

Building Legal Capacity | india 2019

For Persons with Intellectual & Developmental Disabilities

Editor : Nikunja K. Sundaray

National Trust

For the welfare of Persons with Autism, Cerebral Palsy,
Intellectual Disability (Mental Retardation) & Multiple Disabilities
Department of Empowerment of Persons with Disabilities (Divyangjan)
Ministry of Social Justice & Empowerment, Govt. of India

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For Persons with Intellectual & Developmental Disabilities



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Editor :
Nikunja K. Sundaray, IAS
Joint Secretary and CEO

National Trust

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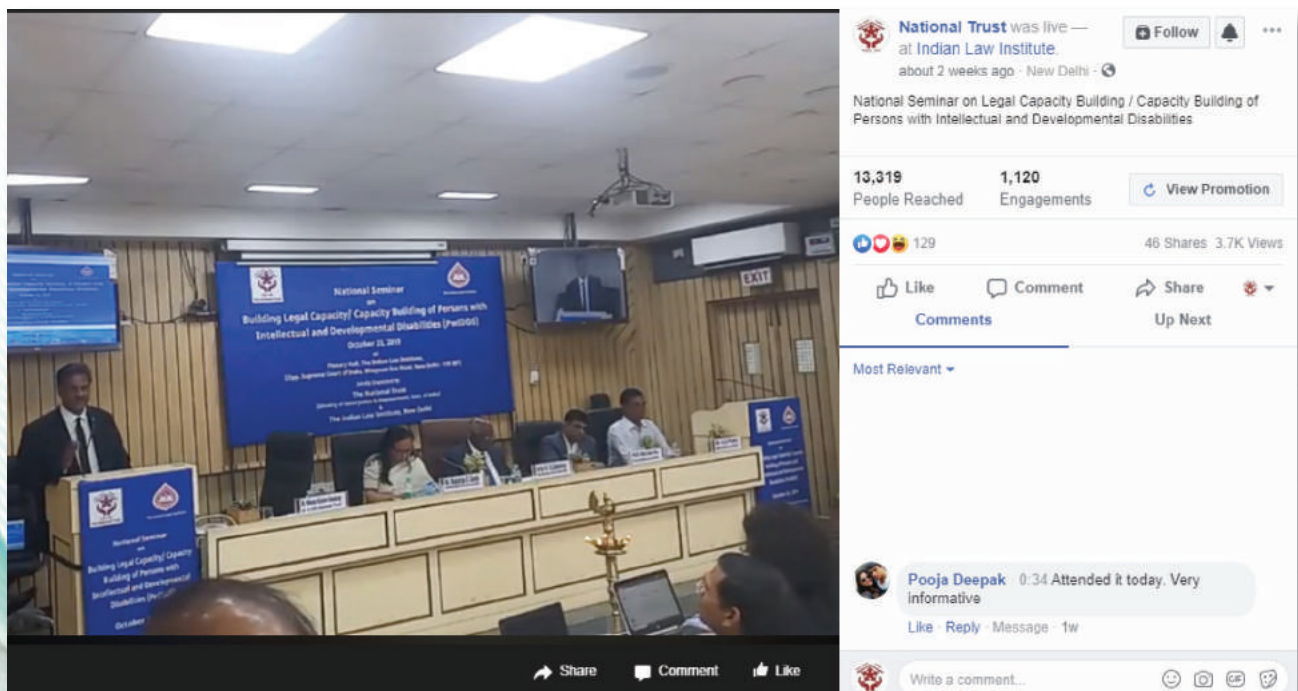
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Final Year Law Student, Law Centre-II, Faculty of Law, University of Delhi*



Social Media outreach:

Live streaming was done and more than 13.3K viewers have seen the programme.

About 1,120 engagements and 56 shares were recorded





SECTION-I

Rights & Entitlements for Persons with Intellectual and Developmental Disabilities

Legal Capacity is a function of the overall capacity building of Persons with Disabilities in general, and Persons with Intellectual and Developmental Disabilities in particular. This compendium seeks to locate the issue of building legal capacity in the above context.

Building Legal Capacity of Persons with Intellectual and Developmental Disabilities

Nikunja K Sundaray, JS&CEO, National Trust

INTRODUCTION

1. Disability

As per World Health Organization (WHO), disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.



2. Intellectual Disability

Intellectual disability is a condition characterized by significant limitation both in intellectual functioning and in adaptive behaviour. Intellectual functions are reasoning, learning, problem solving, etc. Adaptive behaviour covers a range of every day, social and practical skills. Specific Learning Disabilities (SLD) and Autism Spectrum Disorder (ASD) are included under this.

- 2 (a) **Specific Learning Disability (SLD)** - Specific Learning Disability is a heterogeneous group of conditions wherein there is a deficit in processing language, spoken or written, that may manifest itself as a difficulty to comprehend, speak, read, write, spell, or to do mathematical calculations. Specific Learning Disabilities include such conditions as perceptual disabilities namely Dyslexia, Dysgraphia, Dyscalculia, Dyspraxia and Developmental Aphasia. Details of these disabilities are as under -

- 2 (a) (i) **Dyslexia**- Dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge.

(ii) **Dysgraphia** - Dysgraphia is a specific learning disability that affects written expression. It can appear as difficulties with spelling, poor handwriting and trouble putting thoughts on paper. It can be a language based, and/or non-language based disorder. Many people have poor handwriting, but dysgraphia is more serious. It is a neurological disorder that generally appears when children are first learning to write. Experts are not sure what causes it, but early treatment can help prevent or reduce problems.

(iii) **Dyscalculia** - Dyscalculia is a term referring to a wide range of life-long learning disabilities involving Maths. It includes all types of maths problems ranging from an inability to understand the meaning of numbers, to an inability to apply mathematical principles to solve problems.

(iv) **Dyspraxia** - Dyspraxia, a form of Developmental Coordination Disorder (DCD) is a common disorder affecting fine and/or gross motor coordination in children and adults. It may also affect speech.

As per WHO disability is an umbrella term, covering impairments, activity limitations and participation restriction

DCD is a lifelong condition, formally recognised by international organisations including the World Health Organisation. DCD is distinct from other motor disorders such as cerebral palsy and stroke, and occurs across the range of intellectual abilities. Individuals may vary in how their difficulties present: these may change over time depending on environmental demands and life experiences.

(v) Developmental Aphasia - When a person develops a speech impairment following a brain injury (but had no speech problems beforehand), this disorder is called aphasia. Damage usually occurs in the left half of the brain, which is the side responsible for speech, and is often due to stroke (though blunt trauma and brain diseases may cause similar symptoms). Common symptoms of aphasia include difficulty in reading, speaking, listening, and writing; however, there is no underlying change in a person's intelligence, making this a frustrating condition. Approximately one million people in the United States experience some form of aphasia.

- 2 **(b) Autism Spectrum Disorder** - Autism Spectrum Disorder means a neuro-developmental condition typically appearing in the first three years of life that significantly affects a person's ability to communicate, understand relationships and relate to others, and is frequently associated with unusual or stereotypical rituals or behaviour.

3. Developmental Disability

Mental or physical disability, such as Cerebral Palsy or Mental Retardation, that is present during childhood, interferes with normal physical, intellectual, or emotional development, and usually lasts throughout life.

- (a) Cerebral Palsy** - Cerebral Palsy means a group of non-progressive conditions of a person characterized by abnormal motor control and posture resulting from brain insult or injuries occurring in the pre-natal, peri-natal or infant period of development.

- (b) Intellectual Disability (Mental Retardation)** – Mental Retardation means a condition of arrested or incomplete development of mind of person which is specially characterized by sub-normality of intelligence.

Persons with Intellectual and Developmental Disabilities (PwIDDs) face various types of issues in their life. Assessment, Diagnosis and Treatment of PwIDDs need a long procedure and multiple days visit in hospitals. Intellectual and Developmental disabilities is a condition, and not a disease. Hence, there is no treatment for these disabilities but condition of these persons can be improved with proper therapy and training.

4. Perspectives on Disability

Disability is Universal. Disability is neither simply a biological nor a social phenomenon. Everyone will be temporarily or permanently impaired at some point in life. Disability has far reaching consequences for the personality of an individual. Our notions about disability & person with disabilities are generally negative. This calls for an urgent analysis of existing attitude and feeling towards disability. There are more than 1000 million people with disability globally, that is about 15% of the world's population or one in seven people.

Life style of person with cerebral palsy and intellectual disability can be improved with proper professional management through therapy and training

There are more than 1000 million people with disability globally

Majority of persons with other disabilities like Visual, Hearing and Locomotor may not have comprehension problem, but, in Intellectual and Developmental Disabilities, there is comprehension problem in varying degrees in mild, moderate and severe categories.

The common issue facing PwIDDs is the issue of Digital Inclusion as the world goes progressively digital.

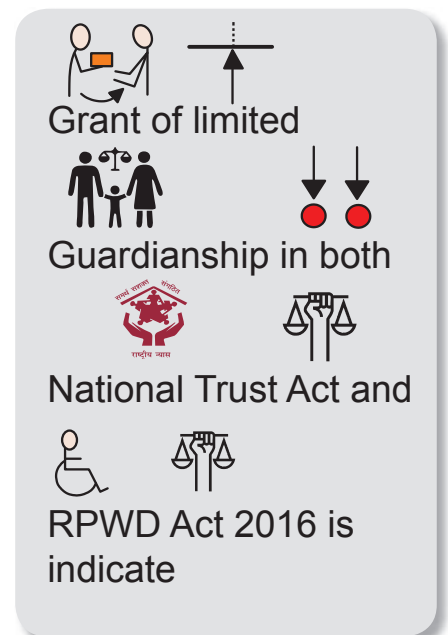
5. Legal Provisions

- Under various laws there are special provisions regarding these aspects like - Civil, Criminal and Contract law.
- The RPwD Act, 2016 needs to be read together with the National Trust Act, 1999 and the benefit of both the Acts shall apply to Persons with Disabilities depending on the case.

(a) United Nations Convention on Rights of Persons with Disabilities (UNCRPD)

The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) in 'Article 12- Equal recognition before the law' states the following-

1. State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. State Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.



The UNCRPD in 'Article 13 – Access to justice' states the following-

1. State Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
2. In order to help to ensure effective access to justice for persons with disabilities, State Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

(b) Rights of Persons with Disabilities (RPwD) Act, 2016 in alignment with UNCRPD:

The Rights of Persons with Disabilities (RPwD) Act 2016 was enacted by the Parliament and received the assent of the President on 20th December, 2016. This Act repealed the earlier Person with Disability, Act of 1995. The Legal Capacity under Chapter-II of RPwD Act 2016 (Rights and Entitlements) are as under:-

- Ensure right, equally with others, to own or inherit property, movable and immovable, control their financial affairs and have access to bank loans, mortgages and other forms of financial credit.
- Ensure that the persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law.
- When a conflict of interest arises between a person providing support and a person with disability in a particular financial, property or other economic transaction, then such supporting person shall abstain from providing support to the person with disability in that transaction.

Provided that there shall not be a presumption of conflict of interest just on the basis that the supporting person is related to the person with disability by blood, affinity or adoption.

- A person with disability may alter, modify or dismantle any support arrangement and seek the support of another.

Provided that such alteration, modification or dismantling shall be prospective in nature and shall not nullify any third party transaction entered into by the person with disability with aforesaid support arrangement.

- Any person providing support to the person with disability shall not exercise undue influence and shall respect his or her autonomy, dignity and privacy.

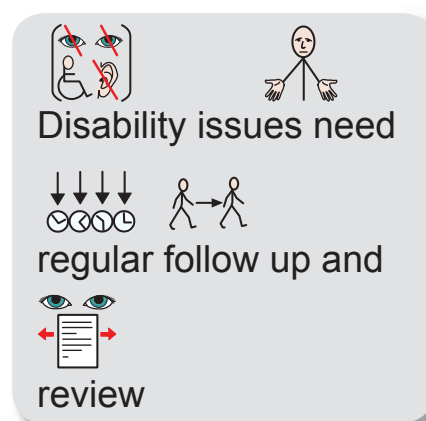
6. Clarification in respect of Guardianship under the National Trust Act, 1999 and the Rights of Persons with Disabilities Act, 2016

The Department of Empowerment of Persons with Disability has already clarified that:-

- The concept of persons with disabilities defined under the RPwD Act, 2016 appears to be distinct, and
- For the purpose of grant of limited guardianship in both National Trust Act 1999 and RPwD Act 2016, there does not appear to be any conflict in the provisions under both the Acts.
- They operate both independently in their respective fields.

7. Review of Literature

Persons with Intellectual and Developmental Disabilities face various issues on undertaking their activities in entire life span. This starts since birth of these persons. The area of Intellectual & Developmental Disability needs regular follow up & review in regard to the day to day Research & Innovation taking place in the field. In order to have insight of the issue, a large number of literature on the subject which includes books, journals, magazines and reports were reviewed.



A brief summary of review of some of the books are as under -

- The book titled **"The parent's guide to Occupational Therapy for Autism and Special Needs by Cara Koscinski"** :- The book focusses on the role and impact of Occupational Therapy (OT) for persons with intellectual and developmental disabilities.
- Supporting children with Learning Difficulties, Holistic Solutions for Severe, Profound and Multiple Disabilities is a book by Christine Turner** :- The book covers a brief introduction to learning disabilities with a detailed categorization of learning disabilities, causes of learning disabilities, diagnosis of learning disability and life expectancy.

- iii. **Life before and after Cerebral Palsy, We are the Voices by Tammy T. Floyd - Westmoreland** is dedicated to the son of the Author D'Jonte' a person with Cerebral Palsy. The book gives a detailed account of birth of a Tammy T. Floyd and the difficulty during and after delivery of the boy.
- iv. **A Bumblebee's Balcony Celebrating Life with Cerebral Palsy by Sundari Sivasubbu :-** The book describes the life journey of author who was born with cerebral palsy, a neuro- skeletal and muscular condition that limits most physical activities and poses several challenges in day-to-day living, including problems with vision, hearing, balancing, coordination, muscle power and motor skills.
- v. **Understanding Autism: A Guide for Parents and Teachers by Onita Nakra :-** This book is designed for the families and professionals who raise and educate children on the Autism Spectrum and information provided will assist parents, educators and teachers to seek the best quality services for their children.
- vi. **Six-Minute Social Skills Workbook by Janine Toole** is a workbook series designed for busy parents and professionals who need easy-to-use and effective materials for working with learners who have Autism, Asperger's and similar social skill challenges.
- vii. **Children with Cerebral Palsy by Archie Hinchclife, illustrations by Barbara Lynne & Clare Rogers:-** The book covers details about what is Cerebral Palsy and how does it affect children; Assessing a child with Cerebral Palsy; How therapists can be good partners, Listening and understanding, Coming to an agreement for action, Case study, Problem defined, Decision reached by both therapist and family, Choosing short-term goals, Exceptionally difficult relationships, Partnership with children etc.
- viii. **Thinking In Pictures by Temple Grandin :-** In this unprecedented book, Grandin who is Autistic delivers a report from the country of Autism. She writes from the dual perspectives of a scientist and an autistic person. The book gracefully and lucidly bridges the gulf between her condition and our own, sheds light on the riddle of our common identity.
- ix. **Mental Retardation – Nature, Cause and Management by George S. Baroff with J. Gregory Olley:-** The book examines three aspects of the disability of mental retardation – its nature, its causes, and its management or treatment.
- x. **Cerebral Palsy by Veena Slaich** is for the rehabilitation and management of cerebral palsied children, especially in relation to their therapeutic and functional rehabilitation and their activities of daily living planning.
- xi. **Issues in the developmental approach to mental retardation by Robert M. Hodapp, Jabob A. Burack and Edward Zigler :-** This book focuses on mental retardation in the developmental psychopathology line. It endeavors to explain the developmental approach and expand it beyond more conventional notions of sequences and stages.
- xii. **Early Management of Cerebral Palsy Including Children with Developmental Delays by Shri Suryakant V Bole and Ms. Vijayalakshmi S Bole :-** The main aim of this book is how with the help of early intervention and timely guidance, the quality of life of the children who are a suspect or having a disability have changed for the better and can be improved.
- xiii. **Teaching Individuals with Physical, Health or Multiple Disabilities (Fourth Edition) by Ms. June L. Bigge, Mr. Sherwood J. Best and Ms. Kathryn Wolff Heller :-** The main aim of this book is to recognize and celebrate the fact that individuals with physical, health, or multiple disabilities participate in all educational and community venues.
- xiv. **Cerebral Palsy: Science and Clinical Practice (Clinics in Developmental Medicine)** is the first comprehensive textbook dealing with neuro-developmental disorder. The book is divided into four sections which cover almost all that is currently known about this challenging motor disorder and provide excellent update on research findings.
- xv. **Management of Behaviour Problems of Children with Mental Retardation (Prevent Disabled from becoming Handicapped) by Dr. Dipti J. Oza & Dr. Ronak Pandit :-** The book covers details about historical, Educational, and legislative perspective about mental retardation, UN Declaration on the rights of Disabled Persons, Early stimulation, Intervention programmes and Associated problems etc.
- xvi. **Stop Autism Now! (A parent Guide to Preventing and Reversing Autism Spectrum Disorder) by Dr. Bruce Fife :-** This book describes that Autism, is not a hopeless condition. It can be prevented and successfully treated without the use of drugs.

- xvii. **Autism Breakthrough - The Groundbreaking Method that has helped families all over the world by Raun K. Kaufman :-** This book gives a step-by-step guide written with humor, inspiring stories and clear practical strategies that readers can apply immediately.
- xviii. **101 games and activities for children with Autism, Asperger's and Sensory processing disorders by Tara Delaney, M.S. :-** This book includes dozens of therapeutic games for kids with autism and sensory spectrum disorders.
- xix. **The Verbal Behavior Approach (How to Teach Children with Autism and Related Disorders) by Mary Lynch Barbera with Tracy Rasmussen :-** In this book author draws on her own experiences as a Board Certified Behavior Analyst and also as a parent of a child with autism to explain VB and how to use it.
- xx. **Understanding Cerebral Palsy, A Guide for Parents And Professionals by Marion Stanton** provides a refreshing and systematic appreciation of condition experienced by people across a wide variety of social contexts.
- xxi. **Molecular and Genetic Basis of Mental Retardation: Basic information, Genetic Aspects and Homozygosity Mapping in Mental Retardation by Muhammad Yasir Zahoor; Shaheen N. Khan and Sheikh Riazuddin :-** The book describes the factors which can contribute to Mental Retardation during prenatal stages of pregnancy.
- xxii. **Planning Multiple Disability Rehabilitation Facilities by US Department of Health, Education and Welfare :-** In this book studies were undertaken to develop and to make available planning criteria for the design of rehabilitation facilities in hospital. The book covers, details about the rehabilitation programmes.
- xxiii. **The Autistic Brain by Ms. Temple Grandin and Richard Panek :-** The book describes the achievements of Ms. Temple Grandin who is one of the most accomplished adults with autism in the world.
- xxiv. **Physical Therapy of Cerebral Palsy by Freeman Miller** is well-crafted text discusses the theory and techniques used by physical and occupational therapists.
- xxv. **Teaching Individuals with Physical or Multiple Disabilities by Sherwood J. Best, Kathryn Wolff Heller and June L. Bigge :-** This book provides special educators and others education professionals with the knowledge and strategies for creating meaningful educational experiences for students with physical, health, or multiple disabilities.
- xxvi. **Understanding Mental Retardation by Patricia Ainsworth and Pamela Baker :-** This book covers the causes of mental retardation, the signs and symptoms of the most common forms of these disorders, and issues of prevention.
- xxvii. **Cerebral Palsies: Epidemiology & Causal Pathways by Fiona Stanley, Eve Blair & Eva Alberman :-** This book is essential reading for all those undertaking epidemiological research in this field.
- xxviii. **Teaching Motor Skills to Children with Cerebral Palsy and Similar Movement Disorder by Sieglinde Martin, M.S., P.T** is the resource that parents, therapists, and other caregivers can consult to help children with gross motor delays learn and practice motor skills outside of therapy sessions.
- xxix. **Educating Children with Multiple Disabilities: A Trans-disciplinary Approach by Fred P. Orelove & Dick Sobsey :-** The book starts with designing Trans-disciplinary services which means a system of providing services to individuals with multiple disabilities that has proved successful – the trans-disciplinary model.
- xxx. **Basic Skills Checklists, Teacher – friendly assessment for students with autism or special needs by Marlene Breitenbach** focuses on pre-academic, readiness, and academic skills expected from learners in the early elementary years and it's helpful checklists in special-needs and inclusive classrooms while serving children with autism and other developmental disabilities.
- xxxi. **Autism - A Handbook of Diagnosis Treatment of ASD by Ms. Sumita Bose :-** This book discusses signs, symptoms, causes, myths, facts, therapies, treatment, education, career and many more things related to autism. It provides practical advice so that the special child can lead a quality life to the extent possible.
- xxxii. **DSE (MR) Manual - Causes, Prevention, Identification and Assessment of Mental Retardation by**

Dr. Narayan Chandra Pati :- This manual attempts to serve the academic needs in the field of Special Education and Rehabilitation.

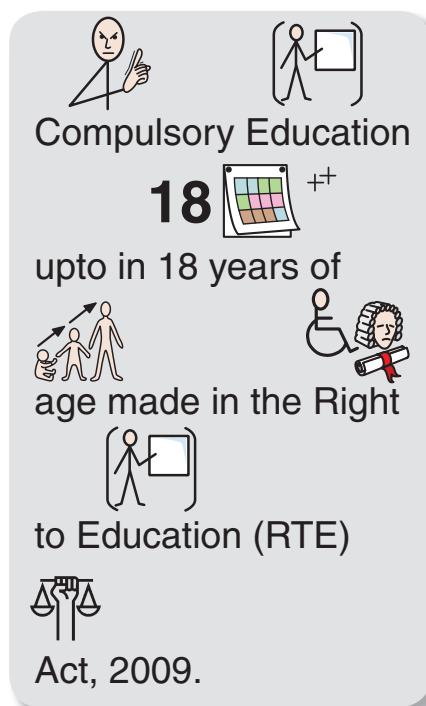
8. The Core Issues

Persons with Intellectual and Developmental Disabilities face challenges in performing their work in their entire life span. This includes –


- Early Detection, Assessment and Early Intervention in the initial 0 to 6 years period. Counseling and training to parents also.
- Providing opportunity to interact and play with peers in the community
- Education
- Opportunity to participate in family and social function.
- Skill Development, employment and livelihood.

Details of these are as under:-

- Early Detection and Assessment - Children with intellectual and developmental disabilities (IDD) can perform better in their life if detected early and proper Assessment and Early Intervention in the initial 0 to 6 years period is done. Counseling and training to parents is required for day to day care of these children on Early Intervention at home.
- Providing opportunity to interact and play with peers in the community - Development of a child depends on the environment and surroundings he is grown up in. For children with special needs, it is important that they should also be given opportunity to interact and play with the peers.
- Education - Children with IDD face difficulty in getting education. Schools do not admit these children in spite of permission of free and compulsory education to all upto in years of age made in the Right to Education (RTE) Act, 2009.
- Opportunity to participate in family and social function - Due to myth of not being known to others in the family and community, parents of persons with IDD hesitate in letting the family and community members known that their child is IDD. Due to this, parents do not take their children with IDD in any family and social function.




Compulsory Education


18  ++

upto in 18 years of

age made in the Right



to Education (RTE)

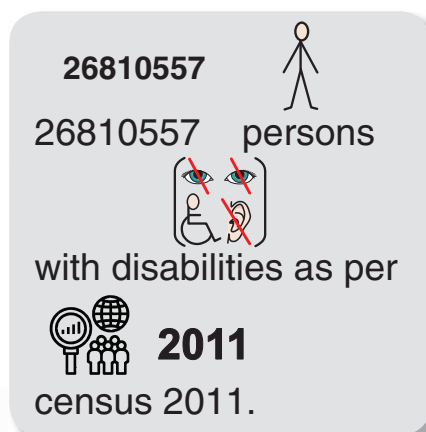



Act, 2009.

9. Population of Persons with Disabilities


The number of Persons with Disabilities, as per census 2011 is as under-

DISABLED POPULATION BY TYPE OF DISABILITY IN INDIA 2011	
In Seeing	5032463
In Hearing	5071007
In Speech	1998535
In Movement	5436604
Mental Retardation	1505624
Mental Illness	722826
Any Other	4927011
Multiple Disability	2116487
TOTAL	26810557




26810557 

26810557 persons



with disabilities as per

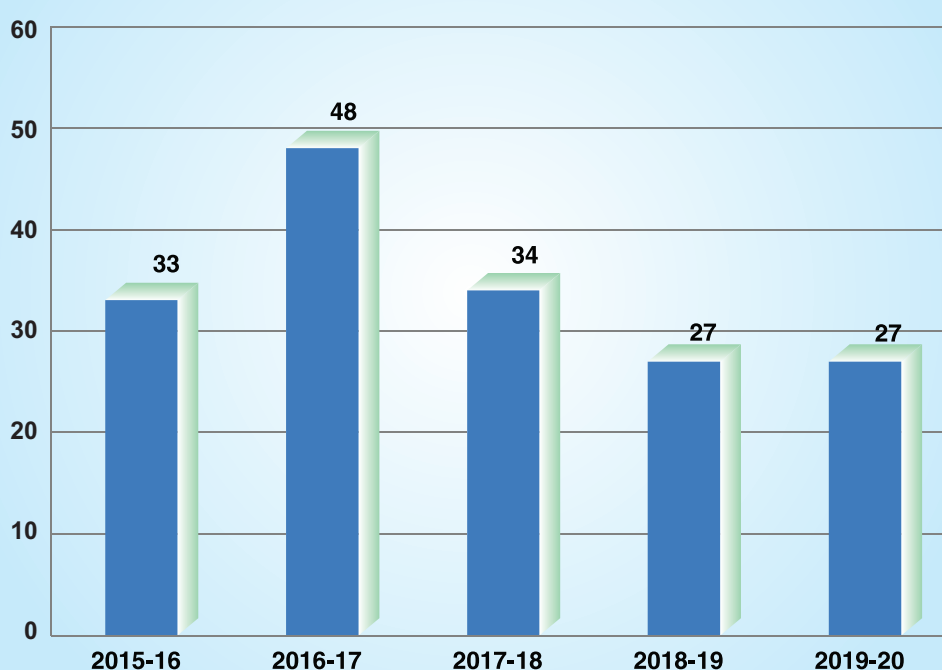
 **2011**

census 2011.

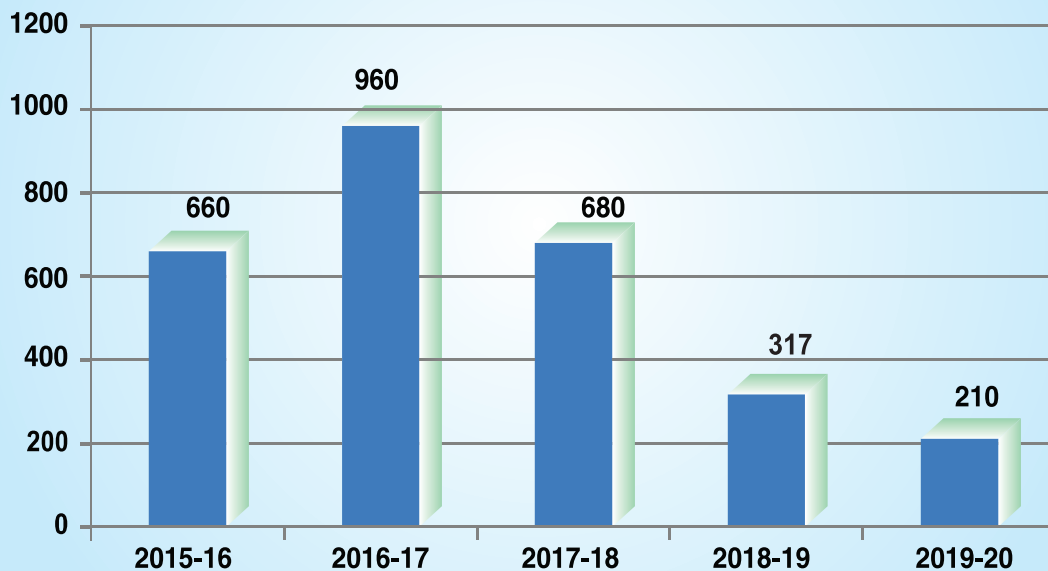
10. Provisions under the National Trust Act, 1999

- (1) Under the National Trust Act, 1999 there is a provision of appointment of Legal Guardian, if required, for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities through Local Level Committee (LLC) set up at district level. The guardianship is conferred as per need with the following obligations:-
 - Maintenance and residential care
 - Management of immovable property
 - Management of movable property
 - Any others
- (2) The National Trust is implementing the following schemes for Early Intervention, Day Care, Residential Care and Health Care of persons with disabilities covered under the National Trust Act:-
 - Disha (Early Intervention and School Readiness Scheme for 0 to 10 years)
 - Vikaas (Day Care for 10+ years Scheme)
 - Gharaunda (Group Home for Adults)
 - Samarth (Respite Care Residential Scheme)
 - Disha-cum Vikaas Scheme (Day Care)
 - Samarth-cum-Gharaunda Scheme (Residential)
 - Sahyogi (Care Associate Training Scheme)
 - Niramaya (Health Insurance Scheme)
 - Badhte Kadam (Community Awareness and Innovative project scheme)

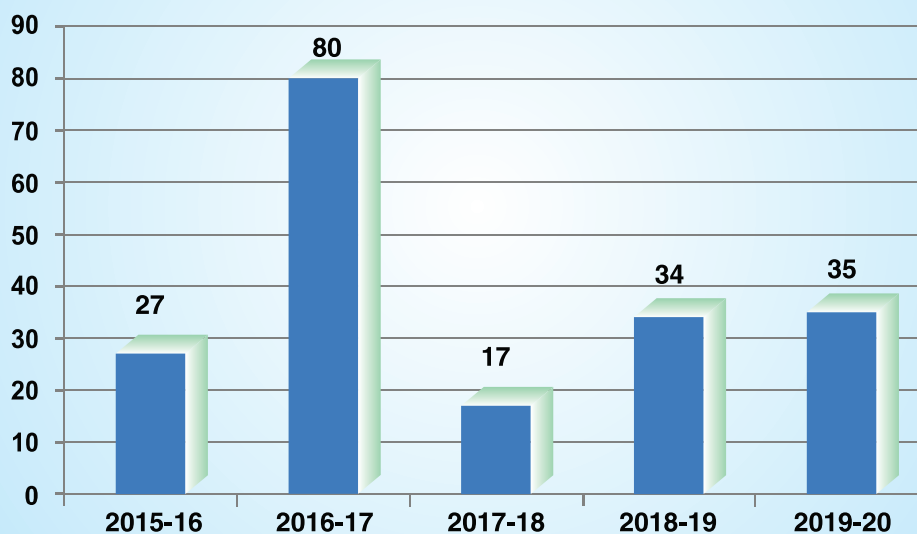
Disha (Early Intervention Scheme)
Number of Centers (Year-wise)



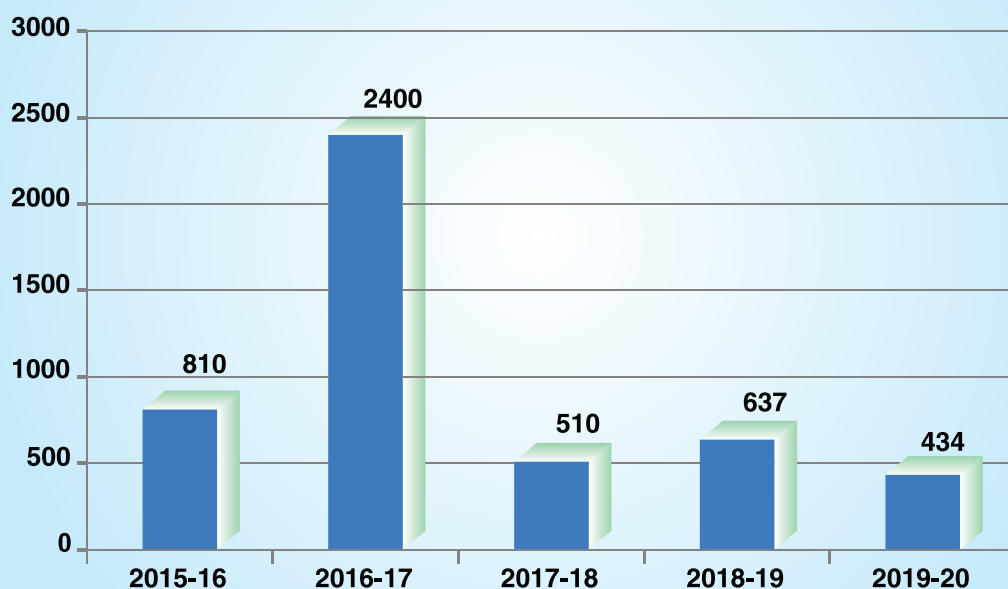
Disha (Early Intervention Scheme) Beneficiaries (Year-wise)



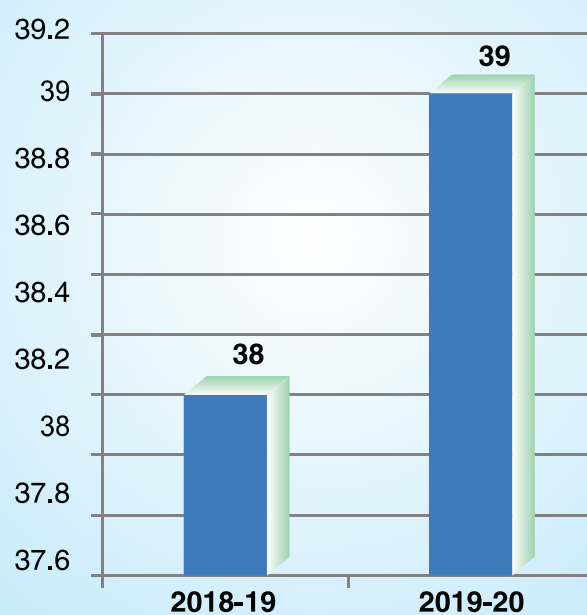
Vikaas (Day Care Scheme) Number of Centers (Year-wise)



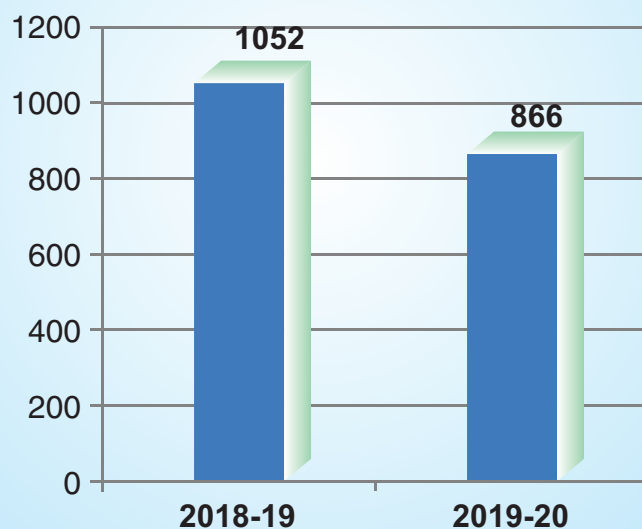
Vikaas (Day Care Scheme) Beneficiaries (Year-wise)



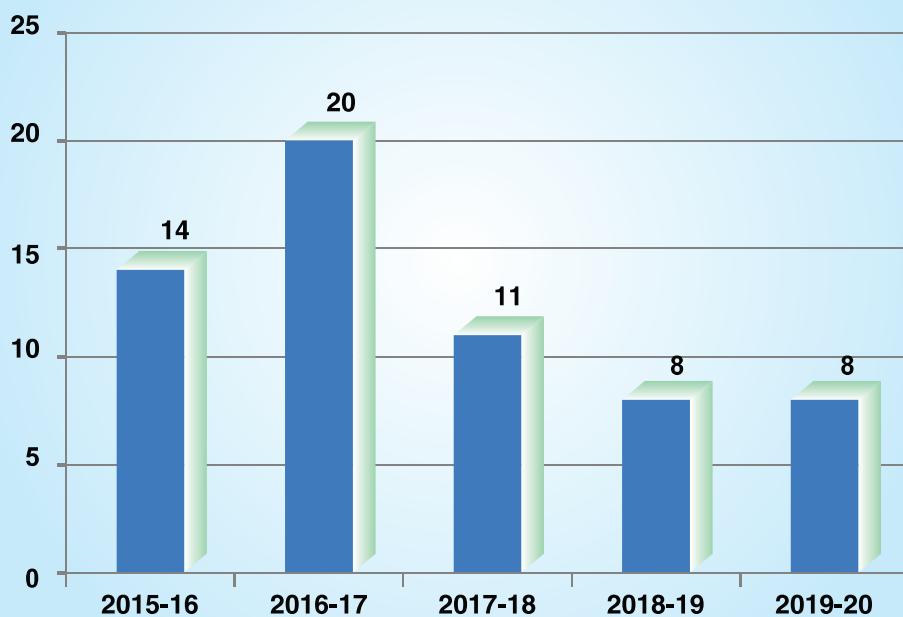
Disha-cum-Vikaas (Day Care Scheme) Number of Centers (Year-wise)



Disha-cum-Vikaas (Day Care Scheme) Beneficiaries (Year- wise)

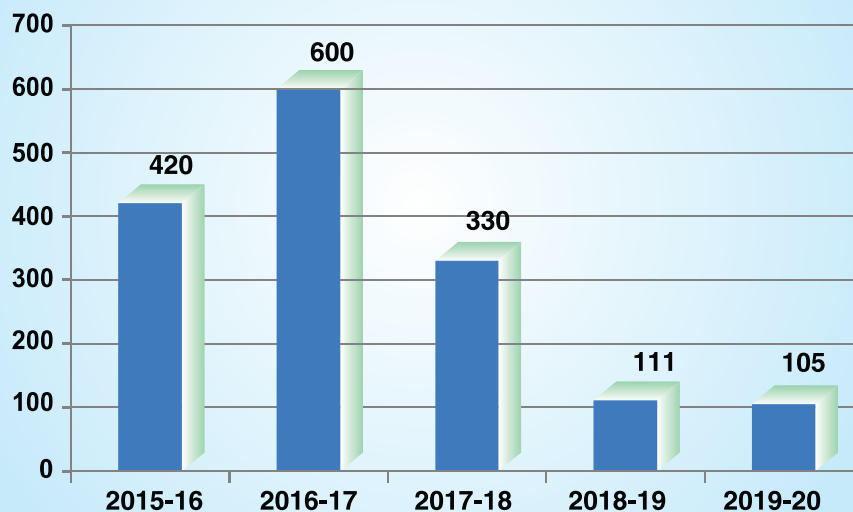


Samarth (Residential Care Scheme) Number of Centers (Year-wise)



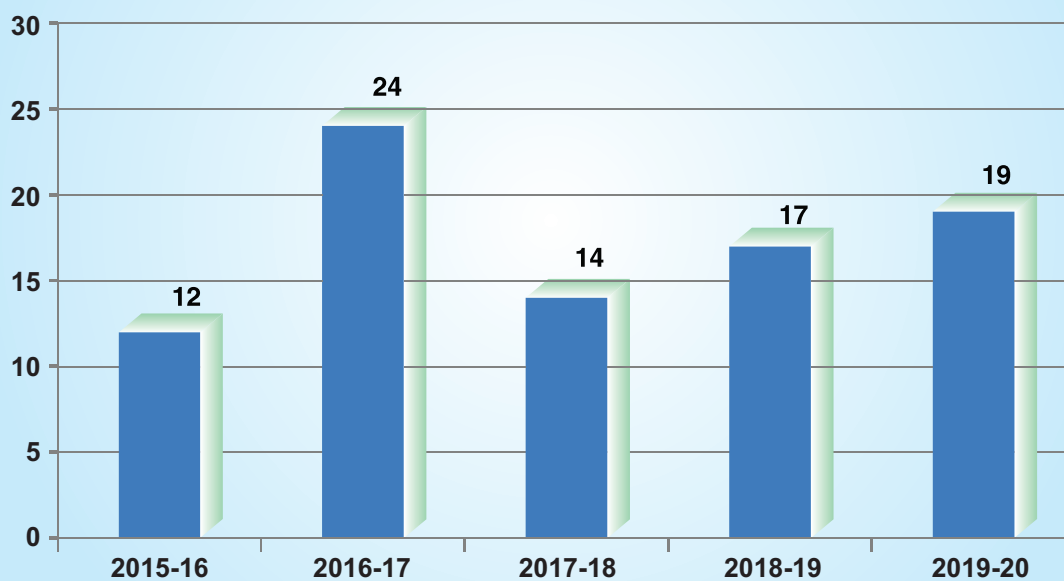
Samarth (Residential Care Scheme)

