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RESEARCH PAPER

Enhancing Early Intervention for Deaf Children: A Study on Individualized Family Service Plans (IFSPs) in Punjab, Pakistan

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ABSTRACT

This qualitative descriptive study delves into the awareness and systematic implementation challenges surrounding Individualized Family Service Plans (IFSPs) for deaf children in Pakistan. Through semi-structured interviews with parents, professionals, and NGO representatives, the research highlights a pervasive lack of awareness among stakeholders, limited access to early screenings, and an absence of formal institutes providing comprehensive support. Thematic analysis of the interview data reveals recurring themes such as limited systematic mechanisms and efforts, limited involvement of professionals in IFSPs, fragmented services and lack of coordination, and barriers to accessibility. The findings underscore the urgency of comprehensive awareness campaigns, systematic screenings, interdisciplinary training, and advocacy for government involvement to address the multifaceted barriers to effective IFSP implementation.

KEYWORDS Awareness, Deaf Children, Early Intervention, Individualized Family Service Plans (IFSPs), Systematic Implementation

Introduction

The realm of early intervention services for deaf children is a vital domain that bears profound implications for their lifelong development and well-being. This study embarks on an exploration of the awareness levels, perceptions, and systemic implementation challenges surrounding Individualized Family Service Plans (IFSPs) in Pakistan. The rationale behind this investigation is rooted in the fundamental need to bridge the existing gaps in knowledge, understanding, and access to IFSPs, which are integral to fostering the holistic development of deaf children. The significance of this study lies in its potential to unearth critical insights that can catalyze positive change by advocating for informed policies, interdisciplinary collaboration, and comprehensive awareness campaigns. By shedding light on the existing challenges and proposing concrete recommendations, this research endeavors to enhance the support system for deaf children and their families, ultimately paving the way for a more inclusive and promising future in Pakistan.

Literature Review

Early intervention encompasses a range of services aimed at bolstering parental capacity to support the development of infants and young children between the ages of 0 to 3 years who exhibit developmental delays or are at risk of such delays. These services are characterized by their collaborative, family-centered approach, designed to address both the child's and the family's needs. At the heart of early intervention services lies the

Individualized Family Services Plan (IFSP), a comprehensive document that guides the systematic provision of early intervention services. IFSPs serve as a roadmap, outlining families' concerns, strengths, needs, and intervention priorities to guide the implementation and evaluation of appropriate services and supports for the child and their family (Aytekin, 2016; Gatmaitan & Brown, 2016).

In 1986, significant legislative reforms were enacted to facilitate the provision of early intervention services catering to infants and children aged 0-3 years, particularly those either diagnosed with developmental disabilities or deemed at risk of such conditions. This legislative overhaul marked a pivotal moment as these services became a nationally mandated law, now operating under Part C of the Individuals with Disabilities Education Act (IDEA) (Bruder et al., 2013; Casanueva et al., 2008; Hebbeler et al., 2012; Jung et al., 2015). Part C of IDEA aims to optimize the developmental trajectories of infants and young children while mitigating the adverse impacts of disabilities they may face (Casanueva et al., 2008). Emphasizing developmental outcomes over mere education, early intervention services and programs prioritize the holistic development of infants and young children (Shonkoff, 2000). At the core of early intervention practices lies the Individualized Family Service Plan (IFSP), recognized as both the foundational framework and a cornerstone component guiding the delivery of early intervention services (Bruder et al., 2011; Etscheidt, 2006; Ridgley et al., 2011).

The Individualized Family Service Plan (IFSP) serves as a comprehensive roadmap that delineates the concerns, strengths, needs, and intervention priorities of families, aimed at enhancing, implementing, and evaluating early intervention services and supports tailored to the child and their family's circumstances (Etscheidt, 2006; Pizur-Barnekow et al., 2010; Ridgley et al., 2011). This essential document outlines the array of early intervention services in a written format, encompassing evaluations that aim to bolster the child and family's progress (Chiarello et al., 1992; Jung et al., 2015). Notably, the development of an IFSP is mandated to commence within 45 days from the initial referral, ensuring timely access to tailored early intervention services (Ridgley et al., 2011).

The Individualized Family Service Plan (IFSP) emerges as a potent tool for fostering cooperation, communication, and interaction between professionals and families involved in early intervention initiatives (Pizur-Barnekow et al., 2010). To this end, the development of an IFSP is inherently rooted in a collaborative team partnership that actively involves families (Campbell et al., 1992). Comprising a blend of family members and professionals, the IFSP team engages in a multidisciplinary or transdisciplinary evaluation process (West Virginia Early Childhood Transition Steering Committee, 2008). Central to this approach is the recognition of families' voices and needs, affording them ample opportunities to articulate their concerns and priorities (Chiarello et al., 1992). In essence, all decisions pertaining to early intervention services, including the selection of appropriate strategies, anticipated outcomes, and functional goals, are arrived at through collaborative efforts between families and early intervention professionals.

