TAMSAAL
ISSN Print: 3007-5939
ISSN Online: 3007-5947
Volume 4, Number 8, 2026, Pages 260 – 298
Journal Home Page
https://tamsaal.pk/index.php/tamsaal/index

Parental Experiences and Factors Influencing Access to Education and Rehabilitation Services for Children with Intellectual and Developmental Disabilities in Punjab, Pakistan: A Sequential Exploratory Mixed-Methods Study

Abeer Fatima[1], Iqra Ashraf[2], Muhammad Shahid Shah[3], Muhammad Kashif[4], Dr. Akram Maqbool[5]

[1]*PhD Scholar, Department of SLP, Division of Education, Lincoln College, University of Malaysia, Email: mrsabeersajjad@gmail.com*
[2]*PhD Special Education, Special Education Teacher, Department of Special Education, Punjab, Pakistan, Email: iqraashraf118@gmail.com*
[3]*PhD Scholar (Special Education) Principal Rising Sun Institute for Special Children Lahore Punjab Pakistan, Member Planning Board RIEP, Ghazali Education Foundation Pakistan, Visiting Faculty Member, Special Education department, UO, Punjab Pakistan, Visiting Faculty Member School of Psychology, MUL, Lahore, Punjab, Pakistan Email: shah4633@gmail.com*
[4]*Special Education Teacher, Department of Special Education, Government of Punjab, Pakistan, Email:mrsabeersajjad@gmail.com*
[5]*PhD Special Education, Child Welfare Center, University of The Punjab, Pakistan, Email: akrammaqbool77@gmail.com*

ARTICLE INFO

Article History:

Received:	*July*	*10, 2026*
Revised:	*August*	*09, 2026*
Accepted:	*August*	*14, 2026*
Available Online:	*August*	*22, 2026*

Keywords:

Intellectual and developmental disabilities; education services; rehabilitation services; parental experiences; access barriers; mixed-methods research; Punjab; Pakistan

ABSTRACT

Background: *Children with intellectual and developmental disabilities (IDDs) require sustained access to appropriate education and rehabilitation services to support their development, participation, and quality of life. However, families in low- and middle-income settings, including Punjab, Pakistan, often experience complex and interconnected barriers that limit their ability to obtain and maintain necessary support. This study aimed to explore parents' experiences of accessing education and rehabilitation services, develop a contextually grounded measurement tool, and examine the underlying dimensions and relative prominence of access barriers.*

Methods: *A sequential exploratory mixed-methods design was employed. In the qualitative phase, 17 parents and primary caregivers of children with IDDs were purposively recruited and interviewed using semi-structured interviews. Data were analyzed through reflexive thematic analysis. Findings from the qualitative phase guided the development of a 33-item questionnaire, which underwent expert evaluation, translation, and pilot testing with 30 parents. In the quantitative phase, the questionnaire was administered to 210 parents and primary caregivers recruited from 11 districts across five divisions of Punjab, Pakistan. Quantitative data were analyzed using descriptive statistics and exploratory factor analysis (EFA).*

Results: *Qualitative analysis generated five themes: navigating a fragmented*

Corresponding Author:
Abeer Fatima
Email:
mrsabeersajjad@gmail.com

DOI: *https://doi.org/10.59075/tamsaal.v4i8.155*

service pathway; financial and geographical barriers; availability and quality of education and rehabilitation services; social and family influences; and parental advocacy, facilitators, and unmet needs. The developed questionnaire demonstrated strong pilot reliability (Cronbach's α = .894). Exploratory factor analysis using principal axis factoring with Promax rotation supported a five-factor structure, including service navigation and coordination, financial and geographical barriers, availability and quality of services, social and family barriers, and system responsiveness and unmet service needs. The data demonstrated suitability for factor analysis (KMO = .89; Bartlett's test of sphericity: $\chi^2 = 4268.54$, df = 528, $p < .001$). The five-factor solution explained 62.4% of total variance, and the overall scale demonstrated excellent internal consistency (Cronbach's α = .91). Financial and geographical barriers represented the highest-rated domain (M = 4.09), followed by system responsiveness and unmet service needs (M = 4.08), service navigation and coordination (M = 3.99), availability and quality of services (M = 3.98), and social and family barriers (M = 3.53).

Conclusion: *Access to education and rehabilitation services for children with IDDs in Punjab is a multidimensional challenge influenced by affordability, geographical accessibility, service availability, professional capacity, coordination mechanisms, and system responsiveness. Addressing these barriers requires strengthening district-level services, expanding trained professional capacity, improving referral and coordination systems, providing financial support, and adopting family-centered approaches to ensure equitable and sustainable access for children with IDDs and their families.*

Introduction

Intellectual and developmental disabilities (IDDs) constitute an important global public health, educational, and social inclusion concern because they can affect cognition, communication, adaptive functioning, learning, behavior, and participation across the life course. Globally, nearly 240 million children are estimated to live with some form of disability, with South Asia accounting for approximately 64.4 million, the largest regional number reported by UNICEF (United Nations Children's Fund [UNICEF], 2021). Developmental disabilities are particularly consequential when appropriate support is delayed, as difficulties emerging during childhood may influence educational attainment, social participation, independence, and later quality of life. Global evidence further demonstrates that the burden of developmental disabilities is disproportionately concentrated in low- and middle-income countries (LMICs), where systems for early identification, intervention, education, and continuing support are often least developed (Global Research on Developmental Disabilities Collaborators, 2018). Despite increasing international attention, children with developmental disabilities continue to experience health inequalities, stigma, exclusion, and inadequate inclusion in service planning and provision (World Health Organization [WHO] & UNICEF, 2023).