Beneficiaries (Year-wise)

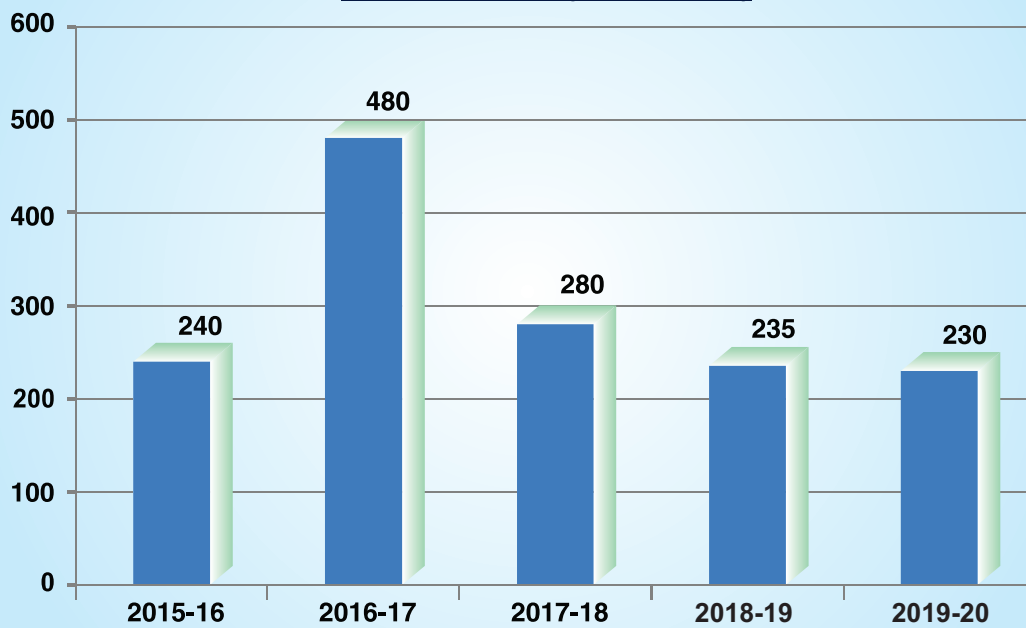


Gharaunda Scheme (Residential Care Scheme)

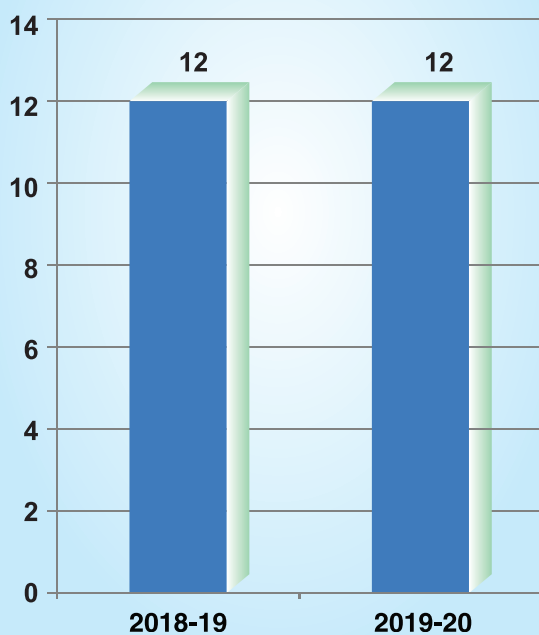
Number of Centers (Year-wise)



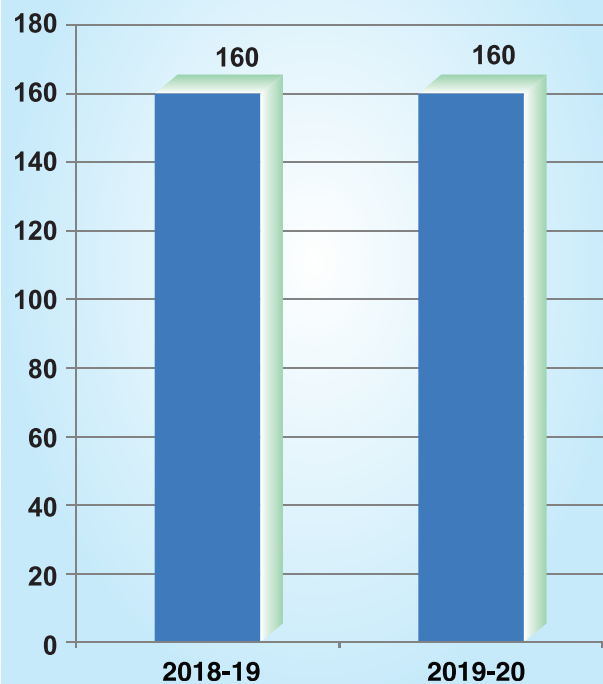
Gharaunda Scheme (Residential Care Scheme) Beneficiaries (Year-wise)



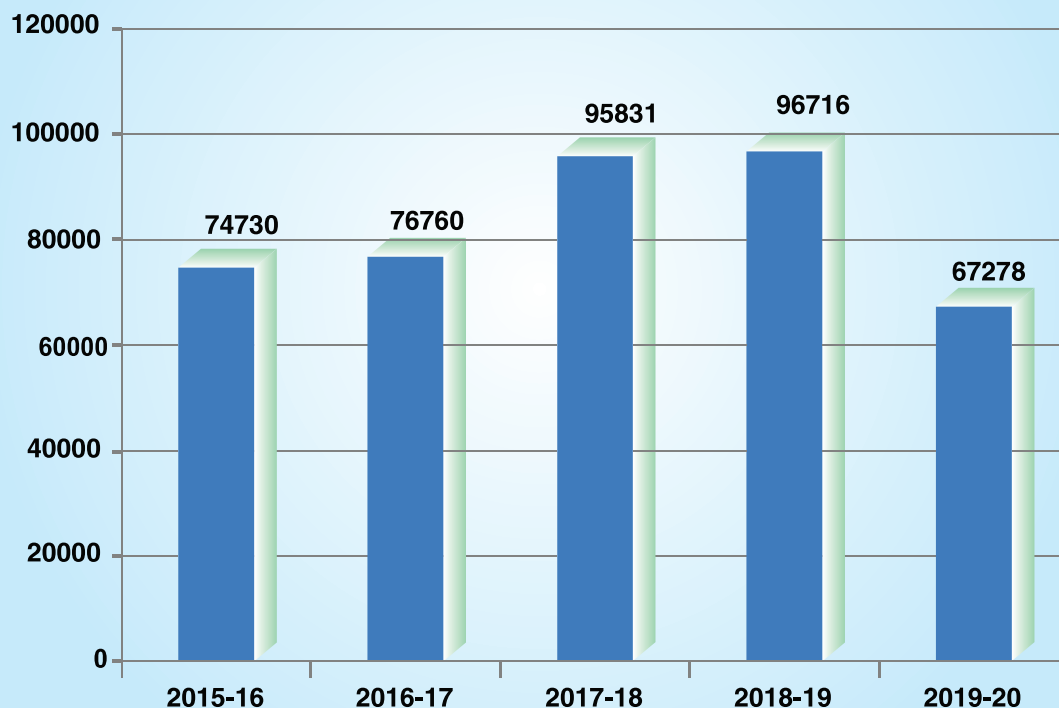
Samarth-cum- Gharaunda (Residential Care Scheme) Number of Centers (Year-wise)



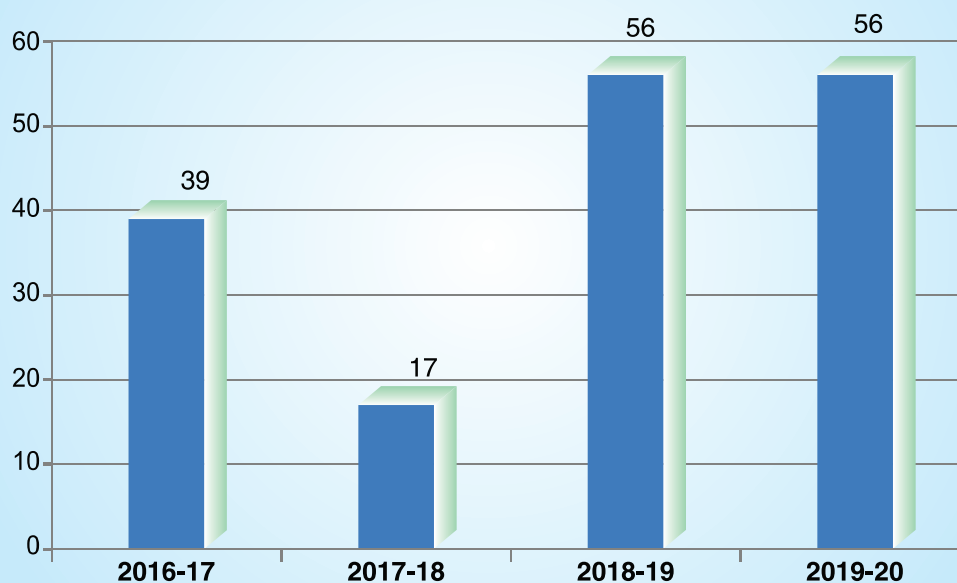
Samarth-cum-Gharaunda (Residential Care Scheme) Beneficiaries (Year-wise)



Niramaya (Health Insurance Scheme) Beneficiaries (Year-wise)

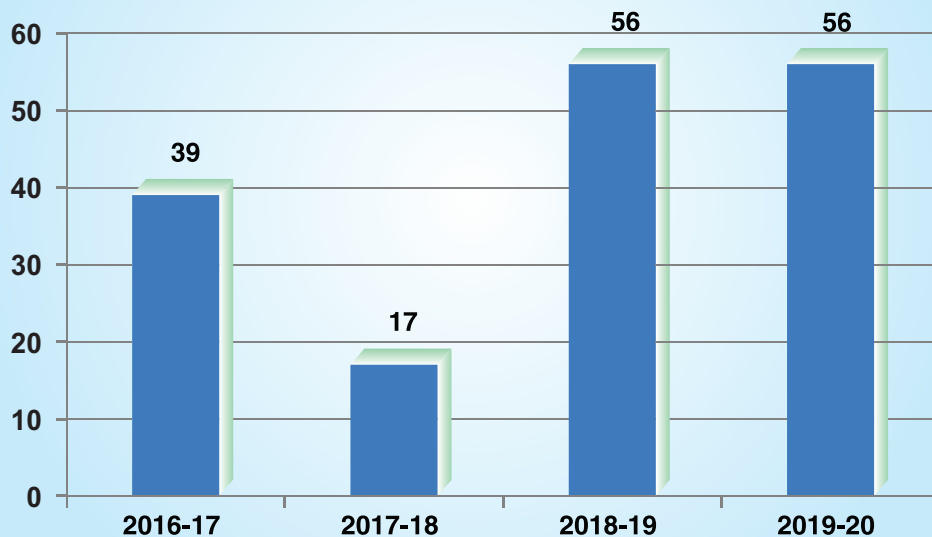


Badhte Kadam (Awareness and Community Interaction) Number of Project Sanctioned (Year-wise)



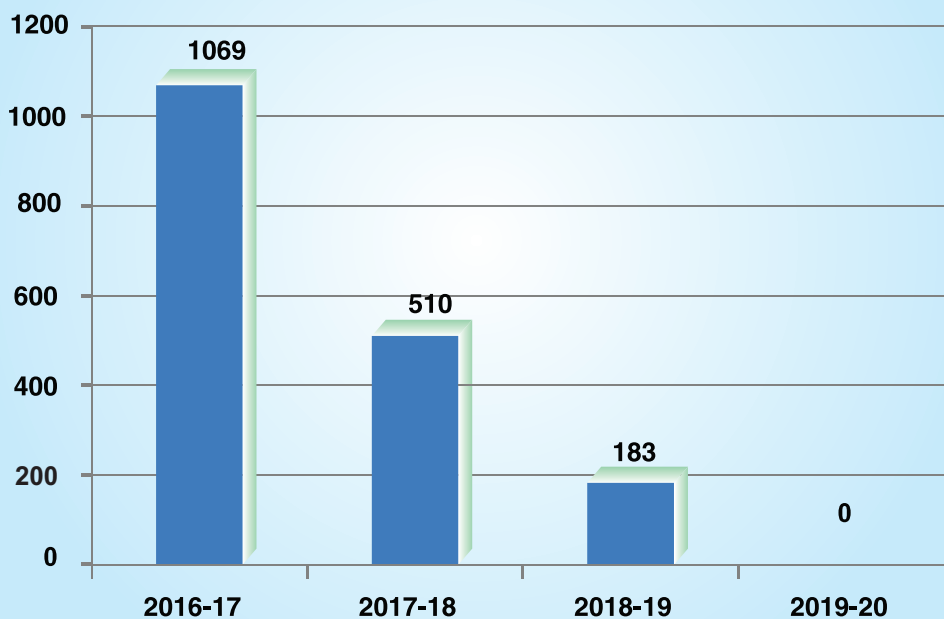
Sahyogi (Caregiver Training Programme)

Number of Centers (Year-wise)



Sahyogi (Caregiver Training Programme)

Total Beneficiaries (Year-wise)



11. The National Trust has compiled some case laws / judgements. Few important case laws / judgements concerning persons with disabilities are as under:-

(1) Jeeja Ghosh Versus Union of India

(2016) 7 Supreme Court Cases 761

Instead of traditional approach of sympathy and help based on medical / welfare model, disabled persons need to be treated with dignity like normal persons based on human rights perspective – Because emphasis is on medical needs, their wider social needs are neglected, thus isolating them from normal people and even their families – Instead of treating them as an object of pity, they should be assimilated in the mainstream of the nation's life – Constitution of India, Arts. 21 and 14.

The rights that are guaranteed to differently abled persons under the Act, 1995 are founded on the sound principle of human dignity which is the core value of human right and is treated as a significant facet of right to life and liberty. Such a right, now treated as human right of the persons who are disabled, has its roots in Article 21 of the Constitution.

Earlier the traditional approaches to disability have depicted it as health and welfare issue, to be addressed through care provided to persons with disabilities, from a charitable point of view. The disabled persons are viewed as abnormal, deserving of pity and are, and not as individuals who are entitled to enjoy the same opportunities to live a full and satisfying life as other members of society. This resulted in marginalising the disabled persons and their exclusion both from the mainstream of the society and enjoyment of their fundamental rights and freedoms. Disability tends to be couched within a medical and welfare framework, identifying people with disabilities as ill, different from their non-disabled peers, and in need of care. Because the emphasis is on the medical needs of people with disabilities, there is a corresponding neglect of their wider social needs, which has resulted in severe isolation for people with disabilities and their families.

However, the nations have come a long way from that stage. Real awareness has dawned on the society at large that the problems of differently abled are to be viewed from human rights perspective. This thinking is reflected in two major declarations on the disability adopted by the General Assembly of the United Nations on December 20, 1971 and thereafter in the year 1975. The position was reiterated in the Beijing Conclave by the Government of Asian and Pacific Countries that was held from December 01-05, 1992 and in order to convert the resolutions adopted therein into reality, the Indian Parliament also passed the enactment, i.e. 1995 Act.

The UNCRPD specifically targets transportation systems such as airlines when it states in Article 9:

“Accessibility – (1) to enable persons with disabilities to live independently and participate fully in all aspects of life. State parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and to communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public.”



And, UNCRPD makes clear that private carriers are covered as well in Article 9(2): “9.(2) State parties shall also take appropriate measures:

to ensure that private entities that offer facilities and services which are open to or provided to the public take into account all aspects of accessibility of persons with disabilities.”

The Hon’ble Supreme Court observed that to most disabled persons, the society they live in is a closed door which has been locked and the key to which has been thrown away by the others. Helen Keller has described this phenomena in the following words: “Some people see a closed door and turn away. Others see a closed door, try the knob and if it doesn’t open, they turn away. Still others see a closed door, try the knob and if it doesn’t work, they find a key and if the key doesn’t fit, they turn way. A rare few see a closed door, try the knob, if it doesn’t open and they find a key and if it doesn’t fit, they make one!”

These rare persons we have to find out.

The Supreme Court awarded Jeeja Ghosh a compensation of Rs.10 Lakh for mental and physical suffering experienced by her through the airline.

(2) Suchita Srivastava and another Versus Chandigarh Administration

(2009) 9 Supreme Court Cases 1

The Hon’ble Supreme Court has laid down the application “substituted judgement” test requires the Court to step into shoes of a person who is considered to be mentally incapable and attempt to make decision which the said person would have made, if she was competent to do so. When the person with disability has “mild mental retardation”, this does not mean that she is entirely incapable to making decisions for herself. It is the “best interest” test alone which should govern inquiry in such cases and not the “substituted judgement” test.

The application “substituted judgement” test requires the Court to step into shoes of a person who is considered to be mentally incapable and attempt to make decision which the said person would have made, if she was competent to do so. This is a more complex inquiry but this test can only be applied to make decision on behalf of persons who are conclusively shown to be mentally incompetent.

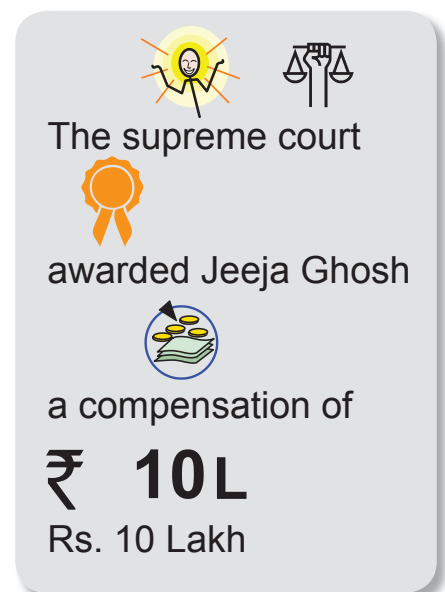
In the present case the victim has been described as a person suffering from ‘mild mental retardation’. This does not mean that she is entirely incapable of making decisions for herself. It is the ‘Best Interests’ test alone which should govern the inquiry in the present case and not the ‘Substituted Judgment’ test.

Lastly, the direction given by the High Court to terminate the victim’s pregnancy was not in pursuance of her “best interest”. Performing an abortion at such a late stage could have endangered the victim’s physical health and the same could have also caused further mental anguish to the victim since she had not consented to such a procedure.

(3) Pramod Arora Versus Hon’ble Lt. Governor of Delhi and Others

2014 SCC online Del 1402

Hon’ble Supreme Court hold that education is the first step for breaking down pre-existing social parries which present full and meaningful participation of person with disabilities in the profiles of life and mainstream of society, as mandated in the PwD Act. The Act says that the mandate of the State is to provide education under Section 26, PwD Act read with Section 3 of Right to Education Act. To place the Court’s findings in context, the mandate of the State to provide education under Section 26, PwD Act read with Section 3, RTE Act is an obligation that must match the demand of education of SWSN and the supply, through public and private institutions. The figures provided by the GNCT make it apparent that Government owned or aided institutions in Delhi do not as of this moment – have sufficient capacity by themselves to cater to CWSN.



The infographic is a vertical grey box with rounded corners. At the top, there are two icons: a yellow sun with a face and a black scale of justice. Below these, the text reads 'The supreme court' in a bold, black, sans-serif font. Underneath is an orange ribbon award icon. The text continues 'awarded Jeeja Ghosh' in a bold, black, sans-serif font. Below this is an icon of a stack of yellow coins with a green arrow pointing upwards. The text then says 'a compensation of' in a bold, black, sans-serif font, followed by '₹ 10L' in a large, bold, black, sans-serif font, and 'Rs. 10 Lakh' in a bold, black, sans-serif font at the bottom.

The emergence of the disability rights movement in several parts of the world, and location of the needs of persons (and children) with disabilities in the discourse within the larger canvass of civil rights, along with gender, minority groups and other marginalized sections' of societies, is a move away from the present, paternalistic model of disability rights. In the model known and practised within country, disability rights are viewed from a medical or charity perspective, where disability is a handicap one is born with. The social model, on the other hand, views disability as the product of pre-existing barriers created by society. Education is therefore the first step for breaking down these barriers, which prevent full and meaningful participation of persons with disabilities in the processes of life and mainstream of society. Each person with disability is presently impeded in a world with barriers that need to be surmounted on a daily basis for mere functioning. Though a small minority (2.1% of the population), they deserve no less than the rights under the PWD Act and the RTE; these are to be given their fullest meaning and content. **It is time all concerned stop viewing those with disabilities as ill and incomplete and instead help them take hold of their lives and provide the admission in the regular school in compliance of Right to Education Act.**

(4) EERA through Dr. Manjula Krippendorf Versus State (NCT of Delhi) and Another (2017) 15 Supreme Court Cases 133

As a contrast to the 2012 Act i.e. The Protection of Children from Sexual Offences Act, 2012 with which we are concerned, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 would make it clear that whichever person is affected by mental retardation, in the broader sense, is a "person with disability" under the Act, who gets protection. The Statement of Objects and Reasons of the said Act reads as under:

"Statement Of Objects And Reasons - The Government of India has become increasingly concerned about the need for affirmative action in favour of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability.

In acknowledgement of a wide range of competencies among these individuals, the Central Government seeks to set up a National Trust to be known as a National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability. The said Trust will be promotive, proactive and protectionist in nature. It will seek primarily to uphold the rights, promote the development and safeguard the interests of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability and their families.

Towards this goal, the National Trust will support programmes which promote independence, facilitating guardianship where necessary and address the concerns of those special persons who do not have their family support. The Trust will seek to strengthen families and protect the interest of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability after the death of their parents.

The Trust will be empowered to receive grants, donations, benefactions, bequests and transfers. The Central Government will make a one-time contribution of rupees one hundred crores to the corpus of the Trust to enable it to discharge its responsibilities.

The Bill seeks to achieve the aforesaid objectives."

Relevant provisions of this Act are Sections 2(g), 2(j), 14(1) and 17(1), and the same are reproduced as under:

Definitions. – In this Act, unless the context otherwise requires -

(a) to (f)

"mental retardation" means a condition of arrested or incomplete development of mind of a person which is specially characterised by sub- normality of intelligence;



(j) “persons with disability” means a person suffering from any of the conditions relating to autism, cerebral palsy, mental retardation or a combination of any two or more of such conditions and includes a person suffering from severe multiple disability.”

Appointment for guardianship.— (1) A parent of a person with disability or his relative may make an application to the local level committee for appointment of any person of his choice to act as a guardian of the persons with disability.”

Removal of guardian.—(1) Whenever a parent or a relative of a person with disability or a registered organisation finds that the guardian is—abusing or neglecting a person with disability; or misappropriating or neglecting the property, it may in accordance with the prescribed procedure apply to the committee for the removal of such guardian.

The principle has been laid down in the said case that reading of the Objects and Reasons of the aforesaid Act together with the provisions contained therein would show that whatever is the physical age of the person affected, such person would be a “person with disability” who would be governed by the provisions of the said Act. Conspicuous by its absence is the reference to any age when it comes to protecting persons with disabilities under the said Act.

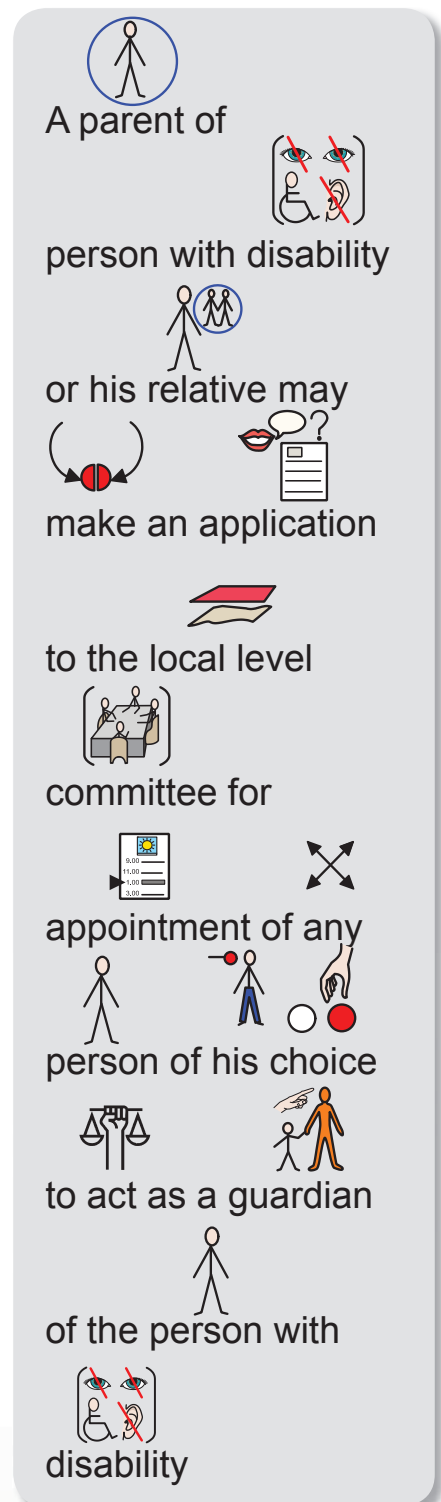
(5) Justice Sunanda Bhandare Foundation Versus Union of India & Others

(2017) 14 Supreme Court Cases 1

The 2016 Act visualizes a sea change and conceives of actualization of the benefits engrafted under the said Act. The Hon’ble Supreme Court stated that the whole grammar of benefit has been changed for the better, and responsibilities of many have been encompassed. In such a situation, it becomes obligatory to scan the anatomy of significant provisions of the Act and see that the same are implemented. The laudable policy inherent within the framework of the legislation should be implemented and no become a distant dream. Immediacy of action is the warrant.

The 2016 Act has been enacted and it has many salient features. As we find, more rights have been conferred on the disabled persons and more categories have been added. That apart, access to justice, free education, role of local authorities, National fund and the State fund for persons with disabilities have been created. The 2016 Act is noticeably a sea change in the perception and requires a march forward look with regard to the persons with disabilities and the role of the States, local authorities, educational institutions and the companies. The statute operates in a broad spectrum and the stress is laid to protect the rights and provide punishment for their violation.

Regard being had to the change in core aspects, we think it apposite to direct all the States and the Union Territories to file compliance report keeping in view the provisions of the 2016 Act within twelve weeks hence. The States and the Union Territories must realize that under the 2016 Act their responsibilities have grown and they are required to actualize the purpose of the Act, for there is an accent on many a sphere with regard to the rights of the disabilities. When the law is so concerned for the disabled persons and makes provision, it is the obligation of the law executing



authorities to give effect to the same in quite promptitude. The steps taken in this regard shall be concretely stated in the compliance report within the time stipulated. When we are directing the States, a duty is cast also on the States and its authorities to see that the statutory provisions that are enshrined and applicable to the cooperative societies, companies, firms, associations and establishments, institutions, are scrupulously followed.

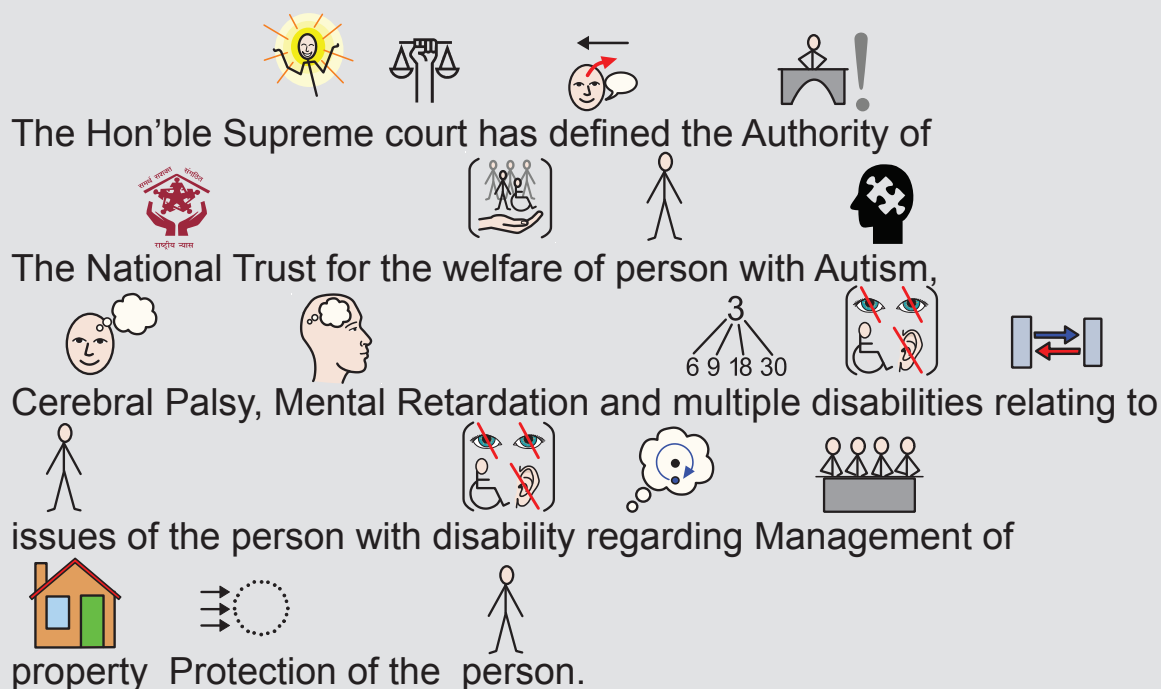
The State Governments shall take immediate steps to comply with the requirements of the 2016 Act and file the compliance report so that this Court can appreciate the progress made.

(6) Mohini Devi Versus State of Punjab through Secretary, Deptt of Home, Civil Secretariat, Punjab, Chandigarh and Others

2011 SCC online P&H 8977

The Hon'ble Supreme Court has defined the Authority of the National Trust for the welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities relating to issues of the persons with disability regarding

- management of property,
- protection of the person and
- appointment of a guardian.



Enabling Persons with Intellectual & Developmental Disabilities (PwIDD) to exercise their legal capacity

Prasanna Kumar Pincha

Structure

This brief write up has been divided into seven parts:

Part one seeks to contextualize the topic at hand

Part two talks about what constitutes legal capacity

Part three gives the UNCRPD paradigm of legal capacity

Part four examines the Indian legal regime in the context of PwDs

Part five discusses some measures for enabling PwIDD to exercise their legal capacity

Part six flags off certain intricate nuances of issues for reflection and resolution

Part seven gives an illustrative set of recommendations, followed by concluding remarks

Abbreviations used in this write-up:

PwIDD: Persons with Intellectual & Developmental Disabilities.

PwD: Persons with Disabilities.

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities.

RPD Act: Rights of Persons with Disabilities Act, 2016.

PwD Act: Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

RCI Act: Rehabilitation Council of India Act, 1992.

NTA: National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.



Special Rapporteur for issues relating to Persons with Disabilities, National Human rights Commission of India, New Delhi.

Former Chief Commissioner for Persons with disabilities, Govt. of India, New Delhi.

Former Chairperson, National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, Govt. of India, New Delhi.



Various acts enabling



Person with Intellectual

and developmental



disability



Making day to day life



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choices is also the



matter of taking legally



binding decisions

Part One

Contextualizing the topic at hand:

Respect for personhood of every individual, regardless of abilities or disabilities, is an integral ingredient of human dignity. To my mind, it is this paradigm of thought which culminated into explicit recognition of all persons with disabilities everywhere as persons before the law and their legal capacity on an equal basis with others both at the international and the national levels. The UNCRPD at the international level and the RPD Act, 2016 at the national level are a case in point.

While there are no substantive issues with regard to recognition of all persons with disabilities as persons before the law, intricate issues seem to surface when it comes to enabling some sections of persons with disabilities, for example, persons with intellectual and developmental disabilities, to exercise their legal capacity. Clearly, these issues call for expeditious resolution. It is against this backdrop that this topic is of utmost contemporary relevance.

Within the larger group of persons with disabilities, there are some sections, such as the PwIDD who require intense and sustained

support; and such support is required both in the matter of making day-to-day life choices as also in the matter of taking legally binding decisions.

Section 2 (L) of the RPD act says, ‘high support’ means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life including education, employment, family and community life and treatment and therapy. Likewise, Section 2 (T) says, person with disability having high support needs” means a person with benchmark disability certified under clause (a) of sub-section (2) of section 58 who needs high support.

Part two

What constitutes legal capacity:

It would be in the fitness of things for us to note that legal capacity essentially has two components, namely, A. Recognition as person before the law; and B. the ability and maturity to comprehend the nature and possible consequences of a given act or omission. These two components correspond to two dimensions of legal capacity, namely, A. legal capacity per se; and B. legal capacity to act. It is, as has been indicated above, in the area of legal capacity to act or of exercising legal capacity that PwIDD may have issues; and, the enormity of issues to be faced by them would depend on the degree of their disabilities, i.e., on whether their disability is mild, moderate, profound or severe.

Part three

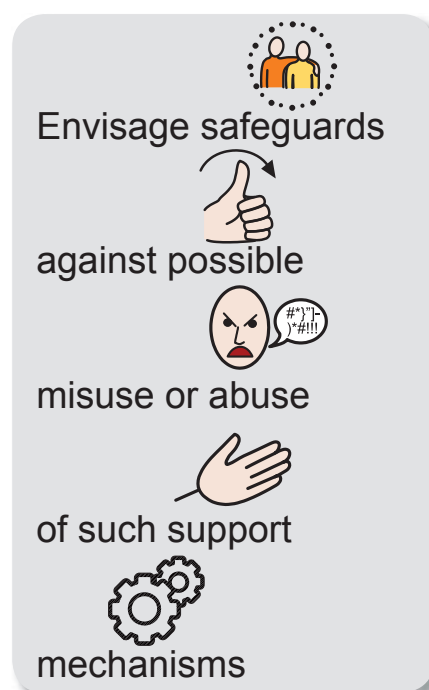
UNCRPD paradigm of legal capacity:

The United Nations Convention on the Rights of Persons with Disabilities to which India is a state party is premised on the philosophy that persons with disabilities are subjects capable of human rights and fundamental freedoms; and not objects needing mere medical care and social protection. As a necessary extension of this foundational philosophy of human rights-based approach, it explicitly recognizes the personhood and legal capacity of persons with disabilities. Article 12 of the said Convention is a case in point. It seeks to A. explicitly recognize all persons with disabilities everywhere as persons before the law; B. recognize legal capacity of all persons with disabilities on an equal basis with others; C. Provide for support arrangements for exercising legal capacity by those persons with disabilities who may need such support; and also stipulate that such support mechanisms shall respect the will, rights and preferences of persons with disabilities; D. envisage safeguards against possible misuse or abuse of such support mechanisms; and, E. stipulate that persons with disabilities shall have the right to own and inherit property, manage and control their own financial affairs, etc.

It goes without saying that Article 12 of UNCRPD on recognition before the law, or for that matter on legal capacity has been the most hotly contested one amongst states parties. Interesting deliberations, particularly, around supported decision-making and substituted decision-making appears to have been quite absorbing; so much so that it does call for a slightly longish narrative albeit to my mind, the distinction between supported decision-making and substituted decision-making appears somewhat misplaced. The distinction should have been between substitutive support and non-substitutive support.

Substituted Decisions Making Mechanism vs. Supported Decision-Making Mechanism in respect of legal capacities of persons with disabilities:

The deliberations of the ad hoc committee on the UN Convention for the Rights of Persons with Disabilities which later got adopted witnessed an absorbing battle of wits on the issue of legal capacity of persons with disabilities. While everyone agreed to recognize persons with disabilities as persons before the law on an equal basis with others, and also their legal capacity to act, opinion was divided in respect of persons with certain specific categories of disabilities, particularly persons with Intellectual / Mental / Psychosocial disabilities. Some argued that for persons with certain specific categories of disabilities, there should be provision of

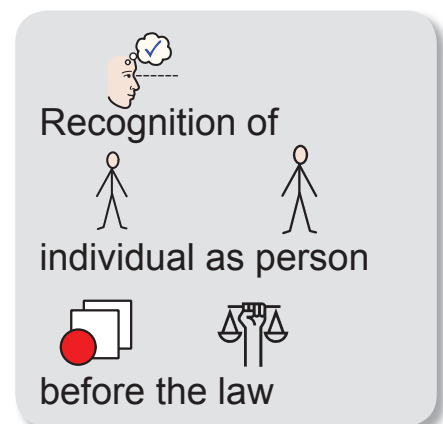


substituted decision-making mechanism since they cannot act on their own. Others however felt that for such categories of persons, there should be provision of supported decision-making mechanism and not for substituted decision-making mechanism. Supported decision making presupposes inherent capacity in every individual. It also underscored the principle of interdependence amongst human beings. After all, existence is not about dependence or independence; rather, it is about interdependence. Substituted decision making on the other hand negates capacity and forecloses all opportunities for a person's capacity to evolve. For example, today, I may need 100% support, but over a period of time the need for support may get reduced.

My perspective: The supported decision-making mechanism finally won the day at the UN headquarters, i.e. in the deliberations of the said ad hoc committee and rightly so. The fact of the matter is that all of us whether disabled or not do need support, for example one needs the support of a doctor during sickness, or for that matter of a legal council to deal with a legal litigation. It also highlights the fact that life on earth is neither about dependence nor independence; rather it is about interdependence.

I however, further feel that the categorization should more appropriately be between substitutive support for decision-making and non-substitutive support for decision-making; rather than between supported decision-making and substituted decision-making for the simple reason that support can be both substitutive and/or non-substitutive. Of course, there is no denying the fact that substitutive support in the matter of decision-making be allowed only in rare and exceptional cases. It should also be clearly understood that substitutive support is not always necessarily equal to guardianship. For example, if I slip into state of coma, and my attending surgeon is to perform a critical surgery on me which may even result in my death, the decision on whether the surgery is to be performed or not will have to be taken for me by my closest relatives. Here, my relatives who decide on my behalf are not my guardians. Nevertheless, the decision taken is a substitutive decision as I was not in a position to decide for myself at that point in time. Besides, the nuanced difference between "legal capacity" per se, and "legal capacity to act" must be clearly understood. While the former constitutes recognition of an individual as a person before the law, the latter additionally includes the ability and maturity to comprehend the nature and possible consequences of a given act or omission.

I further feel that for all practical purposes, my perspective seems to have been vindicated by the corresponding provisions in the RPD Act which we shall see in the immediately following segment of this write-up.



Part four

Indian legal regime in the context of legal capacity of PwD :

Since India is a state party to the UNCRPD which is a legally binding international human rights treaty, it is incumbent on India's part to align or harmonize all its corresponding domestic laws and policies with the said treaty. RPD Act which repeals and replaces the erstwhile PwD Act got enacted as a part of govt. of India's efforts to harmonize all its corresponding laws and policies with the UNCRPD.

