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## Children with Intellectual Disabilities and Role of Public Sector Institutions: An Exploratory Study from District Lahore, Punjab, Pakistan

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**Abstract:** Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior, which are expressed in conceptual, social, and practical adaptive skills. The intellectual disability normally originates from the age of 18 years and restricted learning activity, including acute deficiency or restrictions in individual expertise in numerous fields such as cognitive, language, motor, psycho-social, and particular functioning of everyday living. People with intellectual disabilities have to face a lot of discrimination in Pakistan due to inadequate involvement of the public and private sectors. Keeping in consideration the importance and sensitive nature of the issue, the present exploratory study aims to understand the role of public sector institutions regarding children with intellectual disabilities in district Lahore. Primary data was collected through in-depth interviews with managers of different public sector institutions. The results presented through thematic analysis, and findings highlighted that several gaps existed in services, such as lack of proper mechanisms in the institutions, absence or pathetic check and balance, professional practitioners, training and guidelines, poor and inappropriate infrastructure, and limited participation in sports and extracurricular activities. The study strongly recommended that there should be a review and strict enforcement of policies, awareness among parents, and effective rehabilitation is necessary.

**Key Words:** Intellectual Disability, Intellectual Functioning, Role of Public Sector Institutions, Children with Intellectual Disabilities

### Introduction

Intellectual disability is strongly associated with the behavioral, emotional, and physical ability to perform everyday activities. People with intellectual disabilities remain behind others of their own age and face anxiety, frustration, withdrawal, and acting abnormally to attain attention from others (Staunton et al., 2023). The issue of intellectual disabilities has increased in recent decades, and children are the most affected proportion among the population globally. Children with intellectual disabilities have various difficulties, such as controlling body motions, speaking, drinking, eating, managing their personal needs, and interacting, among others. In most cases, children with intellectual disabilities are partially or fully dependent on life (Hayden et al., 2023).

The problem of intellectual disabilities commonly begins before the child's birth to the age of 18 years. The affected children normally take a longer time to understand, learn, walk, peak, get dressed, and take action, among others (Wang et al., 2022). Intellectual disability, traditionally known as mental retarded is an issue related to cognitive growth and has a significant relationship with individual socio-physical activities. There are multidimensional reasons behind intellectual disability, such as Down syndrome, genetic disorders, infection before, during, or after childbirth, underage childbirth, stroke, and head injury, among many others (Ugwuanyi et al., 2023).

Normally, the issue is observed during the early years of childhood, but it can be diagnosed in the latter time period. However, the diagnostic issue varies from child to child and situation to situation according

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to the availability of health facilities (Kamaludin et al., 2022). The situation in developing countries like Pakistan is critical due to the deficiency of experts and the priorities of health authorities. In Pakistan, people with numerous disabilities have to face a lot of difficulties and discrimination due to a deficiency of facilities. The most vulnerable proportion of patients with disabilities is the children due to the unawareness of families, lack of proper facilities in institutions, meager policy coverage, inadequate awareness facilities, and socio-economic conditions of parents (Ozkan et al., 2023).

Pakistan is among the pioneer signatories of international treaties, including a Convention on the Rights of the child (CRC) adopted by the United Nations. Pakistan ratified this convention in 1990 (Opoku et al., 2020). As per Article 23 of CRC, the mentally or physically disabled child should enjoy a full and decent life recognized by state parties, ensuring their dignity, encouraging self-dependency and assisting the child's active involvement in the society. Government has taken several measures in the form of policies and institutions to address the issues of children with disabilities. Yet, there is no major improvement in the society (Ede et al., 2023).

One of the primary objectives of the current research is an effort to assess the services being provided to children with disabilities, specifically intellectual disabilities, to identify the effectiveness and gaps (Apukhtina et al., 2023). A specific exploratory study is important in determining the nature and extent of services being provided in the institutions to children with intellectual disabilities. Although it differs by age, the prevalence of intellectual disability (ID) is noted to be almost 1% of the whole populace. For the time being, 0.6% is reported to be the prevalence of severe intellectual disability (American Psychiatric Association, 2013)

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18 (Schalock et al., 2010). Restricted learning activity involving acute deficiency or restrictions in individual expertise in numerous fields as follows: cognitive, language, motor psycho-social, and particular functioning of everyday living are the main characteristics of children and students with intellectual disabilities (Vandorpe et al., 2012).

