

Children with Special Needs (CWSN) with Intellectual Disability: A Way to Independent Living

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Introduction

CWSN stands for Children with Special Needs. Children who have some types of disability (challenges) or impairment and need extra help and care or additional support to overcome their challenges are come under this category (CWSN). The children who have unique requirement and may have challenges in their life like communication, mobility, education, self help skill, activity in daily life and social interaction. So, this term (CWSN) recognize the importance to provide appropriate or early intervention and support system to ensure that these children will enjoy equal opportunities. Also they can they can enjoy the facilities and perform their duties of the society. Children comes under CWSN are as follows-

- Children who have learning difficulties, intellectual disabilities and sensory processing issues.
- Physical disabilities or orthopedically handicap.
- Visual impairment.
- Hearing impairment.
- Neurologically handicap

CWSN have faced a wide range of challenges that affect their overall well-being. They struggle with academic area, social interaction, emotional regulation as well as for their physical

limitation, they restricted in mobility and independence.

Among the CWSN, we shall specially focus on Intellectual Disability (ID) which was previously known as Mental Retardation (MR). When a person has certain limitations or challenges in cognitive functioning and skills, including conceptual, social and practical is called ID. According to WHO-“MR refers to significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period. This is a most common developmental disability now days. According to American Association of Intellectual and Developmental Disabilities and , there are three criteria to denote ID. They are:

1. IQ is below 70
2. Significant limitation in adaptive behavior in conceptual, social or practical skills
3. This condition can have by birth or acquire before 18 years

According to the “Mental Deficiency Act” (1927)-“Mental defectiveness as a condition of arrested or incomplete development of mind existing before the age of 18 years, whether arising from inherent causes or induced by disease or injury.”

According to EncyclopediaBritanica- “A state of subnormal evaluation of the human organism in consequence of which the individual affected is incapable of assuming the responsibilities expected of a socially adequate person, such as self-direction, self-support and social participation.”

According to Diagnostic and Statistical Manual of Mental Diseases (DSM-IV) three criteria are there to consider a child as a case of Intellectual Disability or Mental Retardation. They are-

- IQ below 70
- Significant limitation in two or more areas of adaptive behavior
- Limitations becoming apparent before the age of 18

years

"If a person has the ability to take his/her own responsibility, can take his/her own decision and can live on his/her own term means that person is independent. So, the person with ID also has the right to live independently and to have equal opportunities. If the child can maintain daily life activity, health and hygiene with him/her self (as per their ability) then that is also independent living. Now days we can see children with ID able to perform in different types of job(as per their ability) and can earn money to live independent economically. In this paper, the researchers try to find out the ways to independent living for CWSN with ID. To make ID children independent it is necessary to early identification and provides them early intervention.

Objectives

1. To make CWSN with ID survive independently.
2. To determine various ways to make them (CWSN with ID) independent.
3. To make them mainstreaming with society.

Hypothesis

1. CWSN with ID will acquire the skills in the ADL(daily life activity skills) with proper guidance and training.
2. According to their ability they can be put in job and perform well.

Review of Related Literature

1. Corbett, J. (1999). Disability arts: Developing survival strategies. In P. Retish& S. Reiter (Eds.), Adults with disabilities: International perspectives in the community (pp. 171-181). Mahwah, NJ: Lawrence Erlbaum Associates.

This research concern about skills development of disabled children needs to function outside the schools. Also the book showed that problems of transition are not for person with disabilities bur for all persons. The social perception about disabled people is not accurate.

2. Chwalisz, K., & Vaux, A. (2000). Social support and

adjustment to disability. In R. G. Frank & T. R. Elliott (Eds.), *Handbook of rehabilitation psychology* (pp. 537–552). Washington, DC: American Psychological Association.

Here the researchers discussed the various models on social support, e.g. positive supports which affect the CWSN.

3. Crewe, N. M., & Athelstan, G. T. (1981). Functional assessment in vocational rehabilitation: A systematic approach to diagnosis and goal setting. *Archives of Physical Medicine & Rehabilitation*, 62, 299–305.

