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HAND BOOK ON DISABILITY

(According to RPWD Act, 2016)



Preface

About this Hand Book

“Believe you can and you're halfway there”-Theodore Roosevelt

This book is about brief introduction on the types of disabilities according to the RPWD Act, 2016 with basic knowledge on identification and management of various types of disabilities.

Disability is an evolving concept, and that disability results from the interaction between persons with impairments both attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others (Preamble UNCRPD). This handbook on disability will help and improve the knowledge and understanding the persons working in the field of disability and rehabilitation.

My gratitude to Fr. Chandran Riymonds, Executive Director, JVS for providing the opportunity and necessary support to complete this handbook.

Hira Nand
Project Officer
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Disability:

Disability is an evolving concept, and that disability results from the interaction between persons with impairments both attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others. (Preamble UNCRPD)

Disabilities categorised as -

Persons with disabilities: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Persons with Benchmark disabilities: Means a person with not less than forty percent of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority.

Persons with disabilities having high need support:

Section 2 (t) of the Act 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. Section 2 [I] stipulates that “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.

Types of Disabilities

Specified Disabilities -

1. Locomotor Disability



Definition: A person's inability to execute distinctive activities associated with movement of self and objects resulting from affliction of musculoskeletal or nervous system or both).

Causes: (What causes Locomotor disabilities?)

- Polio
- Road traffic accidents
- Infections of bones and joints
- Arthritis-osteoarthritis, Rheumatoid arthritis etc.
- Amputations
- Congenital anomaly (Birth defect)
- Stroke
- Spinal cord injuries
- Brain tumours
- Disaster –Natural and manmade
- Other congenital and acquired conditions

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Signs and Symptoms: (What are the problems may have?)

- May have difficulties in walking
- Weakness in limbs
- Inability in performing day to day activities
- Deformities in bones and joints

Management: (What can be done?)

- Early identification
- Management of underlying causes –primary health centre
- Specialists in physical medicine and rehabilitation /orthopaedics
- For therapeutic management-Rehabilitation centre
- For assistive devices -Rehabilitation centre and NGOs working for locomotor disabilities
- NGOs working in the field of disabilities
- For education –formal school and open school
- District welfare officer (For Schemes)



Sudha Chandran is an Indian film and television actress and an accomplished Bharatanatyam dancer. In 1981, she hurt her leg in a road accident near Tiruchirapalli, Tamil Nadu while coming back from Madras with her parents. Her leg became gangrenous

and her parents opted to have it amputated. However, she subsequently became an established Bharatanatyam dancer.

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2. Leprosy Cured Person

Definition: Persons who have been cured of leprosy and are having extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupation.

Signs and Symptoms:

(What are the problems may have?)

- Loss of sensation in hands or feet
- Manifest deformity and paresis in their hands and feet.
- Loss of sensation and paresis in the eye and eye-lid but with no manifests deformity.



Management: (What can be done?)

- Disability prevention and rehabilitation.
- For prevention of disabilities among persons with insensitive hands and feet – dressing materials, supportive medicine, microcellular rubber (MCR) footwear.
- Training for self-care procedure.
- Correction of disabilities through reconstruction surgery (RCS)-Govt. has recognised 122 institutions for conducting RCS based on recommendations of the state govt. Out of these 60 are govt institutions and 52 are NGO institutions.
- NGO services under SET scheme-43 NGOs getting grants from Govt of India under Survey, Education and Treatment (SET) scheme.

- Various activities undertaken by the NGOs are IEC (Information, Education and Communication), Prevention of Impairments and Deformities, Case detection and MDT (Multi drug therapy) delivery.
- NGOs working for leprosy cured persons supported by State Health (Leprosy) societies.
- Concessions – travel concessions for leprosy affected persons who have bilateral grade II and unilateral grade III.
- Old age pension - leprosy affected persons who have bilateral grade II and unilateral grade III and persons beyond 60 years.
- Shelter employment.
- Legal – all the provision made in RPWD act 2016 should be applicable to leprosy cured persons.

Facts about Leprosy:

Leprosy was renamed “Hansens disease” after Norwegian scientist Gerhard Henrik Armauer Hansen, who in 1873 discovered the slow-growing bacterium now known as *Mycobacterium leprae* as the cause of the illness. It is difficult to catch, and it can take many years to develop symptoms of the disease following an infection. However, people who catch the disease can be cured with antibiotics.

Together, we can put a stop to discrimination and stigma against people with Hansen's disease. We can learn to recognize symptoms and know when to see a physician for diagnosis. Educate yourself and your community and separate the facts from the myths about Hansen's disease.

3. Cerebral Palsy



Definition: Group of non-progressive neurological condition affecting body movements and muscle coordination, caused by damage to one or more specific areas of the brain, usually occurring before, during or shortly after birth.

Causes: (What causes cerebral palsy)

- Prenatal (before birth): infections, prenatal anoxia, prenatal haemorrhage, metabolic disturbances, exposure to harmful radiations and bleeding in first trimester etc.
- Perinatal (during birth): Low birth weight, Premature birth, lack of oxygen to the brain (asphyxia), infections, injuries to brain, jaundice etc.
- Post natal (after birth): head injuries, infections such as meningitis, encephalitis and brain abscess.

Signs and symptoms: (What are the problems may have ?)

- Delayed developmental milestones
- Limbs may be too stiff -spasticity
- Limbs seems too loose-floppy
- Involuntary, jerky and clumsy movements - athetoid
- Abnormal muscle tone
- Poor eating, swallowing, abnormal sleep pattern
- Other problems associated with CP- fits, visual problems, speech and hearing impairments, learning problems

Management: (What can be done?)

- The management of children with cerebral palsy from rehabilitation with early intervention essential to help each child to reach the maximum level of potential in all areas of development to achieve functional independence.
- Therapeutic service to improve functional capacity .
- Assistive devices for positioning and mobility .
- Medical and surgical management in certain conditions.
- For associated problem specialised services i.e. speech therapy counselling , special education may be needed.
- For legal support and concession –guideline for support given in the National Trust for Welfare of persons with Autism, Cerebral Palsy, Mental retardation and Multiple Disabilities Act 1999 and Revised PWD act 2016.
- For education –child with cerebral palsy shall have right to get free and compulsory education till the age of 18 yrs
- Inclusive and special education.