A large number of existing empirical studies (McCoy et al., 2016; Collins et al., 2017; Yoo et al., 2018; Opoku et al., 2020) revealed that although parents had little presumption for their children's health and development safety of their children with intellectual disability from pessimistic social behaviors and limitation of their caregiving load was acknowledged as a benefit by being enrolled in a special health-related institution. Significant access to healthcare institutions, primary childhood care, and growth assistance and education are needed by children with intellectual disabilities (Hoytema et al., 2021).

A successful policy and program implementation is necessary to have careful assessment, consistent quality enhancement, and continuous tracking of the facilities and policy procedures (Almalki et al., 2021). the caregivers of youth with co-existing cognitive and mental health problems can make the treatment decisions more effective, and peer-to-peer support among caregivers, coordinated services, multiple providers, and stakeholders formulating a joint strategy, encourage activation would contribute to a better treatment goal and quality of care (Hayden et al., 2023).

The different factors that will construct that life such as warm, positive, valued connections within a range of groupings (including friendships, classes, and teams); growth and development (and high expectations for learning); the recognition and expression of one's individuality and autonomy; a fundamental sense of safety and ease; and enjoyment of the experience (Kamaludin et al., 2022). The absence of proper socialization, admittance system, poverty, child health conditions, absence of sports and school activities, and overprotecting of children with disabilities. Although the health care institutions had limited assistance to all the unreached children at tehsil or remote levels with low budget, workers, physical infrastructure, and transportation services, the existing special institutes were giving assistance through awareness alteration, modified strategies, educating parents, patients relaxation and enjoyment activities (Hayden et al., 2023).

The institutions of Pakistan, along with multilayered socio-economic and administrative issues trying their best to meet the desired needs of the population. However, the issue of educational settings and



services for children with disabilities stands alarming. Advocacy, legislation, policy involvement, and dialogues addressing this matter have not given the anticipated results. The prime objective of this study is to assess the services being provided to children with intellectual disabilities in the public sector and to identify the effectiveness and the gaps. The knowledge and information provided by the managers was consequently sought to explore this subject.

### Objectives of the Study

- To assess the existing situation of public sector institutions regarding children's intellectual disability
- To understand the role of public sector institutions in enhancing children's intellectual disability
- To examine the challenges faced by public sector institutions to cope with the issue of children's intellectual disability

### Material and Method

#### Participants

The population of this study included different managers (service providers), including social welfare officers, coordinators, psychologists, psychiatrists, and physiotherapists at two major centers in the district of Lahore. The managers were incorporated in the study to investigate their viewpoints regarding the services being provided to children with intellectual disabilities. The information for this research was obtained through in-depth interviews with managers at two centers for children with intellectual disabilities in Lahore.

#### Techniques

The purposeful sampling technique was used in selecting the participants with an in-depth understanding of the relevancy of the research. The selection of purposive sampling techniques includes the important features of the sampled population but does not focus on statistical representations (Ritchie et al., 2014).

The bio-ecological model of human development has been used as a framework for this study (Bronfenbrenner et al., 1998). The biosystem influences the development of a child, for example, their cognitive ability, language, motor psycho-social, and specified functions of day-to-day living, by different adjoining processes. Moreover, being influenced by micro-systems such as the organization and services of educational settings are also considered as some other surrounding systems like meso-system, ecosystem, macro-system, and cronosystem. The institutions are considered micro setting that influences the development of a child in some way and are part of an enclosed bio-ecological system.

#### Procedures

A comprehensive interview guide was developed before approaching the participants. Important themes centered on the past and current developments in service delivery in the center for children with intellectual disabilities were added to the interview guide. A total of 9 participants were approached and interviewed. Prior to the data collection, permission to conduct the interview at centers was sought through letters and personal contact with personnel of the centers. Although permission was granted by the head, all the participants' consents were obtained before conducting the actual interview with them. Pseudonyms were therefore used to present the participants in the study.

#### Data Analysis

The recorded interviews were transcribed and organized for thematic analysis. The meanings in the data were captured and summarized using codes. In the first stage (open coding), codes with similar meanings in the data were clustered into themes, and in the second stage (axial coding), major categories of themes were used.

#### Major Findings

The findings were demonstrated as per the themes acquired from the interviews and demonstrated together to give an extensive picture of the services being provided to children with intellectual disabilities. Where required, the real words of participants were quoted as well.