The family-based approach underpinning IFSPs is guided by core principles that focus on leveraging family strengths, respecting differences and values, enhancing decision-making capacity, fostering collaborative communication, internalizing service approaches, and appreciating informal supports (Bailey et al., 2012).

Early childhood educators bear a profound understanding of their obligations under the Individuals with Disabilities Education Act Part C, which necessitates collaborative engagement with families of young children with disabilities or those at risk of significant developmental delays. Through the utilization of a multidisciplinary approach facilitated by the Individual Family Service Plan (IFSP) process, families and professionals collaborate to discern the requisite services essential for meeting the child's and their family's needs (Brown, 2003). When consensus is achieved among all members of the IFSP team regarding the services and supports to be provided, the process unfolds seamlessly. However, in instances where disagreements surface among providers and/or parents, it becomes imperative for the sake of the child's development that conflicts be swiftly resolved. At times, the resolution of such conflicts necessitates a determination regarding whether the best interests of the child or the preferences of the parent should prevail. Such resolutions are paramount for ensuring the continuity and effectiveness of early intervention efforts (Brown, 2003).

The findings underscored prevalent hurdles, notably scheduling complexities and the logistical challenge of convening all stakeholders. Additionally, the utilization of disparate documentation for goal-setting across programs emerged as a significant obstacle in coordinating services for dually enrolled children and families within frameworks. Recognizing the importance of streamlining processes and minimizing burdens on families, it was emphasized the need to avoid overwhelming families with multiple meetings, personnel, and requirements. To foster more cohesive partnerships and enhance positive outcomes for children and families, it was urged to collaborate closely with their early intervention counterparts. This collaboration should aim to develop coherent and family-friendly policies and practices that promote seamless integration and cooperation among stakeholders (Zhang et al., 2006).

Despite the extensive historical precedence of collaboration across various disciplines including education, health, and social services, challenges to achieving effective teamwork persist, significantly impacting outcomes for children and families within the early intervention (EI) framework. Within the realm of EI, issues such as fragmentation or duplication of services, deficiencies in coordinating the types and frequency of service provision, and inadequate communication and collaboration among team members have been identified as prominent hurdles. These challenges not only impede the delivery of comprehensive and seamless care but also hinder the satisfaction levels of both children and families involved in EI initiatives. As highlighted in the research literature, addressing these obstacles is imperative to enhance the efficacy and impact of teaming practices in EI (Horn & Jones, 2005).

The existing literature underscores the pivotal role of Individualized Family Service Plans (IFSPs) in early intervention practices, serving as a guiding framework for collaborative efforts between professionals and families to address the unique needs of infants and young children with developmental delays or disabilities. Enshrined within legislative mandates such as Part C of the Individuals with Disabilities Education Act (IDEA), IFSPs exemplify a family-centered approach that prioritizes the holistic development and well-being of children and their families. However, despite the recognized importance of IFSPs and the longstanding emphasis on collaboration across various sectors, persistent challenges such as service fragmentation, coordination deficiencies, and communication barriers continue to impede effective teamwork and hinder optimal outcomes in early intervention. Addressing these challenges demands concerted efforts to streamline processes, enhance coordination, and foster greater collaboration among all stakeholders involved in early intervention initiatives. By prioritizing the needs and voices of families, and promoting a culture of partnership and inclusivity, the early intervention community can strive towards realizing its collective goal of empowering children and families to thrive.

Material and Methods

Study Design and Data Collection

This qualitative research study employed a semi-structured interview approach to gather rich and contextual insights from a diverse group of participants. Purposive sampling, a deliberate and non-random sampling technique, was applied within the region of Punjab, Pakistan, to select participants representing various stakeholder groups involved in early intervention services for deaf children. These stakeholders included parents, caregivers, professionals (such as speech therapists, psychologists, special educators, and healthcare providers), and representatives from non-governmental organizations (NGOs) with expertise in disability and special education.

Data Collection Process

Semi-structured interviews were conducted with a total of 89 participants, distributed as follows: 37 parents of deaf children, 40 professionals from different disciplines, and 12 NGO representatives. The interviews were designed to be open-ended, allowing participants to express their perspectives, experiences, and insights regarding Individualized Family Service Plans (IFSPs) for deaf children in Pakistan. The semi-structured nature of the interviews provided flexibility while ensuring that key topics and themes were explored consistently across all interviews.

Data Analysis

Thematic analysis was employed as the primary data analysis approach. Transcriptions of the interviews were meticulously reviewed and coded to identify recurring themes, patterns, and categories. This process involved multiple iterative stages, including data familiarization, initial coding, theme development, and refinement of themes. The analysis aimed to extract meaningful and contextually relevant findings from the qualitative data.