4. Dwarfism



Definition: A medical or genetic condition resulting in an adult height of 4 feet 10 inches (147 centimetres) or less.

Causes: (What causes dwarfism?)

- Most dwarfism-related conditions are genetic disorders, causes of some disorders are unknown.
- Achondroplasia - about 80% of persons with Achondroplasia are born to the parents of average height.
- A person with Achondroplasia and with two average-size parents received one mutated copy of the gene associated with the disorder and one normal copy of the gene. A person with the disorder may pass along either a mutated or normal copy to his or her own children.
- Turner syndrome - a condition that affects only girls and women, when a sex chromosome (the X-chromosome) is missing or partially missing.
- Growth hormone deficiency and other causes.

Signs and Symptoms: (What are the problems may have?)

- Late development of certain motor skills, such as sitting up or walking
- Breathing problem
- Curvature of spine
- Bowed legs
- Joint stiffness and arthritis
- Lower back pain and numbness in legs
- Crowding of teeth

Management: (What can be done?)

- Early diagnosis and treatment can help prevent or lessen some of the problems associated with dwarfism.
- People with dwarfism associated with growth hormone deficiency can be treated with growth hormone.
- In many cases, people with dwarfism have medical and orthopaedic complications can be treated accordingly.
- Physical therapy to strengthen muscles and increase joint range of motion .
- Spine braces to correct curvature of the spine
- For legal support and concession – guideline for support people with dwarfism given in the Revised PWD act 2016.

5. Muscular Dystrophy

Definition: A group of hereditary genetic muscle disease that weakens the muscles that move the human body and persons with multiple dystrophies have incorrect and missing information in their genes, which prevents them from making the proteins they need for healthy muscles. It is characterised by progressive skeletal muscle weakness, defects in muscle proteins, and the death of muscle cells and tissues.

Causes: (What causes Muscular dystrophy?)

- Muscular dystrophy is caused by changes in the genes that are responsible for the structures and functioning of muscles in the body.
- The changes in genes the cause changes in the muscles fibres that interfere with the muscle's ability to function. Overtime, this causes increasing disability.
- These are genetic conditions and can be inherited or an individual may be the first one in their family affected.



Signs and Symptoms: (What are the problems may have?)

- Muscles -abnormality in walking, flaccid muscles, muscle weakness, loss of muscle tone and permanent shortening of muscles.
- Developmental –delayed developmental milestones or learning disability.
- Others –heart problems, constantly walking on tip toe, constipation, difficulties swallowing, fatigue, spinal deformities and shallow breathing.

Management: (What can be done?)

- Currently, there is no cure for muscular dystrophy but medications and various therapies help slow the progression of the disease and keep the mobile for the longest possible time.
- Medications-certain medications to increase muscle strength and slow progression of conditions and heart medications.
- Physical therapy
- Range of motion exercises and stretching exercises
- Breathing exercises
- Braces-prevent muscle shorting and deformities
- Mobility devices-canes, wheelchairs and walkers can help for mobility.
- Surgery: in some cases surgery may need to correct deformities

Facts about Muscular Dystrophy:

- There are eight known types of muscular dystrophy: Becker/Duchenne, Limb-girdle, Facioscapulohumeral, Distal, Emery-Dreifuss, Fukuyama, Oculopharyngeal and Ophthalmoploegic MD.
- Duchenne MD, one of the most common forms of the disease, can be detected by means of genetic studies during pregnancy. Even though the disease may be identified, there's still no way to prevent it.
- One in every 3,000 children is born with this condition.
- Two common forms of MD (Duchenne and Becker) are caused by a genetically inherited deficiency of the muscle protein dystrophin. This condition mostly affects boys. One in every 1,200 people are either born with, or develop late-onset muscular dystrophy.

6. Acid Attack Victim



Definition: A Person disfigured due to violent assaults by throwing of acid or similar corrosive substance. Acid attacks have a catastrophic effect on human flesh and vital organs.

Causes: (What are the causes?)

- Perpetrators of the crime act cruelly and deliberately and are often motivated by deep-seated jealousy or feelings of revenge against a woman.
- An offender first obtains the acid, carrying it on him and then throws to the victim.
- It also often occurs as revenge against a woman who rejects a proposal of marriage or a sexual advantages, another cause of acid attack is conflicts related to dowry or domestic violence.
- Sometimes conflicts regarding inheritance and other property issues are a cause of acid attacks.

Complications: Acid attack survivors who suffer from multiple health complications including-

- Scarring
- Blindness
- Disfigurement
- Breathing difficulties

Management: (What can be done?)

- Due to serious injury to body the victims need multiple reconstructive surgeries to correct disfigured parts of the body.
- Victims need employment, education, safe place to stay.
- Revised Rights of Persons with Disabilities Act 2016 will provide compensation to survivors — who often face workplace discrimination as well as access to job programs.
- Legal support- NALSA (National Legal Service Authority) Scheme- Legal services to victims of acid attack scheme 2016.



Laxmi Agarwal is an Indian acid attack survivor, a campaigner for rights of acid attack victims, and a TV host.

Agarwal was attacked in 2005 at the age of 16. Her story, among others, was told in a series on acid attack victims by Hindustan Times. She has since established grassroots campaigns for tackling the surge of acid attacks; one of her petitions has led the Supreme Court to order the central and state governments to regulate the sale of acid and the Parliament to enable easier prosecutions of acid attack perpetrators. She was the former director of Chhanv Foundation, a NGO dedicated to help acid attack survivors in India. She received the International Women of Courage award at the hands of First Lady Michelle Obama. The movie Chhapaak is based on her life and stars Deepika Padukone in her role.

7. Blindness

Definition: Blindness means a condition where a person has any of the following conditions, after best correction.

- Total absence of sight; or
- Visual acuity less than 3/60 or less than 10/200 (Snellen) in the better eye with best possible correction; or
- Limitation of the field of vision subtending an angle of less than 10 degree.



Causes: (What causes blindness?)

