



Service Needs of The Children With Intellectual Disability

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Abstract: This study has been undertaken to investigate the service needs of the children suffering from intellectual disability. The service needs in terms of health care are those needs that benefit individuals; for example health education, disease prevention, diagnosis, treatment, rehabilitation, terminal care. The purpose of the research study is to understand the service needs of the children with intellectual disability from the perspective of the professionals. The qualitative research method with Descriptive research design was used to fulfill the objectives of the study. The overview of the findings reveals that the majority of professionals recommend for the raising awareness, early interventions, improving services and imparting training programs.

Index Terms – Children, Intellectual disability, Service needs, Professionals, Rehabilitation.

1.1. Introduction

Healthcare is an integral component in the functioning of a society. Health status reflects the plethora of a society. Delhi, being the national capital is the most rapidly expanding and attracting all kinds of services. Need is an important concept in public health. It is used in the planning and management of health services including health improvement, resource allocation, and equity. The need for health services should be distinguished from the need for health. Health service needs are those needs that can benefit from health care (health education, disease prevention, diagnosis, treatment, rehabilitation, terminal care). Mane & Gandevia (1993) stated that a need for health services exists when an individual has a disability for which there is an effective and acceptable treatment or services. Most doctors consider needs in terms of healthcare services that they can supply. Patients, however, may have different views of what would make them healthier—for example, a job, a bus route to the hospital or health center, or decent housing. Whereas, Health needs to incorporate the wider social and environmental determinants of health, such as housing, diet, education and employment. This wider definition allows us to look beyond the confines of the medical model based on health services. There is an attempt to delineate the service needs of children with intellectual disability (CID) identified by the various professionals.

Mental health is the bridge for the development of society. It is difficult to imagine an inclusive and non exploitative society without focus on mental health. Mental health needs of CID are diverse which call for the proper planning and management of the health care delivery system. The mental health services for this group depend upon their needs, thus reviewing the theme mental health needs of CID, becomes imperative.

Clifford (2004) assessed the mental health needs in an elementary school district to address and attend to the mounting mental health needs of a small rural community in southern New Jersey. Findings indicated that community members faced numerous impediments in securing mental health services. Among those prominent impediments were economic, geographic, and availability and affordability of health professionals. Respondents (caregivers) indicated that they were interested in a comprehensive school-based intervention program to address the mental health needs of children.

Jensen, Martin, Perry, Fettes (2008) did a study on child psychiatry in the field of public knowledge and assessment of child mental health problems in America. They did a face-to-face survey of 1,393 adults and special children and used vignettes consistent with diagnoses of attention-deficit/hyperactivity disorder (ADHD) and other developmental delays. Descriptive and multivariate analyses provide estimates of the levels and correlates of recognition, labeling, and treatment recommendations. The results showed that there is low treatment use and adherence despite of the required needs of mental health services. The lack of knowledge was cited as an underlying reason. Mental health specialists face challenges in gaining family participation and there is a lack of public knowledge. They conclude that childhood is very important and special stage in the lifespan, thus the conditions for optimum development should be created in all the spheres of functioning.

Wendy, Reinke, Herman, Puri and Goel (2011) did significant research in mental health practices. The participants included 292 teachers from five schools. Understanding the teacher's perspective provides important information about contextual influences that can be used to bridge the research to practice gap in school-based mental health practices. The study discussed mental health needs and the emotional problems relating to developmental processes. It concluded that children require early identification, home based stimulation, special education, behavioral training for self-care and daily activities and at a later age vocational

training. The promotion of mental health with simple techniques like life skills education (LSE) is essential. LSE not only improves immediate functioning of children, but also has the potential to prevent problems of drug abuse, suicide, delinquency and risk taking behavior.

According to Francis, (2014) nearly 20 – 30 million people are in need of mental health services and every year 200,000 new cases are reported in the world. One third of these need help to cope with a disability resulting from various mental health conditions. These figures do not include the thousands of others who may be suffering in silence without access to care. Against the huge need for mental health services in India there is scarcity of trained human power. Barriers include the prevailing public health priority agenda and its effect on funding. Lack of knowledge and stigma among the public about mental illness is one of the major barriers to mental health in India.

It can be concluded that mental health needs of special children are diverse and the services required to fulfill these needs are not assessed. The parents are also partially aware about the services for children and face large problems in availing them.