In this research 8 scales identified for Factor analysis, which is very important to provide employability with CWSN(ID). Vocational qualification, Medical Condition, Vision, Hearing, and Economic Disincentive are important factors for proper employment.

4. Nester, M. A. (1993). Psychometric testing and reasonable accommodation for persons with disabilities. *Rehabilitation Psychology*, 38, 75–84.

In this research, researcher discussed psychometric testing accommodation in terms of medium, time limits and test content.

5. Connell, C., & Berkowitz, H. (1976). Rehabilitation for the disabled family in stress. Research prepared for the California State Department of Rehabilitation at Los Angeles, Los Angeles, CA.

The California Department of Rehabilitation (DOR) works with consumers and stakeholders to provide services to the CWSN to live independently. They provide the services like job placement, counseling, necessary training with the help of housing assistance, peer support and assistive technology.

Methodology

- Books, Journals, magazines, case history, interview and Research articles
- Research Design : 5 case studies
- Used Tools:

1. Researcher made questionnaire (close ended questions), 3 points scale :

The questionnaire consisting 10 questions on

- doing daily life activity independently
- maintaining personal health and hygiene
- managing emotions correctly and situation wise
- effective communication skill
- sociability
- using assistive device
- essential reading capability
- essential math skill
- following the instructions accurately
- having employability skill

2. MDPS

The Madras Developmental Programming System (MDPS) assesses children's abilities in 18 functional areas including motor skills, self-help skills, communication skills, social interaction, and functional academic skills

3. BASIC-MR

BASIC-MR stands for Behavioral Assessment Scale for Indian Children with Mental Retardation. It's a tool used

- To assess a child's current behavioral level
- To identify problem behaviors
- To help develop support plans for children with mental retardation

Research Design: 5 Case Studies

Case No 1:

Mr.R. 25 years old male having moderate intellectual disability and cerebral palsy. According to his mother and test administer (MDPS), he is able to perform daily

life activity independently. Parents want to make him independent economically also. So, they want to open a stationary shop for him.

Intervention:

The child can be trained in mathematics (preferably use calculator), effective reading skills, control behavioral and emotional issues with the help of counseling and therapy. Also when need help can ask parents for help and guidance. Also need training how to maintain the shop (selling products).

Case No 2:

Master A. 9 years old male having mild intellectual disability. He has behavioral issues also. According to his parents he is under therapy (OT). He is toilet trained, can have food independently but need to improve communication and socialization. Also he is studying in main stream school and takes support of special educator.

Intervention:

The child is under OT but need to go and consult a speech therapist to improve communication skills. In home parents communicates with him effectively like what he has done in school, what he like to eat in lunch/dinner, where he want to go and why, storytelling with the use of flash card/pictorial books. Also visit shopping mall, different types of gatherings/ceremony, park etc.

Case No 3:

Master N. 15 years boy has moderate intellectual disability. He is able to do all his daily life activity independently. Also he is now studying in a mainstream school and makes himself adjusted at the school environment.

Intervention:

Parents and teachers should take care of him that he should not bullied in school and other places. With the help of counseling and therapy, the child is now able to control his emotions and behaviors. If needed, special question paper

may be arranged for him in exam.

Case No 4:

Miss S. 21 years girl has Down syndrome. She is a good dancer and performs in different event with payment. This way she is economically independent and also able to do her all daily life activity independently.

Intervention:

The child should be given proper dance training, counseling, and medication. Also she needs good care and support from her parents.

Case No 5:

Master M. 12 years boy has moderate intellectual disability. He needs good care and support from her parents. has behavioral issues. He is studying in normal mainstream school. He is under medication and counseling. So, he is able to manage in school environment and able to do all his daily life activity independently.

Intervention:

Though the child is under counseling and medication he is improving but need to take care that he should not be bullied in school.

Discussion

Objective No. 1: To make CWSN with ID survive independently

To make CWSN with ID survive independently need training and guidance in following areas like personal care, safety, essential math, household skills, leisure time activity, community living, self-awareness and self-confidence, occupational skill and essential learning. To make these children independent, they need huge quality time and support of their parents. Parents should motivate their children constantly to make their children independent.