Blindness can be caused due to numerous conditions, the leading causes are-

- Cataract-remains the leading cause of visual impairment in all areas of the world except for developed countries
- Glaucoma-it occurs when the pressure of the eye increased and that Childhood blindness -due to refractive causes
- Age related macular degeneration (AMD)
- Corneal opacities
- Diabetes retinopathy
- Trachoma
- Others causes

Management: (What can be done?)

- Treatment of the blindness depends on cause of blindness
- National Program for Control of Blindness (NPCB) emphasis-
 - To reduce the backlog of blindness through identification and treatment of blind at primary, secondary and tertiary levels based on assessment of the overall burden of visual impairment in the country.
 - Develop and strengthen the strategy of NPCB for “Eye Health” and prevention of visual impairment; through provision of comprehensive eye care services and quality service delivery.
- World Report on disability –provides the best available evidences about what works to overcome barriers to health care, rehabilitation, education, employment and support services, and to create the environments which will enable persons with disabilities to equally participate in society.
- Accessible and inclusive communications –ICT (information and communication technology) program for visual impairment, Braille and promoting the availability of materials.
- Social protection program-promoting access to education, health and employment.
- Awareness and advocacy.
- Education –The international council for the education of visually impaired (ICEVI)- Especially promotes equal access and appropriate education for all children and youth with visual impairment.
- Skill and Vocational training.
- Vision rehabilitation-services allow people who are blind or have low vision to continue to live independently and maintain quality life.

8. Low-Vision



Definition: Low-Vision means a condition where a person has any of the following conditions, namely-

- Visual acuity not exceeding 6/18 or less than 20/60 up to 3/60 or up to 10/200 (Snellen) in the better eye with best possible corrections; or
- Limitation of the field of vision subtending an angle of less than 40 degree up to 10 degree.

Causes: (What causes Low Vision?)

The most common cause of Low vision is macular degeneration, a disease of the sensory retina .

Other causes of low vision are-

- Birth disease
- Inherited disease
- Injuries
- Diabetes
- Glaucoma
- Cataract
- Aging

Symptoms: (What are the problems may have?)

• A thorough eye examination is needed to diagnose the causes of low vision. People with low vision may experience the following symptoms:

- Loss of central vision
- Night blindness
- Loss of peripheral vision
- Blurred vision
- Hazy vision

Management: (What can be done?)

• Low vision is permanent it can not be fully corrected but many people with low vision find visual aids helpful. Low vision aids includes-

- Telescopic glasses
- Lenses that filter the light
- Magnified glasses
- Hand magnifier
- Closed-circuit television
- Reading prisms
- Non-optical aids designed for people with low vision are also very helpful including-
- Text reading software
- Check guides
- High contrast clocks and watches
- Talking clocks and watches
- Large print publications, clocks and watches and phones with large numbers .
- Visual aids may improve both sight and the quality of life for many people.

9. Hearing Impairment

Definition: Deaf means persons having 70 DB hearing loss in speech frequencies in both ears;

- "Hard of hearing" means person having 60 DB to 70 DB hearing loss in speech frequencies in both ears.

Causes: (What causes hearing loss?)-

Hearing loss at birth: (Congenital hearing loss).

- Infections such as rubella and herpes
- Premature birth
- Low birth weight
- Birth injuries
- Jaundice and Rh factor
- Maternal diabetes
- High blood pressure during pregnancy –preeclampsia
- The baby not having enough oxygen-anoxia
- Genetics



Hearing loss after birth:

- Ear infections
- Meningitis
- Measles
- Encephalitis
- Chicken pox
- Mumps
- Head injuries
- Loud noise

Management: (What can be done?)

- Early intervention is very important
- **Conductive hearing loss is usually temporary** –it involve medical intervention to address the specific causes
- Hearing aids
- Cochlear implants
- **Sensorinueral hearing loss is permanent** –it is not possible to restore lost hearing, most widely used and effective treatment is hearing aids
- Cochlear implants
- Hearing Assistive technologies
- Child/adult audiological or hearing rehabilitation



Rajeev Bagga

He is the only deaf to win the national titles in singles among the non-deaf twice. Over 59 times he represented the national team in various prestigious

tournaments sanctioned by the Badminton World Federation (BWF) - the Commonwealth Games, Thomas Cup, Malaysian Open, Swiss Open and Asian Badminton Championships. The only deaf player to be listed on the annual BWF rankings.

He has won 12 golds and been singles champion at the Deaflympics from 1989 to 2001, and was named 'Deaflympian of the Century' by the Comité International des Sports des Sourds (International Committee of Deaf Sports) in 2001. In 1991, he won India's highest sports honour, the Arjuna award.

10. Speech and Language Disability

Definition: Speech and language disability means a permanent disability arising out of conditions such as laryngectomy or aphasia affecting one or more components of speech and language due to organic or neurological causes.

Causes: (What causes speech and language delay and/or disorders?)

The cause of speech and language delay and/or disorders are unknown but there can be specific causes including-

- Hearing loss –chronic ear infections may result in decrease speech and language skills
- Neurological disorders- cerebral palsy, traumatic brain injuries
- Autism
- Intellectual disabilities
- Physical impairment –cleft lip and cleft palate
- Vocal abuse or misuse
- Prematurity (Birth)
- Extreme environment
- Genetics



Symptoms: (What are the problems may have?)

- Depending on the cause of speech disorder . Some common symptoms are-
- Repeating sound , which most often seen in a child who stutter
- Adding extra sound and words
- Elongating words
- Making jerky movement while talking , usually involving head
- Blinking several times while talking

- Visible frustration when trying to communicate
- Taking frequent pause when talking
- Distorting sounds when talking
- Hoarseness of voice

Management: (What can be done?)

- Speech and language disorders are serious but are highly treatable –Especially you start early (Early Intervention)
- The common treatment for language disorder is speech and language therapy.
- Individual therapy –this is best for severe conditions that need one-on-one attention.
- Group therapy –best option for young children with language disorders .
- Speech and language therapy may continue throughout a student's school years either in the form of direct therapy or on consultant basis.
- Assistive technology(AT)- very helpful for those whose physical conditions make communication difficult .