Access to appropriate education and rehabilitation is fundamental to improving functioning, participation, learning, and social inclusion among children with IDDs. Inclusive and responsive education systems are expected not only to enable school entry but also to support meaningful

participation, progression, and learning. However, recent evidence from the Asia-Pacific region indicates that children with functional difficulties remain less likely to participate successfully in education and that socioeconomic disadvantage can further intensify educational inequalities (UNICEF, 2023). Rehabilitation is similarly essential because it can optimize functioning and enable greater independence and participation in education, family life, and the community. Yet rehabilitation remains insufficiently integrated into health and social systems in many LMICs (WHO & UNICEF, 2023). A recent systematic review identified shortages of resources and trained personnel, inadequate financing, weak policy implementation, limited community-based rehabilitation, and sociocultural factors as continuing obstacles to equitable rehabilitation access in LMICs (Htwe et al., 2024).

For children with IDDs, accessing services is rarely a single event; rather, it involves a continuing process of recognizing developmental concerns, obtaining assessment or diagnosis, identifying appropriate institutions, arranging school placement or therapy, financing services, traveling to facilities, and maintaining long-term engagement. Parents consequently function as central navigators and advocates within education, health, and rehabilitation systems. Evidence from LMICs shows that financial constraints, geographical inaccessibility, inadequate professional resources, limited awareness, and sociocultural beliefs frequently restrict children's use of health and rehabilitation services (Mwangi et al., 2022). Parents may simultaneously experience stigma associated with their child's disability, which can influence social participation, help-seeking, and interactions with formal support systems (Mitter et al., 2019). Recent qualitative evidence from Pakistan also highlights the importance of family and social support and demonstrates that stigma, discrimination, inadequate support, and fragmented assistance can intensify the demands experienced by families raising children with intellectual disabilities (Lakhani et al., 2024).

These challenges are particularly relevant in Pakistan, where children with disabilities continue to experience inequalities in educational participation. Research conducted in Punjab has demonstrated that geographical distance and dependence on segregated special education institutions can create significant accessibility problems; Hameed and Manzoor (2016), for example, reported considerable travel distances to special schools despite the availability of government incentives and transportation assistance. Household-based evidence has subsequently shown that children with moderate-to-severe functional difficulties are less likely to attend school and tend to demonstrate poorer basic learning outcomes than children without identified functional difficulties (Singal et al., 2020). Similarly, research focusing specifically on rural Punjab found that although some children with disabilities were enrolled in mainstream government and private schools, their probability of school participation and their literacy and numeracy outcomes remained comparatively disadvantaged (Malik et al., 2022).

Difficulties are not confined to educational access; Pakistani families also encounter challenges in locating and sustaining appropriate therapeutic and developmental support. Earlier qualitative work involving Pakistani parents of children with autism identified limited awareness among families and frontline providers, delayed recognition, stigma, and a scarcity of specialist services, particularly outside major urban centers (Minhas et al., 2015). Within Punjab, parents of autistic children have reported substantial social, psychological, economic, and educational concerns, indicating that the effects of inadequate support extend beyond the child to the wider family

system (Ghafoor, 2019). More recent Pakistani research among families of children with intellectual disabilities similarly emphasizes the need for coordinated formal and informal support and stronger government-level services to improve family and child outcomes (Lakhani et al., 2024). Thus, families' ability to access appropriate services may depend not merely on service existence but on whether services are affordable, geographically reachable, culturally acceptable, sufficiently specialized, and responsive to family needs.

Access is therefore best understood as a multidimensional phenomenon shaped by interacting child-, family-, community-, and service-level determinants. The nature and severity of disability may influence school enrolment; recent Pakistani evidence indicates that children with more severe disabilities face greater educational exclusion than those with milder difficulties (Upadhayay & Kakar, 2024). At the same time, financial resources, transportation, geographical location, professional availability, social support, awareness, and administrative or organizational arrangements can facilitate or constrain families' ability to obtain rehabilitation (Htwe et al., 2024). These factors may be especially important in Punjab because of its combination of large urban centers, rural communities, socioeconomic diversity, and uneven distribution of specialized services. International guidance consequently emphasizes the need for coordinated, family-centered, multisectoral systems linking health, rehabilitation, education, and community support rather than addressing developmental disability through isolated services (WHO & UNICEF, 2023).