Objective No. 2: To determine various ways to make them (CWSN with ID) independent.

To determine various ways to make them (CWSN with ID) independent, they should have education according to their needs and ability. Universal Design of Learning(UDL) made to easy for them cope up with all challenges. These children should develop communication skill, managing emotions in right way, proper use of assistive devices, with proper training and guidance. With proper vocational training these children can make their employability better way and economically independent.

Strategies to make Independent:

- Age-appropriate activities: Tasks arrange in simple to complex way. Give them initially the task to clean bed, toys, separating fruits and vegetables etc. Gradually increase the complexity.
- Decision making: According to ability and age give them chance to take decision like to choose dress or playing with toys.
- Problem solving skills: Let them short out their small problems, which increase confidence and self-esteem. Parents and teachers give support when need.
- Routine: If they are in proper routine, they develop positively. So, create daily routine as per their need and ability.
- Independent play: Encourage them to play independently without constant supervision.
- Reinforcement: Everyone likes praise as well as ID children also. So, praise them for their positive efforts. This will help to increase their positive behaviors.
- Make them learn to wait: Parents make sure not to give things when they ask for it. Negotiate with them and make them wait for it. But it is also necessary to give when promised. Otherwise they will learn to tell lies.
- Life skills: Essential life skills like cooking (making tea, sandwich, masala muri, boiled egg, making Maggie etc), managing money, and purchase things from shop introduce gradually.

- **Respect:** Respect and accept them as they are. When they made mistakes, make them understand the cause and support/motivate them not to do that mistake again.
- **Unique ability:** Asses their abilities and according to that ability select goal and arrange programs.

Objective No. 3: To make them mainstreaming with society

We have to create inclusive environment where everyone can participate fully in social, educational and professional life. To promote inclusion some key steps are needed. They are-

a. **Awareness and education:** Awareness camp should arrange to aware teachers, students and general public to reduce stigma. Schools and Universities can arrange programs to encourage an inclusive culture.

b. **UDL:** There should be accessible facilities in school to foster inclusive education students with and without disabilities. Also give them specialized support for ID children to be independent and build friendship and understanding with other children in school.

c. **Inclusion in workplace:** There should be modified duties, flexible working hours and vocational training to help ID person acquire job skills and increase chances of employment.

d. **Social Inclusion:** Different type of community programs and activities such as cultural events, sports, art, craft can create Social inclusion.

e. **Assistive Device:** Now a day's many assistive technologies are there to support CWSN with ID.

f. **Support from family and peer group:** Family and peer support is very important to make ID children feels good and independent.

g. **Policy and advocacy:** According to RPwD Act, 2016 is an act of the Indian Parliament that ensures equal and equitable opportunities and dignity for people with disabilities. On April19, 2017 this act came into effects.

- Person with benchmark disabilities (40% and above) are entitled to certain benefits, that is 4% of the total number of vacancies government job and 1% in others must be reserved.
- Every disable children age 6 to 18 has the right to access free education.
- 5% reservation in all government job and government aided institution with 5 years relaxation.
- Support and teach them how to exercise their legal capacity.
- “Special Court” is there in each district to resolve legal problems.
- This act also provides skill development, rehabilitation, health, recreation and social security.
- Barrier free environment in school, college and work place.
- CWSN children will get books, learning materials and appropriate assistive device with free of cost.

National Trust Act,1999- This act provides facilities like legal guardianship, health insurance and day care for child with ID. Some programs are DISHA,VIKAAS(day care), SAMARTH(Respite care), GHARAUNDA(Group home for adults), NIRAMAYA(Health insurance scheme) et.

CWSN with ID can thrive and perform duties of the society when society works to remove all types of barriers, give mutual respect, treat them as a normal human being, accept them as they are with empathy.