Churchill's Battle with Speech Disorders

The leader who brought his country through World War Two also suffered from speech impairment.

Many journalists referred to Winston Churchill as having a pronounced stutter, with one going as far as saying, “Mr. Churchill is more often fighting himself than his enemies.”

Churchill consulted with a speech specialist who told Churchill he had no pathological problems and that all he needed to overcome his speech impairment were practice and perseverance and Churchill was able to largely overcome his speech impediment by practicing tongue twisters and rehearsing his diction.

11. Intellectual Disability

Definition: A condition characterized by significant limitation in both intellectual functioning (reasoning, learning, problem solving) and adaptive behaviour (skill necessary for communication, interaction and take care).

Causes: (What causes Intellectual disability?)

There are prenatal , perinatal and post natal causes of Intellectual disability.

- Genetic syndrome (Down syndrome)
- Brain malformation (microcephaly)
- Maternal disease
- Environmental influences (alcohol, other drugs toxins, teratogens)
- Labor and delivery related events
- Anoxia at birth (lack of oxygen to the body and brain)
- Hypoxic ischemic injury
- Traumatic brain injury
- Infections
- Seizure disorders



Symptoms: (What are the problems may have?)

- Delayed developmental milestones such as rolling, crawling, sitting, standing and walking.
- Learning and developing more slowly than other children of same age.

- Difficulty in communication and socialization with others
- Lower than average scores on IQ test
- Difficulties in talking or late talking
- Having problems in remembering things
- Inability to connect actions with sequences
- Difficulties with problem solving and logical thinking
- Trouble learning in school
- Inability to everyday tasks like dressing, eating, toileting

Management: (What can be done?)

There is no cure of intellectual disability, but multidisciplinary services and supports play an important role and enable the children/persons to thrive throughout their lifetime .

- Services for child/people with intellectual disability and their families are primarily there to provide adequate support to allow for full inclusion in their society. These services touch their daily lives (health care, education, housing, employment and recreational) and may include- Early intervention, day programs, residential options ,special education ,vocational program and transition programs.
- Support include the resources and individual strategies necessary to promote the development, education interests and well-being of individual.
- Support can come from family, friends , and community or from a service system.

12. Specific Learning Disabilities

Definition: Specific learning disabilities means 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 and includes such conditions as perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia and developmental aphasia.

Types –

A. Dyslexia –

Definition: Dyslexia is a common learning difficulty that can cause problems with reading, writing and spelling.

- It is specific learning difficulties, which means it causes problems with certain abilities such as reading and writing. Unlike learning disabilities intelligence is not affected.

Causes: (What causes dyslexia?)

Exact cause is unknown but some possible causes are-

- Genetics – defects in gene associated with problems in reading performance.
- Acquired dyslexia – occurs in some people due to brain injury, stroke and trauma.



Symptoms of dyslexia – (What are the problems may have?)

- Read and write very slowly
- Confuse with the order of letters in words
- Put letters the wrong way round (such as writing “b” instead of “d”)
- Have poor and inconsistent spelling
- Understand information when told verbally but finds difficulties in written down

Management: (What can be done?)

While dyslexia is a lifelong problem, there is specialist educational intervention that can help children with their reading and writing.

- Early intervention is generally most effective.
- The type and extent of intervention needed will depend on the severity of child’s difficulties.
- Specific intervention plan for each child may be needed.

B. Dysgraphia:

Definition: Dysgraphia is a specific learning disability that effects hand writing and fine motor skills. It interferes with spelling, word spacing, and the general ability to put thoughts on paper.

- It makes the process of writing laboriously slow, with a product that is often impossible to read.

Causes: (What causes dysgraphia?)

- Scientists are not sure that why Dysgraphia happen in children .
- In adults, it is sometimes related to a brain injury.
- In kids, this learning disorder usually occurs along with other learning disabilities such as ADHD (attention deficit hyperactive disorder) and Dyslexia.

Symptoms: (What are the problems ?)

- Kids with dysgraphia have unclear, irregular, or inconsistent hand writing ,shapes, upper and lower case letters ,and cursive and print styles.
- They also tend to write or copy things slowly
- Cramp grip, which may lead to sore hand
- Difficulty spacing things out on the paper or within the margins
- Frequent erasing
- Inconsistency in letter and word spacing
- Poor spelling, including unfinished words or missing words or letters
- Unusual wrist ,body, or paper position while writing

Management: (What can be done?)

Children with dysgraphia have producing writing ,but their intelligence is normal

- There are many ways to help a child with dysgraphia achieve success
Generally strategies fall into three categories-

Accommodations: providing alternatives to the written expression

Modifications: changing expectations or tasks to minimize or avoid the area of weakness

Remediation: providing instructions for improving hand writing and writing skills

C. Dyscalculia:

Definition: Dyscalculia is specific learning disability in math. Kids with dyscalculia may have difficulty understanding number related concepts or using symbols or functions needed for success in mathematics.

Causes: (What causes dyscalculia?)

Exact cause of dyscalculia is known.

- Dyscalculia is often co-occurs with other learning disorder such as dyslexia, dyspraxia and ADHD (attention deficit hyperactive disorder) and specific language impairment.

Symptoms: (What are the problems may have?)

- Has difficulty when counting backwards
- Poor sense of number and estimation
- Weak mental arithmetic skills
- Displays difficulty in recognizing patterns when adding, subtracting, multiplying or dividing
- Avoids tasks that are perceived as difficult and likely to result in a wrong answer
- Has difficulty understanding and doing word problems
- High level of mathematics anxiety

Management: (What can be done?)

A kids with dyscalculia may perform well in other subjects but have very low grades in maths. Taking the following steps that can help the child -

- Visit the doctor to rule out any other health issues such as hearing or vision impairment.
- Consult the teacher who teaches math for the areas where he has most trouble, and any and all strategies that help.
- Ask about other areas to understand complete learning profile that will help to address his further needs.
- Assistive technology can also help. These include graphic tools, math notions tools and graphic organisers for math.
- There are also apps that work on basic number concepts.

D.Dyspraxia:

Definition: A persons with Dyspraxia finds it hard to carry out smooth and coordinated movement.