Despite this emerging evidence, important knowledge gaps remain. Much of the available Pakistani literature has examined either educational participation, particular disability categories such as autism, or specific aspects of family experience; several studies have also relied on relatively small or institution-based samples (Ghafoor, 2019; Lakhani et al., 2024). Consequently, greater understanding is needed of how parents of children with different IDDs navigate both education and rehabilitation services, which barriers and facilitators they encounter, and how these contextually grounded experiences can be translated into measurable dimensions of service access. A sequential exploratory mixed-methods design is particularly appropriate because an initial qualitative phase can generate locally grounded understanding, while a subsequent quantitative phase can evaluate the structure and internal consistency of the resulting instrument and examine the relative prominence of the identified barriers in a larger sample (Creswell & Plano Clark, 2018). Accordingly, the present study aimed to integrate parents' experiences with quantitative evidence to generate a more comprehensive account of access to education and rehabilitation services for children with IDDs in Punjab, Pakistan.

Literature Review

Access to Services for Children with Intellectual and Developmental Disabilities

Access to education and rehabilitation for children with intellectual and developmental disabilities (IDDs) is increasingly understood as a multidimensional process rather than simply the physical availability of a school, clinic, or rehabilitation center. Families must first recognize a developmental concern, obtain an appropriate assessment or diagnosis, identify suitable services, successfully enter those services, and then maintain continued participation. Sapiets et al. (2021) conceptualized access to early intervention as a sequence involving recognition of

need, identification or diagnosis, and eventual provision or receipt of intervention, emphasizing that barriers may emerge at every stage. Similarly, evidence from rehabilitation research indicates that the existence of services does not necessarily translate into meaningful utilization when financial, geographic, organizational, and informational obstacles remain (Bright et al., 2018). Therefore, effective access should incorporate availability, affordability, accessibility, acceptability, continuity, and the extent to which services respond to children's actual functional needs (Adugna et al., 2020).

Parents as Service Navigators and Advocates

Parents occupy a particularly important position within service systems because children with developmental disabilities often depend on them to recognize difficulties, seek professional advice, arrange assessments, make educational decisions, transport children to services, and coordinate interventions delivered by different professionals. A systematic review by Acar et al. (2021) demonstrated that parental involvement is central to early intervention and special education, although mothers remain disproportionately represented in caregiving and service-related responsibilities. In LMIC settings, these responsibilities may become more demanding because formal services are limited and families frequently assume roles that might otherwise be undertaken by professionals or coordinated care systems. Ademosu et al. (2021) found that caregivers of children with neurodevelopmental or mental health conditions in LMICs commonly experienced financial hardship, psychological distress, reduced quality of life, and disruption to family functioning while simultaneously managing their children's support needs. Recent evidence further suggests that caregiver groups and peer-support approaches can reduce isolation and strengthen parents' knowledge and capacity to support their children (He et al., 2024).

Parental navigation is influenced not only by the availability of information but also by the quality of parents' interactions with institutions and professionals. Families may have difficulty understanding referral systems, eligibility requirements, treatment choices, school admission procedures, or the roles of different specialists. Sapiets et al. (2021) identified communication between families and professionals, knowledge of services, previous experiences with providers, and responsiveness of systems as important modifiers of access. At the same time, cultural expectations can influence how parents understand developmental difficulties and the extent to which they become involved in intervention planning; Acar et al. (2021) emphasized that parental involvement cannot be separated from cultural and social context. Consequently, family-centered services require parents to be regarded as active partners in assessment, educational decision-making, rehabilitation planning, and evaluation rather than passive recipients of professional recommendations (He et al., 2024).

Educational Access and Inclusion

Evidence across LMICs consistently demonstrates a disability-related disadvantage in school participation. Using nationally representative data from 15 low- and middle-income countries, Mizunoya et al. (2018) found a consistent and statistically significant disability gap in both primary and secondary school attendance, indicating that socioeconomic characteristics alone did not fully explain the exclusion experienced by children with disabilities. This distinction is

important because improving general school availability may therefore be insufficient unless disability-specific obstacles are addressed. In Pakistan, Virani and Ali (2022) identified inadequate understanding of inclusive education, insufficient teacher preparation, problematic attitudes, limited institutional support, and weaknesses in parent-school collaboration as barriers to effective inclusion. A systematic review focusing on Pakistan similarly concluded that gaps between policy commitments and implementation, limited professional development, insufficient institutional preparedness, and poor collaboration among stakeholders continue to hinder meaningful inclusive education (Kamran & Bano, 2025).

For parents of children with IDDs, educational access may be particularly complicated because school enrolment alone does not guarantee meaningful inclusion. Children may require individualized instructional strategies, communication support, behavioral assistance, accessible learning materials, or collaboration between teachers and rehabilitation professionals. Pakistani evidence suggests that successful inclusion requires a supportive school environment together with competent teachers and active relationships between parents and educational institutions (Virani & Ali, 2022). The broader literature also indicates that disability-related gaps remain even after socioeconomic differences are considered, suggesting that structural and attitudinal mechanisms within educational systems independently contribute to exclusion (Mizunoya et al., 2018). These findings are reinforced by the review of Kamran and Bano (2025), which identified inadequate implementation of inclusive policies and insufficiently prepared educational institutions as persistent national challenges. Thus, examining access requires attention not merely to whether children enter school, but also whether appropriate support is available and sustainable.