It must also be acknowledged that in a certain sense, the NTA preempted both the UNCRPD and the RPD Act as it was enacted way back in 1999. Section 14 of the NTA stipulates that a parent or a relative of a person with disability or a registered organization may, with the consent of guardian apply for legal guardianship. The use of the word 'may' is to be noted. Again, subsection (3) of section 14 enjoins it upon the local level committee to consider if the PwD actually needs a guardian. It therefore follows by necessary implication that even under the National Trust Act, it is not mandatory for PwD governed by the NTA including



for PwIDD to obtain guardianship. Incidentally, the NTA covers four specified categories of PwD, namely, persons with autism, cerebral palsy, mental retardation and multiple disabilities. Section 13 on legal capacity and Section 14 on provision for guardianship of RPD act is reproduced below:

Legal capacity

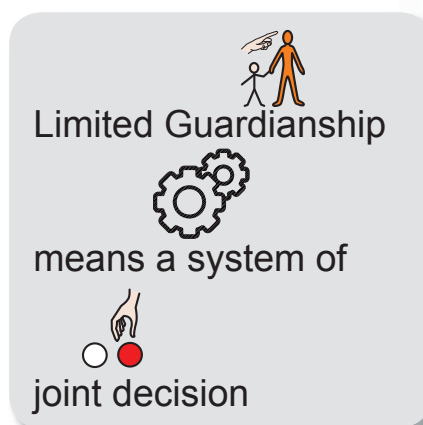
13. (1) The appropriate Government shall ensure that the persons with disabilities have right, equally with others, to own or inherit property, movable or immovable, control their financial affairs and have access to bank loans, mortgages and other forms of financial credit.
- (2) The appropriate Government shall ensure that the persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law.
- (3) When a conflict of interest arises between a person providing support and a person with disability in a particular financial, property or other economic transaction, then such supporting person shall abstain from providing support to the person with disability in that transaction:
Provided that there shall not be a presumption of conflict of interest just on the basis that the supporting person is related to the person with disability by blood, affinity or adoption.
- (4) A person with disability may alter, modify or dismantle any support arrangement and seek the support of another:
Provided that such alteration, modification or dismantling shall be prospective in nature and shall not nullify any third-party transaction entered into by the person with disability with the aforesaid support arrangement.
- (5) Any person providing support to the person with disability shall not exercise undue influence and shall respect his or her autonomy, dignity and privacy.

Provision for guardianship

14. (1) Notwithstanding anything contained in any other law for the time being in force, on and from the date of commencement of this Act, where a district court or any designated authority, as notified by the State Government, finds that a person with disability, who had been provided adequate and appropriate support but is unable to take legally binding decisions, may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person, in such manner, as may be prescribed by the State Government:

Provided that the District Court or the designated authority, as the case may be, may grant total support to the person with disability requiring such support or where the limited guardianship is to be granted repeatedly, in which case, the decision regarding the support to be provided shall be reviewed by the Court or the designated authority, as the case may be, to determine the nature and manner of support to be provided.

Explanation :- For the purposes of this sub-section, “limited guardianship” means a system of joint decision which operates on mutual understanding and trust between the guardian and the person with disability, which shall be limited to a specific period and for specific decision and situation and shall operate in accordance to the will of the person with disability?



- (2) On and from the date of commencement of this Act, every guardian appointed under any provision of any other law for the time being in force, for a person with disability shall be deemed to function as a limited guardian.
- (3) Any person with disability aggrieved by the decision of the designated authority appointing a legal guardian may prefer an appeal to such appellate authority, as may be notified by the State Government for the purpose.

Section 15 of the RPD Act envisages designation of authority to support.

It is thus abundantly clear that Section 13 of the RPD Act seeks to harmonize with Article 12 of the UNCRPD. Section 14 and 15 of the RPD Act are intended to operationalize support related provisions of the UNCRPD stipulated vide said Article 12.

Part five

Measure to enable PwIDD to exercise their legal capacity:

If there is one area which has the strongest claim on the attention of professionals, parents, activists and the academia, etc. is the need for real-time measures that would enable and ensure PwIDD appropriate environment in which they are able to exercise their legal capacity. Absence of an enabling environment is almost as bad as attribution of incapacity to this segment of the population, at least for all practical purposes. In fact, in a situation of this ilk, the lofty ideal of universal legal capacity will continue to remain only on paper without this ideal becoming a living reality for PwIDD.

To my humble way of thinking, this underscores the need for creation of effective, vibrant and committed support networks on a large scale. Such networks may consist of parents and family members of PwIDD, community members, civil society organizations including organizations and institutions working with PwIDD, govt. run organizations and institutions, legal experts, academicians, social workers, and PwD, etc.

Efforts at building and augmenting capacities of these support networks have to be intensified. To this end, a well-thought-out syllabus has to be developed for the training of these support networks and of PwIDD. Such training has to be an ongoing activity. The National Trust created under the NTA, the National Institute for Empowerment of Persons with Intellectual and developmental disabilities, Secunderabad, The National Institute for the Empowerment of Persons with Multiple Disabilities, Chennai, The Rehabilitation Council of India created under the RCI Act, etc. have a definite and distinct role to play in this regard.

Needless to say here that the training of support networks should, inter alia, equip such networks to provide support in the matter of making day-to-day life choices as also in the matter of taking legally binding decisions. Given the stupendity of the task, it is imperative that the Government the Civil Society organizations and the PwD work together in a spirit of partnership and accommodation to make legal exercise of legal capacity a living reality for PwIDD. International cooperation must also be elicited for this purpose. The Ministry of Home Affairs, Government of India must consider issuing appropriate orders making it incumbent on various international and national non-governmental organizations and agencies working in the social sector to set apart a certain portion of their budget for PwD.

The need for organizing sensitization training at periodical intervals of media persons, bureaucrats, elected representatives, corporates, members of legal and judicial fraternity, civil society organizations, etc. also cannot be over-emphasized.

The statutory bodies such as, the National Human Rights Commission of India, The Chief Commissioner and the State Commissioners for Persons with Disabilities do anyway have their role distinctly cut out in the matter of protecting and promoting the rights of PwD including monitoring and overseeing implementation of various legislations meant for the benefit of PwD.

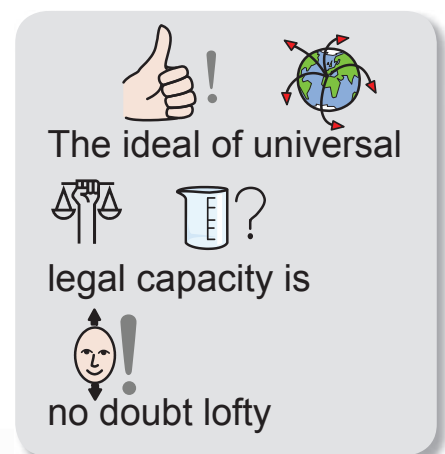
The designation of authorities and constitution of assessment boards for assessing and certifying high support needs be constituted forthwith by appropriate Govt. Likewise, the appropriate Govt. must come up with comprehensive set of schemes and programmes for the creation of support networks and their capacity building and capacity augmentation.

Here, it would also be quite in context for me to state that one must also draw on the experience of organizations which have already implemented some pilot projects in respect of support networks. I understand an organization called Parivaar which is a confederation of organizations of parents of PwIDD did implement some such project.

Part six

Glimpses of some intricate nuances of issues for reflection and resolution:

The ideal of universal legal capacity is no doubt lofty; and, we must spare no effort to make this lofty ideal a living reality for PwIDD as well to the best of our abilities. Having said as above, one must acknowledge that there appear to be some real time constitutional and legal issues which need to be appropriately resolved. The following brief discussion brings to the fore a sting in the tail.



It is common knowledge that the constitution and various laws of India envisage unsoundness of mind as a disqualification for certain purposes; and soundness of mind as a qualification for certain other purposes. How the paradigm of legal capacity envisaged in Section 13 of the RPD Act gets reconciled to the provisions around soundness or unsoundness of mind in the context of persons with intellectual and developmental disabilities?

The second issue which I wish to flag off for reflection and resolution goes as under: the provisions with regard to guardianship as envisaged in Section 14 of the Act invite comments. To my way of thinking, these provisions suffer from mind-boggling ambiguities, and hence, are likely to create confusion of phenomenal order. The said Section 14 is now amenable to multiple interpretations. While the issue being so intricate and nuanced merit separate treatment in a separate write-up. However, it may briefly be stated as follows:

One would see glaring contradiction between the provisions of subsection 2 and subsection 1 of Section 14. While subsection 2 of the said section seeks to declare all guardians appointed under any law for the time being in force as 'limited guardians' on and from the date of commencement of the RPD Act, subsection 1 seeks to retain full or plenary guardianship in as much as it talks of total support where required. Is total support not equal to plenary guardianship? Significantly, subsection 2 does not explicitly abolish plenary guardianship albeit it says that every guardian appointed under any law for the time being in force shall be deemed to function as a limited guardian. While the explanation appended to subsection 1 of Section 14 talks about joint decision making, the same section, in the same breath also confers on the guardian to take decisions on behalf of the person with disability though in consultation with the person with disability; Nevertheless, the decision is that of the guardian's. So, where on earth is the element of jointness in the decision making. It does not require very sturdy commonsense to understand that when I take a decision on somebody's behalf, the decision is attributable to me although it is another matter that the person with disability may have reposed complete trust in me. It is argued that 'need-based guardianship' would have been a better expression than 'limited guardianship' as has been stipulated in the Act. This argument stands somewhat vindicated as guardianship has also been recognized as a support under subsection 1 of section 14. One may recall that it is also argued that the distinction between supported decision making and substituted decision making is misplaced. The distinction has to be between substitutive support and non-substitutive support in decision making. One feels that while Section 14 could have been and should have been better formulated, the intention of the legislature was bonafide in that it wanted to protect the best interests of those persons with disabilities who otherwise would have had to suffer – hence, some grey areas.

It would also be in the fitness of things for us not to lose sight of the fact that my interpretation is that on and from the date of commencement of this Act, the local level committees constituted by the National Trust perhaps cease to be a competent authority to appoint guardians unless the concerned State Govt. designates them as competent authority. Till then, only the district courts can appoint guardians. Interestingly, no provision of the National Trust Act has been repealed or appropriately modified or amended either so as to bring it in line with the corresponding provisions of the RPD Act. So, the issue stands all the more compounded.

Thirdly, who is accountable and/or answerable for the actions or omissions of PwIDD? – The PwIDD? or the support network? or both? Isn't one bound to own up a decision taken by one with or without support? Can one have full legal capacity and at the same time absolve oneself of answerability and accountability for one's own act or omission? Can one have the cake and eat it too?

The fourth issue which I wish to flag off is around the right to vote of a person with severe and profound intellectual disability. Although the right to vote is not a fundamental right under part three of the constitution of India, and although it is subject to various provisions of the constitution and the Representation of the People Act, it is a very important democratic right of a citizen. How does this right operate in the context of PwIDD?

The fifth issue is around criminal responsibility. If a PwIDD commits an act or omission which is an offence in the eye of the law, does he, or does he not get the benefit of absence of mens rea? Especially now when his full legal capacity stands recognized on an equal basis with others?

Part seven

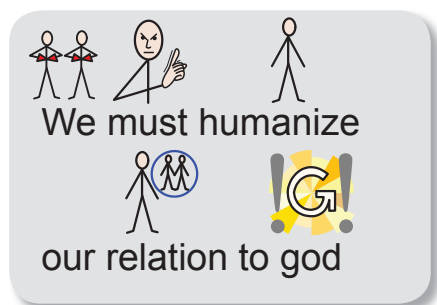
Some illustrative set of recommendations:

The following few recommendations are in addition to the suggestions and recommendations made in part five of this write-up on measures for enabling PwIDD to exercise their legal capacity:

1. Constitute a committee comprising legal and constitutional experts, PwD and bureaucrats to go into the issues flagged off in part six of this write-up and make necessary recommendation to the govt. for their expeditious resolution.
2. Harmonize the NTA and the RCI Act with UNCRPD and the RPD Act either by appropriately amending them or by replacing them with fresh legislations.
3. Harmonize the so-called mainstream legislations with the UNCRPD and the RPD Act in a time-bound manner.

Concluding remarks

Universal legal capacity is a continuously evolving concept. While persons with locomotor and/or sensory disabilities do not have any substantive issues in respect of exercising their legal capacity, there are some challenges with regard to PwIDD which need to be effectively faced. Our understanding of issues and our ability to resolve them is bound to grow as we grow and evolve in experience. Come what may! The best interests of PwIDD should always be kept in mind. While we must, on a continuous basis, espouse lofty ideals, care should be taken to ensure that PwIDD do not suffer in the bargain. Compatibility between our passion and pragmatism of the hour. I wish to conclude with the words of the most venerated saint of this country, Swami Vivekananda: "we must humanize our relation to God; and, divinize our relation to humans".



Students of Vikas Scheme sharing views with Philanthropist, Dr. Nilima Sabarwal, Founder Home of Hope Inc.

Role of Chief Commissioner for Persons with Disabilities in Redressal of Grievances of Persons with Disabilities

By: -Dr. Sanjay Kant Prasad, Dy. Chief Commissioner
O/o Chief Commissioner for Persons with Disabilities

The Office of Chief Commissioner for Persons with Disabilities was set up in September, 1998 with the appointment of the first Chief Commissioner under Section 57 of the Persons with Disabilities Act, 1995. Rights of Persons with Disabilities Act, 2016 (RPwD Act), provide for the appointment of Chief Commissioner for Persons with Disabilities by the Central Government under section 74.

Chief Commissioner for Persons with Disabilities (CCPD) is a quasi-judicial body under the administrative control of Department of Empowerment of Persons with Disabilities. Chief Commissioner for Persons with Disabilities have been given following functions under section 75 of RPwD Act 2016 to safeguard the rights of persons with disabilities in terms of non-discrimination, ensuring equal opportunities and full participation in the society.

- identify, suo motu or otherwise, the provisions of any law or policy, programme and procedures, which are inconsistent with this Act and recommend necessary corrective steps;
- inquire, suo motu or otherwise, deprivation of rights of persons with disabilities and safeguards available to them in respect of matters for which the Central Government is the appropriate Government and take up the matter with appropriate authorities for corrective action;
- review the safeguards provided by or under this Act or any other law for the time being in force for the protection of rights of persons with disabilities and recommend measures for their effective implementation;
- review the factors that inhibit the enjoyment of rights of persons with disabilities and recommend appropriate remedial measures;
- study treaties and other international instruments on the rights of persons with disabilities and make recommendations for their effective implementation;
- undertake and promote research in the field of the rights of persons with disabilities;
- promote awareness of the rights of persons with disabilities and the safeguards available for their protection;
- monitor implementation of the provisions of this Act and schemes, programmes meant for persons with disabilities;
- monitor utilisation of funds disbursed by the Central Government for the benefit of persons with disabilities; and

The powers of Chief Commissioner

The section 77 of Rights of Persons with Disabilities Act 2016 provides that the Chief Commissioner shall, for the purpose of discharging his functions, have the same powers of a civil court as are vested in a court under the Code of Civil Procedure, 1908 while trying a suit, in respect of the following matters, namely: —

- summoning and enforcing the attendance of witnesses;
- requiring the discovery and production of any documents;
- requisitioning any public record or copy thereof from any court or office;



Role of Chief



Commissioner to



redressed the grievances



Monitor utilization of funds



disbursed by the central



government

- receiving evidence on affidavits; and
- issuing commissions for the examination of witnesses or documents.

Every proceeding before the Chief Commissioner shall be a judicial proceeding within the meaning of sections 193 and 228 of the Indian Penal Code and the Chief Commissioner shall be deemed to be a civil court for the purposes of section 195 and Chapter-XXVI of the Code of Criminal Procedure, 1973.

Mechanism for Grievance Redressal in the Office of Chief Commissioner for Persons with Disabilities

- The Office of the Chief Commissioner for Persons with Disabilities received the grievances from person with disability or any other person or an organization on his/her behalf can file a complaint pertaining to non-implementation of the provisions of the Act and the schemes and policies framed for the benefit of persons with disabilities. A Grievances received from the persons with disabilities are dealt under Rule 38 of the Rights of Persons with Disabilities Rules, 2017.
- It is observed that 50% of the grievances received are related to State Governments and its organizations which are after thorough examination forwarded to State Governments for proceeding and taking final view and closed on the part of court of CCPD. Rest of the grievances are used to taken up with the respondent organizations/agencies in the form of "Notice" where respondents are asked to provide their reply with clarification and comments on the issues raised in the complaints.
- It is further observed that around 20% of the grievances are redressed by the respondent organization after receiving notice from O/o Chief Commissioner for Persons with Disabilities. Remaining 30% grievances are processed for proceeding as per Rule 38. The reply/comments received from the respondent organization are forwarded to the complainant for his/her rejoinder, if any. In case the complainant is not satisfied with the reply of the respondent then hearing is scheduled and conducted in presence of both the parties and final order is passed keeping in view the policies/programmes and related provisions of the Act.
- Since its inception in September, 1998, 37,738 cases have been registered in the office of CCPD and 36,049 had been disposed of by the end of September, 2019. It is worth to mention the data of 2019 in terms of case registration and its Redressal.
- Total cases registered from January 2019 to September 2019 is 835 and 869 case were disposed of (including backlog).

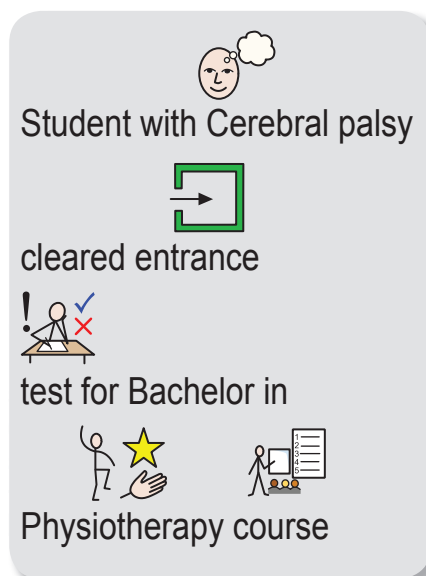
Few examples of redressal of grievances in terms of recommendations / direction of Chief Commissioner of Persons with Disabilities and its compliance.

Dr. Jasvir Singh Vs University Medical Board

- Dr. Jasvir Singh's son Ravdeep with Spastic Cerebral Palsy cleared entrance test for Bachelor in Physiotherapy (BPT) Course.
- The Medical Board found him unfit to pursue the course.
- On the direction of Chief Commissioner for Persons with Disabilities, Ravdeep was admitted to BPT course.

Complainant vs Oriental Insurance Company Ltd.,

- A Person as complainant vide email dated 06/08/2018 submitted that he is a member of Niramaya Scheme as his son is a person with mental retardation with multiple disabilities. He spent rupees one lakh sixty seven thousand on treatment / hospitalization of his son. On submission of claim, he got reimbursement of Rs.40,000/- only whereas the limit is Rs.1.00 lakh.
- Case was taken up with the Oriental Insurance Company Ltd., and a personal hearing in the case was held on 26/02/2019.
- After the direction from the O/o Chief Commissioner for Persons with Disabilities, an amount of dispute of Rs.18,000/- has been transferred to the complainant's account on 25/03/2019 through NEFT payment. However complainant is in the view that National Trust should revisit the scheme and raise the limit of reimbursement in various budget head of the scheme.



Smt. Noorjahan Vs NIEPMD

- Smt. Noorjahan submitted a complaint dt. 12/06/2018 & 09/08/2018 regarding harassment of his son (who is suffering from 90% intellectual disability) by the teacher of NIEPID, Secunderabad where he is studying from 2008.
- She submitted that the teacher torture the student and always misbehave with the parents/guardians of the children. Further she does not have the RCI recognized qualification to teach such children.
- After detailed examination of the complaint, the matter was taken up with NIEPID, Secunderabad.
- After receiving reply from the Respondent (NIEPID), hearing in the matter was scheduled on 14/08/2019 wherein CCPD directed the respondent to take measures to protect children from all form of abuse, violence and exploitation apart from taking official disciplinary action against the teacher.

Shri K. Palaniyappan Vs Department of Financial Services

- Shri Palaniyappan, a person with visual impairment submitted a representation dated 28/05/2018 before the Chief Commissioner for Persons with Disabilities (CCPD) regarding alteration in talking ATMs for better and universal use for the persons with visual impairment.
- The matter was taken up with Department of Financial Services (Respondent) on 16/08/2018.
- After receiving reply from the respondent, hearing in the matter was scheduled on 07/08/2019 and CCPD directed the respondent to provide ATM and other financial facilities to persons with disabilities in general and persons with visual disabilities in particular with secure features. Court recommended that while framing policies, persons with disabilities should be consulted for making accessible and security feature for ATM, incorporating Aadhaar based bio-metric authentication for payments and transaction. Also training and awareness programme for staff as well persons with disabilities could be the inbuilt feature of the policies for financial inclusion of persons with disabilities.

Smt. Minati Boxi Vs South Eastern Railways

- Smt. Minati Boxi, a person with mental retardation submitted her complaint before the Chief Commissioner for Persons with Disabilities (CCPD) regarding non-receipt of double transport allowance, MACP, Pension and excess tax deduction by her department.
- After examination of the complaint, the matter was taken up with her department i.e. South Eastern Railways on 10/01/2019.
- After receiving reply from the respondent, hearing in the matter was scheduled on 29/07/2019.
- During the hearing, the CCPD directed the complainant to approach the Railway administration with all relevant documents. Also directed the respondent to give convenient date and time to her for medical examination & certification. Other issues may also be looked into as per extant rules.

Ms. Bushra Sabir Vs Delhi University

- Ms. Bushra Sabir, a person with 50% locomotor disability filed a complaint dated 06/11/2018 before the Chief Commissioner for Persons with Disabilities (CCPD) regarding denial of admission to MD/MS-UNANI (MAHIR-E-TIB/JAHARAT)-2018 under disability quota by the Faculty of Ayurveda & Unani Medicine, Delhi University.
- After examination of the complaint, matter was taken up with the respondent on 06/12/2018. The respondent sent their reply dated 04/01/2019 but did not submitted the complete facts/documents as called for vide letter dated 06/12/2018.
- Accordingly, a hearing in the matter was scheduled on 18/06/2019 wherein CCPD found that the respondent has violated the provisions under Section 32 of the RPwD Act, 2016 and discriminated the legitimate right of complainant for admission. CCPD directed the respondent to give admission to the complainant to MD/MS-UNANI (MAHIR-E-TIB/JAHARAT)-2018 against the seat reserved for OBC-PwD category. The direction was complied by the respondent.



Shri Shorya Sood Vs Delhi Sikh Gurudwara Management Committee

- Shri Shorya Sood, a person with 80% cerebral palsy submitted a complaint before the Chief Commissioner for Persons with Disabilities (CCPD) regarding denial to go inside the Gurudwara, Sector-11, Dwarka, New Delhi on his wheelchair to have darshan of Shri Guru Granth Sahib ji.
- After examination, the matter was taken up with Delhi Sikh Gurudwara Management Committee on 19/07/2019 and subsequently a hearing was scheduled on 13/09/2019.
- During the hearing, CCPD advised the respondent to either allow the complainant/devotees with disability to go up to the Guru Granth Sahib Ji to have Darshan with their own wheelchair at par with other devotees, or arrangement be made by Gurudwara for the devotees with disability for the purpose of Darshan of Shri Guru Granth Sahib Ji. Respondent is further directed to ensure accessibility of Gurudwara premises for devotees with disabilities in accordance with the harmonized Guidelines and Space Standards for Barrier Free Build Environment for Persons with Disabilities and Elderly Persons issued by Ministry of Urban Development in March, 2016.

Complainant Vs M/o Earth Sciences

- A person as a complaint submitted before the Chief Commissioner for Persons with Disabilities (CCPD) for cancellation of his transfer and retention at the same place for taking care of his daughter who is a child with 65% cerebral palsy and intellectual impairment.
- After examination of the complaint, the matter was taken up with M/o Earth Sciences and hearing in the matter was scheduled on 07/08/2019.
- After hearing both the parties, CCPD directed the respondent to explore the possibility of posting the complainant to some other department but in the main office so that he could take care of the educational and rehabilitation need of his daughter.
- Respondent vide letter dated 27/09/2019 submitted that in compliance of the direction of CCPD, the complainant has been re-transferred to his old place of posting.



Credit : Coloured by Amit Aggarwal, Bliss of Life, Care Project, Manovikas

Title of the paper – “legal capacity – an instrument for enriching lives”

By:- Dr. Shanti Auluck

Chairperson, Muskaan-PAEPID

Defining legal capacity

The legal term for being able to make decisions is “legal capacity”. For people with intellectual and developmental disabilities, self-determination and full citizenship are fundamental principles that underlie the potential enjoyment of human rights. It is the presumption of legal capacity that makes it possible to exercise self-determination and full-citizenship. The right to legal capacity includes the capacity to have rights and the capacity to act on those rights, i.e. the capacity to make legal agreements with others.

Recognition of legal capacity or equal recognition before law is considered a fundamental right of all persons with disability in RPD Act 2016. The Act has kept up the spirit of UNCRPD which has brought an evolved and deeply humanistic understanding of the fundamental human rights through article 12 (i.e. equal recognition before the law or recognition of legal capacity of persons with disabilities—see table no. 1).

Table 1
Article 12 – Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.



It has utmost relevance particularly for certain categories of disabilities namely intellectual disability, autism, mental illness and other human conditions that need complete support even to take care of daily living needs. It believes in respect for all human beings irrespective of their physical, intellectual or mental limitations. However the real challenge lies in translating this understanding into practice making it a reality into people's lives. RPD Act 2016 and its attendant rules, regulations and provisions are supposed to facilitate translation of this vision into reality.

Real challenge before us

On one hand we need to address the ignorance and prejudices of larger society and on other hand we need to create services to address their growth needs. The needed growth opportunities are no different than any other person in the mainstream society e.g. appropriate training and education, training in work/vocation related skills, work/employment opportunity, social inclusion and safe and dignified living. Two additional services required in this sector are family support services and safe living options after the demise of parents or when they become old and sick. All these services are essential for realizing and exercising one's legal capacity to the fullest extent possible.

Who will create such services? Is it realistic to expect that somehow families and NGOs will take care of all these growth needs of PwIDD? Presently, there is no systematic policy to address these issues. Few inadequately funded schemes of the Government, whether of DEPwD (MSJE) or National Trust, are hardly capable of meeting such demands. Provision of disability pension or concessions on income tax provide relief only to parents. It does not create required services and facilities which are necessary to facilitate capacity building of PwIDD that is so essential for realizing and exercising one's legal capacity.

Way forward

1. Law and its provisions should be strong and accountable for its implementation.
2. Incentivize large scale creation of needed services listed above on the line of PPT model.
3. Build cadre of professionals who contribute towards creation of quality services. Such courses should be taught at universities and colleges rather than creating separate teaching institutions.
4. Existing systems and schemes should be reviewed keeping in mind their adequacy. Government Departments that are created to address the needs of PwIDD must have professionals who have knowledge and experience of the field. Their term may be defined along with accountability towards achieving the stated objectives.
5. Legal guardianship too is not a surety against exploitation and we are investing the future of our son/daughter's life entirely in the hands of one person (parents as legal guardians will not last for ever). Creating a well framed support system within the legal framework may provide safety against exploitation as well as necessary support and supervision to PwIDD. This could be a registered trustor supported decision making through a network of persons who are in close touch with PwIDD, understand them and wherever needed provide support to ensure enjoyment of all rights of a citizen.



Children from Disha Scheme giving Stage Performance

National Trust 2.0 : Promoting autonomy as an intrinsic part of the law

By:- Amvalika Senapati, B.A. LL.B, Deputy Director, Advocacy, Shishu Sarothi

Based on the U. S. Supreme Court ruling in the case *Olmstead v. L.C. and E.W.* that the “integration mandate” of the Americans with Disabilities Act requires public agencies to provide services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities”.

“Respect for inherent dignity, individual autonomy and the freedom to make one’s own choices,” as one of the primary guiding principles of the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD), rightly lays stress on the concept of autonomy of persons with disabilities which is of utmost importance in today’s human rights regime. Juxtaposed with this is the status quo of persons with disabilities in India, where the law of the land is precariously perched on contrary stands of ensuring legal capacity on one hand, and also providing for limited guardians on the other. The above position, as envisaged in sections 13 and 14 of the *Rights of Persons with Disabilities Act, 2016* (RPD Act), though limiting from the perspective of the shift of international concept of full autonomy, nevertheless, it is a step forward from the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, which has so long provided for plenary guardianship, a concept which is evidently based on the premise that people with developmental and intellectual disabilities are inherently incapable of deciding their own welfare and need a guardian of both person and property. Moreover, the National Trust Act was seemingly brought about to address the concerns of parents rather than to ensure rights of persons with disabilities themselves and is clearly not aligned with the principles set forth in the CRPD.

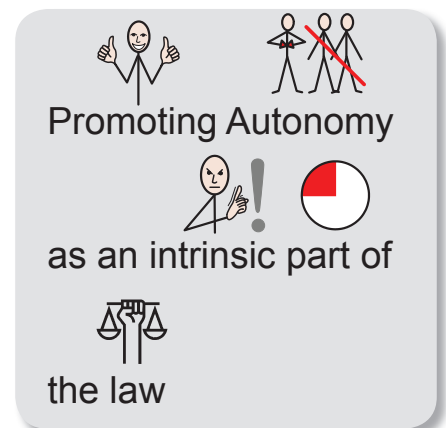
Given this dichotomy between the two laws, there is a need to rethink and reframe the National Trust law of 1999 in the light of the RPD Act, 2016 as well as the UNCRPD. As a law which prescribed for guardianship for ‘adults’ above the age of 18 years of age, the National Trust (NT) Act was considered as one exceptional law at that time, as it catered to the unique requirements of people with Intellectual and Developmental Disabilities (I/DD) with high support needs. However, with the paradigm shift in the approach to disability and the ushering in of the first human rights instrument of the 21st century, the UNCRPD, the concept of ‘guardianship’ as envisioned in the NT Act way back in the 1990s has become obsolete and archaic.

As mentioned, the RPD Act speaks of both ‘legal capacity’ and ‘limited guardian’ and there is a need to deliberate and ponder on these, to decipher the finer nuances of different implications on the ‘autonomy’ of a person with disability.

Clauses (1) and (2) of section 13 of the RPD Act states that the appropriate Government shall ensure that persons with disabilities have rights, equally with others, to own or inherit property, movable or immovable, control their financial affairs and have access to bank loans, mortgages and other forms of financial credit and that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law. This clearly is an enabling provision which recognizes the ‘capacity’ of all persons with disabilities as inheriting all legal rights and enjoying them, irrespective of the nature and degree of disability.

Section 14 of the RPD Act goes on to read as “Notwithstanding anything contained in any other law for the time being in force, on and from the date of commencement of this Act, where a district court or any designated authority, as notified by the State Government, finds that a person with disability, who had been provided adequate and appropriate support but is unable to take legally binding decisions, may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person, in such manner, as may be prescribed by the State Government.”

All things necessary for human existence in terms of Article 21 of the Constitution of India is a right, which, if a person with disability is not able to secure for himself or herself, will negate his or her very right to life. Thus it is envisaged that this is where the state must step in to uphold the right of the individual, if he or she is unable to do so on their own. The fact that there is no straight jacket formula for awarding ‘limited guardianship’ in any particular case, reiterates the fact that ‘guardianship’ can only be resorted to in exceptional circumstances, if



it is sufficiently established that without the same, the welfare of the person with disability would be at stake.

The 'notwithstanding' clause under section 14 (supra), clearly overrides all or any provision of 'guardianship' under any other law as on date and firmly establishes that 'guardianship' now comes under the purview of the RPD Act. As such, the National Trust Act when amended / reframed, has to address special needs of persons with disabilities in all regimes of support systems minus guardianship, as any provision on 'guardianship' under the NT Act would be redundant.

Having said that, there is ample scope to reinforce and strengthen the National Trust law whilst it is now being amended, as it can play a crucial role in the lives of persons with cerebral palsy, autism, mental retardation and / or multiple disabilities, as it is these people with Intellectual and Developmental Disabilities (I/DD) who are continually faced with myriad issues and challenges whilst trying to access their rights.

Personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and always supported, and the National Trust law can be veered towards providing for robust support and putting mechanisms and systems in place which will facilitate and enhance independence of people with I/DD as far as possible. The law can lay down clear mandate on how people with I/DD can access intensive support, in the form of advanced technological gadgets or human assistance or financial aids even, to help them live a fuller life.

Whilst the RPD Act can be deemed to be a generic law in the domain of disability, the National Trust Act has to be seen as a special law meant specifically for the welfare of persons with cerebral palsy, autism, mental retardation and / or multiple disabilities. The National Trust Act to be now amended (referred to as the law hereinafter) should focus on the unique constraints faced by people with I/DD and centre its scope on awareness creation and sensitization on the same; empowerment of persons with these disabilities to live independently; and creating and strengthening facilities to provide support and promote measures for their care and protection; deal with problems of people with disability without family support; and take proactive measures to facilitate access to all rights and equal opportunities for people with disabilities.

The existing schemes under the National Trust Act have to a large extent been a non-starter in many ways in many states across the country, and though the same were revamped a couple of years ago, a huge section of people with I/DD have been unable to access them and been left behind.

Having seen the vagaries of such schemes, one should pause and ponder on the fact if we need yet another battery of beneficial schemes or do we need to have systems in place as clear mandates which will address the need to initiate more novel ways to promote greater self-determination of people with I/DD.

In the aforesaid context, the legislature should incorporate provisions self contained in the Act, as and when it is amended, to address various needs of people with I/DD, instead of delegating and / or entrusting upon authorities to frame schemes and policies from time to time, in as much as, past practice has shown that implementation of provisions through delegated legislation / executive powers does not see the light of the day and / or are subjected to prolonged delays which frustrate / negate the very purpose and intent of the provisions that it aims to achieve.

The law should now look at ways to promote legal emancipation of people with I/DD through supported decision making in place of substituted decision making, thereby allowing the person with I/DD to remain the decision-maker, while choosing supporters to provide decision-making help when needed, self-advocacy, self-determination, independence in various formal/informal setting without limiting the facilitation process to any single model.

The law also needs to provide for health care proxy for a person with I/DD, where the latter can appoint health care agents who will have the authority to make medical care and treatment decisions if the person

The law can also

explore possibilities of

reinforcing capabilities

of individual with

IDD and provide for

options that promote

independent living

becomes incapacitated and this can be executed without involving the Court, to make the process more accessible.

Measures can be in-built in the law which will facilitate in ensuring that 'Limited guardianship' as and when provided, is narrowly tailored and least restrictive and where the individual retains as many rights and responsibilities as possible.

The law can also explore possibilities of reinforcing capacities of individuals with I/DD and provide for options that promote independent living. Facilities provided to people with high support needs like sheltered workshops, and ensuring easy availability of trained care givers and social workers who will supervise and ensure maintenance of standards / quality of care/ living, sheltered employment, participation in community life etc. can cater to their needs at various levels – physiological (caregiving), emotional and social (companionship) - and help facilitate independent living to a large extent. This could be done in the lines of the Olmstead Plan¹, which is a broad series of key activities that the state must accomplish to ensure people with disabilities are living, learning, working, and enjoying life in the most integrated setting.

Needless to say, unless the law incorporates stringent provisions for ensuring accountability of duty bearers as well as care givers and 'limited guardians' towards effective implementation of the law, the law would not deliver and people with I/DD who are more vulnerable and marginalised compared to people with other disabilities will continue to be left-out, shorn of their basic human rights and a life of dignity.



Students of Vikas Scheme from urban slum area of Delhi giving her views

Role of Parents in Building Legal Capacity of Persons with Intellectual and Developmental Disabilities (PwIDDs)

By:- Cdr. Shrirang Bijur, President,
PARIVAAR–National Confederation of Parents Organizations



We are living in a transformational time where new paradigms of human rights, knowledge and networking are emerging. The big question in the mind of parents of persons with intellectual and developmental disabilities is how this is going to benefit their sons and daughters. Are they going to continue to live in the environment of discrimination and denial or will they be part of inclusive society with an opportunity to lead a life like the mainstream citizens. The answer lies in Parents' efforts at transforming their children with **Intellectual Disabilities (ID)**, by enabling them to rediscover own potential and empowering them to recognize their legal capacity to live a life of dignity and purpose.

The persons with Intellectual Disabilities (ID) remain the most marginalized persons in the society. The intellectual disabilities include Mental retardation/ ID, Autism/ ASD and Multiple disabilities involving ID as one of the disability. These persons have one or more disabilities involving lower cognitive ability, challenges in sensory integration, and feeble communication abilities. All these result in their inability to express themselves and understand ways of the world. The social stigma associated with intellectual disability further inhibits PwIDDs to attain the educational, social and economic inclusion.

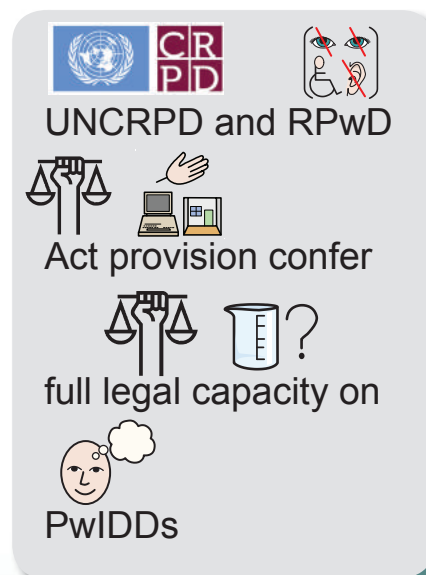
1 Intellectual Disability and Powerlessness

At an individual level, powerlessness can be seen as the belief of a person that his own actions will be ineffective in influencing the outcome of his life events. In the life of a child/ person with intellectual disability this type of notion is reiterated in him/ her every day, in good faith or otherwise, by the family and society.

On another scale, Persons with ID often have had little or no societal interaction and economic capacity and therefore, have lacked the means to gain greater control or generate resources in their lives. Their powerlessness may be a direct result of social out-casting, marginalization, poverty, exploitation and abuse. Many times over bearing protection [within the confines of family] also results in powerlessness at adult age.

2 What National Trust Act, UNCRPD and RPwD Act 2016 means to Persons with Intellectual disabilities.

UNCRPD and RPwD Act provisions confer full legal capacity on PwIDDs. Consequently RPwD Act 2016 provides for only limited guardianship for PwIDDs where the final decision affecting their life has to be their own or a joint one. This 'Limited Guardianship' means a system of joint decision making which operates on mutual understanding and trust between the guardian and the person with disability. However unlike in developed countries the majority of PwIDDs in India are as yet powerless and marginalized in the society and dominated at home. In order for people with ID to take charge of their life, they need to become aware about themselves and their capacity. They require coaching to gain self-confidence, recognize their living environment and communicate their requirements and work with others for effecting change. That is empowerment of persons with ID.



The Mental Capacity Act (MCA) of UK is a good case in point to instill legal capacity. This Act has been in force since 2007 and applies to persons with ID who may not have capacity to make necessary decisions and require support for that. The primary purpose of the MCA is to promote and safeguard decision-making within a legal framework. It enables this by empowering people to make decisions for themselves wherever possible, and by protecting people who lack capacity by providing a flexible community based framework that places individuals at the heart of the decision-making process.

This is in conformity with RPwD Act 2016 Section 15(1) and Section 15(2) which read as follows:

15(1) The appropriate Government shall designate one or more authorities to mobilize the community and create social awareness to support persons with disability in exercise of their legal capacity.

15(2) The designated authority shall take measures for setting up suitable support arrangements to exercise legal capacity for PwDs living in institutions and those with high support needs and any other measures as may be required.

Here the five cardinal operative principles of MCA Act become much relevant to Indian context. The principles 1 to 3 will support the process before or at the point of determining whether someone lacks capacity. Once it is decided that capacity is lacking, then principles 4 and 5 are used to support the decision-making process.

Principle 1: A presumption of capacity

Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise. This means that you cannot assume that someone cannot make a decision for themselves just because they have a particular medical condition or disability.

Principle 2: Individuals being supported to make their own decisions

A person must be given all practicable help before anyone treats them as not being able to make their own decisions. This means you should make every effort to encourage and support people to make the decision for themselves. If lack of capacity is established, it is still important that you involve the person as far as possible in making decisions.

Principle 3: Unwise decisions

People have the right to make decisions that others might regard as unwise or eccentric. You cannot treat someone as lacking capacity for this reason. Everyone has their own values, beliefs and preferences which may not be the same as those of other people.

Principle 4: Best interests

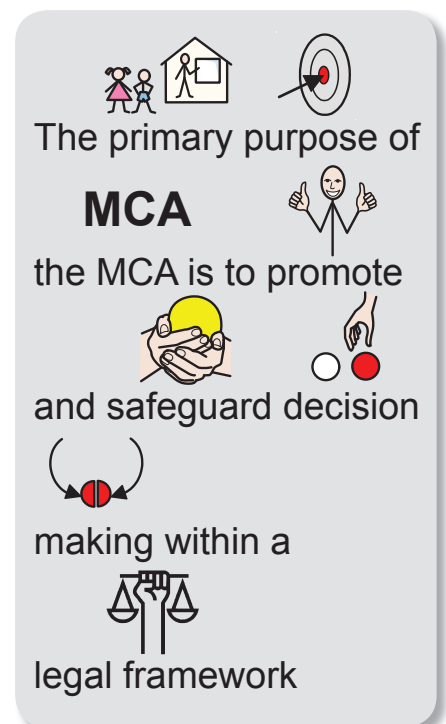
Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests.