- Dyspraxia often comes with language problems and some times a degree of difficulty with perception and thought .
- Dyspraxia does not affect persons intelligence , but it can cause learning difficulties , especially for children.

Causes: (What causes dyspraxia?)

Exact cause is unknown but experts believe the person's nerve cell that control muscles (motor neuron) are not developing correctly .If motor neuron can not for proper connection, for what ever reasons, the brain will take much longer time to process data.

- If dyspraxia develop later in life it is usually due to traumas suffered by brain after a stroke, accident or illness.

Symptoms: (What are the problems?)

Gross motor problems-

- Delayed in reaching normal developmental milestones can be early signs in young children.
- Poor posture

Fine motor problems-activities which require fine motor skills include tying shoelaces, doing up buttons, cutting out shapes and writing.

Language problems

- Speech can be slow and laboured
- Slow to respond to a question even if they know the answer.
- Speech sound often not clearly articulated

Other problems-interest in physical activities, avoids socializing with peers, low self esteem and shows poor attention.

Management: (What can be done?)

Early intervention plays crucial role in recovery process.

- Provide a lots of praise and encouragement
- Recognise and reinforce the child's strength and abilities
- Physical therapy, occupational therapy and speech and language-therapy and other support may be needed according to conditions .

E. Developmental Aphasia:

Definition: Developmental Aphasia is a communication disorder that doesn't affect overall intelligence. It interferes with the ability to speak or understand speech and often causes reading and writing.

Causes: (What causes Developmental Aphasia?)

The cause of Developmental Aphasia poorly understood. It is usually not related to child's level of intelligence. Typically there is no specific cause.

- The condition may be genetic run in the family.
- Aphasia can occur during the developmental period or may happen later in life as a result of brain injury, illness, or disease.

Symptoms: (What are the problems may have?)

The main problems of aphasia include:

- Trouble speaking
- Struggling with finding the appropriate term or word
- Using strange or inappropriate words in conversation
- Challenges in the writing
- Challenges with social communication

Management: (What can be done?)

- Aphasia is treatable but not curable most treatment done around speech therapy.
- Good therapy plan will be built around the individual patient's specific needs.
- Language therapy should begin as soon as possible.
- Rehabilitation with a speech pathology involves extensive exercises in which child read, write, follow directions, and repeat what they hear.
- Computer aided therapy may supplement standard language therapy.

13. Autism Spectrum Disorder

Autism Spectrum Disorder (ASD):

Definition: Autism is a developmental disorder that affects communication and behaviour. Although autism can be diagnosed at any age, it is said to be a developmental disorder because symptoms generally appear in the first two year of life.



Causes: (What causes autism?)

Exact cause of autism is unknown but research suggests that genes can act together with influences from the environment to affect development in ways that lead ASD. Some risk factors include-

- Having a siblings with ASD
- Having elder parents
- Having certain genetic conditions-down syndrome, fragile x syndrome
- Low birth weight

Symptoms: (What are the problems may have?)

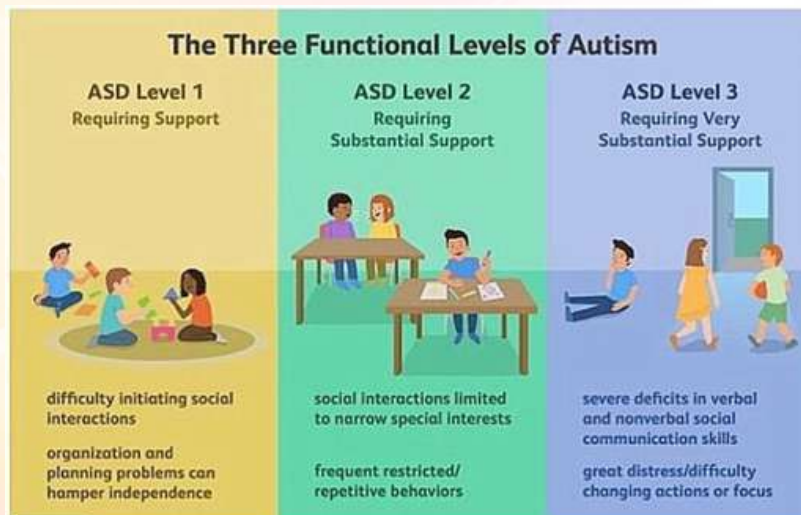
- Children with ASD have difficulty with social communication and interaction, restricted interest, and repetitive behaviours.
- Social communication/interaction behaviours may include-making little or inconsistent eye contact, tending not to look at or listen to people, having unusual tone of voice that sound, sing-song or flat or robot-like and facial expressions, movements and-

gestures that don't match what is being said.

- Restrictive/repetitive behaviours may include- repeating certain behaviours or having unusual behaviours, having lasting interest in certain topics, such as numbers, details, or facts.

Management: (What can be done?)

- Treatment for ASD start should as soon as possible after diagnosis. Early intervention for ASD is important as proper care can reduce child's difficulties while helping them learn new skills and make the most of their strengths. Working closely with a doctor or a health-care professional is an important part of finding the right treatment program.
- Medication- Use of medicines to treat some symptoms that are common with ASD.
- Behaviour, Psychological and educational therapy –child may be referred to professionals who are specialised in providing Behaviour, Psychological and educational, or skills building interventions.



14. Mental Illness

Definition: Mental illness means a substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behaviour, capacity to recognise reality or ability to meet the ordinary demands of life, but does not include retardation which is a condition of arrested or incomplete development of mind of a person, specially characterised by sub-normality of intelligence.

• **Causes:** (What causes mental illness?)

The exact cause of most mental illness is unknown but it becomes clear that many of these conditions are caused by a combination of biological, psychological and environmental factors .

- Biological factors: some mental illness have been linked to abnormal functioning of nerve cell pathways that connect particular brain regions. Nerve cells within these brain circuits communicate through chemicals called neurotransmitters .
- Other biological factors may include - Genetics, infections, brain defects or injuries, perinatal damage , substance use , poor nutrition -and exposure to toxins.
- Psychological factors:
 - Severe psychological trauma suffered as a child such as-, physical and sexual abuse.
 - An important early loss, such as the loss of a parent.
- Neglect Environmental factors: Certain stressors can trigger an illness in a persons who is susceptible to mental illness.