Access to Rehabilitation and Early Intervention

Rehabilitation and developmental intervention present a parallel set of access challenges. A systematic review of 77 studies from LMICs found that access to rehabilitation was generally low and highly variable, while inconsistent measurement of rehabilitation coverage made the true magnitude of unmet need difficult to determine (Bright et al., 2018). For children with developmental disabilities, early access is particularly important because timely intervention can support communication, adaptive functioning, participation, and acquisition of developmental skills. Smythe et al. (2021) argued that early intervention remains insufficiently prioritized in LMICs despite its potential to improve developmental outcomes and strengthen families' ability to support children's participation. Access is further complicated by shortages of qualified professionals, inadequate referral pathways, limited equipment, transportation problems, and services concentrated in urban settings, patterns that have also been documented across resource-constrained health systems (Adugna et al., 2020).

These barriers often interact rather than occurring independently. Families may technically identify an appropriate rehabilitation service yet remain unable to use it regularly because of transportation expenses, repeated therapy fees, lost working hours, distance, or the need to care for other children. The economic dimension is particularly important because disability and poverty frequently reinforce one another; Banks et al. (2017), in a systematic review of 150 studies from LMICs, found strong evidence of a positive relationship between disability and economic poverty. Financial disadvantage can consequently reduce families' capacity to

purchase private therapy, transportation, assistive devices, or supplementary education. Geographic barriers further compound these inequalities because rehabilitation professionals and specialist facilities are often concentrated in larger cities, requiring rural families to bear disproportionate travel costs and time commitments (Bright et al., 2018). These findings support an examination of socioeconomic status and place of residence as potential determinants of service access rather than treating them simply as background demographic variables (Sapiets et al., 2021).

Social, Cultural, and Service-Level Barriers

Social beliefs and community responses can also influence when and where families seek support. Ademosu et al. (2021) found that caregivers' explanations of neurodevelopmental conditions in LMICs frequently incorporated biomedical as well as cultural, traditional, or spiritual understandings, and these interpretations affected subsequent help-seeking. In a scoping review of children with disabilities in resource-constrained countries, Adugna et al. (2020) identified stigma, negative attitudes, inadequate disability awareness, cultural beliefs, poor transportation, and lack of appropriately trained professionals as recurring barriers. Importantly, stigma may operate at multiple levels: parents can encounter negative reactions within extended families and communities while also experiencing discouraging interactions with education and healthcare providers. Caregiver-support interventions may partly counter these difficulties by providing reliable information, practical skills, social connection, and opportunities for parents to learn from families facing similar challenges (He et al., 2024).

Facilitators and Family-Centered Models of Service Delivery

Research from Pakistan also demonstrates that alternative family-centered and community-based models may help overcome severe shortages of specialized services. Hamdani et al. (2015) developed a service-delivery model in rural Pakistan in which trained family volunteers supported families of children with developmental disorders, demonstrating the feasibility of combining task sharing, family networks, community support, and technology-assisted supervision. Similarly, the Parent-mediated Autism Social Communication intervention tested in Pakistan and India showed that an intervention delivered by non-specialist workers could improve important aspects of parent-child interaction, demonstrating the potential value of culturally adapted and parent-mediated approaches in settings with limited specialist provision (Rahman et al., 2016). Subsequent work in rural Pakistan adapted the WHO Parents Skills Training programme for delivery by trained family volunteers, further illustrating how locally available human resources can potentially increase intervention reach (Hamdani et al., 2017).

Evidence from the wider South Asian region strengthens the rationale for treating parents as important partners in service provision. Koly et al. (2021) systematically reviewed parent-mediated interventions for children and adolescents with neurodevelopmental disorders in South Asia and identified improvements across parental knowledge, parent-child interaction, communication, social skills, and several developmental outcomes. However, the review also highlighted the need for greater contextual adaptation and stronger evidence across different South Asian settings and diagnostic groups. Such models should not be interpreted as a substitute for governments providing professional education and rehabilitation services; rather, they

demonstrate that parental knowledge, peer networks, community involvement, and accessible non-specialist support can function as important facilitators where specialist systems are limited (Hamdani et al., 2015). Sustainable access is therefore likely to depend on a combination of formal professional services and family-centered, community-linked approaches (Koly et al., 2021).