Principle 5: Less restrictive option

Someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all. Any intervention should be weighed up in the particular circumstances of the case.

3 Self Advocacy & Mentoring – Empowerment by Parents

Due to inherent deficit in cognitive ability many Persons with ID do not acquire the capacity to enjoy their rights and entitlements, like other PwDs / general population. They need to be mentored to attain such capacity. Such mentoring remains their life time requirement (like braille/ Jaws for blind, and sign language/ hearing aid for hearing impaired). Having such mentorship that enables their social inclusion, decision making (however small), protecting own interest, independent living etc is but an essential assistive system for their life. A mentor coaches Persons with ID in groups to mitigate the effect of intellectual disability by infusing SELF ADVOCACY (स्वसमर्थन). Such coaching is not one time but is held periodically over the time. The persons who go through such self advocacy training are addressed as Self Advocates.



a. What Self Advocacy achieve for Persons with IDs

The Self Advocacy training transforms a person with intellectual disability to recognize himself as a person and his inherent potential. Mentors coach the persons with ID to understand his/ her rights towards Social equality, Non-discrimination, Free access, Social protection, Equal opportunities, Affirmative action and Right to live with human dignity which make their life “meaningful, complete and worth living”. Though unaware the Self Advocates practice these fundamental rights and moves closer to attaining legal capacity. In other words, Self advocacy is a key for persons with ID to unlock his/ her Legal Capacity, with or without the option of having a guardian

b. What is Self Advocacy for Person with ID

Self Advocacy is an interactive process enabled by a trained Mentor by which persons with ID experience personal and social change, enabling them to take action and influence their environment, communities and institutions which affect their lives.

Self advocacy curriculum is designed to inculcate qualities in the PwIDDs; Recognizing self, Recognizing the environment around, Self-confidence that infuses equality with others, Ability to communicate ones views, Understanding of ones rights and responsibilities in social environment, Listening skills, Interpersonal relationships, Problem solving, Decision making, Peer supporting and Self protection .

c. Where all is Self Advocacy required by Person with ID

At home, At school, In public garden, At mall, In public transport, During festivities, At social functions, During shopping, At job interview, In residential home, At assisted workshop, During religious occasions, For social inclusion, For developing a Support system, At work place, To benefit from restricted guardianship.

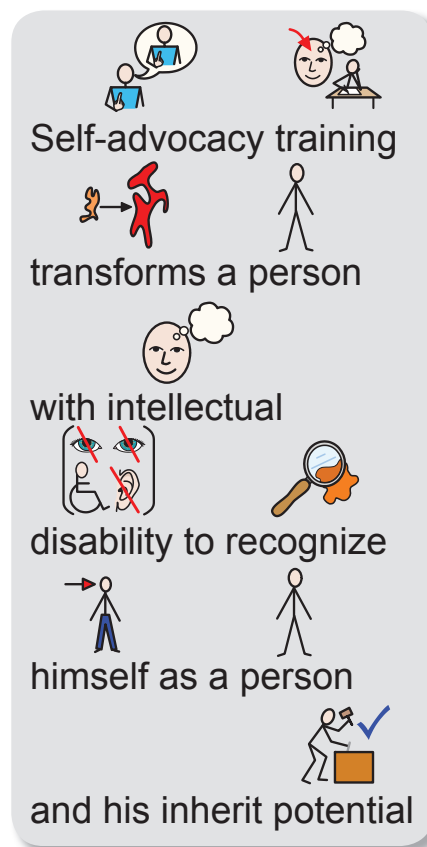
d. Parents’ advocacy

The parents are also much worried about the integrity of appointed guardian after their (parent’s) demise. Therefore the parents have to continuously advocate to government and the National Trust to fulfill the regulatory role in this regards. The Sections 15 & 16 of the National Trust Act stipulate the monitoring of appointed guardian. The advocacy principle; present parents work for the past parents and future parents will work for the present parents.

4 Role of Parent – Mentor in building legal capacity of person with ID.

A Parent-mentor is closely associated in transforming Person with ID in to a Self Advocate. Parent-Mentors are trained during Mentor training to support the decision making capability and capacity of persons with ID. Such training is oriented towards achieving a positive pointers for the following questions:

- Does the person understand the information that is relevant to the decision that needs to be made?
- Can the person hold the information in their mind long enough so that they can use it to make the decision?
- Is the person able to weigh up that information and use it to arrive at a decision?
- Is the person able to communicate his/her decision (by taking, using sign or body language or any other means)?



At the end of the day some persons with ID may still lack the competence to make the decisions because they do not possess the necessary intelligence and understanding to make that particular decision. Still in such cases type and extent of support required will be known. The Parent-mentor also sensitize the support system towards the situational analysis of decisions, in the context of :-

- What is the right option for the Self Advocate (person with ID) in a given situation.
- Will it make a meaningful difference in the life of Self advocate
- What can be done to promote social well being
- How can social relationship with community be enhanced
- How to ensure that Self advocates gets same support to avail incentives and provisions as the other PwDs
- What constitutes "Good life" for a Self-advocate considering the extent and level of disability.

5 Parivaar and Self Advocacy Movement in India

Parivaar is a confederation of 272 parent organizations in India. It took the opportunity to provide support to persons with intellectual and developmental disabilities to recognize own potential and get counted in the society as Self advocates. But nothing comes easy in life and so is the transformation of persons with intellectual disability into Self advocates. Parivaar picked up the nuances of Self Advocacy from Inclusion International and was supported by CBM in this endeavor.

To make self-advocacy a sustainable movement in India, Parivaar planned and formed team of Master trainers to conduct training of trainers in different states of India. That enabled some states to have their own master trainers who could conduct Mentor training for parents & community volunteers. NIEPID and NIEPMD have published the Mentor training handbook that provides step by step approach to potential mentors to coach persons with ID. Hundreds of mentors have been trained across India but Self Advocacy is yet to become a national movement for persons with ID.

But Self advocates are here to create their own identity in a Social Justice framework.

6 Conclusion:

- Parents are the most important link to bridge the gap between Human Rights and Framework of legal guardianship. If parents are made aware about the functionalities involved in a decision making process, they can train their son/ daughter with ID to at least make routine simple decisions.
- The legal capacity guaranteed by CRPD and RPwD Act is a significant achievement towards human rights of persons with ID. In this regards Self Advocacy Training is an important step towards reaching that goal. Self-Advocacy training will enable the person with ID to achieve social adaptation and practice his decision making potential to fullest. The gap, if any, can be made up by guardian or supported decision making environment.
- RPwD Act has regulatory provisions to introduce 'Supported Decision Making' in the country. Parent organizations like Parivaar need to take fresh initiative which can be supported by Social Justice department and the National Trust.
- Self Advocacy is not merely a training or a program but a movement, a way of life, inculcated among the people with intellectual disabilities and in their surrounding environment. This movement is good for persons with ID as well as their parents for social inclusion and harnessing the potential.
- The responsibility of the government to empower Persons with ID with legal capacity does not cease with provision of support system for making decision. Monitoring such arrangement to ensure that it is working in the best interest of person with ID should follow, for which support of parent bodies may be solicited.

Role of parent- Mentor
in building legal capacity.

Parivaar is a
confederation of 272
parent organization in
india

The way of Building Legal capacity of persons with Intellectual and Developmental Disabilities

By:- Bibhuti Bhusana Nanda, Special educator
Open Learning Systems, Bhubneshwar, Odisha

Legal capacity means an individual is able to act or make decisions in various situations and for the action to be recognised as lawful. They need support to overcome barriers to their decision making through reasonable accommodation or making changes in their environment. That should start from the family and expanded to every aspect of their social and political life.

In this point of view, somewhere system is ready to provide participation but participation is poor due to lack of awareness and attitudinal barriers. Somewhere the system and the environment are not accessible for the person with ID and developmental disability. That should be looking after by every citizen of our country. Legal capacity will be increased when they will be free from the over protection and under valuation by the others of their environment. On the other hand, due to lack of appropriate rehabilitation professionals they are deprived from the timely need based intervention and services. So this requirement should be provided on priority basis for building their legal capacity.

The technology is influencing and rapidly changing in every aspect of development and human life. Technology is playing a vital role for making the work easier and quickest. So in this context the application of modern technology will definitely remove the barriers faced by the persons with Intellectual and Developmental Disabilities. It will be helpful for enhancing the legal capacity of the segregated section of human resource of our country and make them independent and productive by which they will develop their legal capacity of their own.

A suitable and accessible environment is required for strengthening their legal capacity through the active and full participation in different aspects of their life. A strong alternative communication is required for strengthening the legal capacity and information sharing. It was found that when someone gains the appropriate information about the different schemes and facilities then definitely they or their parents/guardians will be enabled to strengthen the legal capability by availing the facilities.

It was found that most of the persons with intellectual and developmental disabilities have poor knowledge about what are the legal provisions for them. It is the duty of every citizen of the country not only to make the legal provisions for them but also create awareness and make the system accessible for them. By which the PwIDDs will have easily built their legal capacity. In this regard every institution working for the persons with disability at the grassroots level should have sufficient information and knowledge regarding the legal provisions for ID and persons with developmental disabilities. Each and every institution should work as an information centre for them. In this way they can develop their Legal capacity in a better way.

Vocational training and job should be given to them as according to their specific ability and interest instead of specified qualification by which they will equally and meaningfully participate in different aspects of productive activities instead of maintaining a segregated life.



Legal Capacity means



an individual is able to



act or make decision



in various situation



Free counselling



centres help the



parents and the



person with ID and



Developmental



Disability

Free counselling centres required for the parents and the persons with ID and Developmental Disabilities and services provided at their doorstep for developing their Legal Capacity and ensure the full participation in different aspects of their life.

Rehabilitation professionals, teachers, Lawyers and concerned government and non-government functionaries should have enough knowledge regarding the legal provisions for the person with disability specially the persons with ID and developmental disabilities. By which they will strengthen their legal capacity by the equal and full participation in every aspect of social and political activities in a meaningful way.



Skill Development Training in IT and Data Entry operator at Aaryaman Centre of Excellence (ACE)

Initiatives and Achievements of State Commissioner for Persons with Disabilities, Govt. of Bihar

By:- Dr. Shivajee Kumar, State Commissioner Disabilities, Social Welfare Department,
Govt. of Bihar, Patna



Introduction:

The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) marks a paradigm shift in the way disability is conceptualised. It considers persons with disabilities as holders of rights on an equal basis with others and puts the person at the centre of all decisions affecting him-or herself. Such a rights-based approach to disability has profound implications for legal capacity legislation and its implementation.

Building legal Capacity for IDD and other disabilities in Bihar by:-

- Mobile Courts.
- Sensitization and awareness among public.
- Sensitizing govt. administration personals.
- Helpline Number for PwDs.
- Empowering through Sports and Games.
- Inspection of Special schools.
- Impacts of initiatives and awareness programs.
- Access audits.
- Important Days Celebration.
- Summons and so Cause notices.
- Sharing of Ideas and initiatives.
- Accessible Election

Mobile Courts: In the year 2018 to till the date 23 mobile court at different districts has been organized to attempt to solve the problems of different PwDs.

Madhubani, Bettiah, Bhagalpur, Gaya, Rohtas, Saran, Purnia, Muzaffarpur, Munger, Vaishali, Jahanabad, Saharsa, Bhojpur, Darbhanga, Supaul, Jamui, Patna, Aurangabad, Sitamarhi and Siwan



Settlements of Disputes During Mobile Court-

Execution of Complaints during Mobile Court by State Commissioner Disabilities in the year 2018-19



Sports

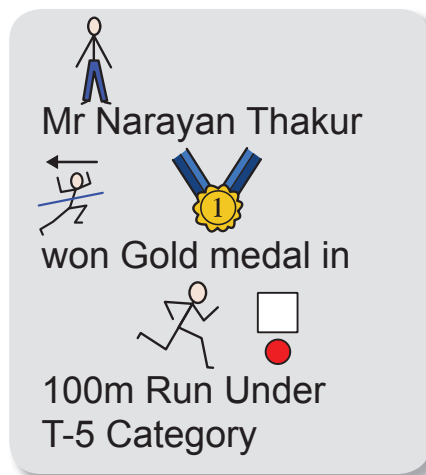
Good news for Para Athletes that Department of Sports (Arts, Culture & Youth Affairs) Govt. of Bihar has taken good decision after our letter to add to cash prize for World Para Athletics Championship and the cash prizes will be now- 75 Lakh for Gold, 50 Lakh for Silver and 30 Lakh for Bronze medal winners for Paralympic Medal Winners in Bihar. Its win of fraternity of Physically Challenged Sports Persons. Good Luck many more yet to come from Govt. of Bihar. Our CM, Social Welfare Minister and Sports Minister are eager to do more and more for Divyagjan (Physically & Mentally Challenged Athletes)

Sports Success Glimpses-

First time in the history of India Athlete of Bihar **Mr Narayan Thakur** from Darbhanga (Concy simri) won Gold in 100M Run under T-35 Category in Para Asian Games 2018 Jakarta today Even in Abled Body also in Men category none of Athlete won Gold in 100m from India Congratulations to Mr Narayan Thakur. He is Cerebral Palsy Athlete.

Sharad Kumar of Bihar (Muzaffarpur) won Gold in High Jump with world record of 1.90M Jump under T42 / 63 category in Asian Para Games 2018 Jakarta (Indonesia) Congratulations to SHARAD

Mr Parmod Bhagat - Para Badminton Player From Bihar (Hajipur) Won two medals Doubles - Bronze Individual- Gold Asian Para Badminton 2018 Jakarta Many Many Congratulations to Parmod Bhagat.



Credit : Coloured by Nishu Jain, Bliss of Life, Care Project, Manovikas

Initiatives by Government of Odisha

By: J Mahala, OAS(S) Joint Secretary to Govt. of Odisha

Prologue:

Ensuring the rights and entitlements of the individuals on the spectrum of intellectual and developmental disabilities and creating an enabling environment for them, is one of the fundamental duty of the State Governments as well as the civil society as a whole. While, legal provisions through the Rights of Persons with Disabilities Act, 2016 (RPWD, 2016) are in place; there is a pressing need to translate the same into practical applicability across various ages and stages of life of a person with different ability. In the context of Odisha, the Department of Social Security and Empowerment of Persons with Disabilities, Govt. of Odisha, has come up with manifold service delivery mechanisms and legal empowerment of persons with intellectual and other developmental disabilities. The services are in cohesion with the provisions of the RPWD Act, 2016 and further activities are being undertaken to augment the efficacy, meaningfulness of legal ethos and practice in the context of disability.

Quantitative Milestones:

Significant Positive Changes through Legislations and Schemes: Best Practices:

Through various services, schemes, rules and entitlements, the Department of Social Security and Empowerment of Persons with Disabilities has brought about positive outcomes in terms of enabling the individuals with intellectual and developmental disabilities, empowerment, legal advocacy, IEC campaigns, and adopting a rights based approach rather than welfare based perspectives. Some best practices include:

- **Facilitating Self-Advocacy:** Self-advocacy and Psycho-education regarding the Acts, provisions, and entitlements are being facilitated with the help of Parent-Therapist Collaboration Programs. Youth and individuals with special needs who are in a better range of cognitive functioning are able to act as self-advocates and stand for their legal immunity across different situations.

- **Life Skills and Governmental Handholding:** The SSEPD Department, through its rights based approaches and partner organizations have been tirelessly working in terms of enhancing the life skills and legal empowerment of children and individuals with developmental disabilities.

Counseling, felicitating exceptional dedicated services, life skills with civic studies and legal frameworks are being reinforced among the masses with Governmental Handholding, civil society organizations and individuals working collaboratively for the cause.

- **Mechanisms to monitor and prevent contravention of provisions under the Acts, rules as well as regulations:** Appropriate

monitoring and grievance redress mechanisms are being undertaken to prevent contravention of provisions under the Acts, rules, and regulations and ensure appropriate actions to be taken in case of infringement. The State, District level officials and other field functionaries work on a joint venture to build the legal capacity of the individuals with special needs and improve their overall quality of life.



Way Forward: Future Vision:

With regard to the vision enshrined in the RPWD Act, 2016, the SSEPD Department envisions to widen the wavelengths of building legal capacity of persons with Intellectual and Developmental Disabilities:

Multisensory IEC:

Research allusions, evidence based studies and observations indicate that individuals with Intellectual Disabilities, Neuro-developmental disabilities including sensory processing disorders, tend to learn well when imparted relevant training through audio-visual as well as multisensory information. The Department plans to develop relevant multisensory IEC to disseminate information and legal capacity building among the individuals with intellectual and developmental disabilities.

Neuro-cognitive Psycho-education and Legal Counseling:

Neuro-cognitive measures are helpful indicators in developing neuro-plasticity of the brain-behaviour linkages and nervous system related impairments. Therefore, developing neuro-cognitive interventions to train individuals on legal aspects is one of the promising fields of support services and legal capacity building. The resource pool of technical experts in the State Department have been engaging in the process of developing neuro-cognitive legal capacity and psycho-education skills in the children and individuals on the spectrum of special needs.

System Strengthening through Rights Based Approaches rather than Welfare Approach:

Right to Life with Dignity as a perspective to love, accept, respect and to work in a sync with the best interest of the individual with intellectual and developmental disabilities are one of the primary focus of the State Department. Imbibing rights based thought and cognitive brainstorming within the individuals, peer-learning, knowledge-exchange; insight sharing and behavioural ergonomics are some of the focal areas of future interventions.

The Differently Abled Senate: Freedom of speech, expression and ensuring one's fundamental rights are the backbone of a successful democracy. Moreover, building a society in which no one is left behind or left out shall help in creating an inclusive world along with legal enabling, meaningful survival and empowerment. The Department envisages strengthening the differently able by facilitating an intrapersonal and interpersonal Senate within them. This shall enhance their legal capacity, advocacy and dignified survival in the society.

Multi-stake Convergence:

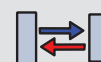
Legal capacity building is incomplete unless stakeholders across all the latitudes of the civil society unite together for a common cause. As a way forward for legal capacity building, the Department also envisions to create inter-departmental and multi-stake convergence to establish information-related and service delivery linkages for the individuals with intellectual and developmental disabilities.



Multi-stake convergence



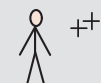
establish information



related and services



delivery linkages for the



individuals with



intellectual and



developmental



disabilities

Initiatives by Government of Lakshadweep

By:- T Kasim, Director, Social Welfare Department Govt. of Lakshadweep

State Pension Scheme:-

The U.T of Lakshadweep Administration is implementing a "State pension scheme" for the following categories:-

- Old age
- Senior Citizens
- Widow
- Differently Abled
- Abandoned Ladies

The scheme also includes disabled for helping special abilities. There are 590 differently abled beneficiaries under this pension scheme. The total pension rate is Rs.1000/- per month.

NSAP Pension Scheme

- There are 68 Differently abled (including all categories) beneficiaries under this scheme, being paid through DBT (Direct Benefit Transaction). The scheme is implemented through District Panchayat. The total pension rate is Rs.1000/- per month including state share (Rs.700/- as state share and Rs.300/- as central share).
- No Central share received from 2012-2013 to till date. However the Central Share is being paid from state own fund.
- The above sanctioned (Central Share) fully utilised and requested to Ministry of Home Affairs / Rural Development for providing the pending Central Share.

Lakshadweep Administration ensures 5% quota in all Sate Govt. schemes for Persons with Disabilities with reference to the Right of Persons with Disabilities Act, 2016.

Day Care Centers

- Three day care centre's are functioning in the Islands of Kavaratti, Androth & Kadmat. Most of Students in these centers belong to Mentally Retarded category.
- Action is on hand to establish 3 more Day Care centers in the islands of Agatti, Amini and Minicoy.
- There are specially trained teachers at each Day care centers for imparting self help skills, speech therapy, writing skills etc...
- Free of cost 'To and Fro' pick and drop facilities to day care center including Nutrition, Learning Materials, Medical Check-up are provided to Specially Abled Children.

Assistance to Marginalised section of society

- The Department arranges to provide artificial limbs, wheel chairs, tricycle, hearing aids etc. to the needy persons (i.e. Differently abled persons) considering their financial difficulty.
- Total 1018 assistive devices for 523 beneficiaries have been procured from KELTRON, Kerala and distributed through Medical Department (NHM).
- The department is also conducting training & workshop programme for empowerment of marginalized people.



Day care and marriage



allowance offered by



state government of



Lakshadweep for the



person with Intellectual



Disability

Rs 1000 NSAP



Rs 1000 NSAP pension



Scheme offer to



person with disability in
Lakshadweep

Marriage Allowance

- “Marriage Assistance to Persons with Disabilities” to support the expenditure during the marriage functions and to encourage the beneficiaries to lead a normal life.
- Under this scheme an amount of 30,000/- will be paid to the Native, disabled/differently abled bride groom/bride. The Scheme is applicable for first marriage only.
- The scheme is for both the APL as well as BPL families, irrespective of income criteria.
- Person having disability (40% and above) is entitled for this scheme.

National Programme for Rehabilitation of Persons with Disabilities

- The scheme is run through ‘the Lakshadweep State Health Society’ under the National Health Mission.
- Activities like, Disability assessment and distribution of aids & appliances like wheel chair, crutches, hearing aids, teaching learning materials, electronic wheel chair, motorized tricycles, tricycles, etc. are carried out.

Specialised Treatment for Persons with Special Abilities

- The department provides Financial Assistance to the disabled persons for specialized treatment at mainland along with one escort.
- The medical department (NHM) certifies the patients needs.
- Till date 76 Nos of beneficiaries have received the benefit.
- Funds are allocated to Medical Department (NHM) based on utilization certificates
- * person with more than 40% disability are eligible for this scheme
- * up to 50% of the total cost is reimbursed.
- * maximum amount is Rs. 1.25 lakh per person.

Scheme for Special Job

- The scheme is for providing the employment to Educated unemployed Persons with special abilities (those who could not get regular employment).
- Engagement of MRWs: total 09 Nos of Multiple Rehabilitation Workers are appointed under the NPRPD(National Program for Rehabilitation of Persons with Disability) scheme for assisting disabled persons to obtain facilities available in the department and to work as a link between department and disabled persons. One each MRW has been appointed in all Islands.
- Lakshadweep Administration ensures 4% reservation criteria in recruitment of Govt job based on RPwD Act 2016.

Action taken on RPwD Act-2016

- Department of Social Welfare & Tribal Affairs is implementing the RPwD Act 2016.
- Appointed State Commissioner for PwDs.
- The Director (Services), Secretariat is maintaining separate roster for PwDs.
- The Medical board is issuing Disability Certificate.
- Resource Persons for Children with Special Need have been appointed under Samagra Siksha Abhiyan(SMSA) and their service being utilized for teacher training purpose for PwDs.
- Department of Sports & Youth Affairs is taking case of Divyangjans also in sports field.
- The State Advisory Board has been appointed Under Chairmanship of Hon’ble Administrator in this UT.
- This UT approached the Hon’ble High Court of Kerala for concurrence of Chief Justice to designate the

Lakshadweep



Administration ensures

4%

4% reservation criteria



in recruitment of



Government Jobs



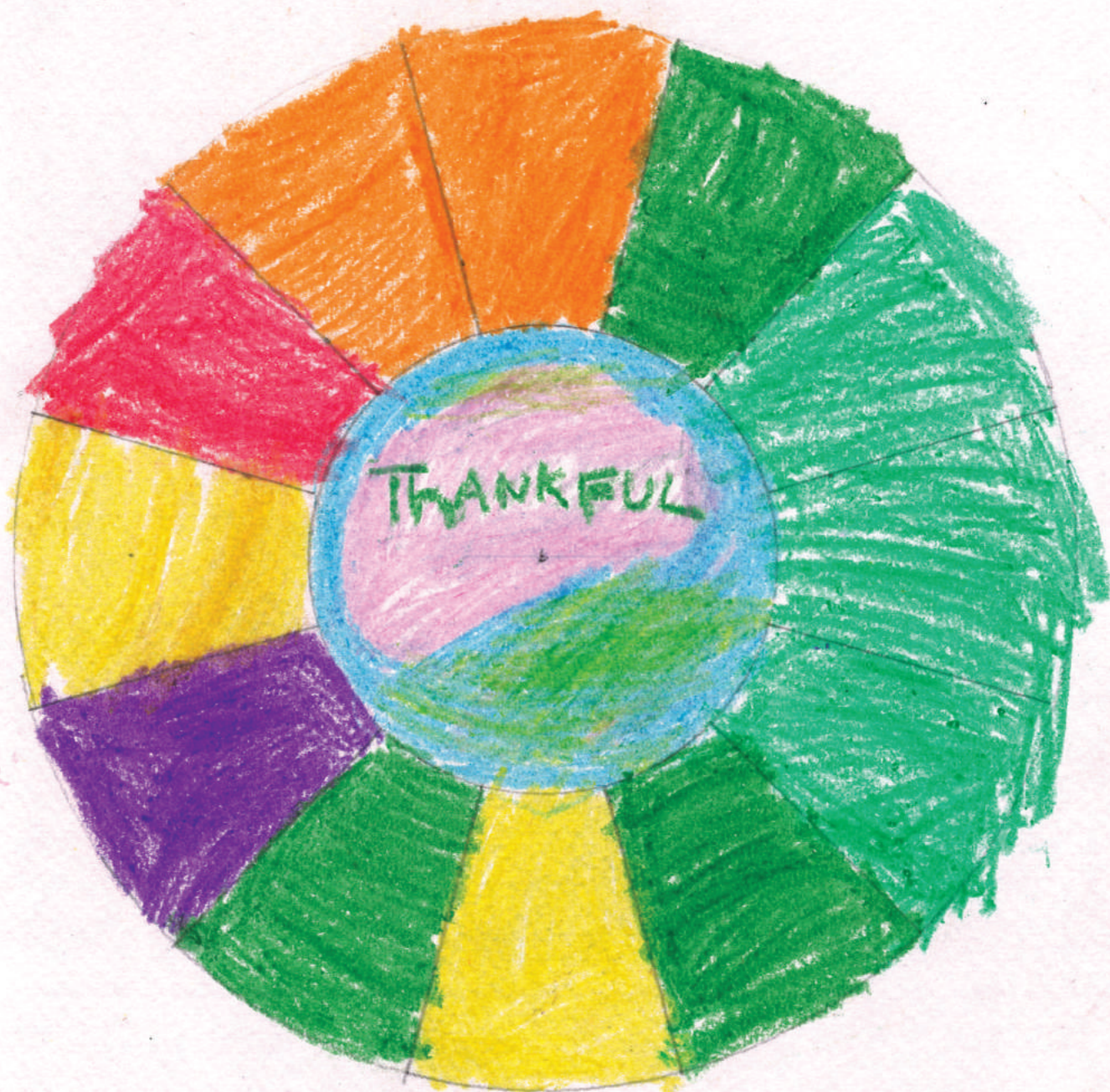
based on RPwD Act.

District Court at Kavaratti as Special Court and to appoint the additional Public Prosecutor as Special Public Prosecutor.

- All the Department under the Administration has appointment Nodal Officer to look into grievances of Divyangjan.
- UT's scholarship scheme being Implemented as such Scholarship schemes for Differently abled.
- The Lakshadweep Public Works Department (LPWD) catering the building requirements of the Administration have already been completed retrofitting in almost all the existing buildings to provide barrier- free environment.
- The Govt ITI Kavaratti is providing required reservation for the Divyangjan for the Vocational Training in various courses.
- The Department of Social Welfare and Tribal Affairs in association with the departments of Education, Medical, Women & CD and Information & Public Relations conducting awareness programmes.
- Training has already been imparted to the concerned officials. Action is on to appoint state level coordinator and collection of Data from the field level functionaries for digitalization.
- Already being to implemented possibilities are being for establishing (starting special school).



Sharing experience with visitor during hospitality skill development training at Manovikas



Credit : Emotions of Wheel by Particepent of Creative Art Therapy Workshop during World Mental Health Day, 2019, Manovikas



SECTION-II

Social Security, Health and
Rehabilitation



Inclusive Education—why it is imperative for Persons with Autism, Cerebral Palsy, Intellectual Disability and Multiple Disabilities in contemporary India....

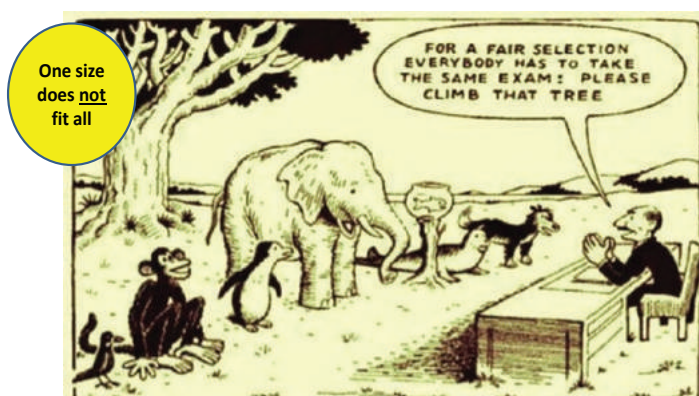
By:- Aloka Guha

Ex-Chairperson, National Trust



1. Introduction

Historically viewed as welfare recipients, persons with disabilities are now recognised under international law as right-holders, with a claim to **the right to education without discrimination and on the basis of equal opportunities**. The United Nations Convention on the Rights of the Child (CRC, 1989), the World Declaration on Education for All (1990), the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities (1993), and the Salamanca Declaration and Framework for Action (1994) all embody measures testifying to the growing awareness and understanding of the right of persons with disabilities to education.¹



One size does not fit all

Each person has her/his individual profile of strengths/ limitations, and needs to be understood as such

Recognition of inclusion as the key to achieving the right to education has strengthened over the past 30 years, and is enshrined in the Convention on the Rights of Persons with Disabilities, which, in India, has been reflected in, and harmonized with, the **Rights of Persons with Disabilities Act 2016, RPwD². Sections 16 and 17 of Chapter III, deal exclusively with Inclusive Education, (or IE) whereas Section 31 of Chapter VI offers a choice to persons with Benchmark Disabilities, (BMD) between Inclusive and Special Schools.** Sustainable Development Goal (SDG) 4, also affirms the absolute need for inclusive quality and equitable education. Given below are the disability - related- targets/indicators under SDG 4.

Need for inclusive
quality and equitable
education

¹. General comment No. 4 (2016) Article 24: Right to inclusive education

² The Rights of Persons with Disabilities Act 2016, was passed by both Houses of Parliament and came into effect in April 2017.

Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all	
4.5 By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples and children in vulnerable situations	4.5.1 Parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as disability status, indigenous peoples and conflict-affected, as data become available) for all education indicators on this list that can be disaggregated
4.a Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all	4.a.1 Proportion of schools with access to: (a) electricity; (b) the Internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) adapted infrastructure and materials for students with disabilities; (e) basic drinking water; (f) single-sex basic sanitation facilities; and (g) basic handwashing facilities (as per the WASH indicator definitions)

Contemporary India is an aspirational India...and so it should be, for ALL Indians, not just for a select few. After all, Education is now a Fundamental Right.³

2. Continuing, Persistent and Pervasive Challenges

While there is general agreement that some progress has definitely been made in IE, in India, especially after the implementation of the IE component of the Sarva Shiksha Abhiyaan in 2001⁴, and later passage of the Right to Education Act/Amendments⁵ in 2009 and 2012 respectively, it is also acknowledged that challenges continue to hinder the full implementation of IE in India. These challenges vary from region to region and include systemic, attitudinal, communicational and structural barriers. **Implicit in the last statement, is the lack of adequate teacher preparation, school readiness, financial constraints, awareness, funding mechanisms, legal remedies and reasonable accommodations.** The unintended consequences of these shortcomings has resulted in the continuation of stereotypes about persons with disabilities, as being unable, unwilling and unacceptable in mainstream institutions of education. **Low levels of awareness about the rights, abilities and talents of persons with disabilities, has resulted in low expectations from policy makers, professionals, communities and even from family members and persons with disabilities themselves.**

Poverty has been perhaps the biggest challenge of all, as low-resourced countries struggle to provide decent levels of education to all its citizens; indeed poverty and disability have a bi-directional link, as explained in the graphic below.

Absolute poverty excludes absolutely, and this exclusion leads to entrapment and entrenchment of persons with disabilities in a cycle of exclusion from health, education, employment and community life.

Poverty has been perhaps the biggest challenge

Disability is no longer thought of as an individual problem, it is considered to be a developmental issue

³ 86th Constitutional Amendment in 2002

⁴ Now subsumed under the Samagra Shiksha Abhiyaan of M/HRD, GOI

⁵ The RTE owes its origins to the 86th Amendment of the Constitution, making Education a Fundamental Right.



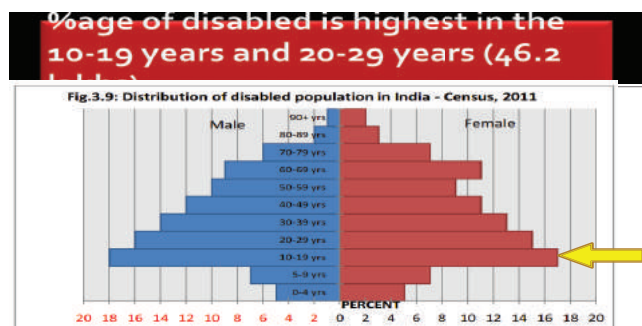
3. Prevalence and other disability-related Data

Disability is no longer thought of as an individual problem, it is now considered to be a developmental issue, and a societal one. While estimates may vary, and Census of India shows 2.21%,⁶ there is growing evidence that individuals with disabilities comprise 5% to 8% of the Indian population (*WHO/ UNICEF World Disability Report1 2011*).

The Table below shows disability-disaggregated data, wherein Movement, Visual and Hearing Impairment are seen to have higher prevalence rates individually, but a combined aggregate of Mental Retardation⁷, Multiple Disability and Any Other (an informed guess would probably include under “any other, more complex disorders like ASD, CP⁸)...this is the group represented by the National Trust and collectively aggregates to roughly 30% of the total population of persons with disabilities in India. The National Trust’s role in IE is a clear and cogent one, especially when it is supported by data that THIS IS THE MOST EXCLUDED GROUP from all economic, social and cultural human rights.

Type of Disability	Persons	Males	Females
Total	100.0	100.0	100.0
In Seeing	18.8	17.6	20.2
In Hearing	18.9	17.9	20.2
In Speech	7.5	7.5	7.4
In Movement	20.3	22.5	17.5
Mental Retardation	5.6	5.8	5.4
Mental Illness	2.7	2.8	2.6
Any Other	18.4	18.2	18.6
Multiple Disability	7.9	7.8	8.1

Source: C-Series, Table C-20, Census of India 2011



⁶ Census of India 2011

⁷ The Census 2011 data predates the RPWD Act 2016, where MR is substituted by Intellectual Disability, ID

⁸ Autism Spectrum Disorders and Cerebral Palsy

4. The case for Inclusive Education

The previous graph shows that the **prevalence of Disability is highest in the age-range of 0-19 years, which are, obviously the school-going age group.** Does that mean that given the RTE, the SSA etc., ALL children with disabilities are going to schools.... Govt. Or private? Nothing can be further from the truth, **there are very significant numbers of the NT's target group who have NEVER been to school,** as the next two graphs show:-

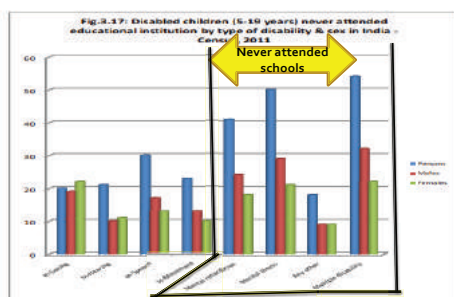


Haben Girma..
pwDB, graduate,
Harvard Law
School

**No child is learning
impaired.**

UNESCO 2005

• 54% of the disabled children with multiple disabilities never attended educational institutions. Also, 50% of the children with mental illness never attended educational institutions.



Disabled non-workers

Type of disability	Students	Dependents
Seeing	28%	42.7%
Hearing	32.5%	38.7%
Movement	19.7%	49.8%
Mental retardation	24.5%	57.7%
Mental illness	9.3%	66.6%
Multiple disabilities	15%	65.9%

The 2 tables shown above are co-related....among children with disabilities, the MOST EXCLUDED from Schools, are those with MR, MI, Any Other and MD⁹. Exclusion from education is directly proportionate to non-representation in the workforce, which, then results in dependence on others, as seen in the 2nd table above.. COSTS OF EXCLUSION are high and is directly reflected in a country's GDP.¹⁰

(i) So, what is the big deal about Inclusive Education?

The most authentic and most endorsed reasons are contained in the UN's General Comment no. 4. on Article 24 of the CRPD "The General Comment is applicable to all persons with actual or perceived disabilities.² The Committee recognizes that some groups are more at risk of exclusion from education than others, such as: **persons with intellectual disabilities or multiple disabilities, persons who are deaf-blind, persons with autism** or persons with disabilities in humanitarian emergencies."



Respect inherent



dignity and autonomy.



Acknowledges individual



requirements and ability



to effectively be included



in and contribute to



society

⁶ Census of India 2011

⁷ The Census 2011 data predates the RPWD Act 2016, where MR is substituted by Intellectual Disability, ID

⁸ Autism Spectrum Disorders and Cerebral Palsy

⁹ Mental Retardation, Mental Illness and Multiple Disabilities

¹⁰ WB Study on Exclusion of PWDs in Bangladesh, 2012

Inclusive education is to be understood as:

- **A fundamental human right of all learners.**
- **A principle that values the well-being of all students**, respects their inherent dignity and autonomy, acknowledges individual requirements and ability to effectively be included in and contribute to society.
- **A means of realizing other Human Rights.** It is the primary means by which persons with disabilities can lift themselves out of poverty, obtain the means to participate fully in their communities, and be safeguarded from exploitation. It is also the primary means through which to achieve inclusive societies.
- **The result of a process of continuing and pro-active commitment to eliminate barriers** impeding the right to education, together with changes to culture, policy and practice of regular schools to accommodate and effectively include all students.¹¹

States parties must ensure that education conforms to the aims and objectives of ICESCR as interpreted in the light of the World Declaration on Education for All (Jomtien, Thailand, 1990) (art. 1), the CRC (art. 29 (1)), the Vienna Declaration and Programme of Action (Part I, para. 33 and Part II, para. 80), and the Plan of Action for the United Nations Decade for Human Rights Education (para. 2).

Regarding article 24, paragraph 3, many **States parties are failing to make appropriate provision for persons with disabilities, particularly persons on the autism spectrum, those with communication impairments and with sensory disabilities**, to acquire the life, language and social skills essential for participation in education and within their communities.¹²

The Committee calls States parties' attention to general comment on article 12 (CRPD/C/GC/1) and stresses that inclusive education provides an opportunity to develop the expression of the will and preferences of students with disabilities, **particularly those with psychosocial or intellectual impairments. States parties must ensure that inclusive education supports learners with disabilities in building their confidence to exercise legal capacity, providing the necessary support at all educational levels including to diminish future requirements for support in its exercise, if they so wish.**

This, then is the reason why the NT's specific group of individuals with disabilities, need IE.

Regarding implementation of IE at the national level, the Committee recommends, .a) Responsibility to rest with Education Ministry, b) need for comprehensive and inter-sectoral commitment across the Government, and c) comprehensive and co-ordinated legislative and policy framework for IE, with a clear timeframe and sanctions for violations.

(ii) Significance of the Role of the National Trust in Inclusive Education (some suggestions)

Why does the National Trust have a very direct and significant role to play for its own target group? It is worth repeating that **IE is the primary means of achieving all other human rights**. It is also **worth repeating that the NT's group of persons with disabilities are the most excluded from education**. The NT must recognize that it also has a role in ensuring successful implementation of specific sections of the RPWD Act. This is in addition to the realization of NT's own objectives, which need to be contemporarized and attuned to the India of the 21 st Century.