These stressors include-

- Death or divorce
- A dysfunctional family life
- Feeling of inadequacy, low self esteem, anxiety, anger and loneliness
- Changing jobs or schools
- Social or cultural expectations
- Substance used by persons or person's parents

Symptoms: (What are the problems may have?)

If several of following occurring, it may be useful to follow up with a mental health professional.



- With drawal-recent social withdrawal and loss of interest in others.
- Drop in functioning –an unusual drop in functioning, at school, work or social activities
- Problem thinking
- Increased sensitivity
- Apathy
- Feeling disconnected
- Illogical thinking
- Nervousness
- Unusual behaviour
- Sleep and appetite changes
- Mood changes

Management: (What can be done?)

- Treatment can help someone with mental illness to minimise the effect of illness and promote recovery.
- It can involve Psychological therapy, and various supports in the community.
- **Psychological therapy-** A doctor, Psychologist and other health professional, talks with the person about their symptoms and concerns and discusses new ways of thinking about and managing them.
- **Medication:** regular medications help the brain to restore it usual chemical balance, so that symptoms are reduced or eliminated.
- Community support programs-Support programs are especially important for those persons with recurrent symptoms or who have a Psychiatric disability. This support may include information, accommodation, help with finding suitable work, training and education, psychological rehabilitation and mutual support group.
- Understanding and acceptance by the community is also very important.

15. Multiple Sclerosis

Definition: Multiple sclerosis means an inflammatory, nervous system disease in which the myelin sheaths around the axons of nerve cells of the brain and spinal cord are damaged, leading to demyelination and affecting the ability of nerve cells in the brain and spinal cord to communicate with each other.

Causes:

(What causes Multiple sclerosis?)

The exact cause is unknown but it is thought to be an autoimmune disorder. This means that immune system attacks the myelin sheath

as if it were an undesirable foreign body, just as it might attack a virus or bacteria. Some risk factors include-age between 20-50 years and more develop in women than men. Genetically passed down the in the genes.

- Lack of sunlight and vitamin D
- Viral infections
- Exposure to toxic substances –this could be heavy metal or solvent.
- Smoking

Symptoms: (What are the problems may have?)

Multiple sclerosis can cause a wide range of symptoms and can affect any part of the body. Each persons with condition is affected differently. Some of the most common causes include-



- Fatigue
- Vision problems
- Weakness and stiffness in the muscles
- Painful muscle spasms
- Tingling, numbness in the arms, legs, face or trunk
- Clumsiness
- Difficulty in remaining balanced when walking
- Loss of bladder control or suddenly needing to urinate
- Persistent dizziness

Management: (What can be done?)

- There is currently no cure of multiple sclerosis, but it is possible to treat the symptoms with medications and other treatments. The treatment for Multiple sclerosis (MS) depends on the specific symptoms and difficulties.
- It may include- **Medications**– several disease modifying drugs are approved for the relapsing form of MS.
- **Rehabilitation:** Rehabilitation plan to help people with MS to improve or maintain their ability to perform effectively at home and at work. Rehabilitation plans include-
 - Physical therapy-this aims to provide people with the skills to maintain and restore maximum movement and functional ability.
 - Occupational therapy- the therapeutic use of work, self care and play activities to increase development and prevent disability.
 - Speech and language therapy.
 - Cognitive rehabilitation- manage specific problems in thinking and perception.
 - Vocational rehabilitation: helps to make career plan, learn job skills, get and keep a job.

16. Parkinson's Disease

Definition: Parkinson's disease

means a progressive disease of the nervous system marked by tremor, muscular rigidity, and slow, imprecise movement, chiefly



affecting middle-aged and elderly people associated with degeneration of the basal ganglia of the brain and a deficiency of the neurotransmitter dopamine.

Causes: (What causes Parkinson's disease ?)

In Parkinson's disease, certain nerve cells (neurons) in the brain gradually breakdown or die . Many of symptoms are due to the loss of neurons that produce a chemical messenger in your brain called dopamine when dopamine level decreases, it causes abnormal brain activity, leading to symptoms of Parkinson's disease. The cause of Parkinson's disease is unknown but several factors may responsible-

for PD include-

- Genetics-specific gene mutations can cause Parkinson's disease.
- Environmental: Exposure to certain toxins or environmental factors -may increase the risk of later Parkinson's disease.
- Age –mostly affects people of age 60 and above.
- Gender-men get affected more than women
- Family history
- Serious head injury

Symptoms: (What are the problems may have?)

The symptoms of PD gradually develop and are mild at first. The three main symptoms of PD affect physical movement .

- **Tremor**- shaking usually begins in the hand or arm and is more likely to occur when the limb relaxed and resting.
- **Slowness of movement (Bradykinesia)**- physical movements are much slower than normal , which can make everyday tasks difficult and can result in a distinctive slow, shuffling walk with very small steps .
- **Muscle stiffness (Rigidity)**- stiffness and tension in the muscle which can make it difficult to move around and make facial expression (mask face) and result in painful muscle spasm.

Management: (What can be done?)

There is currently no cure for Parkinson's disease but treatment are available to help relieve symptoms and maintain quality of life.

These treatment include-

- Supportive therapy –physiotherapy , occupational therapy and speech and language therapy
- Medication
- Surgery for some people
- Diet advice
- A care plan should be agreed with health care team and family and care taker. This will outline the treatments and help what likely to need in the future and should be reviewed regularly.

17. Haemophilia

Definition: Haemophilia means an inheritable disease, usually affecting only male but transmitted by women to their male children, characterised by loss or impairment of the normal clotting ability of blood so that a minor wound may result in fatal bleeding.



Causes: (What causes Haemophilia?)

In haemophilia, the blood doesn't clot as it should be. It is normally an inherited disorder. A person is born with it.

- It happens because of a defect in one of the clotting factor gene on the X chromosomes.
- Haemophilia tend to occur in males, since the gene can be passed from mother to son.

Symptoms: (What are the problems may have?)

