyl making etc. They can also be trained to work in catering units ,gardening, veterinary assistants or helpers in shops etc.

Persons with visual impairment- These individuals need to find employment in areas where, spoken language and listening skills are required. Thus fields like music (verbal / instrumental) telephone operator, teaching etc can be considered.

Persons with hearing impairment-These individuals can find lot of scope in performing arts, craft, as an artists. Also they can find jobs in the field of designing, technical jobs like ITI, or in sports as well.

Persons with psychiatric or emotional problems-Having a job can be greatly therapeutic to these individuals. They are more comfortable in jobs which do not require lot of social interaction. Hence jobs related with physical training, massaging, computer technology, veterinary fields are more suitable.

It is very important for family, society and the employer to understand the abilities as well as certain limitations of PWD and make a positive effort to promote employment foe them. Having a suitable job can go a long way in constructive rehabilitation of persons with disability.

### **Conclusion-**

For the successful rehabilitation of any individual with disability ,a structured programme is essential which should have...

Commitment and vision

Information gathering

Setting goals

Designing the action plan

Implementing the plan

Evaluation of the plan



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