These are Sec. 17 (1) c, f, g, h, I and j as well as Sec.31. Whereas Sec 17 deals with IE.... for NT's Target Group, who are, by all accounts, the most neglected, the most discriminated against, and the most disenfranchised, even within the larger group of children with disabilities... (In fact, that is the foundational basis for the very existence of the National Trust, let us never forget that.). NT is best placed to develop appropriate material on IE for various target groups of the public, including but not limited to, Policy Makers, Parents, and Professionals.... in the Education and Health sectors; also for Community members and for parents of and persons with, disabilities themselves. Families are often discriminated against, by association.

¹¹ General Comment 4

¹² General Comment 4

Active and close coordination with RCI, NIEPMD and NIEPID, as also with NCERT, NIEPA, and CBSE, is highly recommended, for the development of resource material for training and awareness-generation. Perhaps NT should develop a Core Group on IE, of experts, parents and self-advocates.

There should be, at the very least, a campaign, by the NT, on the gains and advantages of IE for its own group of persons with disabilities, which, arguably, is the best roadmap towards independence. (Reference to the 1st Objective of the NT)..

Sections in RPWD Act, related to civil rights, 6,7, 8 and 9....there is a large body of research to prove that persons with the NT's designated disabilities are **MOST PRONE** to harassment, torture, cruelty, sexual abuse and dehumanizing treatment, particularly in long-term residential facilities. The NT has a clear and cogent role to play in advocating for their rights guaranteed to them in the RPWD Act 2016. In doing so, the NT may wish to work closely with the NHRC, through joint mechanisms of monitoring.

Similarly Chapter 16 of RPWD Act 2016, on Offences and Penalties, should also form a major part of the awareness, because it is against THIS target group of NT, that the most heinous offenses are committed. Ch 16 should act as a deterrent.

Section 31 Chapter 6 refers to the creation of “**appropriate environments**” for Persons with Benchmark Disabilities, who have the choice to attend Inclusive or Special Schools, PROVIDED, that “**appropriate environments**” are created for their full development.

There is a very strong case, here, supported by the National Policy on Disability 2006, for **restructuring Special Schools to become School Readiness Programs for IE**. While persons with locomotor and/or sensory disabilities do not have any substantive issues in respect of exercising their legal capacity, there are some challenges with regard to PWIDD which need to be effectively faced¹³. It needs to be pointed out that Special Schools for different types of disabilities function differently. Schools for persons with VI and HI, usually PREPARE STUDENTS FOR HIGHER EDUCATION IN MAINSTREAM systems. But schools for persons with ID, CP, ASD and MD, do not always do so. Many foreign nations have re-designed Special Schools to become catchment areas and pre-school training centers for Mainstream Schools. Currently, there may be a significant number of persons who benefit more from specialized settings, but a larger number may benefit from **preparedness for mainstream schools**, not only for academic benefits but also from development of social, emotional and behavioral skills; **a platform for encouraging bi-directional links between mainstream and special schools should be encouraged by the NT, perhaps through its SNACs/ROs. That is the only way forward, for persons with these four disabilities, and Teachers who engage with them, as well as for Parents.** The right to non-discrimination includes the right not to be segregated and to be provided with reasonable accommodation and must be understood in the context of the duty to provide accessible learning environments and reasonable accommodation.

¹³ Pincha, Article on Legal Capacity, 2019



National Trust



designated disabilities

are most prone to



harassment, torture,



cruelty, sexual abuse



and dehumanizing



treatment particular in



long term



residential facilities.



The National Trust has



a clear and cogent role



to play in advocating



for their rights guaranteed



to them in the RPWD Act.

Moreover, IE has a case for, not just educational upliftment , but social and economic reasons too.

It is imperative therefore, that the NT develops a National Strategy for IE, which fulfils 4 requirements,” availability, accessibility, acceptability, adaptability, and is inclusive REASOABLE ACCOMODATIONS, and that which stresses that inclusive education provides an opportunity to develop the expression of the will and preferences of students with disabilities, particularly those with psychosocial or intellectual impairments. States parties must ensure that inclusive education supports learners with disabilities in building their confidence to exercise legal capacity, providing the necessary support at all educational levels including to diminish future requirements for support in its exercise if they so wish¹⁴.

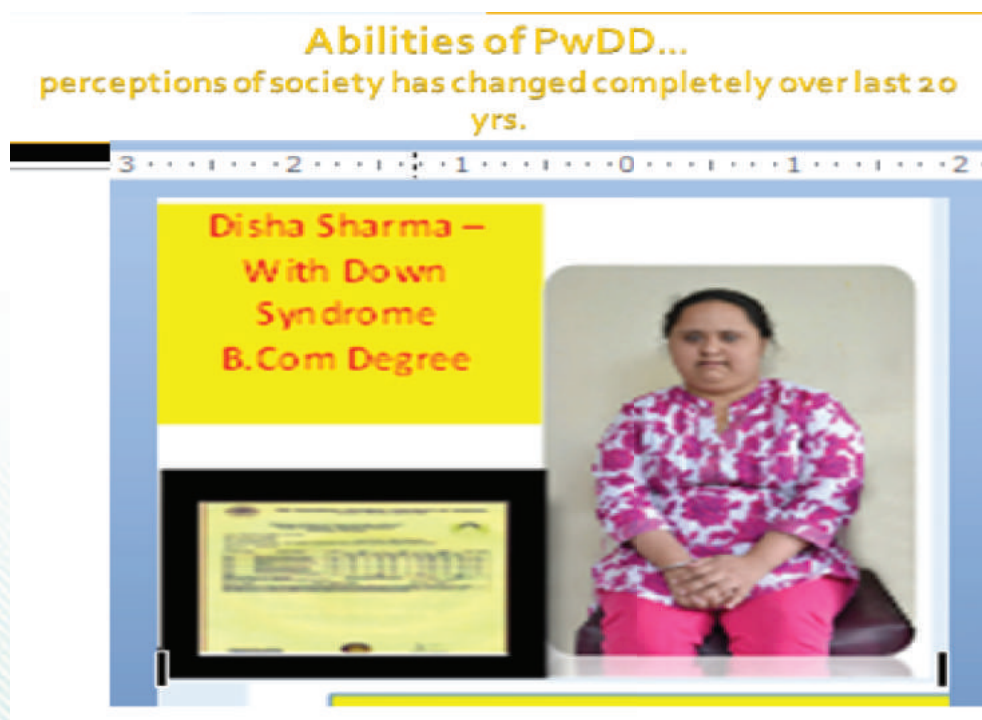
Conclusion

Success stories of persons with these four disabilities, are, almost always based on their education in mainstream schools, (sometimes in Special Schools as well) with the passionate support of family members along with some very dedicated teachers.



Next Steps

The world has moved on since the time the NT was drafted (I was a member of the Drafting Committee),and while some gains in IE for this group have certainly been made, a whole lot more remains to be done...who better than the National Trust to promote, protect and ensure their interests ?



¹⁴ General Comment No.4 , on Art 24 of the UNCRPD

Shruti...India's first deaf-blind Physiotherapist

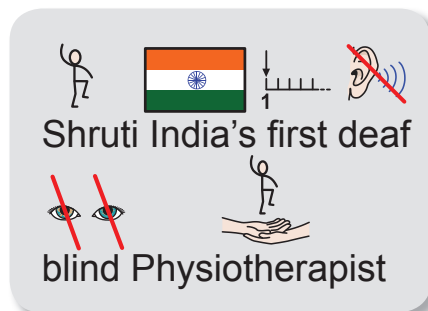


Shruti Singh is the state's, perhaps India's, first deaf-blind physiotherapy graduate. (Photo: Yogesh Chawda)

AHMEDABAD: Shruti Singh, 23, was born with vision and hearing - because of which she can speak fluently, unlike other deaf-blind people. But she has now completely lost her hearing and has only 10% vision, limiting it to 3 to 4 inches ahead.

But disability has not pinned down this free spirit. She was determined to become a physiotherapist and enrolled in

the physiotherapy school at the Blind People's Association (BPA). Shruti, a native of Himmatnagar, couldn't hear the lectures but she read transcripts on the cellphone screen and discussed them with fellow students with sign and tactile language. She



The journey of IE continues..... GAME ON



1993

SUCCESS STORY/BEST PRACTICE

Lalruatsaka, Class-III, Model Primary School Lunglawn, the one who does not have both of his arms, and used to write by using his legs, he has been provided a special chair which is specially made for him by SSA Mission: Lunglei District. He make use of it and very helpful to him.



2008

Neurodevelopmental Disorders: The Journey thus far, The Dreams and Their Realization- going e way; empowering professionals and parents

By- Prof Sheffali Gulati, Chief, Child Neurology Division

Coordinator, DM Pediatric Neurology Programme Faculty Incharge,

Center of Excellence and Advanced Research for

Childhood Neurodevelopmental Disorders Department of Pediatrics, AIIMS, Delhi

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Neurodevelopmental disorders constitute a significant proportion of morbidity handled by Pediatric health care services. These include neurodevelopmental disorders (NDD; like cerebral palsy, autism, attention deficit hyperactivity disorder, intellectual disability, epilepsy vision impairment, Hearing impairment, Learning disabilities and neuromuscular disorders).

With the reduction in neonatal and under-five childhood mortality, there is an increasing burden of NDDs among which Autism-Spectrum-Disorder(ASD), Attention-Deficit-Hyperactivity-Disorder(ADHD), Neuro-Motor-impairments(NMI) and Epilepsy form a significant disease burden. A recent study estimated prevalence of 'any NDD' in 2–9 year old children in India to be 12.0% (95% CI: 10.9–13.2%), and 21.8%

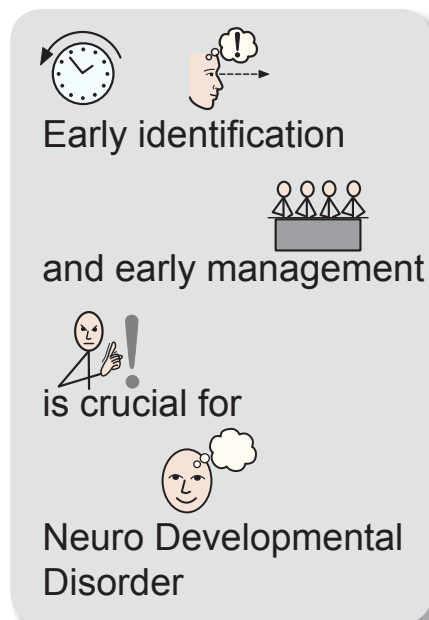
of these had more than one NDD (Arora NK, Nair MKC, Gulati S et al PLoS Med July 2018) Thus these neurological disorders contribute significantly to morbidity among children.

Early identification, correct and early institution of management and identification of associated co-morbidities is crucial. In India, the paucity of trained personnel and lack of knowledge about these disorders has resulted in inadequate management and recognition of these NDD. The Child Neurology Division, Department of Paediatrics at All India Institute of Medical Sciences, New Delhi has made few noteworthy and meaningful contributions in this regard: devising a DM curriculum for Pediatric Neurology, developing indigenous tools for diagnosing these NDDs and performing relevant research. These endeavours would go a long way in serving the children with NDDs.

In order to overcome the scarcity of physicians trained in Pediatric Neurology in our country, DM Pediatric Neurology programme was initiated in 2004, at All India Institute of Medical Sciences, under the Child Neurology Division as a part of Department of Pediatrics a first of its kind in South Asia,

Apart from providing twice weekly outpatient, 5 specialty clinics, inpatient, 24X7 emergency and telehelpline/tele-consultation services to >10,000 children each year, the division is actively involved in developing screening and diagnostic tools, arranging Continuing Medical Education, Public Health Lectures, radio and television programmes and contributing to articles in print media for caregivers and physicians

Four diagnostic instruments for autism (Gulati S, PLoS One March 2019), ADHD (Gulati S, Neurology India (in press), epilepsy(Gulati S, Epilepsy Res Feb 2017) and neuromotor impairments including Cerebral Palsy (Gulati S, Frontier Public Health. Nov 2017) have been developed, validated in clinical trials and subsequently converted into freely downloadable mobile application(Pedneuroaiims Diagnostics) which is freely available on

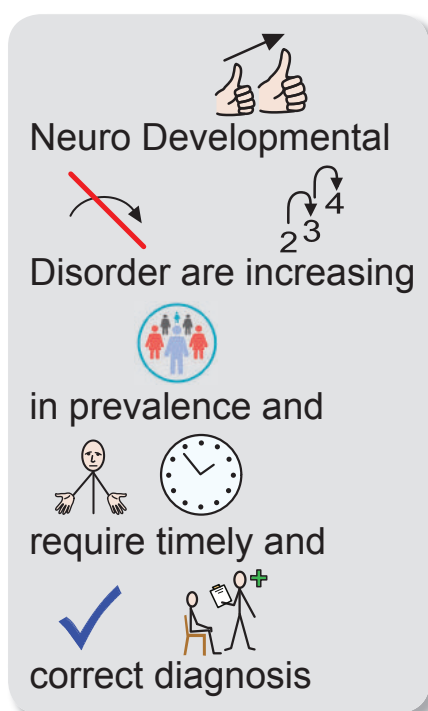


google play store and ios platform. A screening tool for diagnosing early signs of autism have been developed and a screening tool for early identification of Neurodevelopmental disorders has been validated .

This was supplemented with launch of an interactive webpage (www.pedneuroaiims.org), with information on various neurodevelopmental disorders(NDDs). CME activities include National Conferences, National training workshops to train master trainers in Autism (In collaboration with National Trust; training material available on website), Symposia on NDDs, Developmental and Neurological examination for students and Pediatricians, are freely available on website, E-learning modules (<https://pedneuroaiims.chalopadho.com>) on 38 Neurological/ Neurodevelopmental disorders and a Neuropharmacopeia: drug book have been compiled.

Bilingual parent information booklets on various NDDs are freely available. A freely available remediation program for learning disability and registry on NDDs are being developed. About 50 radio and television educational programmes, disability certification and helpv in ensuring inclusive education are other social welfare activities. On an average, yearly about 100 postgraduate students and 300 physicians are being trained. Mobile applications have been downloaded on more than 2000 mobile phones and are being used by more than1500 physicians across the country. The webpage gets an average of >17,000 hits monthly. Weekly about 100 caregivers receive teleconsultation. Yearly about 350 children receive disability certificate and 5, 000 caregivers receive parent information booklets.

NDDs are increasing in prevalence and require timely and correct diagnosis. Technology aided, affordable and innovative modes of diagnosis, such as these, can help empower caregivers and healthcare providers in a significant way, particularly in resource constrained settings.



Building Legal Capacity of Intellectually disabled Person

Dr. Asmita V. Balgaonkar

President, Jivhala Society for Mentally Handicapped. Solapur, Maharashtra. 413001

Mobile : 09021108686

asmitabalgaonkar23@gmail.com

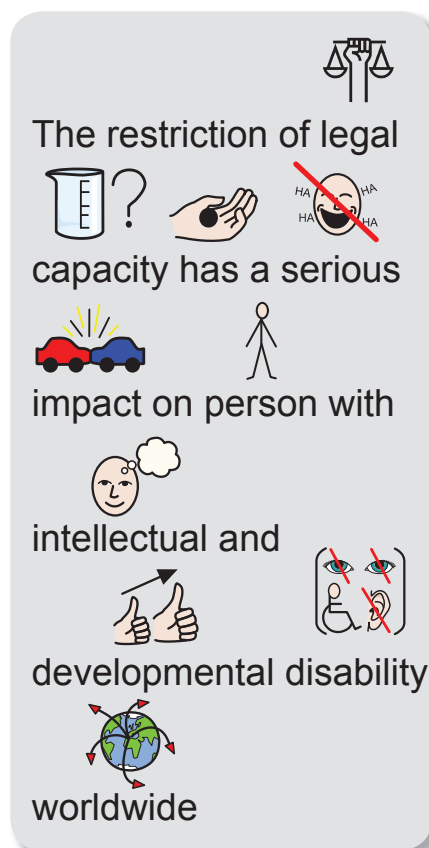
In the society, people are not aware about various kinds of laws for intellectually handicapped, so firstly it is important that people should be aware about it. Awareness programs should be conducted to reach the laws and its importance towards the public. Due to lack of awareness regarding these laws, very few people get benefit of various governments schemes and laws.

All parents are anxious about the future of their children. This anxiety becomes multifaceted for parents of children with developmental disabilities. These parents have to deal with the fear of ensuring a secure future for their child. Their concerns are not limited to financial protection but also ensuring that a guardian can be appointed to safeguard their child's best interests, upon their demise. The state carries an equal responsibility and needs to support these parents by providing robust laws and policies to ensure the rights of people with intellectual disabilities are protected.

People with disabilities all over the world have endured unequal treatment and discrimination on the basis of having a disability. A common problem in many countries is that people with disabilities themselves are not aware of the rights they have, and do not know how to file a complaint or to let the authorities know when their own laws are not being enforced. When discrimination occurs, there is often no one else present except the person or entity that discriminates and the individual being discriminated against. Disability discrimination cannot be successfully exposed and rooted-out without the active knowledge and participation of people with disabilities.

The restriction of legal capacity has a serious impact on persons with intellectual or psychosocial disabilities worldwide. Restricting a person's legal capacity makes it much harder for that person to live independently and as a full member of society. Unfortunately, women and men with intellectual or psychosocial disabilities usually have their legal capacity taken away or restricted solely because they have a disability. The UN Convention on the Rights of Persons with Disabilities (CRPD) states that people with disabilities have the right to equality before the law. All people with disabilities should have the same access to their rights as other people, and the same ability to exercise their rights. Courts, judges, and governments should not presume that a person with an intellectual or psychosocial disability is unable to exercise their rights just because they have a disability.

Various schemes are provided under The National Trust Act for the benefit of children suffering from autism and other disabilities. It is to be ensured that all PWD enjoy legal capacity on an equal basis with others in all aspects of life and has the right to equal recognition everywhere as any other person before the law and have the right, equally with others, to own and inherit movable and immovable property as well as control their financial affairs (Sec 13). It is also provided that a PWD with benchmark disability who consider himself to be in need of high support, he/she or any other person or organization in his behalf may apply to the authority appointed by the Government for the same and the authority shall take steps to provide support accordingly (Sec 38). However, the PWD would have the right to alter, modify, or dismantle the support system and in case of conflict of interest, the supporting person would withdraw from providing the support [sec 13(4&5)]. It has been provided in the section 14 of the Act that a District Court or any designated authority, as notified by the State Government, finds that a person with disability, who had been provided adequate and appropriate support but is unable to take legally binding decisions, may be provided further support of a limited guardian to take legally binding decisions on his behalf in consultation with such person, in such manner, as may be prescribed by the State Government. It is also provided that



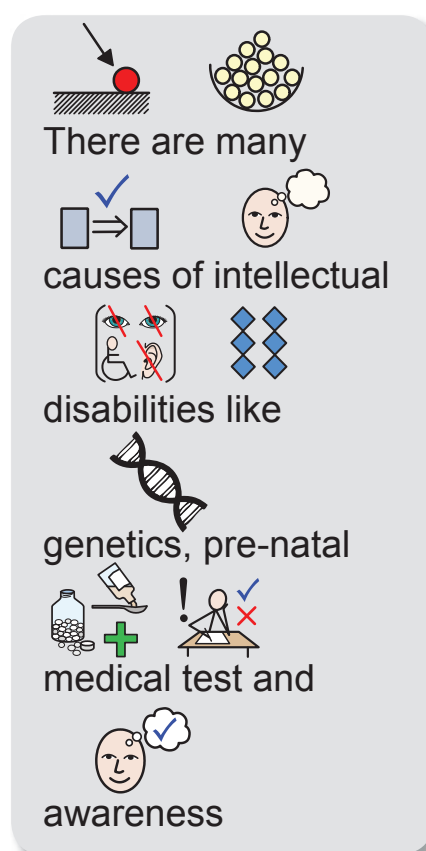
the District Court or the designated authority, as the case may be, may grant total support to the person with disability requiring such support or where the limited guardianship is to be granted repeatedly. In these cases the decision regarding the support to be provided shall be reviewed by the Court or the designated authority, as the case may be, to determine the nature and manner of support to be provided. Limited guardianship has been explained to mean a system of joint decision which operates on mutual understanding and trust between the guardian and the person with disability, which shall be limited to a specific period and for specific decision and situation and shall operate in accordance to the will of the person with disability. It is also provided that on and from commencement of the Act, every guardian appointed under any other law for time being in force shall be deemed to function as a limited guardian.

There are thousands of institute, schools, workshops which works on rehabilitation program for intellectually disabled people. Few of them work very actively which is really appreciable but mostly it can be noted in metropolitan cities. Why is it because might be these programs and facilities are not yet reached up to its grass root but like towards rural areas in which public mostly suffer due to lack of awareness and lack of programs, information regarding rehab program and its schemes. So they can't take its benefit.

Government can take some more steps for rehabilitation of intellectually disabled people. They can supply government tenders to rehab institutes with concession facility. e.g. parking tender production tender (applicable for workshops). Intellectually disabled person can do Class 4 jobs, some small and easy work. Intellectually disabled person can have capability to understand and do small financial transaction. So they should be given chance to step out to do small jobs which increases their self confidence and happiness of earning and responsibility. So such government tenders should support to rehabilitation institute so that they can give them work noticing the capacity of disabled people and also depending on their skills. In society generally people don't take risk to keep them for jobs. So these kind of tenders are very important for disabled peoples. Society sometimes might give chance to physically handicap, hearing and blind disabilities, speech impairments etc but they are not capable to handle intellectually disabled people because normal public can't understand nor can handle their behavioral problems and capabilities. So its important to give such kind of tenders to these institutes who can handle them properly and can even train them in proper way to work in small government tenders. Government can think of tenders like class 4 jobs, sweepers, washerman, co-assistant helpers, pheun etc. Government supply various kinds of rehab aids help like wheel chair, jaipur foot orthosis, hearing aids, etc which are not that in used to intellectually disabled person. Infact these peoples needs more other aids like IQ test kit, intellectual test kits, educational aids, occupational equipments, etc depends on their disabilities and behavioral problems.

So the main point of era is government should supply above needed mentioned equipments and aids other then which they already supply to disabled people.

Prevention and its causes:- there are many causes of intellectual disabilities like genetics, pre natal medical test and awareness. There are some cases whose main cause is lack of prenatal care. So its important to bring medical awareness to pregnant women. Some important test like 3D,4D,5D sonography should be made compulsory to pregnant women in her 5th and 7th month of pregnancy to avoid such cases to be born. If first child is disabled due to some cause then it should be some extra compulsory medical test law to be conducted before taking second chance to prevent disabilities. Another main and common cause is consanguineous marriages which is maximally practiced in India. It should be stop to prevent disabled cases. Such marriages should be banned by government by making some law.



Paper Title : Access to Justice for Women with Disabilities- Status Report from Puducherry

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Effective access to justice is essential for ensuring the respect, protection, and fulfilment of all human rights. Women and girls with disabilities,¹ however, experience disproportionate barriers to accessing justice due to discrimination and stereotypes that are based on both their gender and disability. This lack of access to justice—itself a violation of their rights—increases the vulnerability of women with disabilities to other human rights violations, including violations of their bodily integrity and right to be free from violence, as perpetrators of this violence realize that they can act with impunity when the justice system fails to address the violence.

Case Study : 1

I am, Jeniffer. I am a 29-year-old orphan. I realized that I was disabled only when I grew up and saw others moving around freely, unlike me. I couldn't move both my legs and my left hand. I was brought up in a Government-run Home for Disabled. Not all of my friends are like me. I always needed help. Someone had to carry me to wherever I wished to go, even to the rest room. I longed to play and have fun like the others. I used to wait for hours to get someone to carry me even for nature's call. I learnt to control my urge however painful it got. I found it difficult to freely express anything to anyone. I was continuously scolded and it was humiliating. I was always compared with other healthy children and was denied support, or got delayed support. I was also physically tortured like beating, pinching, leaving me for hours together in the toilet even after repeated calls for help etc., When I thought I should end my life, an artist came to our home to teach us on basics of drawing and painting. Artist Sir said I was very talented and asked me to pursue it. With this my whole life changed, I had a meaning to live. Few of my canvas got sold. But my life in the home never changed. They took away the money I received from the sales. I tried to raise my voice against the injustice but it fell on deaf ears. When visitors or social activists came I was locked in the room for they feared that I would expose them.

As I was interviewing Jennifer, she asked me with folded arms 'Can you help me out?', with tears.



Case Study : 2

My name is Anita. I live with my parents and my brother. I am completely dependent on others for all my daily activities. My family never wanted to send me to any school or for any training. My only earning is the monthly pension I get from the government. The money is entirely spent by my brother. He has access to my ATM card and he operates it. I cannot ask any money or any details about where & how he spends my pension. My father thought my brother would take care of me throughout his life so willed even my share of the property to him. Today after my father's death, I am abused and ill-treated and do not know what to do...



Case Study 3 :

My name is Stella, I am 32 years old and the sole bread winner of my family. I am an M Phil in psychology and work as a content writer earning a handsome salary. I am also a PWDs rights activist and travel all around the country helping other PWDs. 3 months ago I booked myself through an online portal into a hotel. On reaching the hotel, seeing my disability I was denied a room saying I would spoil their sheets. In an unknown town not knowing what to do I called a lawyer and explained to him my situation. The minute I told him about my disability, he made an excuse stating I would not be able to pay his fees. I am a rights activist well versed in the law of the land yet...

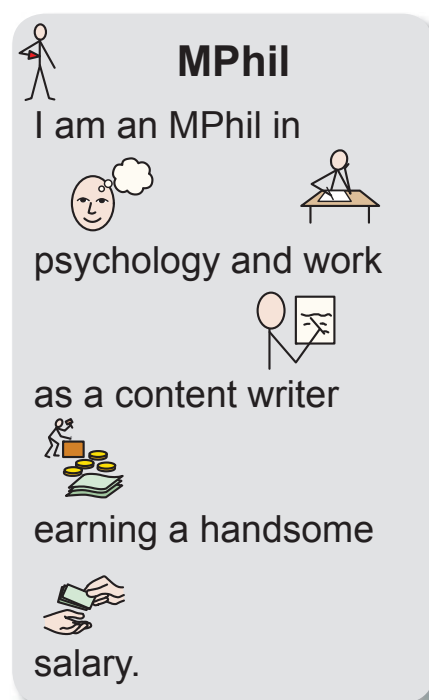
I. Background

- a. **Women with disabilities are disproportionately subjected to gender-based violence**

Women with disabilities are at least two to three times more likely than women without disabilities to experience violence and abuse, and they are likely to experience abuse over a longer period of time, resulting in more severe injuries. These include among others: abandonment; neglect; denying women with disabilities needed care; changing the accessibility of the environment around women with disabilities; involuntary sterilization and "other medical procedures performed without free and informed consent, including those related to contraception and abortion;" involuntary institutionalization; and "the administration of electroshocks, chemical, physical, or mechanical restraints" without consent.

- b. **Women with disabilities face significant barriers to accessing justice following gender-based violence**

In order to prevent gender-based violence against women with disabilities, it is essential to ensure their access to justice. Due to discrimination based on both their gender and disability, however, women with disabilities face significant barriers to accessing justice following gender-based violence. Women with disabilities face several types of barriers to accessing justice—including legal barriers, accessibility barriers, attitudinal barriers, and economic barriers.



(i) **Legal Barriers**

Laws and policies can directly or indirectly prevent women with disabilities from accessing justice mechanisms. In particular, laws that strip women with disabilities—particularly intellectual and psychosocial disabilities—of legal capacity or declare them as being of “unsound mind” may prevent them from testifying in court, including when they are the victims of violence, or may allow police or courts to call into question such testimony based solely on disability.

Even where laws are in place to ensure access to justice for women with disabilities who are victims of violence, they may not reach many women with disabilities or may not be effectively implemented.

- For instance, in **India**, although the Criminal Law (Amendment) Act 2013 outlaws violence against women with disabilities in institutional settings, in practice women with disabilities have effectively no access to the justice system when they are institutionalized, either to challenge forced institutionalization or to report violence committed against them in institutions. Indeed, a 2014 report by Human Rights Watch found that of the 128 instances of abuse they documented against women with disabilities in Indian institutions, none of the women had been able to file First Information Reports or otherwise access redress mechanisms to address their forced institutionalization or the verbal, physical, or sexual abuse committed against them.
- States may also lack legal protections against some forms of violence that specifically affect women with disabilities, serving as an additional barrier to justice. In **India**, under the Medical Termination of Pregnancy Act, 1971 (as amended in 2002), guardians can consent to abortions for women with psychosocial disabilities, leading to forced abortions. Although the Supreme Court of India in 2009 found that guardians of women with “mild to moderate” intellectual disabilities cannot similarly provide consent to abortion on behalf of their wards, the Court did not strike down the provisions of the Medical Termination of Pregnancy Act, 1971, that allow for forced abortion of women with psychosocial disabilities. The Court in fact distinguished between psychosocial and intellectual disabilities, stating that, as per the law, a guardian could still provide consent for terminating pregnancies of women with psychosocial disabilities. The recently-adopted Rights of Persons with Disabilities Act 2016 also still allows for forced abortion “in severe cases of disability” where both the doctor and guardian consent.



The way ahead :

- ▶ Create accessible “know your rights” programs targeted at women with disabilities to ensure that they have the information they need to be confident in accessing justice mechanisms.
- ▶ Train the police force, other emergency responders, and other justice system actors.
- ▶ Ensure access to free legal aid.
- ▶ Abolish systems of guardianship that allow guardians or others to make important decisions & Establish regimes that provide women with disabilities with support services, to make their own decisions and to participate in justice mechanisms.
- ▶ Train advocates who not only understand the regulatory environment but who also can interact effectively and comfortably with persons with disabilities.
- ▶ Technology also can make justice accessible.
- ▶ Women with disabilities must be themselves included in the justice system as jurors, lawyers, judges, clerks, police officers, or other justice system actors, to ensure they are included and that their voices are heard throughout the process

Even with “**The Rights of Persons with Disabilities Bill - 2016**”, will the harassment stop? The bill needs to be implemented with immediate effect, poverty, lack of awareness, fear of social stigma and yet-to-be-friendly system in form of police, lawyers/legal system. Access to justice for women with disabilities not only requires that the police and courts are available for them, but also that these arenas are fully accessible and inclusive.

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Title of the paper:

Creating of Resources based on student's learning style enhances the performance and classroom management of children with special needs in an inclusive school

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Abstract

In India, Inclusive education for children with disabilities still has a long way to go. Though our law has made policies to ensure inclusive education in all government and private schools, but finding out which inclusive practices are the best for proper inclusion of children with special needs is the challenge. All schools are looking for best inclusive practices **without adding on extra cost to their budget**. Inclusive education requires **collaborative efforts** of the administration, principal, parents, teachers and special educator. But due to lack of proper teacher training in most schools **special educator is held accountable** for the progress of children with special needs. This study emphasizes on collaborative efforts of the teachers, special educators, children with special needs and their parents to frame resources which best suits the learning style of CwSN.

In this paper a comparative research is made between two groups of students with special needs (10 in each group). **One receiving specially created resources based upon their learning styles in the classroom** and the other group receiving regular resources just like everyone else in the class. All these students in both the groups are taken from general classrooms where along with their peers they participate in all curricular and extra-curricular activities. After a period of three months **the individualized education plan** of all the students with special needs in both the groups was assessed. Also the students' academic performance was assessed by evaluating their report cards.

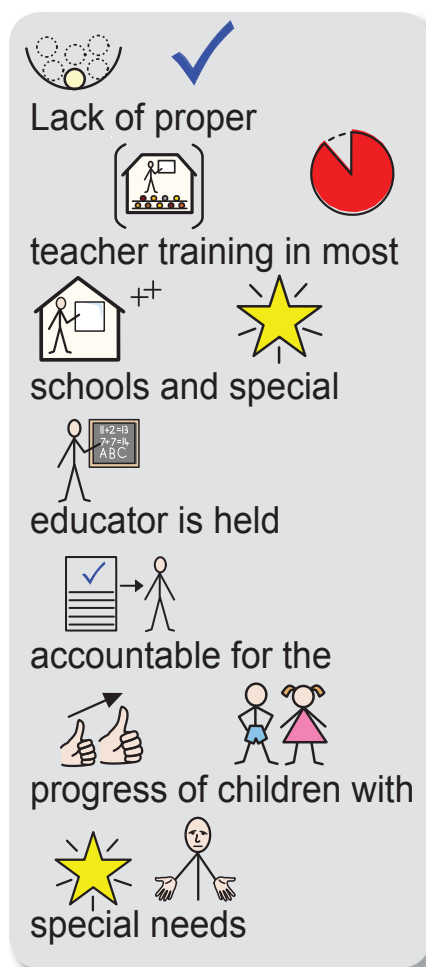
The results of the study indicated that the group receiving specially created resources based upon their learning styles revealed better outcomes /grades as compared to the group not receiving it. **Increased understanding of concepts** led to **better classroom management and better classroom response**, which resulted in **students better performance**.

Keywords: CwSN (children with special needs, inclusive education, I.E.P.(Individualized education plan), classroom management, classroom instructions.

Introduction

Inclusive education happens when children with and without disabilities participate and learn together in the same classes. Inclusive education is based on the simple idea that 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.

Inclusive education in India Various initiatives for teaching of children with special needs (CWSN) along with normal children in main stream schools popularly known as IE (Inclusive education) are being taken at different levels but still 95 percent of CWSN are out of mainstream schools. Even the schools where IE is in operation, infrastructural facilities required for inclusive teaching-learning processes are poor. Capability of



teachers required to deal CWSN along with normal children also appear to be poor reflecting the poor quality of training for IE. The only point of satisfaction is that importance of IE has been recognized and government is working hard to provide universal education to CWSN under IE.

Though policies have been framed by our government to ensure that mainstream schools should be prepared to include CWSN but schools are **lacking trained professionals** and resources for proper inclusion. Another big hurdle is the **budget**. As inclusion of CWSN with complex needs requires **accessibility , special resources and assistive devices** .The schools are often reluctant to add on any extra cost to their budget . There is **also huge scarcity of trained rehabilitation professionals in our country** which makes inclusive education a distant dream.

Classroom management refers to the wide variety of skills and techniques that teachers use to keep students organized, orderly, focused, attentive, on task, and academically productive during a class. When classroom-management strategies are executed effectively, teachers minimize the behaviors that impede learning for both individual students and groups of students, while maximizing the behaviors that facilitate or enhance learning. Generally speaking, effective teachers tend to display strong classroom-management skills, while the hallmark of the inexperienced or less effective teacher is a disorderly classroom filled with students who are not working or paying attention.

In inclusive education the general education itself makes the education of children with disabilities as its integral part. This implies that the teacher should be equipped with skills to address the educational needs of children with disabilities to a minimum extent. This calls for strengthening the pre service teacher preparation programme with adequate component of inclusion of children with disabilities. Inclusive education creates effective classroom where the educational needs of all children are addressed irrespective of their ability. **Total inclusion occurs when general classroom teachers take most of the responsibilities of the classroom.** If a specialist takes care of the children with disabilities in a general classroom it is not total inclusion.

Mainstream schools with inclusive education in India have special educators and resource rooms for educating and supporting CWSN. This goes against the idea of proper inclusion. Due to lack of teacher training the general education teacher feels that **the progress ,management and accommodation of CWSN is the sole responsibility of the special educator** .

There has been a few studies conducted in the field of inclusive education and teachers support or role in it.


According to a study by Ajay .K. Das, Ahmed B. Kuyini, Ishwar .P. Desai indicated that teachers did not have access to support services in their schools. The educational reform literature in special education is unanimous about the availability of support services for the successful implementation of inclusive education programs. This study provides valuable insights into teachers' readiness to implement inclusive education programs in their schools.

Another study by Kumar Sanjeev and Kumar Khagendar indicates that inclusive schools have to address the needs of all children in every community and the central and state governments have to train their teachers to manage inclusive classrooms.


But there was a huge need for a study to be conducted in terms of ideal inclusive practices that work in inclusive schools.

Rationale of the study


"Necessity is the mother of invention" can be appropriately quoted here as my necessity to provide mainstream education to my son with




Classroom management



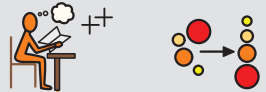
refers to the wide variety



of skills and techniques



that teacher used to



keep students organized.



The progress management



and accommodation of



child with special needs



is the sole responsibility



of the Special Educator

special needs became the prime reason for the study. Being a mother of a child with special needs I could see that none could understand his abilities because of his complex needs. He has cerebral palsy due to which he cannot write and has cortical vision impairment. This meant that most of the standard resources that were provided by the school could not help him. This motivated me to empower myself so I did B Ed. in special education along with few other certificate courses on learning disability from RCI and then struggled to enroll him in a mainstream school along with a group of parents of children with special needs in the city. But unfortunately the school did not have a special educator so I joined too. I got a resource room where I could take one on one sessions with students with special needs. I was spending 40 minutes with each child everyday and working primarily on their reading, writing and communication skills and also developed their I.E.P. I also coordinated with the subject coordinators to create special resources /worksheets for them. But there was continuous pressure from the teachers to take on the responsibility of other subjects as they showed their inability to teach them. Though I guided them continuously on the strengths and abilities of the students but I realized that the teachers by then had developed certain ways of accommodating these children. Each teacher had her own way. Some were very sympathetic so did not expect CwSN to do much. Others felt that it was not right to educate them in general classrooms and should sit in resource room all day. I could see that despite my guidance the teachers were not able to teach them appropriately in general classrooms. Due to which the academic performance of CwSN was very poor. The problem was that as a special educator I did not have the time to teach them all subjects that would go against the whole idea of Inclusive education, **Management of CwSN in general classroom** was not appropriate as most of the time these children were sitting idle, they had no idea what was going on in the class and the teacher could not interact with them at all. The inability of the teacher to understand the needs of the CwSN was also because of the huge strength of the students in a classroom and lack of appropriate resources for CwSN. The teacher was using standard worksheets which were meant for all kinds of learners. This resulted in no response of CwSN in the classroom. A child with cerebral palsy who can't read or write couldn't do anything besides listen to teacher's instructions. Whereas a student with autism who is a visual learner did not pay attention to the instructions, and the worksheets contained complex sentences which he couldn't read, so he too couldn't understand in class.

Understanding the problem I came up with a solution. A solution to identify the learning style of each CwSN and create the resources based upon it. We primarily classified all CwSN in two groups: first one included visual learners and second one included auditory learners. A meeting was conducted with all the subject coordinators in the school and they were guided to create two kinds of resources for all the subjects which is the **theme of this study**.

Methodology

After detailed discussion with the management regarding my plan /method they agreed to give their full support. This decision was made realizing that maximum time spent in school was in their general classrooms. If this method could help improve the quality of that, it could mean better classroom management, better classroom instructions and better academic performance of CwSN.

A cluster sampling method was used to select participants for this study. Total of 20 children with special needs were divided into **two groups(10 each)**. All the participants belonged to age group 3 to 17 years studying in grade 3 to grade 8. The children in both groups had mixed disabilities as the selection was not based on their IQ or category/ degree of disabilities.

Children in both the groups were given special education for 40 minutes everyday. Children in both the groups attended all co curricular activities along with their peers according to their regular class timetables.

CwSN in first group were assessed to know their learning style and categorized as visual/auditory learner. A series of meetings were organized with teachers, parents, CwSN and planning for resource building was made. Out of 10 students 6 were identified as visual learners and 4 as auditory learners. Teachers of all subjects along with their coordinators worked as a team to write the script for recording their instructions from the textbooks in the form of an audio CD. These CD's were then given to the parents and also to the special educator to be used in the resource room. They also created visual resources in form of pictures/diagrams/signs/symbols/flowcharts from the textbooks and started using them in classrooms for visual learners. Two CwSN were given both types of resources. In the second group teachers continued to use the same kind of standard resource as was used for the entire class.

For better comparison and monitoring between both the groups, a feedback notebook was maintained by the special educator which had to be filled by the teachers weekly noting the academic performance of the CwSN, his verbal and written response, concept understanding. The special educator read it and gave suggestions accordingly.