## Objectives and policy

The participants of the study viewed the objectives of the centers as an integral part of the delivery of services for children with intellectual disabilities. The participants from centers A and B both discussed the objectives of the institutions in brief. One of the participants from center A explained their mandated objectives as assessment, advice, guidance, daycare facilities, boarding facilities, treatment, training and rehabilitation of children, psychiatric treatment, and counseling services for the family. One of the participants from Center B explained their mandated objective as provision of healthy and happy environment to children, organizing educational programs, promoting vocational and occupational training, counseling sessions of parents and children, and providing referral services. One of the participants from Center A pointed that:

*“Even though it is a part of our mandate, we don’t have a doctor in our center. And for the purpose of treating any medical condition, we have to take the child to some clinic or hospital, depending upon the nature of their illness.”*

All the participants from center A were also of the view that the center was unable to perform the mandated objectives. *“Although a lot of objectives were being achieved, still some of them were unaddressed due to lack of support and inadequate resources.”*

Another participant from center A pointed out: *“If there is a proper mechanism and check & balance approach in the center, the mandated objectives can be achieved.”*

This point meets up with the data in the literature specifying that to make a program or policy successful, monitoring and evaluation will prove to be a positive step in achieving the goals (Collins et al., 2017).

## Special Education Instructor

The participants consider the accessibility of special education teachers as a significant part of the education service provision for children with intellectual disabilities in Lahore. The participants from Center B pointed out that their center has an approach to special education instructors. The participant from Center B explained that instructors have the knowledge and the experience needed to assist in learning and handling the children. The participants from center A reported a lack of special education instructors in their respective centers, and the duty of a special education instructor is being performed by the different managers of the center collectively. Participant from center B pointed that:

*“Special education instructor has been a priority of the center. Apart from hiring instructors with degrees in special education, the center is providing special education trainings and workshops to the instructors who are handling or working with children with intellectual disabilities.”*

Special education instructors should be experts. They must possess a fine understanding of special education and have fine interactivity expertise in order to deal with children. The content of the work while dealing with children with intellectual disabilities can be categorized into teaching, instructing, coordination, and supervision.

## Services

The participants from centers A and B both explained the services being provided to the children with intellectual disabilities. The combined services from both the centers include provision of food, clothing, shelter, vocational services, occupational services, rehabilitation services, different treatments, and trainings. One of the participants from Center A pointed out: *“We provide the children with three meals a day, including two tea/snack breaks at 11:00 am and 5:00 pm”.*

Another participant from Center A added: *“3 dresses every 6 months are being provided to the children, according to the weather demands”.* One of the participants from Center B stated: *“Our center emphasizes work-related training to children according to their mental and physical age to put them in a better position to earn a living when they leave the center.”*



The participants from both centers indicated that these services can be made more useful with the social support of family and financial resources from the government. The participants suggested that centers for children with intellectual disabilities should be promoted as they are working for the well-being of children. The above findings revealed that established centers for children with intellectual disabilities are working within their capacities, but they need support and encouragement from the government to improve these services and provide a beneficial environment to the children with intellectual disability and their parents as well.

## Discussion and Conclusion

This research was conducted to investigate and recognize the significance of centers in service provision for children with intellectual disabilities in Lahore. The study sought the views of participants from two centers for children with intellectual disabilities. The study participants are of the opinion that these centers are providing services more than their resources and capacities, but a lot of things need to be addressed. The findings of the study revealed a lack of proper mechanisms in the institutions, check and balance, professional practitioners, trainings and guidelines, inappropriate infrastructure, and limited facilitation and participation in sports and extracurricular activities. It is concluded that children with disabilities are suffering, humiliated, and neglected in society; however, the institutions that are supposed to protect them from all of these harms are also lacking the required standards, policies, and expertise to deal with this sensitized population.

The study excluded the experiences of children and their parents. This limitation in the study information made it impractical to differentiate the situation of services being provided. Although it is significant to feature the viewpoints of managers inside the centers, a comparative technique may have enhanced the research. Nevertheless, the results have given beneficial details that could enlighten policy-makers in the designing of needs and services for children with intellectual disabilities in Lahore. There is a requirement for further studies that investigate and give comprehension of how to modify centers and assist the service delivery plan in Lahore. It is recommended that there should be a review and enforcement of the policies, awareness of communities and stakeholders, and implementation of different programs, including rehabilitation, community mobilization, and advocacy for children with disabilities.

## Recommendations

Children with disabilities are suffering, humiliated, and neglected in society; however, the institutions that are supposed to protect them from all of these harms are also lacking the required standards, policies, and expertise to deal with this sensitive population. It is recommended that there should be a review and enforcement of the policies, awareness of communities and stakeholders, and implementation of different programs, including rehabilitation, community mobilization, and defense for children with disabilities.

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