1.2. Objectives of the study

To understand the service needs of the children with intellectual disability from the perspective of the professionals.

2.0. Methodological Plan

The methodological plan provides insights into the nature of the study and the research design followed in the present study.

2.1. Nature of the study

The researcher used both qualitative research methods to fulfill the objectives of the study. This method was by and large preferred in understanding the service needs from the perspective of the professionals because it provides more scope to the respondents to express what they might have experienced. The selected verbatim of the professionals are supplemented with abbreviated codes to strengthen the transparency in the study. The names of children have also been changed to keep the confidentiality.

2.2. Research Design

According to Burns and Grove (2003), descriptive research “is designed to provide a picture of a situation as it naturally happens”. It may be used to justify current practice and make judgment and also to develop theories. For the purpose of this study, descriptive research was used to obtain the opinions of different professionals on existing services with a view to improving the standard of care for this group.

2.3. Universe and the sample for the study

The non-probability sampling techniques were used to draw the required sample. The universe for the study comprised of professionals (heads, clinical psychologists, social workers and special educators) from different government hospitals, institutions, regulatory bodies and NGOs providing services for children with intellectual disability.

2.4. Sampling unit

The unit of the study was the service providers in various capacities, including head, clinical psychologist, social worker and special educator from each NGOs, government hospitals, institutions and regulatory bodies.

2.5. Sampling Procedure

The professionals were selected from the agencies (Government hospitals, Institutions, Regulatory bodies and NGOs) providing mental health services to CID using non-probability technique in two stages. In the first stage, the agencies were selected while in the second stage stakeholders in various capacities were selected from those agencies.

First Stage: Selection of Agencies (government hospitals, Institutions and regulatory bodies and NGOs):

Hospitals

The researcher selected the hospitals with the non-probability technique using a purposive method of sampling. All the hospitals which provided the disability certificate to the CID were included in the study. The researcher ensured that at least one hospital from each zone of Delhi constituted the sample of the study. Thus, the total hospitals from which the professionals were selected to stand at thirteen.

Institutions and Regulatory bodies

All the six agencies in Delhi, comprising- three Institutions and three regulatory bodies were included in the sample as they are important for obtaining information on policies, legislations and service delivery mechanisms.

Non-Government Organizations

For collecting the data from non-government organizations, a list of 32 NGOs for CID was derived from PWD Act. The researcher approached all of them requesting to permit her to collect data from the professionals. In total 23 NGOs gave permission to conduct the research study. These 23 NGOs constituted the sample of the study.

Second Stage:

The professionals from the four ranks of service delivery were selected, i.e. heads (prime position), clinical psychologists (assessment of CID), social workers and special educators (directly engaged with CID and their parents) from the above selected hospitals, institutions and regulatory bodies and NGOs.

2.6. Total Sample size

Thus, the total sample size from both the groups comprised of-

Stakeholders	Agencies			
	Government Hospitals	Institutions and Regulatory bodies	NGOs	Total Agencies
Heads	7	6	11	Total Sample Size 24
Clinical Psychologist	6	1	9	16
Social Workers	6	4	11	21
Special Educators	-	-	5	5
Total Sample Size	19	12	36	67

2.7. Source and Methods of Data Collection

For the purpose of the research study, data were collected from both primary and secondary sources. The primary source of data comprised brief interview guides for different professionals making use of interview method. One focused group discussions (FGD) guide was used to conduct a guided discussion with the available professionals on the needs of CID. The secondary sources for collecting the information included use of published material mainly comprising research reports, Online references were made for journal articles, studies at Jstore, Proquest, as well as information available on internet, reports and publications of Government agencies and International Organization such as WHO, UN etc.

3.0. Results

The services identified for CID by the Professionals, become the normative needs as these are expressed by the professionals who are working for the children with ID. The following points show the set of services identified by the professionals for the CID:

3.1. Raising awareness and promoting advocacy

Awareness implies having knowledge or being aware and well informed about the concept of disability in children, its causes, characteristics, assessment and interventions. The professionals shared that people are not fully aware about the concept of ID, many parents think it is a disease, they have misconceptions like, "*as the child grows older, the condition will diminish or the marriage will cure the intellectual disability*" (P30). There are many myths in the minds of people, which are often triggered by supernatural beliefs, fear, lack of understanding and prejudices. These common myths and stereotypes emerge repeatedly in the society. The heads, psychologists, social workers and special educators- all unanimously asserted on the need for creating awareness among the general population to diminish stigma and discrimination associated with ID.