Results and Discussions

After a period of six months the I.E.P. 's and academic report card of CwSN of both the groups was compared. Both the groups showed academic improvement(reading, writing and communication skills) as in their I.E.P and progress report card, but CwSN in the first group showed better improvement .

There was a marked difference when their general classroom academic profiles were compared in which they are graded according to their academic performance in all subjects.

Grades of CwSN in the first group had shown much more improvement as compared to grades of CwSN in the second group.

The feedback notebooks of CwSN was compared and noted that in the feedback notebook of CwSN in the first group the feedback given by the teachers became more positive and teachers started to believe in the potential of CwSN, became more comfortable ,could give better instructions in the class , they were able to get the work completed in the special resources, better verbal and written response of CwSN and teachers had started to come up with new ideas of their management of CwSN, the behaviour of CwSN became better in class. All this led to parent satisfaction which was clearly noted in the I.E.P. meeting. The rapport between the teacher and CwSN improved. This also led to an improvement in creating special resources as the teachers were better equipped with the knowledge of the strengths and abilities of CwSN. This led to better classroom management and classroom instructions.



The feedback notebooks of CwSN in the second group remained consistent throughout without any marked changes in student academic performance, parent satisfaction and the concept understanding .

The results of the study indicated that the group receiving special resources based upon their learning style revealed better outcomes / grades as compared to the group not receiving it. **Creating resources based upon the learning style of CwSN** led to **better learning outcomes and classroom management** . The important stakeholders involved were **parents of children with special needs** who were very satisfied with the progress of their children and appreciated the efforts made by the school. They reported that CwSN were more confident and happy as they were more confident and their grades improved. **The special educator** reported that most of the **IEP goals could be accomplished**. Teamwork of teachers to create special resources for CwSN helped them immensely. Most **teachers** reported feeling more **positive and confident** working with children with special needs after using these resources in classroom. They could manage **the behaviours of CwSN** in the classroom in a better way as special resources helped them to understand and this also lead to an improvement in their **class response**. All this had lead to better academic performance of CwSN.



Suggestions



In India the government has framed policies like RTE(Right to Education), SSA(Sarv Shiksha Abhiyan),IEDC(Integrated Education of Disabled Children), MID DAY MEAL etc to ensure inclusive education to all irrespective of their background, economic status and abilities due to which all govt. and private schools have been instructed to accommodate children with special needs but there is a huge scarcity of qualified rehabilitation professionals in our country due to which quality education to children with special needs is not provided. Schools are not ready to add on any extra cost to their budget in terms of infrastructure


  
Creating resource based

 
upon the learning style



 
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The important

 
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with special needs


IEP goals could be


accomplished

 
Behaviour of CWSN

or manpower. Moreover private schools which are not aided by the

government refuse to comply to any conditions. Even Schools which are inclusive and have special educators are not indulged into good inclusive practices as a lot of research has to be done in this area as to what strategies work ,which inclusive resources and practices are best.

So as this study has shown very good outcomes for providing quality education to CwSN I suggest this practice should be implemented in all the schools . The biggest reason in doing so is that it is cost effective and does not add any extra monetary burden on the school budget. Secondly it is based on optimal utilization of present resources and manpower. Thirdly it provides practical training to the teachers to work with CwSN and if the special educator holds regular in house training of all school faculty the school will be better equipped to manage any kind of disability.

Training at regular intervals in collaboration with different NGO's working in this field can have a greater impact on providing holistic development of CwSN.

I suggest further research can be done as how school resources can be efficiently used to cater to the needs of CwSN.

List of Students with Special Needs who have Benefitted from my Intervention

Name of the student	Grade	Disability	Quality indicator
1. Niteshwar	III	ADHD	Class Behaviour and Academic performance
2. Divneet	III	Dyslexia	Academic performance
3. Vansh	III	ASD	Class Behaviour
4. Danish	III	Down Syndrome	Class Behaviour
5. Razaik	IV	Dyslexia	Academic performance
6. Awaleesh	IV	Mild mental retardation	Academic performance
7. Ranveer	III	ASD	Class response
8. Aehnoor	V	ASD	Class Behaviour
9. Armaanjeet	V	ASD	Class Behaviour and Academic performance
10. Yuvraj	V	Cerebral Palsy	Class response and academic performance
11. Trisha	V	Down Syndrome	Class Behaviour and academic performance
12. Hukum	V	Dyslexia	Academic performance
13. Niyati	VI	ASD	Academic performance
14. Avyam	VI	ADHD	Class Behaviour
15. Manas	VI	Cerebral Palsy	Academic performance
16. Roshni	VI	Cerebral Palsy	Class response
17. Ira	VI	Cerebral palsy	Class response
18. Kavish	VI	Cerebral palsy	Class response and academic performance
19. Akarshan	VI	ASD	Class behaviour
20. Samrath	VI	Dyslexia	Academic performance
21. Prabhnor	VI	Cerebral Palsy	Academic performance
22. Abhiraj	III	Muscular dystrophy	Class response
23. Sanyam	VII	Cerebral Palsy	Class response and academic performance
24. Khushi	VIII	Slow learner	Academic performance
25. Bhavika	VIII	Low vision	Academic performance

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Paper from World Health Organisation

By:-Dr Gaurav Gupta, World Health Organisation



WHO Perspective

As per WHO estimates, approximately 15% of the global population is estimated to have some form of disability i.e. more than 1000 million people globally or one in seven people. Of this number, between 110 - 190 million adults experience significant difficulties in functioning. It is estimated that some 93 million children – or one in 20 of those under 15 years of age – live with a moderate or severe disability. The number of people who experience disability will continue to increase as populations age, with the global increase in chronic health conditions. National patterns of disability are influenced by trends in health conditions, environmental change and injuries like road traffic crashes, falls, violence, humanitarian emergencies including natural disasters and conflict, unhealthy diet and substance abuse. An estimated 80% of people with disability live in developing countries. All over the world, stigma associated with disabilities prevents the affected population from leading a fruitful and productive life.

People with disability face widespread barriers in accessing services, such as those for

- health care (including medical care, therapy and assistive technologies),
- education,
- employment, and
- social services, including housing and transport.

The origin of these barriers lies in, for example,

- inadequate legislation, policies and strategies;
- the lack of service provision; problems with the delivery of services;
- a lack of awareness and understanding about disability; negative attitudes and discrimination;
- lack of accessibility; inadequate funding; and
- lack of participation in decisions that directly affect their lives.
- lack of ability to express their opinions and seek, receive and impart information and ideas on an equal basis with others and through their chosen means of communication

These barriers contribute to the disadvantages experienced, particularly in developing countries

- poorer health,
- higher rates of poverty,
- lower rates of educational achievement and employment,
- reduced independence and
- restricted participation.



WHO's work

The International Classification of Functioning, Disability and Health, known more commonly as ICF, is a classification of health and health-related domains. ICF is the WHO framework for measuring health and disability at both individual and population levels. ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 and operationalized through the WHO Disability Assessment Schedule (WHODAS 2.0) which was developed through a collaborative international approach with the aim of developing a single generic instrument for assessing health status and disability across different cultures and settings.

The Convention on the Rights of Persons with Disabilities came into force on 3 May 2008. It outlines the civil, cultural, political, social and economic rights of people with disabilities. WHO is participating in the UN Inter-Agency Support Group (IASG) to promote and implement the Convention.

WHO launched the World Report on Disability on 9 June 2011. It provides the evidence and highlights priorities relevant to operationalizing the Convention; It synthesizes the best available evidence on how to overcome the barriers faced by PwD in accessing health, rehabilitation, support and assistance services, their environments (such as buildings and transport), education and employment.

In May 2013, the Sixty-sixth World Health Assembly resolution (WHA66.9) on disability endorsed the recommendations of the World Report on Disability. The assembly requested WHO and organizations of the United Nations system, a comprehensive WHO action plan based on the evidence in the World report on disability, and in line with the Convention on the Rights of Persons with Disabilities (adopted by the United Nations General Assembly in resolution 61/106)

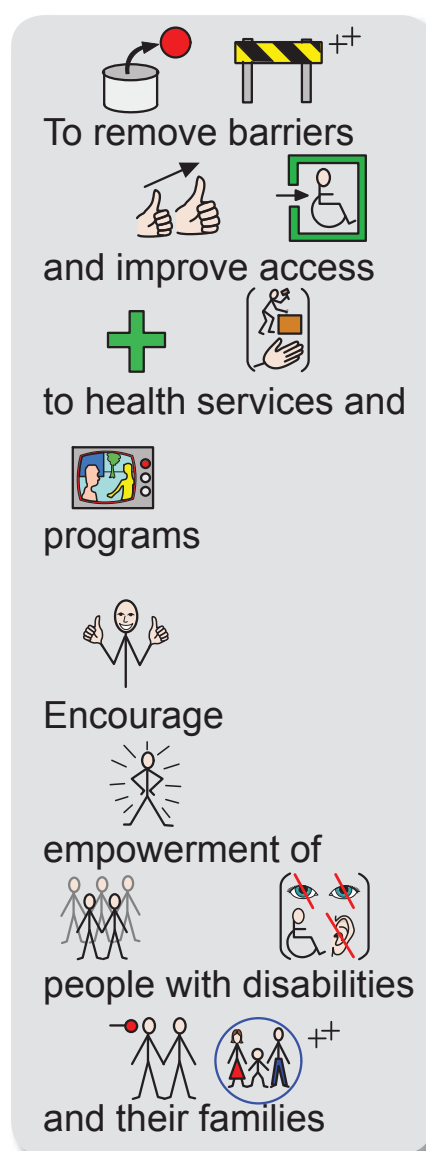
With the aim to ensure better health for all people with disability, and in consultation with Member States, WHO developed the Global Disability Action Plan 2014-2021 in the year 2015. This action plan supports the implementation of measures that are designed to meet the rights of persons with disabilities, as enshrined in the Convention on the Rights of Persons with Disabilities. This action plan agrees on 3 objectives:

- *To remove barriers and improve access to health services and programs*
- *To strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation*
- *To strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services*

It proposed actions for member states, and the international and national partners.

Community-based rehabilitation guidelines have been developed primarily for CBR managers by WHO in collaboration with ILO, UNESCO, International Disability and Development Consortium (IDDC) or CBM, Handicap international, the Italian association, Light for the world, the Norwegian association of disabled, and Sight savers along with 180 individuals and representatives of nearly 300 organizations mostly from LMIC. CBR is now a multisectoral approach and provides guidance on how to:

- develop and strengthen CBR program
- promote CBR as a strategy for community-based development involving PwD
- support stakeholders to meet the basic needs and enhance the quality of life of PwD and their families
- Encourage empowerment of people with disabilities and their families



This was followed by the development of Community-based rehabilitation indicators manual and CBR matrix to provide an overall representation of CBR.

Further, an online learning community program called INCLUDE guides the user through different information modules and provides tools to assist users to develop an action plan around management and the five components and corresponding elements of CBR matrix, based on CBR guidelines i.e. health, education, livelihood, social and empowerment.

WHO estimates that more than one billion people (mostly older people and people with disabilities) are in need of one or more assistive products. With populations ageing and the rise in non-communicable diseases, this number is expected to increase to beyond two billion by 2050. However, only 10% of these have any access. To address the substantial gap between the need for and provision of assistive technology, WHO established the Global Cooperation on Assistive Technology (GATE). It is based on 5 P, i.e. people, policy, provision, products and personnel.

Assistive technology products can prove to be of great help in mobilization of persons with associated locomotor disabilities. In the year 2016, WHO published a list of 50 priority Assistive Technology Products List which can be adopted and/ or modified in accordance with the country needs. Achievement of each of the 17 SDGs can be facilitated by the use of assistive products. Without promoting the availability of assistive products, the SDGs cannot be achieved equitably. Assistive products can be considered as both a mediator and a moderator of SDG achievement.

Standards for prosthetics and orthotics were published by WHO and USAID in 2017. The Public Health, Innovation and Intellectual Property (PHI) Team is responsible for promoting innovation in the discovery, development, production and delivery of essential health technologies. PHI has developed a web-based platform on innovation and access following the structure of the GSPA-PHI.

World Health Organization (WHO) estimates that more than 70 million people need a wheelchair and only 5 to 15% have access to one. In addition, there is a shortage of health and rehabilitation personnel with the knowledge and skills to provide a wheelchair that meets the user's specific needs. Guidelines on their provision along with training package have been published by WHO.

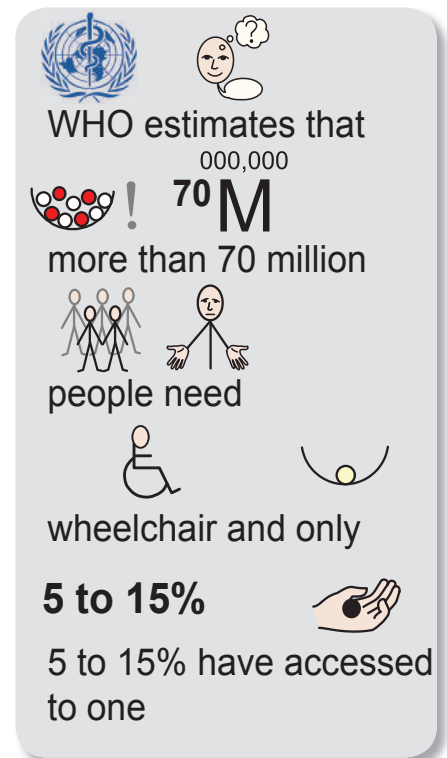
The Global strategy and action plan on ageing and health was adopted by 69th WHA in 2016. World Health Day 2012 was dedicated to Healthy Ageing, with the theme, 'Adding life to years', there is a global appeal to create age -friendly environments.

3 December is International Day of Persons with Disabilities (IDPD) when WHO joined partners to celebrate "a day for all". This theme reflects a growing understanding that disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life.

WHO Quality Rights Initiative aims to improve the quality and human rights conditions in inpatient and outpatient mental health and social care facilities and empower organizations to advocate for the rights of people with mental and psychosocial disabilities. Create community-based and recovery-oriented services that respect and promote human rights, recovery, and independent living in the community; develop a movement of people with mental disabilities to provide mutual support, conduct advocacy and influence policy-making processes; reform national policies and legislation.

Sustainable Development Goals: Out of the 17 SDGs, those dealing with social determinants of health (SDG 1, 2,4,5) affect the lives of people with special needs indirectly, while SDG 3 (Targets 3.4, 3.5, 3.6,3.8,3.9) affect the disabled population directly.

SDG target 3.8 aimed at achieving Universal Health Coverage, which has also been the World Health Day theme for the last two years, also creates visibility for wider dissemination and to reach out to the population in need. WHO continues to work to empower the persons with disabilities.



Modulating Engagement Behavior in Intellectual Disability: An Occupational Therapy Perspective

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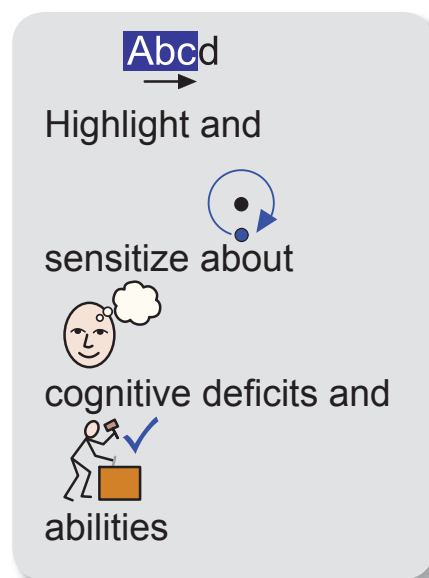
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Objective

To highlight and sensitize about cognitive deficits & abilities, multisensory stimuli & strategies and their implication on sensorimotor & perceptuomotor modulation processes

Recommendations

- The assessment & intervention process involved in intellectual disability must target the underlying elementary component behaviors to modulate the sensorimotor network, building responses for improving cognitive as well as interactive sensorimotor learning & processing abilities in variable context.
- The service providers involved with rehabilitation of children with developmental disabilities must include expert occupational therapy professionals to guide and enforce therapeutic learning through developmental continuum.
- The service centers must encourage provision of supply of therapeutic materials for orienting and engagement responses based on sensorimotor therapy to be distributed by occupational therapist.
- The rehab team must be educated about learning and training based on sensorimotor engagement for the therapeutic processes involved to maximize early potentialities of a child with ID/DD.



Modulating Engagement Behavior in Intellectual Disability: An Occupational Therapy Perspective

Intellectual disabilities in practice often regarded as discrete conditions which reflect the multi-dimensional limitations in an individual's functioning.¹ Intellectual Disability earlier known as Mental Retardation is a condition of arrested or incomplete development of brain, characterized by impairment of adaptive & learning skills manifested or to be acquired during the developmental period interfering with the overall level of intelligence-cognitive, language, sensorimotor and social abilities. This condition of sub-average intellectual functioning has associated domain of lack of postural adjustment responses & abilities, normal sensorimotor experiences, processes and modulation deficits interfering with normal developmental and maturation processes. Rather than merely a defect in the person, the disability resides in the fit between the person's capacities and the context in which they live or function. Although IQ is the deciding factor for diagnosis of Intellectual Disability, still the tests conducted for screening and assessment itself has wide variations across the evaluator's interpretation. There have been reported high margins of error in the measurement of both IQ and adaptive functioning, meaning that conclusions reached (particularly in the severe – profound ranges of cognitive impairment) can be of questionable accuracy. The diagnosis of intellectual disability acknowledged as a matter of clinical judgment, has been emphasized. Due weight-age had been given to the functional skills, environmental and personal interaction based on intellectual demands in different context in order to solve problems, decide, judge or plan for execution of task/work.⁵ The person with IQ less than 70 with the efficiency of performing the task in

different context with efficient problem solving, decision-making, judgment based on individual's intellectual demands and not scholastic demands, posed serious conflicts amongst evaluators regarding labeling them as intellectually disabled.

The population of intellectual and developmental disabilities is diverse & complex and manifest varying levels of function with respect to skills of daily living, as well as varying cognitive, intellectual, social, physical, emotional and behavioral capabilities throughout their life cycle.

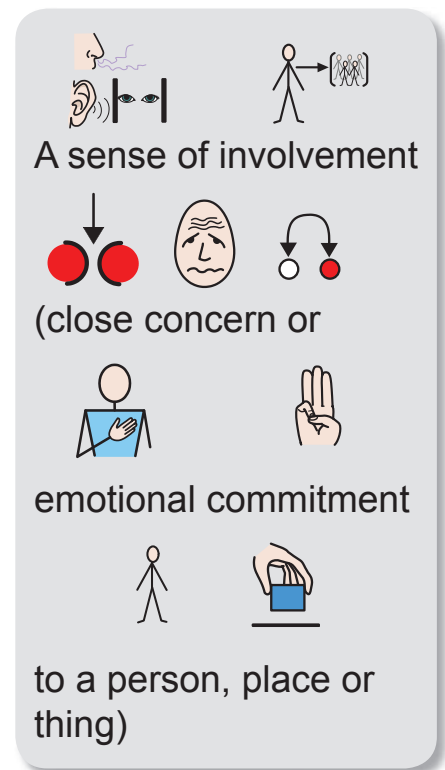
The intellectual disability results in impairment, disability & handicap limiting the engagement & participation of an individual affecting his performance which arises out of inability to experience, interpret as well as interference involved in the process of experiencing, understanding, interpreting and learning through the process of input, throughput and output. This is essential for normal maturational processes adversely affecting learning abilities & skills. The learning difficulties reflect general intellectual functioning limitations with problems in attention, executive functions gross & fine motor skills and abilities with presence of compensatory strategies ⁷.

They experience difficulties in integrating and modulating information from various senses.⁹ These sensory disabilities may lead to hypo- or hyper-sensitivity to particular stimuli within the environment leading to sensory seeking /avoiding/withdrawn and non-reactive behaviors leading to poor development of environmental interaction strategies.¹⁰

The presentation in children with intellectual disability reflects multiple sensori-motor problems during initial developmental period, supported by Piaget's cognitive theory which puts a great deal of emphasis on early sensori-motor stage i.e. 0-2 years of child development for later development of cognitive/intellectual and adaptive process. ¹¹

Occupational therapy places a good deal of rationale in analyzing & interpreting sensory and motor dichotomies and the active engagement of child must be observed across different stage of growth and development. The term 'engagement' is sometimes used on its own, but more often reference is to "engagement in occupation(s)", "occupational engagement", "engagement in activities", or "engagement with the environment and/or people". It has been defined that a person might experience four different sensations or feelings when engaging in occupation: A sense of involvement (*close concern, or emotional commitment to a person, place, or thing*), Choice, Positive meaning (*what one is doing is significant or important to oneself or others*) and Commitment (*towards a person, activity or thing*)¹¹. The occupational therapists' reasoning considering people "occupational engagement" has been explained using Model of Human Occupation (MOHO) from multidimensional perspective. ¹² They define this as their "doing, thinking and feeling under certain environmental conditions" and explain how this engagement is shaped by individuals' volition, habituation and performance capacities along with the environment.

The complexity of engagement becomes more apparent when considering that it can be seen as having different dimensions, viz choose or make decisions, commit, explore, identify, negotiate, plan, practice, reexamine & sustain. ¹³ The fields of occupational therapy and occupational science contribute to an understanding of the nature and importance of human engagement in occupation. Human life is seen as characterized by the doing of occupations and in many ways what we do.¹² Occupational therapists have emphasized upon the potential for sensori-motor processing, development and learning that comes from engaging in occupations. ¹¹ Efforts made to measure the extent of engagement in activity or occupation, are suggestive of the possibility of engaging at different levels or to different degrees. One way of looking at levels of engagement is to consider the degree to which an individual engages in a way that is meaningful to them, including how what is meaningful, might link developmentally with their abilities. An individual's motivation to engage in a particular occupation is affected by the meaning, or the significance or importance it has to them. This suggests that supporting someone to engage in that occupation is unlikely to be successful without a good understanding



of its subjective meaning to them and the level of engagement they are developmentally likely to be able to achieve. The terms “engagement” and “participation” in activity are sometimes used synonymously.

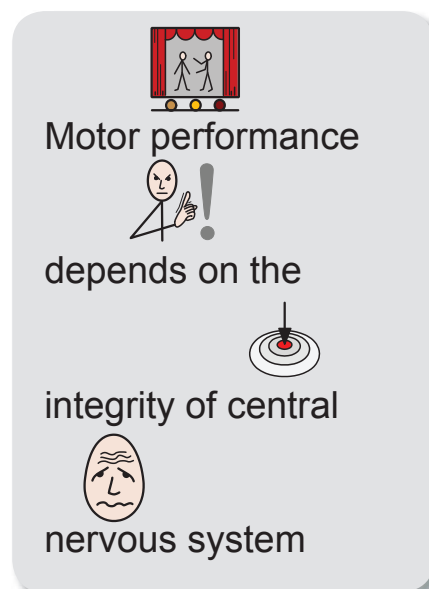
The unique contribution of occupational therapy to this population is in its ability to provide professional solutions to the functional limitations they experience as a result of the intellectual disability. These limitations may present in all human occupational areas of activities of daily living including the ability to learn, work, play & leisure as well the ability to involve in social participation. Henceforth, the occupational therapy assessment process focuses on identifying and defining an individual's priorities and the factors that enable or limit his/her occupational performance. This assessment process among people with intellectual disabilities is ongoing, and usually takes place in the client's natural environment (e.g. residential, educational, occupational or recreational facility). As the occupational therapist observes the client's performance, the therapist attends primarily to aspects of performance skills, such as motor skills (*position, stability or mobility*), process skills (*attention, initiative, choice or organization in time and space*), and communications skills (*establishing eye contact, cooperation or methods of expression*). Both assessment & intervention process for people with intellectual disability, is an ongoing process that is both gradual & dynamic.

The understanding of the mental health needs from treatment & rehabilitative perspective remains incomplete, largely because of difficulty with assessment and diagnosis, diagnostic overshadowing and uncertainty as to the relevance of generally used criteria. ¹¹The intervention is provided throughout the life cycle in accordance with the client's changing needs, desires and preferences in all areas of occupation. It often requires repeated drills and practice to achieve internalization and learning, and performance in a variety of contexts to enable generalization. As is the case with respect to assessment, the intervention is preferably carried out in the client's various daily environments. This enables and encourages the client's participation in many contexts of his/her life. The occupational therapy interventions for people with intellectual disabilities are specifically adapted to the client with respect to the degree and type of support needed as well as the context. Interventions may include direct treatment as well as environmental adaptations, guidance, monitoring and counseling (including of the family, the educational staff, the clinical staff, employers and others). ¹⁷⁻¹⁹

Motor performance depends on the integrity of central nervous system and the mood and motivation of the individual. In children with ID, developmental retardation or deviation of the central nervous system limits the motor development. Considerable part of the motor development is predetermined and governed by the maturation of specific neural mechanisms and their activity, in conjunction with sensory feedback. The brain has to reach a degree of maturity before it is ready to execute a certain skill. ²⁴With few systems functioning, the sensory-motor afferents give the child very little input, which will result in poor body image and reduced activity. These children with ID also often lack motivation which can aggravate their immature motor behavior.

The sensori-motor development is affected to a variable extent and the children with ID often have immature, slow, poorly developed motor and sensory functions. The motor developmental level is lower for fine motor skills and visuomotor control than for postural control and locomotion. Skilled fine motor performance with independent finger movements puts great demands on the central nervous system, which is probably the reason why children with ID had a very low developmental level in this area. ²⁸As the sensori-motor impairments, results in disabilities and handicap, the severity of the sensori-motor dysfunctions needs attention as these sensori-motor problems during early developmental years are often forgotten and neglected. Parents need support and advice by an occupational therapist on how to handle their children in everyday life for the impairments in gross and fine motor function, coordination, balance and perception individually or in a group and ensure the children proper care, training and education to describe and evaluate their motor capacity and functional abilities in a meaningful and appropriate way. ³⁰

Meaningful activities are suggested to recognize and take into account the sensory level, with their awareness of individual sensory stimuli within an activity than the activity as a whole. Occupations enable people to

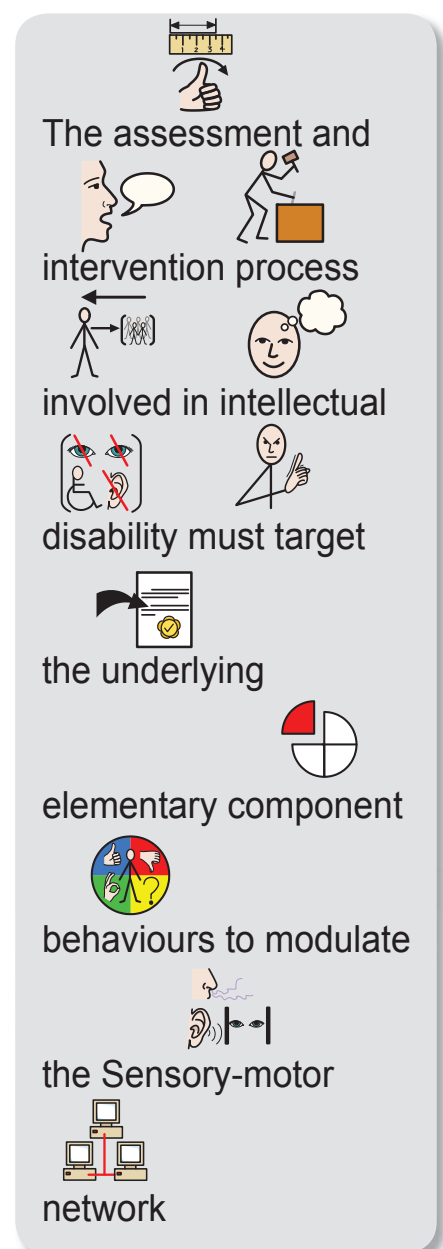


participate in various contexts to enhance health, well-being and quality of life.²⁶ The Pool Activity Levels illustrate the different degrees of ability someone with a cognitive impairment may have to engage in occupation. Pool describes four different “activity levels”, ranging from reflex activity level, sensory activity level, exploratory activity level & planned activity level.²⁵⁻²⁶

The researchers have emphasized upon the impact of an “individualized sensory environment” on adults with severe and profound intellectual disabilities’ interactive behavior outside of that environment. A total of five categories (without specifying their theoretical basis) to describe participants’ interactive behaviors on a spectrum from passive or self-focused engagement, to engaging with another person and then engaging simultaneously with a person and object (*i.e. Self-neutral engagement, Self-active engagement, Person engagement, Object engagement & Person-object engagement*) had been emphasized. Also, the Model of Human Occupation highlights the “intimate and reciprocal” relationship between people and their environment, with these individuals’ occupational engagement particularly dependent on the opportunities, resources, constraints and demands of their social environment.^{12,28-29} But the implication of the role of postural behavior activity, engagement & participation had been neglected.

A majority of the children with ID needs the evaluation of their sensori-motor development & postural behavior and its modulation using appropriate strategies & approaches such as habit training, NFDR to target abnormal postural behavior responses. The postural behavior can be modulated using NFDR approach which has placed due emphasis on postural ontogenesis for building of movement and postural control with respect to the environment. The NFDR also develop the paradigm of interactive framework to regulate movement & its behavior under controlled & graded stimuli and understanding & interpretation of its responses. The technique augments to modulate the internal mechanisms of the tonal characteristics, if affected as in cerebral palsy, by varying the relative configuration of body segments (altering and grading positioning mechanics) and regulating muscle stiffness (via graded loading of the body segments). Moreover, the muscle can be recruitment synergistically via neuromuscular procedures and techniques by altering and varying support surface configurations and their dynamic characteristics in response to external stimuli. This, in turn improves the activation thresholds of the postural and segmental muscles. The altered positioning mechanics and varied support surface configurations helps in the generation of direction-specific postural behaviors and the integration of vestibular, proprioceptive and labyrinthine input in a graded fashion³². This optimum sensory input also helps to minimize muscle stiffness at the neural level and thereby promoting optimal motor behavior, which accounts for the changes in muscle tone and reflex behaviors and processing, improving & modulating sensori-motor learning experiences. This provides a rhythm to enhance participation & engagement thereby improving quality of life.^{29, 31}

To summarize, the assessment & intervention process involved in intellectual disability must target the underlying elementary component behaviours to modulate the sensori-motor network, building responses for improving cognitive as well as interactive sensori-motor learning & processing abilities in variable context.



Recommendations

1. The assessment & intervention process involved in intellectual disability must target the underlying elementary component behaviors to modulate the sensori-motor network, building responses for improving cognitive as well as interactive sensori-motor learning & processing abilities in variable context.
2. The service providers involved with rehabilitation of children with developmental disabilities must include expert occupational therapy professionals to guide and enforce therapeutic learning through developmental continuum.
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4. The rehab team must be educated about learning and training based on sensori-motor engagement for the therapeutic processes involved to maximize early potentialities of a child with ID/DD.

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Tonal & Postural behavior: An early identifier / clinical marker of Abnormal Sensory motor processing in Developmental Disabilities

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Objective

To highlight and sensitize about the early markers of abnormal sensori-motor processing and modulating these deficits / processes in children with developmental disabilities to facilitate initiative towards capacity building for global development within functional context.

Recommendations

- Posture-motor behavior is a guiding tool for modulating abnormal **sensory-motor behavior & deficits in children** with developmental disabilities, therefore its identification and intervention plays a major role as a facilitator towards sensori-motor progress and development.
- **Evidence based guiding framework** will aim at individual capacity building of children with various disabilities improving their Quality of Life (QOL).
- The workforce involved with rehabilitation of children with developmental disabilities need expert occupational therapy professionals for aiming at early markers of sensorimotor behavior.
- Postural behavior are deficient in these children so priority to this domain of practice in occupational therapy for identification & intervention must be given.
- Funding and support for all therapeutic equipment's, aids, sensorimotor tools and learning material should be provided after the endorsement of Qualified Occupational Therapy professionals.

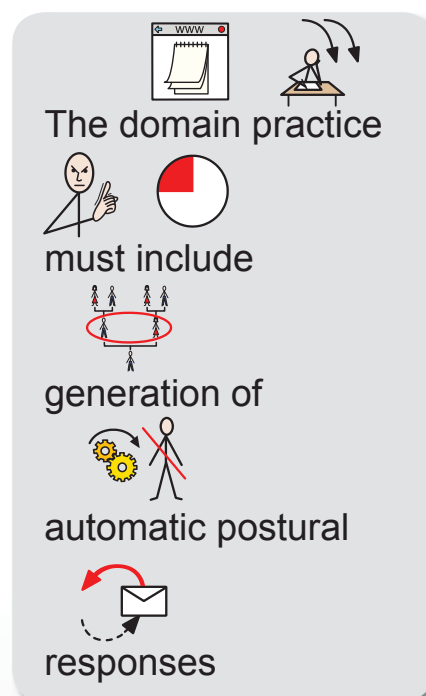
Presentation

The children with developmental disabilities are known to manifest impaired, poorly developed tonal & postural reaction responses. The importance of both tonal & postural behavior assessment and management has been emphasized.

These behavior can be identified and modulated by occupational therapy professionals using various assessment and novel treatment strategies such as Neuro-Facilitation of Developmental Reaction (NFDR) technique, NDT SI therapy etc. The modulation of these behaviors is a key element of early intervention and aims at developing motor precursor as a basic functional unit of postural control and sensorimotor & cognitive development. They are important for attainment of not only posturo-motor but also cognito- perceptual behavior.

Evidentially quoting it as, has been pointed by the great Piaget, that early sensorimotor behavior, which begins at birth continues till the age of two years, is extremely critical for cognito-motor, perceptual and social development.

The sensorimotor development is preceded by reflex behavior which modulates based on the inputs from the environment, and is considered as a pedestal towards motor & postural development. The physical and



sensori-motor environment plays a critical role in building elementary behaviors or in modulating key markers of global development. Therefore, the enriched therapeutic environment would nurture and foster child to overcome the physical barriers in terms of sensorimotor and postural deficits leading or aiming towards social and functional development.

The domain of practice must include generation of automatic postural responses that develop during first year of life and considered important, for regulation of posture, as a standard of practice,. It plays a crucial role for overall development of normal motor behavior, postural control, gross motor functional abilities and perceptual & cognitive development.

Functional correlates

Infants develop skills through a coupling between their sensory and motor systems. Like typical Newborn infants the aim must be to provide a pool of resources towards interpretation of sensory information so that it can be used to modify movements and organize the postural control system based on the task demands. Importance of movement variability and postural control in infancy explores the interactions between the sensory, motor, and postural control systems in development infants.

Maturation of postural behavior facilitates blending of mobility and stability patterns and also provides an insight into the motor potential of children with developmental disabilities. It helps in gaining independence in functional mobility and equilibrium so that child can engage in occupational activities as well.

Postural Reactions (10) include righting reaction, equilibrium reaction and protective arm extension. They are based on multiple sensory input (both internal & external) modalities, usually acting as a whole & it require cortical integrity & develop postnatally as a basis for normal motor behavior .

A lack of variability in early movement or postural control may be an indicator of atypical development. The children with developmental disabilities have lower levels of postural complexity compared with healthy infant/children. (Dusing et al). Their limited experience using a variety of postural control strategies in a non-repetitive fashion limits their adaptability to changing task demands. As a result their ability to learn motor tasks, such as head control and reaching, may be delayed. It is suggested that reduced postural complexity may be useful in discriminating those infants with developmental delays (Kyvelidou et al).

Maturation of postural



behaviour facilitated



blending of mobility



and stability patterns

Collection of Evidence pool -- literature

Eva Brogren et al (2007) observed that there is a problem in postural modulation in CP and emphasized that training in cerebral palsy should be targeted at enhancing task-specific function (and development of APA) of the ventral muscles instead of focusing on antigravity training of the extensor muscles.

Wen-Yu Y. Liu ⁽²⁵⁾, et al (2007) in their study on anticipatory postural adjustments found that the children with CP show greater variability and significantly shorter amplitude of the anticipatory postural adjustment and center of pressure excursion. They concluded that the **intervention should aim at facilitating these abnormal anticipatory postural adjustment responses**.

Haley SM. 1986 did a study on Postural reactions in infants with Down syndrome and assessed the relationship of **postural reactions to chronological age and to motor milestone development**. She emphasized that the intervention should focus on the facilitation of postural reactions to enhance motor development.

Mandich M et al (1994) in their study on Motor development, infantile reactions and postural responses of preterm, at-risk infants concluded **that there lies a relationship between infantile patterns, automatic postural reactions and motor development**.

Consideration of postural reaction as neurological correlates towards functional independence

Neuroscience studies have shown that different brain regions are associated with each network alerting, orienting and executive control. Orienting consists of three operations, namely disengagement, movement and engagement each associated with separate brain areas ³. The perception and execution of musculoskeletal control and movement via unbiased attentional sensorimotor task training are mediated primarily by the central nervous system and involve the integration of 3 main subsystems: somatosensory, vestibular, and visual.

The motor and postural task performance can be modified by regulating these variables and increasing the attentional demands of a task/activity in a graded manner. The ability to regulate and direct attention releases the child from the constraints of only responding to environmental events and means, they are able actively to guide their attention towards the information-rich areas key for learning ^{7,8}.

The capacity of young infants to exercise control over their allocation of attention can be enhanced via occupational therapy techniques which aims at improving reflex modulation and postural reactions considering elementary to posture-motor and functional independence.

These findings indicate that an external focus /environment promotes automaticity in movement control, with the consequence that the effectiveness and efficiency of motor performance is enhanced. Importantly, there is evidence to suggest that an individual's focus of attention not only influences performance temporarily, but that it affects the learning & refining of sensorimotor task performance skills.

Recommendations

- The govt schemes must foster building on these elemental Posture-motor behavior as a guiding tool for modulating abnormal **sensorimotor behavior & deficits in children** with developmental disabilities, autism etc.
- Occupational therapy process is a must for early identification and intervention of atypical sensorimotor and postural behavior playing a major role as a facilitator towards sensorimotor development.
- Govt must ensure ongoing implementation of evidence based guiding framework at all rehab centers/ institutions which will aim at individual capacity building of children with various disabilities improving their Quality of Life (QOL).
- The workforce involved with rehabilitation of children with developmental disabilities need expert occupational therapy professionals for aiming at early markers of sensorimotor behavior.
- Postural behavior are deficient in these children so priority to this domain of practice in occupational therapy for identification & intervention must be given NFDR technique can serve as a potential marker and a guiding tool *in modulating sensorimotor processing in developmental disabilities*.

Funding and support for all therapeutic equipment's, aids, sensorimotor tools and learning material should be provided after the endorsement of Qualified Occupational Therapy professionals only.

- Occupational therapy intervention such as NFDR, principally focuses on elemental units of postural dynamics to regulate/modulate the spatiotemporal characteristics of motor postural behavior considering postural reaction modulation as an important parameter.

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Best Practices for Building Legal Capacity of persons with Developmental Disabilities & Multiple Disabilities at NIEPMD

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Legal capacity is best translated as the capacity for rights and capacity to act. Having legal capacity enables us to choose where and with whom we want to live, to vote, to choose medical treatment, to defend our rights, to make decisions etc. The Article 12 of UNCRPD recognizes that persons with disabilities have legal capacity on an equal basis with others. It also recognizes that some people with disabilities require assistance to exercise this capacity, so the States must do what they can to support and safeguard them.

It is often most challenging to develop legal capacities of individuals with developmental disabilities, autism spectrum disorder, cerebral palsy, learning disabilities, intellectual disabilities, deaf-blindness and multiple disabilities; due to limitations in communication or cognitive abilities. National Institute for Empowerment of Persons with Multiple Disabilities (Divyangjan), NIEPMD's mission is to generate new knowledge and to promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community, and to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. As a national resource centre NIEPMD achieves this mission by providing research, demonstration, training, \

technical assistance to maximize the full inclusion and integration into society, employment, independent living, family support, economic and social self-sufficiency of individuals with disabilities of all ages.

NIEPMD has established inbuilt exercises for legal capacity building by having an independent Parent Advisory Boards for each of its services, namely:

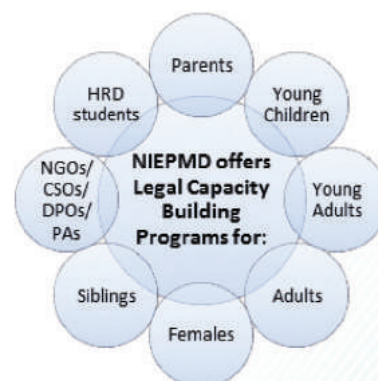
- School services
- Clinical services
- Vocational and Skilling services
- Independent Living services

We also offer an on-going support to NIEPMD Parent Association, which is a registered parent body.