Research Gap

Overall, the literature suggests that access to education and rehabilitation for children with IDDs is shaped by interacting child-, family-, socioeconomic-, geographic-, cultural-, and service-level factors. International studies provide strong evidence concerning rehabilitation shortages, educational exclusion, poverty, parental burden, and the role of family-centered interventions, while Pakistani research demonstrates important challenges related to inclusive education and the feasibility of parent-mediated service models (Banks et al., 2017; Koly et al., 2021). Nevertheless, important limitations remain. Much of the available literature examines education and rehabilitation separately, concentrates on a single disability such as autism, evaluates a particular intervention, or recruits families already connected with institutions. Pakistani evidence on inclusive education also indicates persistent implementation challenges but does not comprehensively explain how families navigate multiple educational and rehabilitation systems over time (Kamran & Bano, 2025). Consequently, relatively little is known about how parents of children with diverse IDDs in Punjab experience the complete pathway of seeking, obtaining, maintaining, or failing to obtain required services. A sequential exploratory mixed-methods study is therefore warranted to first identify parents' context-specific experiences, then develop and evaluate a questionnaire grounded in those experiences, and finally quantify the relative prominence of the resulting access barriers in a larger sample.

Statement of the Problem

Children with intellectual and developmental disabilities (IDDs) in Punjab, Pakistan, continue to experience considerable difficulties in obtaining appropriate educational and rehabilitation services. Evidence from Punjab indicates that geographical distance, limited institutional capacity, inadequate infrastructure, and restricted availability of specialized services contribute to unequal educational access for children with disabilities (Hameed & Manzoor, 2016). Household-level evidence from rural Punjab further shows that children with disabilities are less likely to attend school than their peers without disabilities and, even when enrolled, experience poorer learning outcomes (Malik et al., 2022). Similar problems are evident in accessing therapeutic and rehabilitation-related support. In South Punjab, parents of children with autism have reported barriers related to limited awareness, inadequate availability of healthcare facilities, affordability, and difficulties in reaching appropriate services (Haider et al., 2024). However, existing research in Punjab has largely examined education, healthcare, particular disability groups, or specific services separately. There remains limited evidence explaining how parents of children with diverse IDDs navigate both education and rehabilitation services and how these experiences can be translated into contextually valid dimensions of access. Therefore, a sequential exploratory mixed-methods study was undertaken to explore parents' experiences, develop and psychometrically examine a contextually grounded questionnaire, and quantify the relative prominence of the barriers identified across a larger sample in Punjab.

Research Objectives

1. To explore parents' experiences of accessing education and rehabilitation services for children with intellectual and developmental disabilities in Punjab, Pakistan.

2. To identify the key barriers and facilitators perceived by parents when seeking and maintaining education and rehabilitation services for their children.

3. To develop and evaluate the content validity, factor structure, and internal consistency of a contextually grounded questionnaire derived from the qualitative findings.

4. To quantify and compare the relative prominence of the identified barriers to education and rehabilitation services in a larger sample of parents and primary caregivers.

Research Questions

1. How do parents of children with intellectual and developmental disabilities experience the process of accessing education and rehabilitation services in Punjab, Pakistan?

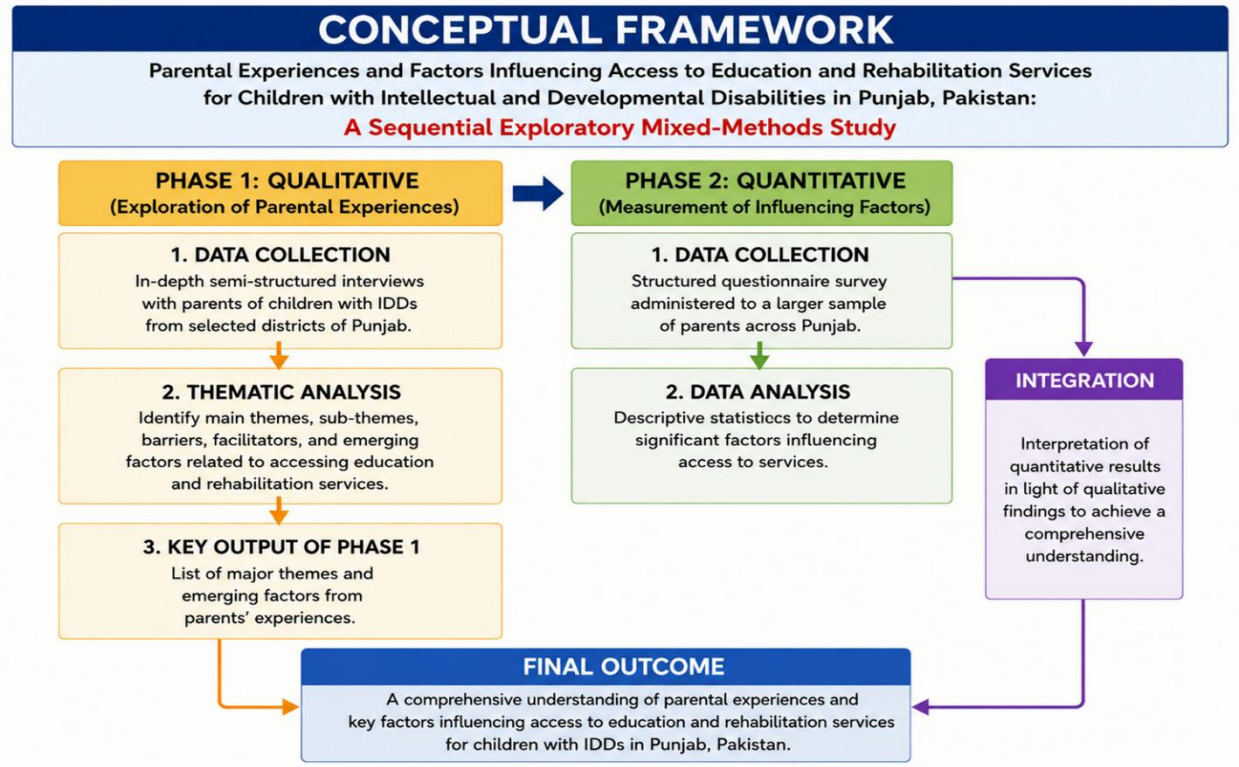
2. What barriers and facilitators do parents perceive when seeking and maintaining education and rehabilitation services for their children?