HEADS

The large majority of Heads (22/24) identified the need to create an enabling environment for social inclusion of the CID by providing equal opportunities and protecting their rights. They all supported following service needs to sensitize people-

- Regular advertisements to enhance the awareness on the importance of empowerment of parents of children with intellectual disabilities.
- Creating support groups
- Welfare schemes and programs on the community radio, news channels and newspapers. Integrating the topic- 'Disability and its types' in the NCERT books in schools.

Eighteen out of 24 heads were of the view that a joint initiative from the Government, NGOs and Private sector is required to create awareness among people about the genetic counseling and antenatal care to curb the incidence of ID.

CLINICAL PSYCHOLOGISTS

Most of the clinical psychologists (13/16) shared that there is an impending need to create a wide-ranging awareness amongst the people about the special characteristics of the children with ID. They emphasized on the fact that it is important to have the conducive environment for the recreation and positive development of CID including-

- Hands on learning
- Unified games
- Outdoor activities
- Accessible buildings, transport and websites.

SOCIAL WOKERS

Many social workers (19/21) reflected to bring to the notice of all stakeholders, including the civil society about the legal rights of the CID as enshrined in the constitution and legislations. Twelve amongst them, emphasized to encourage voluntary action for ensuring effective implementation of the present legal provisions and welfare schemes.

SPECIAL EDUCATORS

Nearly all the special educators (4/5) emphasized on the need for the social integration of CID. Parents and the general public should be made aware through public education about the causes, prevention, early detection, training, misconceptions and right attitudes towards the persons with ID.

3.2. Development of Early Intervention Centers

The Early intervention centers (EICs) focus on helping young children (2 - 6 years) with early indicators of developmental delays and disabilities. The concept of Early Intervention arises from the fact that during the early years, the brain is more receptive and these young children benefit immensely in early years. The Early Intervention focuses on helping children with disabilities learn the basic skills during the first three years of life, such as:

- Physical (reaching, rolling, crawling, and walking)
- Cognitive (thinking, learning, solving problems)
- Communication (talking, listening, understanding)
- Social/emotional (playing, feeling secure and happy)
- Self-help (eating, dressing).

HEADS

Heads (20 out of 24) raised a need to develop an interdisciplinary team in every hospital and NGOs working in the health sector to assess the cases with ID. Trained professionals from different fields should come together to prepare a comprehensive intervention plan for CID. They should be assessed and managed in the interdisciplinary team, consisting of clinical psychologists, psychiatrists, speech therapists, developmental therapists, physicians and social workers. In addition, cases should not be diagnosed in a multidisciplinary band, wherein the case meets each professional individually; rather case must be assessed and managed by an interdisciplinary team together. This will also reduce the stress of parents to get appointments and visit all the specialists individually. Nearly two third of Heads, also shared that the services should be tailor made to satisfy the unique needs of CID. There should be a team based approach with focus on positive development.

CLINICAL PSYCHOLOGISTS

The clinical psychologists (12/16) said, the services are required for the children with severe ID. The available services only cater to the children with borderline, mild and moderate IQ as a consequence, the children with severe IQ are left behind. This category is not enrolled in behavior modification, occupational therapy, life skills and vocational training programs. Therapies for them should be created and designed with the help of intensive support machines. Apart from this, special protective services are needed to be started for them.

Availing and updating tools of psychological assessments is very crucial, two clinical psychologist (B09) and (B10) shared that, *'we don't have the accurate psychological tests to diagnose ID in Indian children, we have tests like Stanford-Binet Intelligencetest and Wechsler Adult Intelligence Scale instead of Bhatia performance test which measures the intelligence of children from less educated families'*. Children with ID share an attribute of being a minority group amongst all the disabilities. The CID are diagnosed with the same psychological tests that are used for adults and other learning disabilities. Binet-Kamat Intelligence Test, Wechsler Intelligence Scale for Children, Bhatia Performance Test of Intelligence and Raven's Progressive Matrices tests must be made available in all the hospitals and there should a stringent regulations should be there while assessing CIDs.