Ethical Considerations

The research adhered to a strict ethical framework to ensure the protection and well-being of participants. Informed consent was obtained from all participants, detailing the purpose of the study, confidentiality measures, and the voluntary nature of participation. Anonymity was maintained, particularly with respect to the NGO representatives, as per ethical considerations.

This methodological approach facilitated the exploration of awareness levels, perceptions, and challenges associated with IFSPs for deaf children in Pakistan, and the use of semi-structured interviews allowed for the collection of nuanced and in-depth insights from a diverse group of stakeholders.

Demographic Information of Participants in the Study

Parents of Deaf Children (N=37):

- **Gender Distribution:** Among the parents of deaf children, 62.2% were mothers, while 37.8% were fathers.

- **Family Structure:** Within this group, 18.9% were single parents, while the majority, accounting for 81.1%, were part of a joint family system.

- **Education Levels:** The educational backgrounds of the parents varied, with 24.3% having primary education, 16.2% having completed elementary education, 24.3% having secondary education, 2.7% identifying as illiterate, 10.8% having post-secondary education, 10.8% holding graduate degrees, and another 10.8% possessing postgraduate qualifications.

- **Parental Deafness:** A notable 8.1% of the parents reported experiencing deafness themselves.

- **Occupational Diversity:** The parents represented diverse occupational sectors, with 16.2% working as government employees, 29.7% in the private sector, 18.9% as business owners, 10.8% as vendors, 13.5% as daily wage earners, and 10.8% being unemployed.

Professionals (N=40):

- **Professional Categories:** Among the professionals involved in the study, each category accounted for 25%, with 10 professionals each being speech therapists, psychologists, special educators, and healthcare providers.

- **Employment Status:** In terms of employment, 52.5% held government positions, 30% were engaged in private clinics or setups while also maintaining government jobs, and 17.5% were exclusively employed in the private sector.

- **Experience Levels:** The professionals brought varying levels of experience to the study, with 12.5% having 0-5 years of experience, 27.5% possessing 6-10 years, 22.5% having 11-15 years, 20% with 16-20 years, and 10% boasting more than 20 years of professional experience.

NGO Representatives (N=12):

- **Areas of Expertise:** Among the representatives from non-governmental organizations (NGOs), 41.7% had expertise in special education, 33.3% were trained in sociology, and 25% had backgrounds in healthcare.

- **Experience within NGOs:** Regarding their experience within NGOs, 33.3% had between 0-5 years of experience, 50% had 6-10 years, and 16.7% had more than 10 years of experience in their respective organizations.

Thematic Analysis

Based on the findings from interviews with parents, professionals, and NGO representatives, several relevant scholarly themes were identified:

Lack of Awareness and Information Gap among Parents

A significant finding is the widespread lack of awareness among parents about Individualized Family Service Plans (IFSPs) for their deaf children. Many parents first heard about IFSPs during the interviews, indicating a substantial information gap within this population (Krishnan & Donaldson, 2013).

Age-Related Interest and Regret among Parents

Parents of deaf children aged 0-3 years expressed a strong interest in learning about IFSPs and availing early intervention opportunities. They recognized the potential benefits of early support for their children.

Parents of children above the age criteria for early intervention expressed regret over missed opportunities during their child's crucial early years when timely intervention could have been most effective.

Government Responsibilities and Reliance on Professionals

Some parents expected the government to take the initiative in reaching out to them and providing services and support for their deaf children. This suggests an expectation that government agencies should play a central role in addressing their children's needs.

Despite some parents being aware of certain services, such as hearing aids and speech therapy, they still perceived these as government responsibilities, leading to a reliance on professionals and potential misunderstandings about their own role in their child's development (Fitzpatrick et al., 2017).

Limited Knowledge of IFSP Purpose and Components

Parents generally lacked understanding regarding the purpose, benefits, and specific components of IFSPs. They expressed uncertainty about how to initiate and pursue these plans and where to seek guidance.

Challenges in Early Detection and Screening

Challenges were identified in the early detection of hearing loss in children. Health professionals often did not provide information about hearing loss during pregnancy or conduct proper screenings after birth, except in cases where deafness was already known to run in the family.

The use of formal screening methods like Otoacoustic Emissions (OAE) or Auditory Brainstem Response (ABR) tests was limited, resulting in missed opportunities for early detection (Jahangir et al., 2023).

Parental Concerns, Fear, and Society's Role

Parents expressed ongoing doubts, fear, and reluctance to accept their child's hearing loss, often due to societal misconceptions and negative attitudes. Some chose not to share their child's hearing loss due to fear of being targeted or pressured by their families.