3. What content-valid factor structure and level of internal consistency does the questionnaire developed from the qualitative findings demonstrate?

4. Which identified barriers are most and least prominent among the larger quantitative sample of parents and primary caregivers?

Theoretical Framework

This study was guided by the Andersen Behavioral Model of Service Use, which was adapted to explain access to education and rehabilitation services for children with intellectual and developmental disabilities. The model proposed that service utilization was influenced by predisposing, enabling, need, and contextual factors (Lederle et al., 2021; Khraisat & Al-Bashtawy, 2023). In this study, predisposing factors included parental education, knowledge, beliefs, and previous service experiences. Enabling factors included family income, transportation, social support, distance, affordability, and availability of services. Need factors included the child's type and severity of disability, functional limitations, and perceived need for support. Service-related factors included the availability of trained professionals, waiting time, institutional procedures, service quality, and coordination between education and rehabilitation providers. The framework was considered appropriate for the sequential exploratory mixed-methods design because the qualitative findings first identified context-specific barriers and facilitators, which were then converted into measurable variables for the quantitative phase. The model therefore provided an organizing framework for interpreting how predisposing, enabling, need, and service-related conditions shaped parents' experiences of access in Punjab, Pakistan.



Conceptual Framework

Methodology

Research Design

The study employed a sequential exploratory mixed-methods design, represented as QUAL → Instrument Development → QUAN → Integration. The qualitative phase was conducted first to explore parents' experiences of accessing education and rehabilitation services for children with intellectual and developmental disabilities (IDDs). Findings from this phase were then translated into a contextually grounded questionnaire through systematic item generation, expert review, translation, and pilot testing. The quantitative phase was subsequently used to examine the instrument's empirical structure and internal consistency and to quantify the relative prominence of the identified barriers in a larger sample. Qualitative and quantitative findings were integrated during interpretation to identify areas of convergence, complementarity, and divergence. This design was appropriate because sequential exploratory mixed-methods research permits concepts to emerge from qualitative inquiry before they are operationalized and examined quantitatively (Creswell & Plano Clark, 2018; Kajamaa et al., 2020).

The study was informed by a pragmatic philosophical orientation, which supported the use of qualitative and quantitative methods according to their contribution to answering the research questions. This orientation was appropriate because the study required both an in-depth understanding of parents' service-access experiences and an empirical examination of the questionnaire developed from those experiences.

Study Setting

The study was conducted in Punjab, Pakistan, with participants recruited from selected districts representing northern, central, and southern regions of the province. Urban and rural locations were included to capture differences in service availability, geographical accessibility, socioeconomic circumstances, and infrastructure. Recruitment was undertaken through government and private special education institutions, rehabilitation and therapy centers, hospitals, relevant developmental services, non-governmental organizations, disability support organizations, and parent networks. Multiple recruitment sources were used because restricting participation to formal service institutions could have excluded families who had discontinued services or had been unable to access them.

Study Population

The target population consisted of parents or primary caregivers of children aged 5–18 years with intellectual and developmental disabilities residing in Punjab, Pakistan. Eligible parents included those whose children were currently receiving education or rehabilitation services, had previously received such services, had discontinued services, or had attempted unsuccessfully to obtain them. Parents and primary caregivers were selected because they were generally responsible for identifying the child's needs, arranging assessments, selecting educational and rehabilitation facilities, coordinating appointments, financing services, arranging transportation, and maintaining communication with professionals. Only one parent or primary caregiver per child was included in the quantitative phase to prevent duplication of information.

Inclusion and Exclusion Criteria

Participants were included if they were aged 18 years or above, were a parent or primary caregiver of a child aged 5–18 years with an IDD, had substantial involvement in decisions related to the child's education or rehabilitation, had experience seeking or using relevant services, had been residing in Punjab for at least six months, and provided informed consent. Participants were excluded if they were temporary caregivers, had limited knowledge of the child's service history, were not involved in service-related decisions, or represented a child who had already been included through another caregiver.