SOCIAL WORKERS

Approximately, three fourth of the Social Workers talked about need to improvise antenatal care and antenatal screening of expecting mothers. A social worker (C08) shared, *'... primary care should be strengthened to reduce ID, after all, prevention is always better than cure'*. Early detection and management play crucial role in minimizing the influence of ID. Universal Immunization Program, particularly the use of vaccines of measles, mumps, and rubella (MMR) is very crucial in the prevention of ID. Five amongst them shared prenatal screening of high risk cases, newborn screenings and follow-up of 'high risk' infants should be included in the Reproductive and Child Health Programs. More than half of the social workers (15/21) recommended appropriate services to manage behavior and emotional problems of CID. Temper tantrums, ADHD, sleep disorder; aggression and self-injury are the prominent ones which aggravate the condition of CID. A proper mechanism to deal with these difficulties is required. One of the Social workers (C15) said- *'behavior disorders are frequent in children with ID, it creates problems in everyday life, it is crucial to adopt an interdisciplinary approach in treating these behavior problems'*. A team of doctors from varied fields, based on their clinical experience shall give behavior modification therapies and work closely with the caregivers.

SPECIAL EDUCATORS

Three out of five special educators (3/5) shared that early intervention helps in developing the skills for future learning, reduces the occurrence of associated disabilities and CID can attain the maximum potential with early intervention stimulators.

3.3. Community Based Rehabilitation (CBR) Programs

The CBR is a comprehensive approach, used in situations when resources for rehabilitation are available in the community. The major objective of CBR is to ensure that people with disabilities are able to maximize their physical and mental abilities, have access to regular services and opportunities and achieve full integration within their society. The purpose of CBR is to solve problems related to disability with the involvement of the community. A stakeholder (B05) argued that *'In India, people living with ID are likely to be isolated, abused and deprived of their fundamental human rights, they have extremely limited access to support mechanisms and health services and they also excluded from community-based rehabilitation (CBR) programs'*. There is

a need to strengthen the CBR programs and support initiatives for the CID. Another said (C14) '*there is so much rush of cases at our center... CBR program is required to settle these cases in their communities, with services at doorstep*'.

HEADS

As per the heads (22/24), strengthening CBR will ensure that families of ID have access to regular services to achieve full integration within the community. People from the communities must be involved in planning, decision making and evaluation of the programs with multi-sectoral coordination. Also, referral system must be there for those differently able who cannot be managed at the community level. One of them (A07) shared '*Government should develop a National Task force for outreach activities and awareness generation programs to alert the public about the developmental disabilities and their management*'.

CLINICAL PSYCHOLOGISTS

About half of the Clinical psychologists (7/16) identified community support essential for CID. According to them, parents need to allow their CID to interact with the people in the neighborhood and community, organize awareness programs for the general public. They can also hold exhibitions of their work and contribute by writing literature projecting their capabilities.

SOCIAL WORKERS

The social worker (19/21) found, social interaction of CID at the community level need to be promoted. The parents must take initiatives to build better relationships in the neighborhood, by inviting children from the neighborhood for small parties or get together to their house. This will give a chance to other children to mix up with CID. Parents could also use this opportunity for explaining the child's disability to other children and how they can contribute.

SPECIAL EDUCATORS

According to special educators (3/5), voluntary organizations should come forward to set up more special schools and sponsor a child coming from poor families. Fundraising programs and donation drives are other ways to mobilize and channelize community resources.

3.4. Parent Training Programs

The parent training programs is an important area in which intervention is required to empower the families of CID. Parents play a pivotal role in the early development of the child. Parents are believed to be the role models for their children. They are sometimes recognized as the painters of their child's life, their knowledge and awareness about the disability gives direction to the course of management. Professionals reiterated that the parents play an important role in the training and rehabilitation of their child. They are the first teachers, socializing agents and primary caregivers for their children.

HEADS

As per the heads (16/24), home training programs to handle special children are definitely needed for the parents. Training plans should be developed to facilitate effective parenting skills and promote positive interactions between parent and child.. Videotapes and role plays can be used to help parents learn the concept of ID. Further, they said-parents should be made to join the Support groups so that they can learn from each other.