Stress and societal fear played a significant role in parents' reluctance to vocalize their child's hearing loss and seek help (Wallhagen, 2010).

Limited Systematic Mechanisms and Efforts

Professionals acknowledged the absence of systematic screening and diagnostic systems in healthcare institutes and hospitals, leading to late detection and delayed interventions.

While there was a desire for systematic mechanisms, individual efforts from government, parents, and professionals were perceived to be inadequate (Olusanya et al., 2007).

Limited Involvement of Professionals in IFSPs

Professionals reported that they were not commonly involved in formal IFSPs but were pursued for their services, often after the loss of critical early intervention years.

A lack of awareness among parents about their rights and responsibilities was noted by professionals.

NGOs Support and Focus on Basic Needs

NGO representatives indicated that their organizations primarily focused on addressing basic needs and assistive devices for special needs students, rather than specific IFSPs.

There was limited attention to linguistic, cultural, and educational circumstances, and collaboration among institutions was emphasized.

Lack of Knowledge about Policies and Mechanisms

Stakeholders across the board, including parents, professionals, and NGO representatives, lacked sufficient knowledge about national and international legislations and policies related to IFSPs.

A notable absence of a systematic mechanism for IFSPs from planning to implementation was observed throughout the process (Sambah et al., 2020).

Fragmented Services and Lack of Coordination

The absence of a centralized institute or service provider for IFSPs highlights the fragmented nature of early intervention services for deaf children in Pakistan. This fragmentation can lead to inefficiencies, missed opportunities, and challenges in coordinating care.

Barriers to Accessibility

Without a single institute offering comprehensive services, parents may face difficulties in accessing the full spectrum of support and interventions needed for their deaf children. This can include delays in receiving services and logistical challenges in navigating multiple service providers (Majrooh et al., 2013).

Need for Interdisciplinary Collaboration

Successful IFSPs often require input and services from multiple disciplines, including speech therapy, audiology, special education, and more. The absence of an institute that brings these disciplines together underscores the need for greater interdisciplinary collaboration (White et al., 2010).

Capacity Building

The absence of a comprehensive institute indicates a potential need for capacity building within the existing healthcare and education systems to better support deaf children and their families. This includes training professionals in various fields to provide early intervention services (Boavida et al., 2014).

Conclusion

In conclusion, this study sheds light on the critical challenges and gaps in the awareness and implementation of Individualized Family Service Plans (IFSPs) for deaf children in Pakistan. The findings underscore a pervasive lack of awareness among parents, professionals, and NGO representatives regarding the purpose, benefits, and components of IFSPs. Moreover, the absence of a formal institute offering comprehensive early intervention services further complicates the landscape of support for deaf children. Parents expressed interest in IFSPs, particularly when their children were within the crucial 0-3 year age range, emphasizing the importance of early interventions. However, those with older deaf children expressed regret over missed opportunities. Systematic screening and diagnostic mechanisms were found to be lacking, leading to late detection and delayed interventions. This study highlights the urgent need for comprehensive awareness campaigns, interdisciplinary collaboration, policy advocacy, and the establishment of formal institutes to provide holistic early intervention services, ultimately ensuring a brighter future for deaf children and their families in Pakistan.

Recommendations

Comprehensive Awareness and Advocacy

Develop and implement comprehensive awareness campaigns targeting parents, professionals, and the general public to increase understanding of IFSPs and the benefits of early intervention for deaf children. Advocate for government involvement and policy support to promote IFSP awareness and implementation.

Early Screening and Intervention Programs

Establish systematic and routine hearing screening programs for newborns in healthcare institutions, utilizing formal methods like Otoacoustic Emissions (OAE) or Auditory Brainstem Response (ABR) tests. Promote regularized screenings and diagnostic systems within healthcare and educational institutions to ensure early identification and intervention for deaf children.

Professional Development and Interdisciplinary Collaboration

Provide interdisciplinary training and capacity-building programs for professionals involved in early intervention, emphasizing collaboration across various disciplines. Encourage non-governmental organizations (NGOs) to focus their efforts on the development and implementation of IFSPs, enhancing the expertise and support available to deaf children and their families.

Institutional Support and Resource Allocation

Advocate for the establishment of formal institutes or centers that can offer comprehensive early intervention services, including IFSPs, as a one-stop solution for deaf children and their families. Facilitate partnerships between public and private sectors to enhance the accessibility and quality of early intervention services, ensuring that no deaf child is left behind.

Policy Development and Implementation

Strengthen the policy framework by advocating for the development and enforcement of policies and legislations that support the rights and needs of deaf children, including access to IFSPs. Empower parents with knowledge about their rights and responsibilities in their child's development and early intervention process, fostering greater parental engagement and advocacy within the system.

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