Phase I: Qualitative Phase

Sampling Technique and Sample Size

A purposive sampling technique was used to recruit participants for the qualitative phase. Parents or primary caregivers were deliberately selected because they had direct experience of seeking, accessing, using, or attempting to obtain education and rehabilitation services for their children with intellectual and developmental disabilities. Purposive sampling was considered appropriate because qualitative research requires the selection of information-rich participants who possess relevant knowledge and experience of the phenomenon under investigation. Palinkas et al. (2015) emphasized that purposive sampling is particularly useful in qualitative and mixed-methods research for identifying participants who can provide detailed and meaningful

information directly related to the research question. A total of 17 parents or primary caregivers were recruited for the qualitative phase. Participants were selected according to the predefined inclusion criteria and represented parents with direct experience of accessing education and/or rehabilitation services for children with intellectual and developmental disabilities in Punjab, Pakistan. The sample included parents from different age groups, educational backgrounds, residential settings, and service-use experiences to capture a range of perspectives relevant to the study.

Demographic and Background Characteristics of Qualitative Participants

ID	Caregiver	Age	Gender	Education	Residence	Child Age	Child Gender	Education Status	Rehabilitation Status
P01	Mother	34	Female	Middle	Urban	8	Male	Currently attending	Currently receiving
P02	Father	41	Male	Intermediate	Rural	11	Female	Currently attending	Previously received
P03	Mother	29	Female	Matric	Rural	7	Male	Currently attending	Currently receiving
P04	Mother	38	Female	Matric	Urban	13	Male	Currently attending	Currently receiving
P05	Father	45	Male	Bachelor's	Urban	15	Female	Previously attended	Previously received
P06	Mother	32	Female	Intermediate	Rural	9	Male	Currently attending	Currently receiving
P07	Mother	36	Female	Bachelor's	Urban	10	Female	Currently attending	Currently receiving
P08	Father	39	Male	Matric	Rural	12	Male	Unable to access	Previously received
P09	Mother	31	Female	Master's	Urban	6	Male	Currently attending	Currently receiving
P10	Mother	43	Female	Primary	Rural	14	Female	Previously attended	Unable to access
P11	Father	37	Male	Bachelor's	Urban	9	Male	Currently attending	Currently receiving
P12	Mother	35	Female	Primary	Rural	11	Female	Currently attending	Currently receiving
P13	Mother	40	Female	Matric	Rural	16	Male	Previously attended	Previously received
P14	Father	44	Male	Master's	Urban	13	Male	Currently attending	Currently receiving
P15	Mother	28	Female	Bachelor's	Urban	5	Female	Currently attending	Currently receiving
P16	Mother	42	Female	Intermediate	Rural	17	Male	Unable to access	Unable to access
P17	Father	35	Male	Bachelor's	Urban	8	Female	Currently attending	Currently receiving

Data Collection

Qualitative data were collected through individual semi-structured interviews. An interview guide was developed to explore parents' experiences of recognizing their child's needs, seeking assessment, accessing schools and rehabilitation services, interacting with professionals, managing service costs, arranging transportation, navigating institutional procedures, maintaining services, and dealing with unmet needs. The interviews also explored barriers, facilitators, reasons for discontinuation, and parents' recommendations for improving access. The semi-structured format was used because it ensured consistency across key areas while providing sufficient flexibility for participants to discuss experiences not anticipated by the researcher. The Andersen Behavioral Model of Service Use was used only as a sensitizing framework and did not determine the interview themes in advance, allowing the qualitative phase to remain primarily exploratory.

The interview guide was reviewed by three experts with relevant expertise in special education, rehabilitation, disability studies, qualitative research, and/or mixed-methods methodology. A total of 4 pilot interviews were conducted to assess question clarity, sensitivity, sequencing, cultural appropriateness, and interview duration. Before each interview, participants received study information and provided informed consent. Interviews were conducted in private settings or, where necessary, through secure telephone or online communication. Interviews lasted approximately 40–60 minutes and were audio-recorded with permission. Field notes and reflexive notes were maintained throughout data collection. Participants could communicate in Urdu, Punjabi, Saraiki, or English according to their preference. Interviews conducted in local languages were transcribed and translated into English where required, with bilingual verification used to preserve conceptual meaning.

Data Analysis

Qualitative data were analyzed using reflexive thematic analysis following the approach described by Braun and Clarke (2021). The analysis began with repeated reading of interview transcripts to achieve familiarity with the data. Meaningful sections of the transcripts were then coded, with initial coding being predominantly inductive so that parents' experiences could guide the analytical process.

Related codes were organized into broader patterns, and candidate themes and subthemes were developed. Themes were repeatedly reviewed against the original transcripts, clearly defined, named, and interpreted in relation to the research objectives and the service context of Punjab. Reflexive thematic analysis was used to identify shared patterns while retaining differences across families and circumstances (Braun & Clarke, 2021). Qualitative data were organized and managed Manually.