CLINICAL PSYCHOLOGISTS

About three fourth (12/16) of clinical psychologists observed that parents need to accept the child first. They need to shed their inhibitions about the child's condition. Then, they can go for professional help and collaborate with other parents to form the parents association. Both mother and father of the child should participate in the activities of parent association and apart from them, other members could be included such, as well wishers, patrons, technical experts and other active and concerned individuals.

SOCIAL WORKERS

According to the social workers (15/21), parents need to be active in participating in policy making programs at local, state, national and international levels related to welfare and rehabilitation programs for their CID. One of the social worker (C09) shared '*caregivers and parents need to be dynamic in public cooperation and participate at different levels for the welfare of CID*'. Another social worker suggested to reimburse the conveyance of caregivers. They have to go regularly for therapies and other services in hospitals and institutions for which they take a leave from their jobs, thus need is to reimburse the travelling conveyance for the case and caregiver of the day.

SPECIAL EDUCATORS

The two special educators said more and more parents' groups should come forward and parents need to organize and voice the condition and requirements of their children. Parents associations can act as the pressure groups for government and therapy group for its members.

3.5. Quality of Services

The Indian health care system offers a range of health services. Many people, especially the poor receive unacceptably low-quality primary and hospital care (Das 2016). The rapidly growing burden of chronic diseases makes the low quality of care highly salient for the health policy. Recent studies among low-income countries have documented lower levels of knowledge of health recipient and have found large gaps between the health knowledge and the care provided, sometimes called 'know-do gaps'. (Mohanani, Vera-Hernández, Das, Giardili, Goldhaber-Fiebert 2015). Low quality of care is due to the lack of incentives in the

health system or information problems in the health care market, combined with a lack of accountability among providers and poorly functioning governance systems in the health system.

HEADS

Almost all the heads (20/24), raised the issue of prioritizing the research in the field of ID. They suggested that employing research methods such as observations of service providers, their performance, experience of exit patients, interviews of inpatients demonstrate the potential of research to measure the quality of services in the area of ID. One shared "*what gets measured, gets attention*" (A04). Ideally, government should use the data from administrative sources and household surveys for the quality improvement and for accountability in health care delivery. The health research will generate data and gaps which will definitely draw attention of the health care system in this area.

CLINICAL PSYCHOLOGISTS

Nearly, three fourth of clinical psychologists (12/16) demanded the easy availability and accessibility of the services. They admitted that there exists mismanagement in the delivery of services. One clinical psychologist (B05) said '*it takes around one year to get the disability certificate and six months for the assessment*', this is the allotted time for the parents of CID in a renowned Institute. Easy availability of the health services and simple health care system would be beneficial for the parents and CID. Parents require well equipped rehabilitation institutions with sheltered workshops and skill training centers. The already established centers and institutes of training for individuals with ID are grungy in service quality, they need to be improved and services must be readily available.

SOCIAL WORKERS

More than half of the social workers (15/21) stressed for the appointment of special educators in all the schools. The Education Boards should make it mandatory for all affiliated schools to appoint a special educator to promote inclusive education. This rule has been in place since 2015, but many schools are not following it. The attention has to be made for the affiliation bylaws which provide and promote inclusion of students with disabilities/special needs in the regular school as per provisions under existing laws and policies. The teachers in the schools can detect specific disabilities in children at the early stage, preferably, when they are in the primary school or after they complete the age of nine years. Improving the quality of health care at the system level requires a focus on governance issues, including improving public-sector management, building institutional capacity, and promoting a culture of data-driven policies.

SPECIAL EDUCATORS

As per the suggestion of the special educators (2/5), inclusion of CID in mainstream setting- with appropriate support for their individual learning needs- can help them to learn better skills for day to day life. Such integration will also address the misconceptions and ignorance about ID amongst the wider public. Children with mild disability can be accommodated in mainstream schools, while children with moderate to severe disability can be admitted in special schools.

From the above discourse it can be concluded that children with intellectual disability often has a number of different assessments and consequently have multiple and complex needs. They require an interdisciplinary approach to take their care in order to deal with complex multimorbidity, social and psychological issues. An interdisciplinary approach can improve healthcare processes and the levels of satisfaction. It also avoids duplication of assessments, leading to more comprehensive and holistic services.

4.0. References

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