Interpretation of the Hypothesis:

1. Hypothesis No. 1: CWSN with ID will acquire the skills in the ADL (daily life activity skills) with proper guidance and training:

Independently survive means not only economically independent but independent to do daily life activity like brushing, combing, eating, clothing, maintaining health and hygiene, socialization, meaningful communication and

maintain safety rules. If they guided and train according to their need and ability, they can live their life independently. To foster this, society should be barrier free in physical, mental, attitudinal, instructional, technological, and social.

2. Hypothesis No. 2: According to their ability they can be put in job and perform well:

ID children can live their lives to the fullest in a society which will be barrier free in physical, mental, attitudinal, instructional, technological, and social aspects. ID children are also able to perform their duties towards society/country with training and guidance. As on the base of their ability if they put in job, they perfume their duty in very good way. This is easily reflected in Case No. 4 where 21 years old with Down's Syndrom, Miss S is a professional dancer. So, it's the duty of both the family as well as the society, to make them mainstreaming with empathy.

Conclusion

Independently survive means not only economically independent but independent to do daily life activity like brushing, combing, eating, clothing, maintaining health and hygiene, socialization, meaningful communication and maintain safety rules. If they guided and train according to their need and ability, they can live their life independently. To foster this, society should be barrier free in physical, mental, attitudinal, instructional, technological, and social. ID children are also able to perform their duties towards society/country with training and guidance. As on the base of their ability if they put in job, they perfume their duty in very good way. So, its family and society's duty to make them mainstreaming with empathy.

Inclusive education promotes equal opportunities for all children, including CWSN with ID

If we want to ensure the success of Intellectual disable people in inclusive education, there are various interventions and support systems are available. They are-

1. Individualize Education Plan (IEP)- This program is based on education, leaser time activity, vocational

training. This is designed by teachers, parents and special educators collaboration. This is goal based program.

2. Assistive technology/device used: Assistive devices help them independent.

3. Special Education Support: Special education support such as special educator, speech therapist, occupation therapist, psychologist and therapist need to develop them. Need based intervention should be there.

They should be given age-appropriate responsibilities like chores, allow them to make small decisions, encourage problem-solving skills, establish routines, provide opportunities for independent play makes Intellectual Disable children independent. For this they should be provided motivation and positive reinforcement.

So, parents should follow some simple guidelines like, make your child to perform simple house hold works such as cleaning bed and room, disposing garbage, arrange books and copied on the reading table, watering plants, separate fruits and vegetables, keep them proper place, fill water in bottle, clean utensils etc. Also do not fulfill their unnecessary demands and make them understand the value of money. Give them tasks and after complete the task, give money and ask them to keep it in a piggy bank. This will help them to learn that earning money is not easy. Parents should make boundaries and stick to them without feeling guilt. Also prepare child to adjust all types of environment. Let them (older children) plan their own life. Avoid over protecting. In this way we can make the child independent as per their ability. So, make your child independent can be both gift and struggle. Please remember that the more you help, the less they can learn.

References

Chwalisz, K., & Vaux, A. (2000). Social support and adjustment to disability. In R. G. Frank & T. R. Elliott (Eds.), *Handbook of rehabilitation psychology* (pp. 537-552). Washington, DC: American Psychological Association.

Connell, C., & Berkowitz, H. (1976). Rehabilitation for the disabled family in stress. Research prepared for the California State Department of Rehabilitation at Los Angeles, Los Angeles, CA.

Corbett, J. (1999). Disability arts: Developing survival strategies. In P. Retish & S. Reiter (Eds.), *Adults with disabilities: International perspectives in the community* (pp. 171-181). Mahwah, NJ: Lawrence Erlbaum Associates.

Crewe, N. M., & Athelstan, G. T. (1981). Functional assessment in vocational rehabilitation: A systematic approach to diagnosis and goal setting. *Archives of Physical Medicine & Rehabilitation*, 62, 299-305.

Gold, D. (1996). Attempts to create friendship in the lives of students with disabilities: The case of 'circles of friends. Dissertation Abstracts International Section A: Humanities and Social Sciences. Aug.; Vol. 57(2-A) 0638.

Nester, M. A. (1993). Psychometric testing and reasonable accommodation for persons with disabilities. *Rehabilitation Psychology*, 38, 75-84.

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