- Haemophilia symptoms includes excessive bleeding and bruising.
- The severity of symptoms depends on how low the level of clotting factors is in the blood.
- Bleeding occurs externally and internally.
- Any wound cut, bite, or dental injury can lead to external bleeding.
- Spontaneous nose bleeding is common.

- There may be prolonged or continued bleeding after bleeding previously ceased.
- Signs of excessive bleeding include blood in the urine or stools.
- Bleeding can also happen within joints, like knees and elbows causing them to become swollen, hot to touch and painful to move.
- Internal bleeding in the brain following a bump on the head and causes headaches, vomiting, lethargy, clumsiness, vision problems, paralysis, seizures and behaviour changes.

Management: (What can be done?)

The main treatment of haemophilia involves receiving replacement of the specific clotting factors that may need through a tube place in a vein (Replacement therapy).

- Clot-preserving medications (anti-fibrinolytics)- these medications help prevent clot from breaking down.
- Fibrin sealants- these medications directly apply to wound sites to promote clotting and healing.
- Physical therapy – regular exercises reduce risk of joint damage by protecting them and muscles building such as walking, swimming, and cycling and avoid contact sports such as wrestling, football and hockey that are not safe for people with haemophilia.
- Avoid certain pain and blood thinning medications.
- Practice good dental hygiene.
- Protect from injuries that could cause bleeding –kneepads, elbow pads, helmets and safety belts all may help prevent injuries from falls and other accidents. Keep home free from furniture with sharp corners.
- Let people know the condition –every one around people with haemophilia should know the condition and make them aware of its effects.

18. Thalassemia

Definition: Thalassemia means a group of inherited disorders characterised by reduced or absent amounts of haemoglobin.

Causes: (What causes Thalassemia?)

- Thalassemia is caused by mutations in the DNA cells that make –the substance in red blood cells that carries oxygen throughout the body.
- The mutations associated with Thalassemia are passed from parents to children.
- Thalassemia disrupts the normal production of haemoglobin and healthy blood cells.
- This causes anaemia with anaemia blood doesn't have enough red blood cells to carry oxygen to the tissues.



Symptoms: (What are the problems may have?)

- The symptoms of Thalassemia vary depending on the types of Thalassemia.
- Symptoms will not show until the age of six months in most infants with beta Thalassemia and some types of alfa Thalassemia .
- This is because neonates have a different type of haemoglobin , called foetal haemoglobin . After six months normal haemoglobin starts replacing the foetal type and the symptoms may begins to appear. These include-

- Jaundice and pale skin
- Chest pain
- Shortness of breath
- Poor feeding
- Headaches
- Greater susceptibility of infections
- Skeletal deformities may result as the body tries to produce more bone marrow.
- Drowsiness and fatigue
- Cold hands and feet
- Leg cramps
- Delayed growth
- Dizziness and faintness

Management: (What can be done?)

Treatment depends on the type and severity of Thalassemia

- Blood transfusions :These can replenish haemoglobin and red blood cell level.
- Iron chelation : This involves removing excess iron from the blood stream.
- Bone marrow and stem cell transplant.
- Surgery –to correct bone deformities.
- Medications and supplements.

Living with Thalassemia– people with Thalassemia are adviced to-

- Follow a healthy diet and healthy life style.
- Get a suitable amount of exercise.
- Maintain contact with friends, organisation working with Thalassemia and support networks help to keep a positive attitude.
- Attend all regular appointments .

19. Sickle Cell Disease

Definition: Sickle cell disease means a haemolytic disorder characterised by chronic anaemia, painful events, and various complications due to associated tissue and organ damage; "haemolytic" refers to the destruction of the cell membrane of red blood cells resulting in the release of haemoglobin.

Causes: (What causes sickle cell disease?)

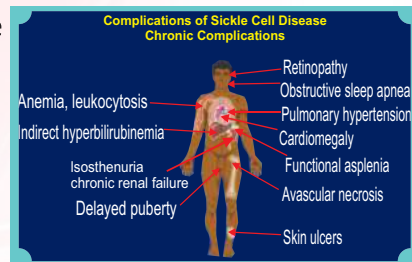
- The cause of sickle cell disease is a defective gene, called a sickle cell gene.
- People with the disease are born with two sickle cell genes, one from each parent.
- If people born with one sickle cell gene, it is called sickle cell trait. People with sickle cell trait are generally healthy, but they can pass the defective gene on to their children.

Symptoms: (What are the problems may have?)

People with sickle cell disease start to have signs of the disease during first year of life, usually around 5 months of age.

Early symptoms of sickle cell disease may include-

- Painful swelling on hand and feet.
- Fatigue and fussiness from anaemia.
- A yellowish colour of the skin (jaundice) or whites of the eyes (icterus).
- The effects from sickle cell disease vary from person to person can change over time. Most of the signs and symptoms of sickle cell disease are related to the complications of the disease. They may include severe pain, anaemia, organ damage, and infections.



Management: (What can be done?)

A number of different treatments are available for sickle cell disease-

- Rehydration with intravenous fluids helps red blood cells return to a normal state. The red blood cells are more likely to deform and assume the sickle shape if dehydration occurs.
- Treating underlying or associated infections is an important part of managing the crisis, as the stress of infection can result in a sickle cell crisis.
- Blood transfusions improve transportation of oxygen and nutrients as needed.
- Supplemental oxygen is given through a mask. It makes breathing easier and improve oxygen levels in blood.
- Antibiotics to prevent infections in younger children.
- Pain relievers for acute and chronic pain.
- Childhood immunisation to prevent infections.
- There are other treatments for specific complications.
- To stay as healthy as possible, make sure that you get regular medical care, live a healthy life style, and avoid situations that may set off a pain crisis.
- Get support from organisation working for people with sickle cell disease or patient support groups.

20. Multiple Disabilities

Definition: Multiple Disabilities (more than one of the above specified disabilities) including deafblindness which means a condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems.

Some example of multiple disabilities-

- Deafblind (Visual impairment + Hearing impairment)
- Visual impairment + Hearing impairment + Intellectual disability
- Visual impairment + Intellectual disability
- Cerebral Palsy + Intellectual disability + Visual impairment / Hearing impairment

Causes: (What causes multiple disabilities?)