Additionally, for building **legal capacity of parents** of individuals with developmental disabilities and multiple disabilities, NIEPMD conducts various pilot studies and keeps innovating activities for building the legal capacity of parents. Some of these activities include:

- Individualized Parent Training Programme
- Domain-Specific Parent Training Programme eg. Government schemes, benefits and concessions, RPwD Act, National Trust Act and its schemes, Managing adolescence issues, Stress Management, etc.
- Promoting formation of Self-Help-Groups
- Promoting formation of Cooperatives
- Promoting formation of Parent Association
- Resilience Development Programme
- Facilitating "Reaching the Right" Program
- Introspection and exploration workshop for "What is Best, and How to get it?" etc

Moreover, we also proactively link parents to "*Parivaar*" – A National Federation of Parents Association; conduct exposure visits to various Parent Associations, Self-Help Groups, Self-Employment models, Disabled People



Organizations, Parent Supported employment setup etc. Also, we have a dedicated wing for information dissemination for parents of children and adults with developmental and multiple disabilities.

For developing **legal capacity in young children** NIEPMD constantly explores methodologies and experiments numerous unique activities with the target group to help them evolve with innate capacities. Few of the unique initiatives and programs of the institute towards this goal are:

- Early intervention for readiness-skill development towards building legal capacity
- Positive Psychology Development Programme
- Communication Skill Development Programme
- Presentation Skill Development Training Programme
- Decision / Choice Making Skill Development Programme
- Public Speaking Skill Development Programme
- Distress Communication Programme
- Grievance elicitation programme
- Assertive skill development & anger control program
- Group player and leadership programme
- Community use skill development programme



To build the **legal capacity among young adults**, the institute undertakes several competency-based programmes to help them grow into empowered adults. Following are the some of the ongoing and intended initiatives for the purpose:

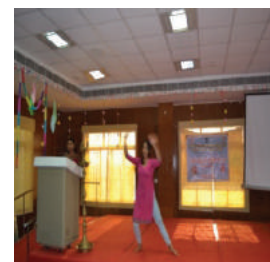
- Resilience Development Programme
- Negotiation Skilling Programme
- Perseverance Skill Building Programme
- Positive Attitude Building towards Self
- Positive Attitude Building towards Persons with disabilities
- Positive Attitude Building towards others
- Unified Events to empower for being included, such as Sport competitions, Cultural programs, Recreation and leisure events etc.
- Exposure visits to explore and gain real-life experiences; like by engaging with different stakeholders, visiting utility or public places etc
- Formal College-Culture induction program

Building **legal capacity of adults** with developmental or multiple disabilities requires employing a collaborative process to promote her/his legal capacity. Therefore, the initiatives of the institute are geared towards engaging different stakeholders and community, some of these programmes are:

- Formal Training for Self-Advocacy
- In-House Internship Programme to Empower towards Inclusive Employment
- Simulated Open Employment Programme
- Towards Independence Programme, for
 - Personal Domain



- Domestic Domain, and
- Community Use Domain
- Exposure to Youth Events
- Exposure to Job Fairs
- “Help Me” – Simulation Programme on legal capacity
- Drama Therapy – Simulation Programme on legal capacity
- “No Sympathy, Treat Me Like All” – Culture for All Beneficiaries
- Mother-Child Paired Rehabilitation Program for individuals with High-Support Needs
- ICT Training
- Entrepreneurship Development Programme



NIEPMD takes great pride in taking special measure for building **legal capacities of females** with developmental or multiple disabilities. Apart from creating gender awareness and social & economic empowerment, the institute intends to promote enabling mechanisms for their access to resources, opportunities and decision making power. With this plan and intention, following is our strategic initiatives:

- Sex Education Program
- Alarming Skill Development
- The “We-get-period” programme
- The “We’re not maid” programme



Siblings are often powerful sources of support for not just the individual with special needs but also to the parents and family. They may have a natural and intuitive understanding of the needs of their siblings and express high levels of empathy and compassion. The most important starting point is to support the relationship building between siblings through opportunities for shared experiences and enjoyment. Additionally, to build the legal capacity of the siblings, the institute organizes following events for them:

- Resilience Development programme
- Workshops on legal capacity
- Domain specific sibling training program like understanding rights, advocacy, inclusion at home and community, Acts and Policies, assisted living etc.

Special programs for building legal capacity of NGOs, Civil Society Organizations, Disabled People Organizations and Parent Associations; are also taken up on high priority, as their reach out to the target group is huge. These initiatives involve building up skills and abilities to develop effective and well-managed organizations that make best use of their resources towards sustainability. Some of these plans and programmes include:

- Advocacy development programme
- Awareness program on Acts and Schemes
- Training on project management
- Training on NGO management
- Training on convergence and resource mobilization



NIEPMD runs various cross-disability and cross-discipline HRD programmes from certificate, diploma level to post-graduate level. The students of these pre-service HRD programmes are the professionals of tomorrow. Considering the intense need of sensitization among both existing and fresh professionals, it is important that

we focus on building legal capacity of during the pre-service training. Therefore, the institute throughout the year and during the course of their study, engages them in the following programmes:

- Workshops on building legal capacity of person with disability and parents
- Chartered Lectures on building legal capacity
- Formal Curriculum on building legal capacity
- Interaction with Disability-Rights Advocates & Self-Advocates
- Empathy Development Sessions

Collaborating with other organizations based on similar missions, increases efficiencies and promote building capacity. It also enables us to collectively develop knowledge and skills for incorporating a more comprehensive and customized approach to capacity building. Below we provide some specific programs that we developed with our partners:

- *Parivaar*– A National Federation of Parent Associations
 - Developed Manual for Self-Advocacy
 - Support Parent-Meets by technical inputs
- CBM India
 - Mother-Child Joint Economic Rehabilitation Programme
 - Entrepreneurship Development programme
 - Self-Employment models
- *Nai Disha*– an adapted training package of Melbourne University



This an overview of NIEPMD's past, present and future capacity building initiatives/ strategies / projects. We remain committed to the creation, development and diffusion of new innovations for building legal capacity; and strengthen coherence and synergies among all stakeholders and community at large to help facilitate the legal capacity of persons with developmental and multiple disabilities.

In the coming years, we intend to enhance building legal capacity of the target population by strengthening technical and scientific collaboration, through training, exchange of experiences and expertise, knowledge transfer and technical assistance. We are strongly driven by the thought of Dr.Abdul Kalam, "*Building capacity dissolves differences. It irons out Inequalities.*"



* * * * *

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Concept on – “Building legal capacity of Persons with Intellectual and Developmental Disabilities”

By: Dr S P Das, Director, SVNIRTAR



While assessing children for Mental Retardation/ Intellectual Disabilities/ Developmental Disabilities. It is necessary to keep certain things on mind about what is Intellectual and Developmental Disabilities. Intellectual Disabilities is characterized by –below average Intelligence or mental ability and a lack of skills necessary for day-to-day living. People with Intellectual Disabilities can do learn new skills, but they learn them more slowly. There are varying degrees of Intellectual Disabilities from Mild to Profound.

According to International Classification of Disease (ICD-10) Classification of Mental Retardation (MR) is 4 types depending on IQ-

1. Mild(IQ 50-70)
2. Moderate(IQ 35-50)
3. Severe(IQ 21-35)
4. Profound(IQ<20)

From educational perspective, the first group is considered as educable, the second as trainable and the last two groups are Custodial, which need close supervision even for self help skills.

Apart from Intellectual Disabilities, there are also other form of Disabilities .i.e. Developmental Disabilities. Developmental Disabilities are severe long term problem. That may affect Physical, mental and both the physical and Mental abilities.

Physical Developmental Disorder-Blindness

Mental Developmental Disorder Include-Autistic Disorder, Asperger's Syndrome , childhood disintegrative disorder ,Learning Disabilities and ADHD.

Both the Physical and Mental Developmental Disorder-Down syndrome, Rett's syndrome

It is very important to understand normal physical and Mental Disabilities before going to legal aspects of Intellectual And Developmental Disabilities. Some of the commonly occurring mental disorders are discussed below:-

1. **Autistic Disorder** :- Children with Autism have difficulties relating to and communicating with other people.
2. **Asperger's Disorder** :-This disorder is without significant delay in language or cognitive development.
3. **Learning Disabilities** :- Learning Disabilities have average intellectual functioning and yet they show inability to read, write, spell, do mathematics in the class.
4. **ADHD** :- Inattention, Hyperactive, Disruptive behavior and impulsivity are common in ADHD.
5. **Down syndrome** :- It is condition in which a person has an extra chromosome and it is associated with intellectual disability.
6. All the persons with intellectual and development disabilities shall be or who are being treated as such persons, shall be treated with humanity and respect for the inherent dignity of human. There shall be no discrimination. The discrimination and misconceptions have a negative impact on treatment and care received by persons with disabilities.

Building
legal capacity of
Person with Intellectual
and developmental
disabilities
is important

The term Human Rights in a broad sense means those claims which every individual has or should have upon the society, in which he/she lives. It was the plea of progressive incorporation of the norms of human rights and liberal jurisprudence in the respective legal system of nation and states that created the necessity and urgency of initiating appropriate steps for the care and treatment of persons with disabilities.

Rights are protected under many different laws. There are some especially important pieces of legislation that explicitly discuss disabilities rights. These are the-

- Rights of Persons with Disabilities(RPWD)Act-2016
- Mental Health Policy (2014)
- National Trust Act
- Persons with Disabilities Act
- Americans with Disabilities Act (ADA)
- Individuals with Disabilities Education Act (IDEA)
- Rehabilitation Act

1. Rights of Persons with Disabilities(RPWD)Act-2016

Right of Persons with Disabilities (RPWD-Act-2016 will replace the existing PwD Act-1995, which was enacted 21 years back. The types of Disability have been increased from existing 7 to 21 and the central government will have the power to add more types of Disabilities.

The 21 disabilities are :-	
1. Blindness	11. Muscular Dystrophy
2. Low vision	12. Chronic Neurological conditions
3. Leprosy cured persons	13. Specific Learning Disabilities
4. Hearing impairment (deaf and hard of hearing)	14. Multiple Sclerosis
5. Locomotors Disability	15. Speech and Language Disability
6. Dwarfism	16. Thalassemia
7. Intellectual Disability	17. Hemophilia
8. Mental illness	18. Sickle cell disease
9. Autism Spectrum Disorder	19. Multiple Disabilities including deaf blindness
10. Cerebral Palsy	20. Acid Attack Victim
	21. Parkinson's disease

2. Mental Health Policy(2014)

Mental Health Policy was launched in October 2014. It was launched on the National Mental Health Day Celebration for the first time by the Govt. The main goal of the mental health policy as stated in mental health policy such as-

- To reduce distress, disability, exclusion morbidity and premature mortality associated with mental health problems across life-span of the person.
- To enhance understanding of mental health in the country.
- To strengthen the leadership in mental health sector at national, state, and district level.

3. National Trust Act (1999)

To enable and empower persons with disability and independent living as far as possible within and as close to the community.

- To provide support and facilities to enable the disabled person to live with their own family.
- Support registered organizations to provide needs based crisis services to the families of the disabled.

- Address problems of the disabled without family support.

4. Persons with Disabilities Act, (1995)

This act responsibility of the state towards the prevention of disabilities, provision of medical care, education, training, employment and rehabilitation of persons with disabilities.

- Create a barrier free environment.
- Counteract any situation of abuse and exploitation of person.
- To make special provision of the integration of persons with disabilities into the social main stream.

5. The Americans With Disabilities Act:- (1990)

This act prohibits discrimination against people with disabilities in many different settings. This law includes five titles:-

- I. Employment
- II. State and local govt. Activities
- III. Public Transportation
- IV. Public Accommodation
- V. Telecommunications relay services.

6. The Individuals With Disabilities Education Act (IDEA):-

This Act passed in 1975 under the name "Education for All handicapped children Act", this law mandates that children with disabilities must receive a free and appropriate education (FAPE). It also provides financial assistance to help educational agencies comply with federal laws and provide required services to students with disabilities. The name Individuals with disabilities education Act (IDEA) emerged in 1990, when amendments to the education for all handicapped children Act were made IDEA describes the services that must be provided to students in elementary and secondary schools and emphasizes the concept of Individual education programs (IEPS).

- IDEA protects children which includes people upto age 21, who are eligible for special education.
- Provide funding to help states and education agencies meet special education requirement.
- Parents must be given a written notice if their students are evaluated for learning difficulties, identified as having a disabilities or placed in a special in a special education program.
- An impartial hearing should be provided when parents object to something about how their child has been evaluated, Identified or placed.
- All children in special education programs should have an individual education programs (IEP)

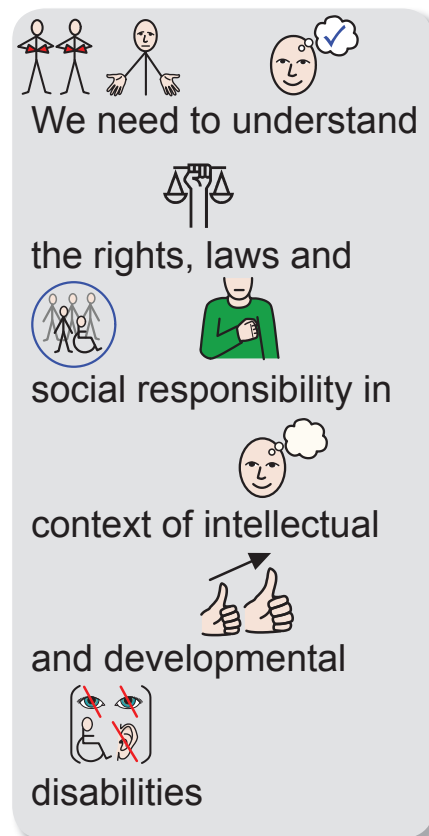
7. Rehabilitation Act:- (1973)

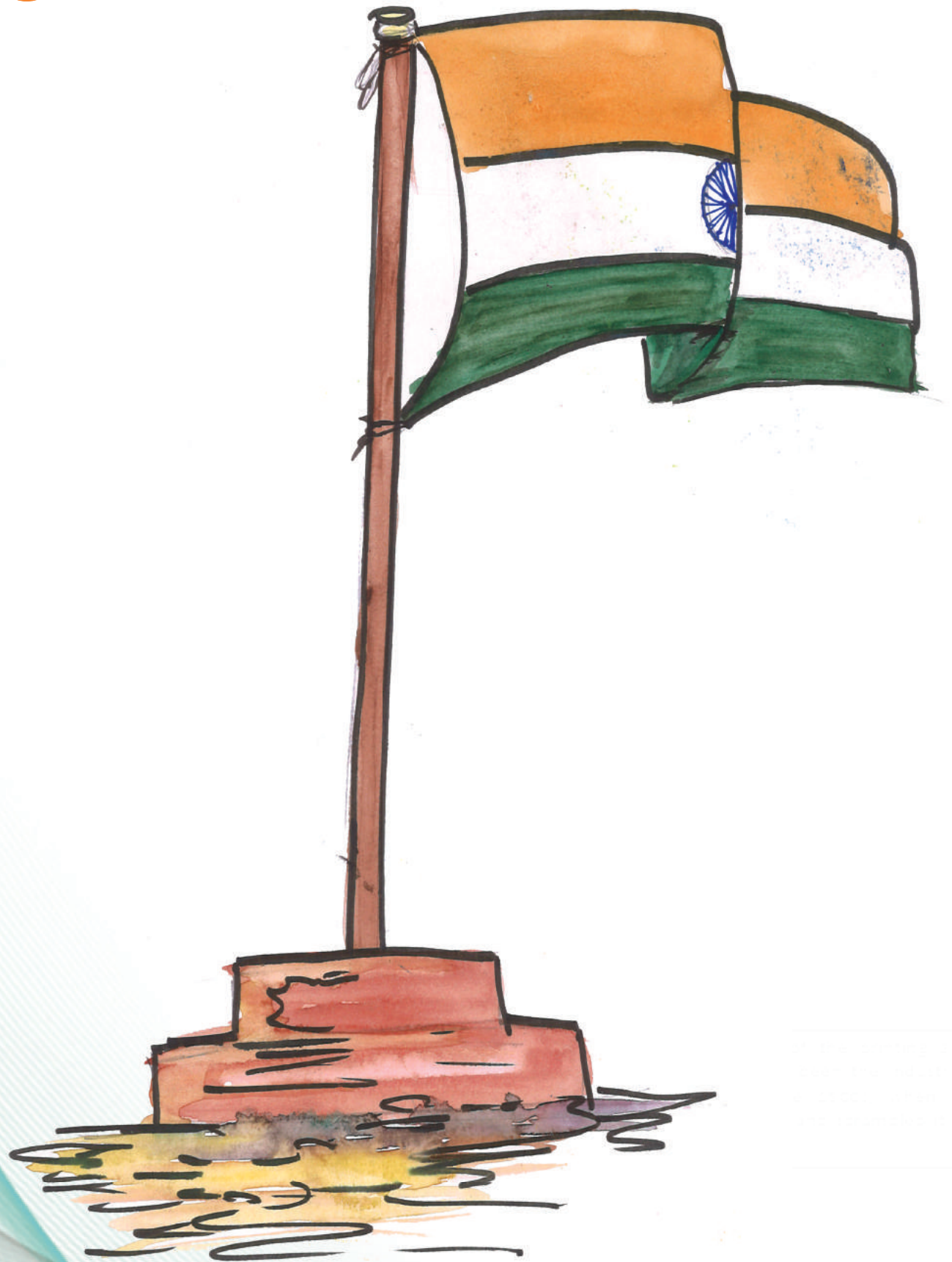
Section 504 of the rehabilitation Act, passed in 1973, was the first piece of civil rights legislation to specifically address the rights of people with disabilities.

- The people with disabilities are defined as those who have a physical or mental impairment that limits a major life activity, such as walking, seeing, hearing, speaking, learning or working. They must be able to provide a record of their disability, and be "regarded as having such an impairment".
- Parents must be notified if their students or children are evaluated for learning difficulties, identified as having a disability or placed in a special education program.

Conclusion:

As professionals working or intending to work in the area of mental health, we need to understand the rights, laws and social responsibility in context of Intellectual and Developmental disabilities. So as to be able to provide better services and facilities to the persons, and their families.





Credit : Coloured by Vikash, Class 8th, Manovikas School for Inclusion



SECTION-III

Success Stories



Early Intervention Success Story: Humera Vasimbin Kathiri

By:- Smt PNR Society, Bhavnagar, Gujarat

Humera Vasimbin Kathiri – A child with enormous strength to survive by fighting against all circumstances.

Age: 6 years

Diagnosis: Quadriplegic Cerebral Palsy with severe Intellectual Disability

Category: BPL

The Journey

When Humera's parents were told by the doctors that their daughter had Cerebral Palsy with severe Intellectual Disability, prognosis against the treatment was poor and her future looked bleak. Her mother, a housewife, was stunned.

The Impact Of Care Under Disha Cum Vikaas Day Care Centre

Despite being given such tragic news, her parents refused to accept that Humera could not improve and progress, and they made plans to attend the Disha cum Vikaas Day Care Centre supported by National Trust, New Delhi which is run by PNR Society, Bhavnagar, Gujarat. Humera's mother came to the centre first, when Humera was 2½ years old. Humera was totally unable to hold neck at the time and sit upright. Her mother began implementing the project's multi disciplinary program. Her father made sure to give Humera ample opportunity to be on the floor in the prone position, to help him begin the pathway toward neck holding.

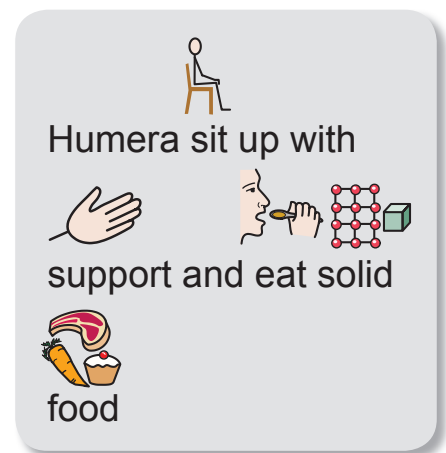
Parents began to see progress day by day, and mother made plans to start the sitting position with full support. When mother attended the multi disciplinary program for last two years continuously, Humera had already begun to make good progress. Since last 2 months, she had started to hold the neck lasted for few minutes and able to sit with full support for 10 minutes.

Humera was evaluated and staff members were very impressed by her progress. Parents were advised to follow the treatment plan at home too. Humera's progress continued to inspire her parents and the staff. Then parents started to train her for eating of solid foods with assistance. She is now able to hold the food and take it in mouth with assistance.. Humera has made very significant progress. She had a history of gag reflex till the age of 3 years which made her difficulty to eat and swallow food. Training under Speech Therapy session has solved the problem.

Humera Today

Although she has been on the program for last two years, she has been able to hold neck, sit with support and eat solid foods with assistance. Mother says, "We have always seen daily miracles, but we're watching huge miracles now, and so I am pleased to see her sit alone... She's going to be a near healthy kid."

We are all looking forward to see Humera continues on her pathway to wellness



Story of Shri Anil Dhanjibhai Dabhi

By:- Smt PNR Society, Bhavnagar, Gujarat

Anil Dhanjibhai Dabhi is a child with Down's Syndrome and joined the Vikaas Day Care Centre supported by National Trust and run by PNR Society, Bhavnagar in the month of January, 2017. He is having disability of 75%. His age is 15years 7 months. The child comes under trainable category of Intellectual Disability. He has been given training at Pre Vocational Training Unit . He is now able to prepare various products like best from waste(basket from old newspaper), key chains, doormats, paper bags, painting works, show piece for door side decoration, etc. He is progressing rapidly towards financial independence in his daily life. The Child belongs to very low socio economic status and father is working very hard. In spite of limitation of time due to earning of livelihood his father trying to help his child with great dedication.

Today's Status of Anil

At present, Anil is shifted to Vocational unit of Nataraj Special School for the Children with Cerebral Palsy. He is busy in mass production of various items like greeting cards, office files, paper bags, cloth bags, etc.

His work schedule is dependent on order for purchase and he also participated various stalls in exhibition, mela, cultural events, etc. and sells maximum products .

We are happy to see innocent smile on his face when he use to keep his earning in the pocket safely after hard work.

Anil's parent is now very proud and confident that Anil will become independent in future life without hindrance.



Credit : Hand painting by Gaurav and Ankur, Bliss of Life, Care Project, Manovikas

Story of Akshay Bhatnagar

By:- Pratibha Bhatnagar (Mother of Akshay), Jaipur, Rajasthan

This is an unbelievable struggle and success story of a Divyang Akshay Bhatnagar, who is affected with Autism, a neurological developmental disorder.

The boy was born on 14.01.1992 and his disability was discovered in 1996. At that time, the doctors did not even know much about autism. Disability certificate have been given to these persons mentioning M.R. instead of Autism. Neither admissions in Schools for AHD persons was possible nor was there any support from the society and from the system too.

In 1999, after the refusal of many schools at the time of admission in class-I, Akshay got admission in a normal school with great difficulty. When parents approached for Disability Certificate, parents had to argue, mentioning Autism instead of M.R. in the Disability Certificate, referring, to the National Trust Act, 1999, in which Autism was included as Disability for the first time. It was Akshay Bhatnagar, due to his struggle Autism was included in CBSE as Children with Special needs.

At the time of College admission, Akshay again faced rejection and discrimination. His parents approached the Commissioner Disability and got the admission in the college. While provided opportunity, Akshay Bhatnagar created a history by becoming First Graduate of Rajasthan and possibly in India in 2014. There was no reservation for Autistic persons. For this purpose, his mother struggled very hard to highlight this issue to the State and Central Government and Chief Commissioner for Persons with Disability (CCPD) and Corresponded to them, and many Seminars were attended to raise this issue.

Finally, Akshay Bhatnagar filed a writ petition in the Rajasthan High Court in July 2016 for getting reservation in Government Jobs. After that RPWD Act came into force in 2016, when 1% reservation was given to Autistic Persons. For the timely enactment of the rules, after unnecessary delay by State Government of Rajasthan in Rules framing, Akshay Bhatnagar's mother filed a PIL to provide 1% reservation finally rules notified on 24.01.2019.

In 2018, Akshay had to file a writ petition in Rajasthan High Court, Jodhpur Bench to provided facility of Scribe and Prompter, which was not provided in Rajasthan to any kind of PwDs, as it was non-compliance of guidelines issued by MSJE, Gol of February-2013. Akshay got the favourable order from Rajasthan High Court and appeared in competitive exams. For every vacancy, Akshay had to take the shelter of High Court to get an interim relief to appear in all the competitive examination. It has been a never before seen struggle, that was done to fight for rights in the field of Disability like Autism and this struggle has opened the way and has removed the barriers for millions of Autism affected persons and other PwDs of the Country.

Finally, Akshay Bhatnagar, after cracking a competitive exam, has become first Autistic Employees of this Country to get a Government Job. Akshay's success against all Odds, speaks a lot his achievements— State Award-2017 Role Model Category, National Award 2018, Cavinkare Ability Mastery Award-2019, Brand Ambassador of Jaipur District by Election Department of Rajasthan in Parliament Election-2019, Winner of 2 Gold and a Bronze in State Para Athletic Championship.

This is a success story in which the struggle and the insistence on making a PwD his own way in which he got the full support from his family. His mother Pratibha Bhatnagar studied all the laws related to disability herself and became a Para Legal Volunteer at District Legal Aid Services Authority, Jaipur Metro. She started the fight for the rights of the Person with Disability and finally won.

Akshay Bhatnagar, age 27, living in Jaipur (Rajasthan) established himself as the ROLE MODEL in the field of Autism in the Country, who is motivating entire country along with people related to the disabilities, parents and general masses.

Little steps to success: Vihaan and Nidhi's journey

By:- Action for Autism, Delhi

Autism is a lifelong neurobiological condition that affects the way a person communicates and relates to people around them. Children with autism have difficulty on relating to others in a meaningful way. Their ability to develop friendships is generally limited as is their capacity to understand other people's emotional expression. Some children, but not all, have accompanying learning disabilities. Autistic individuals sense the world differently and may show atypical responses to sensations. Any one or more of the senses may be affected.

Post an autism diagnosis, most parents begin the long and sometimes challenging search for schools and interventions for their children. Parents often arrive at Action For Autism (AFA) armed with a list of therapies and therapists, schools and centers. The whole idea is to make the parents believe in themselves and also to make them realize the fact that it is not just the trained professionals who can make a difference to their child's life. Most parents are yet to discover their own skills, and to learn how parents themselves drive and shape their child's learning and happiness. The AFA programme known as the Parent Child Training Programme (PCTP) is intended to change those beliefs.

The programme provides a nurturing environment where parents work with their children under the guidance of an experienced, trained therapist. During the duration of the programme, parents are given theoretical and practical knowledge about teaching and behavior management technique incorporating elements of internationally acclaimed 'best practices' for autism, including Structured Teaching, Applied Behavioral Analysis, Verbal Behavioural Analysis and other interaction based strategies.

The program has five clear intended goals: Increases in 1) parent empowerment, 2) parent acceptance, 3) parent understanding of autism, 4) parents' teaching skills and 5) decrease in parent and family stress. Child functioning is expected to improve through changes in parents. Long-term goals of the PCTP include 1) increased advocacy activities among the parents (ranging from talking about autism openly to initiating programs and other activities) and 2) enhanced family functioning. Among these components, the empowerment and acceptance aspects of the program are considered most central to the philosophy of the PCTP.

Started as Mother Child Training in 2001, over time the PCTP has evolved both in content and participation, and has begun reaching a more mixed population of fathers, siblings, grandparents, and other primary carers. The batch of July 2018, had 10 mothers with kids of 2 to 6 years. The families participated from all parts of the country, with a mix hope and skepticism in their hearts. The batch comprised of hardworking mothers and their bright kids.

This batch had a 2.4-year-old boy named Vihaan who was diagnosed with autism earlier in April the same year. Vihaan's preliminary diagnosis detailed non responsiveness to calling his name and initiating a brief eye contact but not maintaining it. His doctor observed that Vihaan was more focused on objects/ activities rather than the person and his interaction with new peers was abysmally poor. He would also find it difficult to sit in one place and had a very low attention span. When Vihaan joined PCTP he was not pointing at objects or looking at objects when someone pointed. He could say numbers, alphabets, a number of rhymes and sing songs but did not even have need based communication. Her mother, Nidhi shares her account of a doctor visit when she was asked that how many meaningful words can Vihaan speak. Nidhi said that both the parents only managed to recall not more than 40 words. As any autistic child Vihaan would at times cry vehemently that often led to hitting his mother.

To talk of some of the positive changes that were noticed just after the PCTP sessions, Vihaan not only started beautifully responding to his name but now a year hence also responds on enquiring about his name. From not only pointing to things to now asking "what is this?" And it doesn't stop there. He talks about most of the things around him and also comments about the situation or actions. So if he sees a dog he will ensure he shows it to others and then describe what the dog is doing "Oh! See the dog is running". Nidhi says that now going on car rides is even more fun because they get updates of all the cars and animals from the little commentator. Yellow car, white car, another white car, auto and the list goes on. He is now potty trained and communicates about his all other physiological needs too.

For parents of children on spectrum their child's haircut day is episodic. With Vihaan it was no different, the parents dreaded the haircut day and just kept postponing it. Two months later from PCTP, Vihaan happily had his haircut, and now he gleefully goes to the saloon and even has his favouritebhैया there. Vihaan who would

often call his mother as “aye” now not only calls her mumum but he understands the concept of family. The other day Nidhi was talking about family to him as “Vihaan, Mumma and Adu (that what he calls his father). The little one went on to say “No! Vihaan, Mumum, Adu, Baa (Nidhi’s mother-in-law), Nanu (Nidhi’s father), Nani baa (Nidhi’s mother), Mamu (Nidhi’s brother) & Dadu (Nidhi’s father-in-law)” and “Chintan” (Vihaan’s most favourite person). A year has passed of the PCTP and now Vihaan speaks full sentences, uses colloquial expressions (as in “Hello friends”, “All four of you” etc), interacts with not only kids of his age group but also with guests.

The one aspect of PCTP where the mothers have leveraged a lot was certainly the schedules. The participatory approach of the mothers themselves making the cue cards and working on their child to follow the schedules and brought a sea change in their lives. Schedules bring a lot of predictability in their routines and the children learn to function independently. Post PCTP, the mothers who have reinstated schedules at their homes will vouch for the fact that their lives have become a lot easier.

Nidhi shares that earlier, though Vihaan enjoyed his school, each morning there would be an episode of crying when he had to leave for school. However, since she has started schedule for the morning Vihaan takes his card and leaves happily for school. One day while going down the stairs he even said “happy to go to school”. Vihaan is appreciated by his teachers in school and is always complimented for being such a good mannered child.

Sleeping was another area of concern as before PCTP Vihaan would not sleep before 2-3 AM. At the PCTP, Nidhi learnt the need for introducing a robust sleep routine to help regulate the sleep wake cycle. After having introduced the same with Vihaan, his mother shares that now he follows a sleep routine beautifully and is asleep by 10.00 PM and wakes up at 7.00 AM all fresh and charged up.

A spillover, yet crucial area PCTP has addressed that it has imparted immense control to the mothers. This has been reported by the mothers that post PCTP they have become comfortable taking their child out in public places, ready to stand up against criticism and are more aware than before. Nidhi shares that post PCTP she learnt to focus on the positive aspects of her child, and approaching challenges as opportunities. Thus the PCTP spread awareness, information and knowledge through a ripple effect; of parents (mostly mothers) not just armed with knowledge but also empowered, and in their turn becoming resource persons and master trainers for other mothers.

As one of the expressions of success of PCTP, Nidhi speaks her heart out, “After Vihaan, the best thing to happen in my life was joining PCTP”. AFA, you are the reason behind all the good things happening in our lives...”



Story of Partha, Shanta, Sajal, Ratna & Payel

By:- Abhoy Mission, Agartala, Tripura

First of all, let's start with the story of Partha. He was affected with Cerebral Palsy. He was not admitted in normal school and studied in our pioneer Special School of Tripura "Swabalamban". He could not speak properly but we could understand his voicing due to our long time acquaintance with him. Knowing his physical and mental condition, everyone became intimate gradually with Partha. He had a keen interest in study and singing as well but it was very hard for him to sing. One day Partha requested our singing teacher, to compose a lyric from Rabindra Sangeet in order to perform on the occasion of Rabindra Jayanti in his neighbourhood. There was a keen interest of Partha to flourish himself before all. He started to learn singing with the lyrics, "Sankocher-o Bihabalatay Nijero Apoman". The singing was going on but after a while, Partha stopped his signing and started to cry. We all asked Partha, why were you crying? Partha replied "the exam of my sister started very early, so I could not carry on my singing for few more days in the house because my voice range is very high". He told that "during the exam of my sister, Baba would go to the school with swadist Tiffin for the sister. But when I used to sit in the exam in my school, my father did not attend me.....". At the time of exam in Swabalamban, Partha studied at home instead of attending the school as well as always thought when he would appear in the Madhyamik Exam and when he would be self reliant by way of performing a job. But when he could not overcome his thoughts due to different hurdles, an intense uneasiness stirs into him and inspired him to destroy everything.

There was another LOVELY GIRL named Shanta who was partially blind and Mentally Retarded. But she intended to attend school every day. She used to go to school by auto rickshaw. One day there was a server storm and the whole city was flooded with water. It was hard for her to move. The water reached to knee level in front of our school. Her father departed her mother and mother was engaged in job. In that day her mother went to office and their house was vacant. In the mean time, Shanta reached to the School alone without her rented auto. We all were surprised to see her. But we were delighted greatly seeing her positive response towards the school and study. However, she was provided with dry clothes and thereafter, asked her heartedly, "Shanta, Why did you come to school in such a foul weather?" Hearing her reply, the eyes of all filled with glittering tears. She replied, **"If we did not come to school, with whom would you continue the classes and moreover, I could not resist myself but attending the school"**.

SAJAL was a deafblind boy. He was deaf. Side by side, he was nearsighted and could see only through a very narrow visual field. He could comprehend a picture or an object by taking it very close to his eyes. His speech was very much incomprehensible. But we had to confront troublesome situations due to his immense curiosity and zeal. In our SAMARTH project, arrangement for solar power supply was made with facilitation from Science and Technology Department and the machines of solar power plant were kept safe in a separate room. One day, Sajal was not found for long time. We all fell into anxiety as because his mother and father were traceless and he was nurtured by his step-sister before his enrolment in this project. In the process of searching, Sajal was traced in the room where machines for solar plant were kept. Most of the parts of the machine were found unfastened and remained scattered on the floor. Sajal was found examining the parts with his limited vision and perhaps trying to understand how the machine came into being. He was also inquisitive about mason work and was found moving around the masons and their assistant who used to come to Abhoy Ashram, where the SAMARTH Project was operated. From time to time, he used to eat, unnoticed, the meal brought by the masons and their assistants. One day, masons constructed bamboo-made platform for mason work and material prepared by mixing cement and sand for plastering was kept in a container. We all became stunned by observing that Sajal was throwing plaster material on wall, under construction, with mason tool (trowel) and providing plaster coating on the wall with his hands very smoothly. **We had no other way than to greet the exercise of residual capacity in a deafblind boy.**

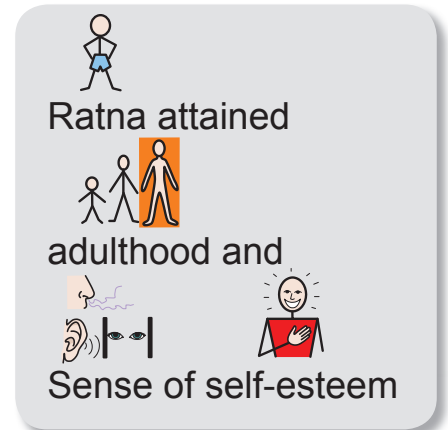
Another day, again Sajal was not found long time. Thorough searching was made and then Police was informed accordingly. It arises in our mind to enquire about Sajal in his -sister's house. She was residing in Jirania Engineering College area, almost 40 Kilometers away from our project area. We went there and found Sajal in good strength of mind with smiley face. Despite his limitations in using his senses, he could travel to a distant place independently. After some days we made consultation with his -sister to take back him in our home. But it was revealed that he already became engaged as mason-assistant in the ongoing construction work of National Institute of Technology building and **it seemed that the society accepted them really**

In the last phase of monsoon season of Tripura, number of children with special needs was being enrolled in Reach & Relief scheme. One of those days, in just after mid-noon, a gentleman was found standing with a special need child on his lap. He said that he was directed by District Disability Rehabilitation Centre (DDRC), West Tripura District to enroll his special need child in the SAMARTH project. The gentleman was a low-vision person and belonged to a BPL family. Name of the child was **RATNA**. The 05 year old child is suffering from cerebral palsy along with mental retardation. She could not lift her body in straight posture and used to move with use of her all four limbs. After admission, Ratna was brought under physiotherapy treatment. Gradually symptoms of improvement started appearing in her body. She was admitted to nearby inclusive school. At that time she used to go to school in wheel chair. Slowly she learnt skill of movement with use of her lower limbs only. But she was walking with fairly bent posture. Tumbling tendency

was prominent at the time of walking in initial stage. Upto senior primary stage, system of no detention of students came into effect. Ratna gradually promoted to standard X in her school. She appeared in the Test Examination and allowed to appear in the Secondary Examination under Tripura Board of Secondary Education. Instead of providing attention to her study, Ratna was more attentive to deal with small children and extending helping hand to old age beneficiaries of Abhoy Ashram. If anybody else provided help to the elderly persons, by feeling hurt, she used to take no meal on that day. Her School made an effort to take approval for taking writer in the examination. Through our long experience we observed that parents took the assistance of scribe to qualify their special need children in Secondary Examination with 1st Division, though such children was not in a position to count properly. So, we did not provide our consent in such effort by the school. Ratna appeared in the Secondary Examination. During examination, writing answer by Ratna used to get completed before all other examinee. On query, Invigilators used to notice that only her name and few lines were written by her in the answer sheet. When result was out, it was noticed that Ratna could not pass the Secondary Examination. But no change in mood was noticed in behavior of body language of Ratna. She kept herself busy in the welfare activities of aged persons. Ratna attained adulthood in 2018. We have been receiving Grant – in -Aid for Old Age Home from Ministry of Social Justice & Empowerment, Govt. of India for long. In 2018, we proposed name of Ratna for Multidisciplinary staff of Old Age Home to the Ministry of Social Justice & Empowerment. Ministry provided approval and Ratna received recognition as staff of Old Age Home. **Ratna is now our colleague.**

PAYEL was admitted to SAMARTH project in 2006. Around same time, we took effort to enroll our special need children in nearby inclusive school. Side by side there was provision of special school in our complex. Our special need children were very much eager to go to school. But the teachers always raised the issue of lack of training in their favour to deal such children in inclusive school as an excuse. Verbally, they used to express their inability to manage such children in classroom environment. They were always asking the children not to come to school; rather they should attend the examinations only. One day, we sent the Coordinator of SAMARTH project to the school as our representative. She went there and raised the issue of negative behavior to our children. Teachers told that the ability of our special children for pursuing the course of study was lying at bottom level, that's why they found little reason for such children to attend the classes on regular basis. Coordinator of the project replied humbly that intelligence and adaptive ability of the most of the children were very poor to follow the course of study, but regular attendance in inclusive school helps to augment their socialization level. But positive development regarding improvement at socialization level noticed after a certain period. Parents who came to meet their wards in the project area, used to hand over minimum amount of Rupees to their children as a token of their affection. Those children accumulated the amount donated by their parents purchased hair clip and bindi, chocolates for their female teachers (aunty) as gift.

Mid-day meal is provided in school. One teacher told our special need children, "You are coming to school only to take food of mid-day meal". They felt insulted and embarrassed. After coming to the Coordinator of the Project, they expressed their unwillingness to go to school. They told "madam aunty, we shall go to school, but never take any Mid-day meal. **"Sense of self esteem already developed in number of our children"**.