There are several factors that cause severe and multiple disabilities. They include-

- Chromosomal abnormalities
- Premature birth
- Difficulties after birth
- Poor development of the brain and spinal cord
- Infections
- Genetic disorders
- Injuries from accidents
- Metabolic disorders
- Negative prenatal environment influences
- Sometimes cause is unknown



Symptoms: (What are the problems may have?)

People with multiple disabilities have a combination of various disabilities that may includes-

- Limited Speech or communication
- Difficulties in basic Physical mobility
- Tendency to forget skills through disuse
- Trouble generalising skills from one situation to another
- A need for support in daily living and major life activities
- They may also have sensory losses and behaviour and or social problems

Management: (What can be done?)

Most children with multiple disabilities will need some degree of support throughout their lives. Depending on the disabilities that are involved.

- Mild multiple disabilities may only need occasional support for particular tasks.
- Children with more severe disabilities will need ongoing interventions.
- Ensure the necessary support is available and that assistive and adaptive equipment is prepared.
- A whole range of service delivery systems are available today The service delivery may include-
- Hospital-based rehabilitation
- Institution-based rehabilitation
- Community-based rehabilitation
- Home-based service
- Short-term respite care centre
- Parents and caretaker may contact institutions and organisations for proper care, inclusion and mainstreaming of individual with multiple disabilities.

21. Chronic Neurological Conditions

Chronic Neurological Conditions:

These conditions are not clearly defined in Revised PWD Act 2016 that which conditions can include in the category of Chronic Neurological Conditions except Multiple Sclerosis and Parkinson's disease. These conditions may be decided by a medical board.



The Rights of Persons with Disabilities Act -2016

- The Lok Sabha passed “The Rights of Persons with Disabilities Bill -2016 on 16 December, 2016. The Bill will replace the existing PWD act, 1995, which enacted 21 years back.
- The Rajya Sabha already passed the Bill on 14, December, 2016.
- *The silent features of the Bill are:*
 - Disability has been defined based on an evolving and dynamic concept. The types of disabilities have been increased from existing 7 to 21 and Central Government will have the power to add more types of disabilities.
 - Speech and Language disability and Specific Learning Disabilities have been added for the first time. Acid attack victims have been included Dwarfism and Muscular dystrophy have been inducted as separate class of specific disabilities. The new categories of disabilities also included
 - Three blood disorders, Thalassemia, Haemophilia and Sickle cell disease In addition, Government has been authorised to notify any other category of specified disabilities.

- Responsibility has been cast upon the appropriate government to take effective measures to ensure that the persons with disabilities enjoy their rights equally with others.
- Additional benefits such as reservation in higher education, government jobs, reservation in allocation of land, poverty alleviation schemes etc. have been provided for persons with benchmark disabilities and those with high support needs.
- Every child with benchmark disabilities between age group of 6 and 18 years shall have right to free education.
- Government funded educational institutions as well as government recognised institutions have to provide inclusive education to the children with disabilities.
- For the strengthening the Prime Minister's Accessible India Campaign, stress has been given to ensure accessible public buildings (both government and private) in a prescribed time-frame.
- Reservation in vacancies in government establishments has been increased from 3% to 4% for certain persons or class of persons with benchmark disabilities.
- The Bill will provide for grant of guardianship by District Court under which there will be joint decision-making between guardian and children with disabilities.
- Board based Central and State Advisory Boards on Disability are to be set up to serve as apex policy making bodies at Central and State level.
- Office of the Chief Commissioner of persons with Disabilities has been strengthened, who will now be assisted by 2 Commissioners an Advisory Committee comprising of not more than 11 members

ABOUT JVS

The Jan Vikas Samiti (JVS) was established as the social wing of the Varanasi Province of the Indian Missionary Society in 1997 and registered under Societies Registration Act 1860. Integral development of the marginalized and underprivileged sections of the society, particularly of women, children, scheduled caste, schedules tribe and persons with disabilities are the major focus area of JVS' activity in North India.



VISSION

We visualize an inclusive, just and humane society based on the values of equity, justice and freedom.



MISSION

Empowerment of the marginalized people of the society, especially the dalits, persons with disabilities, women and children through a process of awareness, organizing, collective action and advocacy for raising their socio-political, educational, economic and health status and promotion of environment.



STRATEGY

A continuous process of animation and advocacy among men and women to become aware, form and organize into groups and federations and to take actions for integrated participatory and sustainable development.

VALUES

We believe in the dignity of the human persons, their rights to rule and manage their own lives by developing their inherent potentials and making the optimum use of the opportunities before them. We therefore not only own them and value them but also manifest them in all our endeavors to make this world a better place for all especially the poor and the marginalized for whom we have a preferential option.



The dignity of the human being



Solidarity



Equity



Transparency



Justice



Professionalism

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drawn from experts in various disabilities.

- Similarly, Office of the State Commissioner of persons with Disabilities has been strengthened, who will now be assisted by Advisory Committee comprising of not more than 5 members drawn from experts in various disabilities.
- The Chief Commissioner for persons with Disabilities and the State Commissioner will act as regulatory bodies and Grievance Redressal agencies and also monitor implementation of the Act.
- District level committees will be constituted by the State Governments to address local concern of Persons with Disabilities. Details of their constitution and the functions of such committee would be prescribed by the State Governments in the rules.
- Creation of National and State level Fund will be created to provide financial support to the persons with disabilities. The existing National Fund for Persons with Disabilities and the Trust fund for the Empowerment of Persons with Disabilities will be subsumed with the National Fund.
- The Bill provides for Penalties for offences committed against persons with Disabilities and also violation of the provisions of the new Law.
- Special courts will be designated in each district to handle cases concerning violations of Rights of Persons with disabilities.
- The New Act will bring our Law in line with the United Nation Convention on the Rights of Persons with disabilities (UNCRPD), to which India is a signatory. This will fulfil the obligations on the part of India in term of UNCRPD. Further, the new law will not only enhance the Rights and Entitlement of Divyangjan but also provide effective mechanism for ensuring their empowerment and true inclusion in to society.