Story of Mohammad Mustaf

By:-Samuha Samarthya, DISHA cum VIKAS Center, Koppal, Karnataka


Mohammad Betageri is an 8 year old boy from Koppala. His father, Mabu Hussain, is a labourer. His parents first noticed his disability, when he was 1.5 years, which deters him from moving his neck, sitting correctly and crawling, shortly after his birth, putting him through a number of treatments, none of which seemed to work well, as they were only temporarily.

A Samuha - Samarthya friend then referred him to Samuha - Samarthya Koppal, which brought them to our Early Intervention Center about 2 years ago. There, the experts started therapy that has been going on, as he still frequently comes here.



Intervention: Samuha-Samarthya Community Based Rehabilitation workers did detailed assessment of her condition in DISHA cum VIKAS center, Koppal. A proper counselling to the parents about child disability then child assessment, proper set of goal towards child, proper positioning, physiotherapy and regular exercise, proper food. These are the skills provided to the parents

After all these practices at present days the child is well improved in proper sitting, walking with balance, sleeping and proper consumption of food. Their parents learnt physiotherapy and them practicing it with their children at home. He is identifying all vehicle sounds and observing the animals, bird's picture and recognizing them very properly. Parents are very happy about his healthiness and also good improvement in physically and mentally growth. Also said DISHA cum VIKAS centre helped him to improve his condition.





✓ 


Proper intervention,


professional and parent



involvement improved





Mohd. Mustaf's sitting



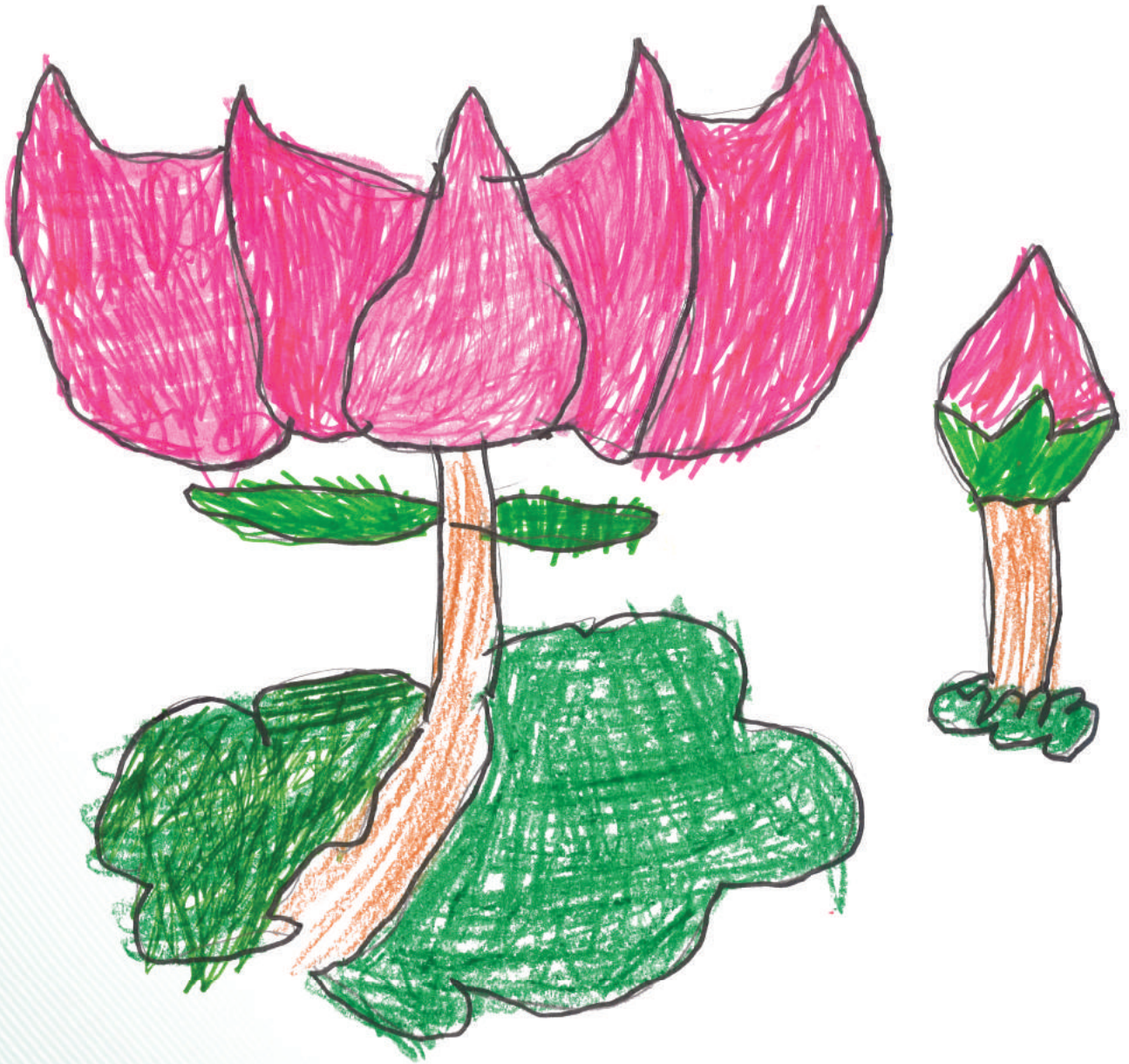
posture, walking with

balance, sleeping and

✓  

proper intake of food.



Credit : Painting of National Flower Lotus by Saumya Mehra, Manovikas School for Inclusion



SECTION-IV

Event Report



National Seminar on “Legal Capacity Building / Capacity Building of Persons with Intellectual and Developmental Disabilities (PWIDD)”

Manmeet Kaur Sareen & Kanika Kalra

Final Year Law Student, Law Centre-II, Faculty of Law, University of Delhi

REPORT ON THE WORKSHOP ON PWIDDs

Introduction:

The National Workshop on Building Legal Capacity of Persons with Intellectual and Developmental Disabilities (PwIDDs) was jointly organized by Indian Law Institute and the National Trust for the persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities to address the issues concerning PwIDDs. The National Trust is a statutory body of the Department of Empowerment of Persons with Disabilities (Divyangjan), which was set up under the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 and it aims at enabling, empowering, strengthening and providing support to Persons with Disabilities (PwDs).

The workshop was conducted on 23rd October 2019, Wednesday at the Plenary Hall of Indian Law Institute with three technical sessions where luminaries from various fields and Government Departments presented their research, ideas, opinions and recommendations. The primary purpose of the Workshop was to bring together experts from various fields in order to efficiently understand and address the issues concerning PwIDDs and come to effective solutions for the issues faced by them.

Workshop Objectives:

- To discern issues faced by PwDs & PwIDDs in various spheres of life;
- To understand challenges faced by PwDs and PwIDDs not just physically but also socially and psychologically;
- To address the concerns of parents of children with disabilities;
- To analyse the developments that have happened and the path that needs to be adopted;
- To achieve a collective vision by fostering collective effort uniting experts from all spheres to efficiently address the catena of issues and provide easy and effective solutions.



INAUGURAL SESSION

The Workshop commenced with the Inaugural Session at 10:00 AM. Justice K.G. Balakrishnan graced the occasion as the Chief Guest for the Inaugural Session and other dignitaries on the dais were Prof. (Dr.) Manoj Kumar Sinha, Shri Nikunja Kishore Sundaray, Ms. Shakuntala D. Gamlin and Mr. S.C. Prusty.

Welcome address by Prof. (Dr.) Manoj Kumar Sinha, Director, Indian Law Institute

The workshop began with the welcome address by Professor Manoj Kumar Sinha. While welcoming the Chief Guest, Justice KG Balakrishnan, mentioned that when the Hon'ble Justice was a chairman of NHRC, a MoU was signed between ILI and NHRC to conduct training



¹ (2018) 2 SCC 397

programs. These programs have been conducted by ILI for the last 7 years and each year 6 training programs are conducted on human rights aspects. Professor Sinha highlighted that these programs are made for enforcement officers who are involved in the enforcement to identify and locate challenges in enforcement and implementation where the main problems lie citing the example of Jija Ghosh where he said that the woman who fought for the rights of the disabled had to herself undergo harassment. He further highlighted the three issues regarding persons with disabilities addressed in the judgment by the Hon'ble Supreme Court of Disabled Rights Group v. Union of India¹:

- (i) The 5% reservation in favour of the disabled was not reaching the right people;
- (ii) Problem in accessibility;
- (iii) Need of improvement in teaching methods.

He laid emphasis on the issues of implementation and while thanking the National Trust, he said that along with teaching, an education institute must organize workshops, seminars, conferences etc. like the present one. Towards the end he mentioned that there are various other issues associated with disabilities like stigma, lack of appropriate support and community based services etc. and he concluded on the note that the aim of the workshop was to get some suggestions and consensually arrive at solutions which should be worked on.

Address by Shri Nikunja Kishore Sundaray, JS & CEO, National Trust

While introducing the workshop and issues associated with people with disabilities, he stated that the sessions have been planned in such a way that various organisations can come together and present their opinions, views, ideas and recommendations with respect to the challenges faced by persons with disabilities. He suggested that disability is an intersection of social and biological development and not an affixation, and therefore the best approach is to look at this issue having a human rights approach apart from the laws. In this context, he laid emphasis on two aspects – capacity building and legal guardianship.

While quoting Socrates “Justice is giving each man his due” and connecting this with capacity building, he emphasized that there are two parts of legal capacity. The first part is that they have rights which all other citizens enjoy like the constitutional and statutory rights. The second part of legal capacity is the special rights to them which include the basket of rights created by the United Nations Convention on Rights of Persons with Disabilities (UNCRPD), the Rights of Persons with Disabilities Act, 2016 (RPDA) which was made in consonance with UNCRPD, and the various judgments given in matters concerning persons with disabilities. He further stressed on the point of capacity building of the community and family because, as emphasized in the National Trust Act 1999, persons with disabilities have to live in the community and in family. Therefore, both supportive and substitutive decision making are extremely important. He mentioned that it is often overlooked that enforcement and capacity building begins with education, skill development and gainful advantage where he applauded Ms. Shakuntala D Gamlin, Chairperson of National Trust, for playing a pioneering role in raising awareness about these issues especially about inclusive education, early rehabilitation and partnership with all national institutions at the international forums.

Coming to the aspect of legal guardianship, Mr. Sundaray put forth the legal conundrum posed by the 1999 Act and the 2016 Act on the aspect of legal guardianship which is that on one hand the former provides for doctrine of election in guardianship and 2016 Act has a transactional variation by virtue of the recusing provision provided therein. He also suggested that there should be courses in education institutions or referral courses on internet in order to make legal guardians understand their rights, duties and obligations as per the law.

The next issue which was highlighted by Mr. Sundaray was about certification which is important for various purposes including proper empirical evidence in CENSUS. According to him there were improvements regarding this aspect in urban areas but rural areas still lagged behind.



Another problem that specifically concerns PWIDDs is the problem of comprehension as per Mr. Sundaray because they are a minority segment relative to the PwDs who, form a majority segment and comprehension issues with respect to them might be peculiar to them, depending on the severity of the condition.

Mr. Sundaray went on to observe that rights of persons with disabilities is an international movement and India cannot be seen in isolation. As per Global Data of WHO everybody will face disability of some sort and approximately 15% of the world is disabled. Therefore, disability is a universal problem.

He further stated that the maximum cases concerning persons with disabilities in the past 6 years and gratitude to Supreme Court which is one of the most powerful institutions of the world as it fills the silence in law. Further, he also applauded the Government of India for doing wonderful work in this sphere.

In his concluding statements, he thanked Prof. Sinha for collaborating and having all the special guests together to carry out this workshop, and further conveyed that National Trust is trying its best to fulfill its mandate, but in order to effectively achieve its goals with target population it requires whole hearted cooperation of all organisations. He finally thanked all the dignitaries on and off the dais to be present.

Presidential Address by Ms. Shakuntala D. Gamlin, Chairperson, National Trust and Secretary, DEPwD

Ms. Shakuntala D. Gamlin is the first woman from the North-East region to reach the level of Secretary post in the Central Ministry. She also represented India in the 22nd session of the UN Committee on CRPD at Geneva.

In her Presidential address she laid great emphasis on the idea of **COLLECTIVE VISION**. She started by applauding the legislature of India. She conveyed that India has taken leadership that has been appreciated internationally by having a country law which is so much in consonance with UNCRPD. Therefore, as per her, there is lot of scope to do as far as the Act is concerned. It is clear that the intent of our legislators is to see that full enjoyment of human rights is guaranteed and enforced. However, she pointed out that what is important to be discussed are the issues with regard to implementation. The Act



being a new one, its Rules were initially notified by only 1-2 states but in the last 1.5 years. The Rules have been notified by 21 States. In her opinion, the reason only why the States are hesitant to notify the Rules was not because there is no intent or purpose but because disabilities as a subject has always been relegated to the peripheral. She explained it by saying that often it is the civil society organisations, the experts, the researchers and the legislators who may have felt that they have themselves been affected because of which RPwD Act. peripherl 2016 fructified, but when it comes to implementation, the COLLECTIVE VISION needs to be developed. In her idea of COLLECTIVE VISION she elaborated that various issues from reasonable accommodation, to legal capacity, to providing accessible infrastructure and assistive tools, to inclusive education, to participation of specially-abled persons in art, culture and sports, all of these require support of each and every one in society as the rights of PwDs, touches every aspect of human existence; from the very simple and basic to the very complex. According to her, in order to implement the idea of COLLECTIVE VISION institution and capacity building is a must. She explained it by saying that we have a host of individuals who are experts in their own field but what is needed is that we need to work together in partnership and getting all these individuals together for a COLLECTIVE VISION that takes a lot of effort, deliberation and requires understanding of the sensitivity of the issues. Build road maps and collaborative efforts to achieve the desired results.

She went on elaborating on the fact that sensitizing people an the issues regarding disability is critical. She gave the example of the Civil Aviation Ministry. She mentioned that Civil Aviation Ministry has done extremely well and has created a dedicated channel for disabled people for security at airport thereby facilitating smooth transaction. However, still there are issues where sometimes security personnel could not understand the caliper as an assistive device or the devices that are required by a disabled persons without which the disabled passenger's mobility is affected. Therefore, she said, sensitizing the security and the standard operating protocols, and standardizing technology so that they become accessible, is itself a great stride towards achieving the goals.

Citing the example of Urban Development, she said there are gaps in the harmonized by-laws for buildings with respect to toilet designs in rural areas etc. However, she said that the government's intent to do the needful is evident from the fact that the rights of PwDs is being talked about today. Such gaps can be overcome with proper feedback from disabled users, innovators and employers.

She went on to elaborate on early intervention centers and intervention programs. As policy makers, requirements of disabled children like their toilet manners, the tools they need, their literacy levels must be enabled for them to enjoy the fruits of inclusive education; if a child is congenitally impaired he can be provided rehabilitative intervention in his early years. But the question is again whether there is a center where the rehabilitative team can work together with a medical team, parents and community for the growth and proper development of the child. She informed that the Hon'ble President has gifted such a centre to our National Institute that encouraged us to start such centres in our NIs and CRCs.

Talking about the international movement, she said that today there is a universal transition in the approach where the whole world is moving from the medical model to the rehabilitative or social model. She stated that we are still at crossroads with mental health issues, meaning thereby, trying to discover as to whether they are psycho-social issues or whether they are medical issues? We must develop synergies between both to achieve the desired results.

She opined that it is the need of the hour for experts to decide as to how should convergence happen and collective vision be developed because there is a need for everyone to work together by way of which reasonable opportunity and capacity can be built of institutions and human resources so that all persons can enjoy their rights equally. In this light, she commended Mr. Sundaray as CEO of National Trust for having organised such a conference and stated that National Trust has taken leadership in getting all experts, civil society organisations, legal luminaries and policy makers together because, this is the need of the hour without partnership of all these stakeholders, it would be difficult to achieve the stated objectives. She concluded by saying that – Society needs to evolve where laws take a backseat and ethics and sensitivity need to take a front seat. Thereby, the intent and purpose of the law with its stated objectives are easy to achieve without much ads.

The Compendium Titled 'BUILDING LEGAL CAPACITY FOR PERSONS WITH INTELLECTUAL & DEVELOPMENTAL DISABILITIES, INDIA, 2019' was released by the Hon'ble dignitaries on the dais.

Inaugural Address by the Chief Guest, Justice K.G. Balakrishnan, Former Chief Justice of India and Former Chairman, NHRC

In his Inaugural address, Justice K.G. Balakrishnan commended the 1999 Act by saying that it is wonderful and allows everyone to take pro-active steps for people with multiple disabilities, but he said that there is a long road ahead.

According to him one of the biggest problems regarding the issues of disability is the usual tendency to suppress the disabilities. In India, according to him, parents try to hide children with disabilities and do not take them out. Therefore, he suggested, there is a need to educate the family and community about the ways to behave and deal with persons with disabilities and there is a need for attitudes to change.

He observed that in the Act there is a National Level Board and there exist Local Level Board. He opined that there should compulsorily be State Level Boards because there are persons with disabilities in the entire country having varied ailments and it is very difficult for a National Board to solely work towards its betterment. Therefore, in order to achieve *greatest happiness of the greatest number* (Bentham), there is a need for State Level Boards. He advised that State should come with larger funds and such children should be provided with special schools, hostels and facilities. According to him, it is necessary to create friendly environment and provide user-friendly facilities in public areas

He also stressed on the requirement of conjoint effort from various expert bodies and organisations like NGOs, activists, experts etc. for proper implementation of legislation.

He concluded on a positive note explaining the need of education by narrating a beautiful incident where he had decided a case of a disabled girl and allowed her to continue her pregnancy and give birth. Two years ago, Hon'ble Justice met the lawyer of the girl where the lawyer told him that the child had become bright and was doing well.

In the end he congratulated the Trust and commended the efforts of organising the workshop.

Vote of Thanks by Mr. S.C Prusty, Registrar, ILI

Mr. Prusty delivered the vote of thanks to all the dignitaries and commented that in case of a child with PWIDD, the mother undergoes through a lot of stress. Therefore, there is a need to empower all stake holders.



TECHNICAL SESSION I DIFFERENT PERSPECTIVES ON DISABILITIES

The first technical session of the Workshop began at 11:15 AM where four speakers delivered their presentations on various perspectives on disabilities from medical perspectives to social issues.

1. **Professor Sheffali Gulati, HOD, Child Neurology Division, Department of Pediatrics, AIIMS, New Delhi**

Professor Sheffali Gulati's presentation was regarding the neuro-developmental disorders (NDDs) and she also emphasised on the role of technology in efficiently dealing with such disorders. She started by stating that neuro-developmental disorder is not just about the patient but it is a family-centric issue as it affects the family at large.

She pointed out that today there has been a paradigm shift from decline in mortality, where smaller children with such disorder survive now, to increase in morbidity, and NDDs account for more than 25% of disease related morbidity.

She provided for 3 strategies for prevention of NDDs:

- (i) Primary prevention – before conception
- (ii) Secondary prevention – identifying high risk children and diagnosing at earliest stage possible
- (iii) Tertiary prevention – rehabilitation

She emphasised on the need for proper ascertainment, early identification and management tools. Ascertainment issues require proper and early redressal in her opinion, because 12% of children between age group of 2-9 years have NDD and 21.8% have more than 1 NDD. Therefore, she stressed on the fact that there is a dire need for early intervention mechanism to prevent NDDs.

She further raised the importance of public awareness to be carried out simultaneously with technological advancement. This is because family members need to know how to deal with a child suffering from NDD and, she mentioned that 70% of mothers of autistic children are clinically depressed. She also said that issues regarding legal guardians and certification need to be addressed

She went on to share that an electronic application service has been launched by AIIMS for diagnosing NDD and storing the same data which helps doctors in both timely and early diagnosis. Emphasising on evolving technology, she opined that Bio Markers and Artificial Intelligence are good technologies for early detection.

In her concluding remarks she suggested that everybody should learn acute seizure control and CPR. She finally ended by saying that what is required of the people is to understand and empathise with a family with a child suffering from NDD rather than categorising them and then stigmatising them.



2. **Dr. Nimesh Desai, Director, Institute of Human Behaviour and Allied Sciences (IHBAS), New Delhi**

Dr. Nimesh Desai in his presentation conveyed the issues surrounding psycho-socio disabilities and the social stigmatisation. He started by sharing an observation that the common Indian mentality is not to recognise the social realities. He posed a question: whether psycho-socio disability can be a legal concept? He opined that law does not recognise social realities because 'Acts' do not change social realities. According to him, laws still need to fill a lot of lacunas like in cases where mental health patients have enough money to undergo treatment but because of being in some sort of temporary or permanent unconsciousness they cannot access their accounts themselves and no law allows



He provided insights surrounding this issue and explained that psycho-socio disability are major concerns with the human CPU and therefore conveying one's idea becomes difficult. He suggested against compartmentalisation of such people. He went on to suggest that it is important to differentiate between mental illness and mental retardation. He opined that the exclusion of mental retardation from Mental Health Act, 2017 is only to decongest mental health community. He also pointed out that the right to refuse treatment contemplated in UNCRPD cannot be conceived from the point of view of persons with mental illness and therefore this cannot be accepted within the Indian ambit. Dr. Desai concluded by saying that disability in the brain and mind is different from physical disability and this distinction has to be maintained.

3. Dr. Gaurav Gupta, World Health Organisation (WHO)

Dr. Gaurav Gupta gave insights on the issues faced by the disabled and the steps taken by WHO in furtherance of their upliftment. He listed out the following challenges faced by PwDs:

- (i) 15% of global population has some disability
- (ii) Position of PwDs is weak in the family and community due to stigmas attached with disabilities and lack of awareness;
- (iii) The employment reservation for people of this category is still not going into the right hands;
- (iv) There is inaccessibility of proper healthcare infrastructure and quick addressal systems;
- (v) There is lack of proper education facilities and schemes.

Dr. Gupta highlighted the need for strategizing at the national and international levels. He enlisted the following initiatives which are being taken by the WHO:

- (i) International Classification of Functioning, Disability and Health (ICF) are provided and regular trainings are being organised for measuring on the individual and population level;
- (ii) Community based rehabilitation guidelines were instituted during the international consultation to review community-based rehabilitation in Finland in 2003 by WHO in collaboration with Member States. This included empowerment of families by supporting them to meet the basic needs and quality of life of people with disabilities and their families.

He concluded by mentioning the International Day of Persons with Disabilities which is celebrated on 3rd December each year and he commented that this a day for all because everybody is potentially aging and would in one way or another be disabled.

4. Dr. Meenakshi Batra, Pandit Deendayal Upadhyaya National Institute for Persons with Physical Disabilities (Divyangjan), New Delhi



Dr. Batra laid emphasis on the importance of Occupational Therapy, which relates to the cognitive defects and abilities. Talking about children between the age of 0-2 Years, she stated that presentation in children with intellectual disability reflects multiple sensorimotor problems during initial developmental years. Thus, she explained that Occupational Therapy places a good deal of rationale in analysing and interpreting sensory and motor dichotomies. Further, she highlighted that the activities must be conducted in a manner to ensure that the child is actively involved through the different stages of growth and development. This shall ensure practical solution to the functional limitations they would otherwise experience as a result of the intellectual disability.

Occupational therapy therefore, she said, is the assessment process focusing on identifying and defining an individual's priorities and factors that restrain him/ her from undertaking such activities. The same is determined by the Therapist based on the client's performance in the motor skills, in the communication skills, process skills etc. She

explained that for the purpose of doing so, it is necessary to maintain constant eye contacts, notice the positioning and stability in motor acts, or make a note of the initiatives taken by the client etc.

The requirement for this assessment and intervention process is therefore to target towards the underlying elementary component behaviours to modulate the sensorimotor network, building responses for improving the cognitive as well as interactive sensorimotor learning and processing abilities.

In the end, Dr. Batra made the recommendations such that intervention processes target the elementary component behaviours to modulate sensorimotor network. Even in the case of rehabilitated individuals, Expert occupational therapy professionals should be hired to guide and enforce therapeutic learning through the developmental continuum.

It is also essential for the service centres to encourage supplying therapeutic materials for orienting and engaging the responses based on sensorimotor therapy. What amongst all is the most important is her suggestion for the rehab team to be educated about the sensorimotor engagement for therapeutic process.

TECHNICAL SESSION II

RIGHTS AND ENTITLEMENTS FOR PWIDDs (DIVYANGJANS) AND INITIATIVES TAKEN BY GOVERNMENT

The second technical session of the Workshop began at 12:15 PM where four speakers from governmental bodies as well as parent organisations delivered their presentations giving an insight on the current status and the aims for a better future for the PWIDDs.

1. **Shri Prasanna Kumar Pincha, Former Chief Commissioner for Persons with Disabilities, Government of India, New Delhi**

Mr. Prasanna Kumar Pincha, who was the first Chief Commissioner for Persons with disabilities, Government of India enlightened the gathering by talking about the rights of the persons with Intellectual and Development Disabilities and their rights to exercise their legal capacity. Putting forth the philosophy of the UNCRPD, he accentuated on the point that each individual's personhood is to be respected regardless of his abilities and disabilities and that the same constitutes to be an integral part of his right to human dignity. Such individual has human rights and fundamental freedoms, and is therefore, not to be treated as an object needing medical care and social protection. Article 12 of the UNCRPD works on the same lines, where it recognises the person with disability before law, recognizes the legal capacity of this individual on equal basis with others and thirdly, provides for support arrangements.

While appreciating India's stand on complying with the International statute of UNCRPD, Mr. Pincha emphasized on the intricate issue with respect to certain provisions of the RPDA, where he stated that a distinction has to be made between the degree of support required by the persons with different disabilities. This, he said, requires an expeditious resolution.

Explaining 'Legal Capacity', he mentioned the 2 essential components, namely- recognition before law, and, ability and maturity to comprehend the nature and possible consequences of a given act or omission. When this legal capacity is to be detected for a person with disability, it is essential to keep the degree of disability under consideration, i.e. whether this disability is mild, moderate, profound or severe. This point was further mentioned u/s. 14(3) of the PWD Act, which enjoins upon the local level committees to consider if the PWD actually needs a guardian.

Further, Mr. Pincha suggested that a proper, vibrant and committed support network should be created on a large scale in order to ensure that the PWIDDs get proper environment to exercise their legal capacity. He stated that there has to be a well-thought-out syllabus for training these networks and that such activities are required to be of an ongoing nature. These recommendations were also made to the Ministry of Home Affairs, Government of India.



He raised various issues such as- who is answerable for the acts or omissions of the PWIDD? If they commit an offence which is punishable in the eyes of law, would they or would they not be liable for their acts, especially when they did not have the mens rea? Would the PWIDD be given voting rights? etc.

In conclusion, he stated that there is a need for harmonizing the mainstream legislations with the UNCRPD and the RPD Act in a time-bound manner and under no circumstances should the best interest of the PWIDD be compromised upon. Quoting Swami Vivekanand, he said “We must humanize our relation to god; and. divinize our relation to humans.”

2. **Dr. Sanjay Kant Prasad, Dy. Chief Commissioner of PwD**

Dr. Sanjay Kant Prasad, in his presentation, provided an insight into the office of Chief Commissioner of PwD (CCPD) and the redressal mechanism established therein for the complaints. He began his presentation by enlightening us that the Chief Commissioner and other Commissioners are appointed under Section 57 of the RPDA.

Mr. Prasad gave the following information about the complaints and their redressal at the office of CCPD:

- (i) Compliance has increased manifold under RODA because of the provisions of increasing awareness and rule of penalty;
- (ii) 50% of the complaints that are received are related to States which are forwarded to the State Commissioners which shows that people are not aware about State Commissioners. Out of the remaining 50% of the complaints, 20% are redressed at the time of notice and 30% are processed after which directions are given;
- (iii) In certain cases it is being seen that the order of CCPD is becoming valueless because S. 76 of the Act provides that in case of non-compliance, CCPD can be informed by the non-complying authority with reasons. However, most orders are being complied with.
- (iv) Cases addressed by the office of CCPD pertain to insurance, pension, harassment, admissions, issues at religious places like gurudwaras, transfer cases etc.
- (v) 36,000 complaints out of 37,000 have been redressed and the remaining 1,000 are under process.



3. **Shri Shivajee Kumar, State Commissioner for Persons with Disabilities, Bihar**

Mr. Shivajee Kumar enlightened us about the implementation of the RPDA in Bihar and the various schemes launched in the State to uplift the disabled. He started by delightfully informing us that the Supreme Court has said that Bihar is in complete compliance with RPDA. The following are some of the schemes and benefits provided in Bihar amongst those enlisted by Mr. Kumar:

- (i) 101 Buniyaad Centers have been opened for aiding the disabled;
- (ii) In the financial year 2018-19, 97,058 certifications were complete;
- (iii) Requirements under Section 72 of RPDA have been complied with;
- (iv) *Parvarish Yojna* has been launched whereby State will provide monetary compensation to all disabled kids without parents including siblings
- (v) *Chatra Yojna* has also been launched to ensure easy availability of equipment like wheelchairs and assistive tools at such children's' doorstep



He concluded by stating that unsound is not equal to intellectually or physically disabled and that there is still a long way to go for complete upliftment.

4. **Cdr. S.N. Bijur, President of PARIVAAR**

PARIVAAR is a national confederation of Parents Organisations to empower PWIDDs and the families of such children. Cdr. Bijur highlighted the importance of SELF ADVOCACY. He started by saying that whenever a parent calls him for joining PARIVAAR, he asks them three questions:

- (i) Are you happy about your child?
89% of the parents say yes
- (ii) Are you worried about your child?
100% of the parents say yes they are worried as to what will happen to their child after their death
- (iii) Are you members of the National Trust?
Only 1% of them are.



Therefore, he suggested, there is a need to make people aware about the trust and organisations which are there so that they can take help and also make suggestions.

Cdr. Bijur then highlighted that powerlessness is one of the main reasons due to which PWIDDs are not being able to become capable and this powerlessness is created in their minds in many ways:

- (i) Powerlessness is created by parents when they do not accept the child;
- (ii) Powerlessness is created by family when they hide the child and carry out discrimination within the household;
- (iii) Powerlessness is created by the system when such child is made to go to a special school while his brother, friend or cousin goes to a regular school
- (iv) Powerlessness is built when they are not allowed to be put in important positions which makes such a child doubt himself even if he is capable of handling such positions.

He suggested that the transition from powerless to powerful can happen by making them socially inclusive through SELF ADVOCACY so that they can understand themselves and their personality and by giving the opportunities of making small decisions or speaking up in groups. It is necessary to establish communication with them and they should not be underestimated. He firmly believed that self-advocacy is necessary for building legal capacity. It is necessary that they should be put in positions of power like Board of National Trust because their presence is necessary. There is also a need to educate family and community and monitor activities of the legal guardians.

TECHNICAL SESSION III

HUMAN RESOURCE DEVELOPMENT AND CAPACITY BUILDING

The third technical session commences at 1:30PM whereby 4 speakers gave an insight about the current developments and the strategies needed to be adopted to develop PWIDDs as human resources.

1. Dr. Aloka Guha, Ex-Chairperson, National Trust on Empowerment of Caregivers

Dr. Aloka Guha in her presentation pointed out the issue of stigmatisation and the need to change the approach of looking at the issues of PWIDDs stressing on Inclusive Education and the need to make changes in the smallest ways for effectively developing the disabled.

Dr. Guha started by stressing on education saying that Jija Ghosh could not have fought without education. She laid great emphasis on the importance of education and said EDUCATION = EMPOWERMENT. She pointed out various cases where children with PWIDD have done extremely well through education:



- (i) Ms. Haben Gima – pwDB, Harvard Law School Graduate
- (ii) Ms. Disha Sharma – a girl with down syndrome with B.Com Degree
- (iii) Ms. Shruti Singh – India's first deaf-blind physiotherapist

She mentioned that as per UNESCO, no child is learning impaired, and the fact that there is a high correlation between students who have never been to school and dependents shows the importance of education.

She stated that, as per the RPDA Act, a disabled person is not a person with impairment per se but a person with barriers. She divided the barriers into three kinds:

- (i) Institutional
- (ii) Environmental (poverty, physical barriers, communication gaps)
- (iii) Attitudinal (people do not see the benefits that are offered by PWIDDs because they have no expectation and they have a negative attitude towards PWIDDs)

She suggested that awareness needs to be created to fight these barriers and such awareness can be created by a body like a Trust through a rights-based model.

She further laid emphasis on inclusive education. She compared this with 3 phases in swimming:

- (i) Phase I- where a person is told he cannot swim
- (ii) Phase II- where the person is thrown into the water
- (iii) Phase III – where it is decided that person will be taught learning slowly

She opined that inclusive education is the fundamental right of disabled persons for three reasons:

- (i) Economic benefit – for job and poverty alleviation
- (ii) Social Benefit – Education will help socially because PWIDDs are excluded for having bad behaviour
- (iii) They are entitled to not be discriminated by being segregated.

Dr. Guha made the following suggestions and recommendations:

- (i) National Strategy of Inclusive Education must be developed
- (ii) Offences in chapter XVI of RPDA should be included in awareness programs and campaigns
- (iii) Section 31 of RPDA provides that children with benchmark disabilities have an option to either join a special school or a regular school. However, the problem is that the pre-condition of having appropriate environments is being overlooked by special schools, and this is required to be addressed.

- (iv) There is a need to provide reasonable accommodation for such students as a part of Samagra Shiksha and CBSE is in the process of providing it.
- (v) There is a need of involvement of parents in inclusive education as well as the National Trust.
- (vi) Partnership can be entered into for formulation of integrated schools as in RPDA
- (vii) Regular schools need to be equipped to accept such kids and monitor their growth. She gave the example of Sampoorana Tripura where equipment were adopted in all schools in Tripura plus 1 – year training program was carried out to address the needs of these children.

She suggested that as a starting point, partial inclusion can be taken up in order to eventually achieve complete inclusive education in the 12-step pyramid for inclusive education.

Dr. Guha left us on a reflecting note by quoting Larry Chalfan: *We do so much to prepare our children for the future, but are we doing enough to prepare the future for our children...*

2. Dr. S.P. Das, Director Swami Vivekanand National Institute of Rehabilitation Training and Research (SVNIRTAR)



Dr. S.P. Das, through his presentation gave us insights on locomotive disabilities and the activities undertaken by the Institute to improve the lives of the disabled. The entire objective of the institute is to focus on areas and scopes of its activities with a constant strive for quality in performance for substantial wellbeing of the differently abled persons. The Institute, as explained by Dr. Das, has various departments like the department for prosthetics and orthotics, department of speech and hearing, department of physical medicine and rehabilitation etc. and they have cured various children with locomotive disabilities enabling them to lead a better life. He raised concerns as to why CSR activities are not undertaken for betterment of conditions of such persons with disabilities. He concluded by comparing PwDs with God Jagannath who

lives a quality life. He said that here lies the disability paradox where disabled people don't get quality life. The aim is that even if they have poor functioning, they should have an excellent quality of life.

3. Dr. Himangshu Das, Director National Institute on Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai

The aim of the institute is to provide need based comprehensive rehabilitation through team approach facilitating inclusion, ensuring empowerment of persons with Multiple Disabilities and their families and by substantiating field-based research and development of human resources. Dr. Das stressed on manpower development and stated that people with disabilities do not seek sympathy but want to be treated alike. The Institute has established inbuilt exercises for legal capacity building by having an Independent Parent Advisory Boards for each of its services:

- (i) School Services
- (ii) Clinical Services
- (iii) Vocational and Skilling Services
- (iv) Independent Living Services

He conveyed that the institute conducts programs for the purpose of re-mingling the children with their siblings and parents. The idea therefore is to build legal capacity of all stakeholders.

Dr. Das concluded by quoting our Former President, Dr. APJ Abdul Kalam – Building capacity dissolves differences. It irons out inequalities.



4. Ms. Saakshi Sinsinwar

Ms. Saakshi delivered a presentation on substance abuse disorder in connection with NDD. Clarifying the technical terms, she stated that mental disorder is NDD and in psychology it is intellectual disorder as per the diagnostic manuals. She said that there is a connection between substance abuse and Intellectual disability – misdiagnosis of intellectual disability leads to social exclusion which causes the patient to take to social evils like substance abuse. So the need is to uplift them socially (as a collective), psychologically (as interspersed individuals) and legally (as citizens having rights and duties). As per her, RPDA helps in achieving these objectives by including psychiatrists and paediatricians. She also opined that autism spectrum is an untapped potential.

She concluded by quoting Simone de Beauvoir – *Man must not attempt to dispel the ambiguity of his being but on the contrary, accept the task of realizing it.*



Delegates of National Seminar on “Legal Capacity Building / Capacity Building of Persons with Intellectual and Developmental Disabilities (PWIDD)”

VALEDICTORY SESSION

The Valedictory Session commenced at 4:15PM and was graced by Justice Arijit Pasayat, Former Judge, Supreme Court of India who delivered the valedictory address.

Valedictory Address by Hon'ble Dr. Justice Arijit Pasayat, Former Judge, Supreme Court of India



The valedictory address by Justice Pasayat was moving where he narrated personal incidents of his experiences with PwDs. He began by sharing with us about the school he built in Cuttack for special children, named Ankur, in remembrance of his elder son who was an autistic child who died 15 years ago. Later that school was taken over by authorities and renamed as Sahay.

Justice Pasayat stressed on the human rights issues that PwDs face and how they are treated to be Unwanted by their own families and community. He mentioned that families in India are reluctant to introduce their children to outsiders.

He said that our Constitution provides for a life with dignity and not of mere animal existence. He narrated an incident in this context where he mentioned that when he was chairman of NALSA, he was shocked to see people with disabilities chained in some places. He told his Secretary that they should be unchained and to this he said

that if we cannot control them we should accept that we cannot do it, but chaining them is a violation of human rights. He explained that all of us have deficiencies and none of us are flawless. PwD means a person who does not have the sanity of a normal person but then normal person may not have the sanity of the existing super-intelligent persons but that does not make us less humans. Similarly, PwDs are not less humans. According to him the starting point is to understand PwDs and their deficiencies, and we need to realise that their deficiencies do not make them less humans.

He further stressed on the aspect that they need to be made to feel Wanted. They do not need sympathy, they need understanding. Quoting another incident, he said that in Ankur there was a function which was organized where the children were supposed to sell the things they made. So, Justice Pasayat requested that these children be paid a bit more than normal price for their items. One child came back with a Rs. 5 note in his hand rejoicing his earning as though he had earned a lottery of Rs. 1 crore which brought tears into the eyes of all. The mother of the child then thought that the child was not a complete loss. In another incident, when Justice Pasayat was Chairman of State Legal Services Authority, he said that there were posts of peons where he said the two Mongolian boys who were specially abled must be put and they would share the salary of Rs.10,000 i.e. of one person amongst them. After one of the boys got his share of Rs. 5,000, he bought a new shirt and pant and was the first one to arrive in the office to tell others that he is dressed in a new cloth.

In light of this, Justice Pasayat said that God never treated these people/children differently. Just like everyone, they have different intellectual abilities. They want us to recognise this and motivate them. He further stated that there is no likelihood of resistance if a person wants to grow and, he believes, that miracles do happen.

In his concluding remark he stated that if you treat such people well, their love for you will grow and their faith in humanity will build. According to him, everyone should feel wanted. Finally he said that the National Trust is actually the trust that the people of this country repose to wipe out discrimination against PwDs, and that this Trust, with everyone's support will not just be national but will become international.

Vote of Thanks by Mr. S.C Prusty, Registrar, ILI



Mr. S.C Prusty delivered the vote of thanks, thanking Justice Pasayat and all other speakers for taking time out and making the Workshop a success.

NOTE

NOTE

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. In the bottom-left corner, there is a decorative graphic element consisting of overlapping, wavy shapes in shades of teal and light blue, creating a modern, abstract look. The rest of the page is plain white.

समर्थ सशक्त संगठित



राष्ट्रीय न्यास



National Trust

For the welfare of Persons with Autism, Cerebral Palsy,
Intellectual Disability (Mental Retardation) & Multiple Disabilities
Department of Empowerment of Persons with Disabilities (Divyangjan)
Ministry of Social Justice & Empowerment, Govt. of India

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