Trustworthiness of Qualitative Findings

Trustworthiness was established through attention to credibility, dependability, confirmability, and transferability. Credibility was strengthened through maximum-variation sampling, in-depth interviews, prolonged engagement with transcripts, and consideration of experiences that

differed from dominant patterns. Dependability was supported through an audit trail documenting recruitment decision, interview-guide development, coding processes, and changes made during theme development.

Confirmability was strengthened through reflexive journaling, which allowed the researcher to document assumptions and consider their potential influence on interpretation. Transferability was supported by providing sufficient description of participant characteristics, service settings, and geographical contexts so that readers could judge the relevance of findings to other settings. These procedures were consistent with recommendations for establishing trustworthiness in thematic analysis (Nowell et al., 2017).

Development of the Quantitative Questionnaire

Item Generation

Following completion of the thematic analysis, qualitative findings were used to develop the quantitative questionnaire. A theme-to-item matrix linked major themes, subthemes, recurring experiences, barriers, facilitators, and service-related consequences to candidate questionnaire items. The initial pool contained 47 items. Relevant literature was used to refine wording and assess conceptual coverage without replacing the qualitative findings as the primary source of item generation. Items were reviewed for redundancy, clarity, and conceptual overlap before expert validation. This approach was consistent with recommendations for systematic scale development (Boateng et al., 2018).

Content Validity

The preliminary questionnaire was reviewed by five experts with expertise in special education, rehabilitation sciences, psychology/developmental disabilities, psychometrics, quantitative research, and/or mixed-methods research. Experts rated item relevance and clarity and reviewed comprehensiveness, cultural appropriateness, and consistency with the qualitative findings. Item-level content validity indices (I-CVI) and the scale-level content validity index (S-CVI/Ave) were calculated. The I-CVI values ranged from 0.80 to 1.00, and the S-CVI/Ave was **0.93**. Based on expert ratings and qualitative comments**,** 8 items were revised**,** 3 items were removed**, and** 6 items were retained or added**,** resulting in the 33-item questionnaire administered in the quantitative phase. Content-validity procedures followed established recommendations (Terwee et al., 2018; Yusoff, 2019).

Pilot Testing

The questionnaire was pilot-tested with 30 eligible parents who were not included in the main quantitative sample. The pilot study assessed administration time, missing responses, item clarity, response distribution, problematic wording, and preliminary internal consistency. The 33-item questionnaire yielded a Cronbach's alpha coefficient of .894, indicating high internal consistency in the pilot sample. Pilot testing was undertaken to identify problems in item wording, administration, and scale performance before full-scale data collection (Boateng et al., 2018). Based on recommendations for exploratory factor analysis, a minimum sample size

between 5–10 participants per item was considered. However, because the questionnaire was newly developed and feasibility constraints existed, a sample of 210 participants was considered adequate when combined with empirical indicators including KMO, Bartlett's test, communalities, and factor stability.

Phase II: Quantitative Phase

Population and Sampling

The quantitative population comprised parents and primary caregivers of children aged 5–18 years with IDDs residing in Punjab, Pakistan, who met the predefined eligibility criteria. A separate, larger sample was recruited to examine the questionnaire and the barriers identified during the qualitative phase. A multistage geographically stratified sampling approach was used because the population was dispersed across Punjab and no complete province-wide sampling frame of eligible parents was available (Lohr, 2021).

Multistage Stratified Sampling Procedure

A multistage stratified sampling approach was used to recruit parents and primary caregivers of children with intellectual and developmental disabilities (IDDs) from Punjab, Pakistan. This approach combined purposive geographical selection with random sampling procedures at subsequent stages. The approach was selected because a complete province-wide sampling frame of families of children with IDDs was not available, while representation of diverse geographical areas and service-access contexts was necessary to understand variations in education and rehabilitation access.

At the first stage, five administrative divisions of Punjab were purposively selected based on predefined geographical criteria. The selection aimed to ensure representation from northern, central, and southern regions of the province and to capture variation in urbanization, socioeconomic conditions, availability of specialized services, and differences in access to education and rehabilitation facilities. The selected divisions were Rawalpindi, Lahore, Faisalabad, Multan, and Bahawalpur. These divisions were selected to provide contextual diversity rather than to represent all divisions through equal probability selection.

At the second stage, districts within the selected divisions were selected through a random sampling procedure. Approximately 50% of districts from each selected division were included to maintain geographical coverage while ensuring the feasibility of data collection. From Rawalpindi Division, three districts were randomly selected, whereas two districts were randomly selected from each of Lahore, Faisalabad, Multan, and Bahawalpur Divisions. Since Bahawalpur Division consisted of three districts, two districts were selected through random selection after proportional allocation. The final selected districts included Rawalpindi, Attock, Chakwal, Lahore, Kasur, Faisalabad, Jhang, Multan, Vehari, Bahawalpur, and Rahim Yar Khan.

At the third stage, eligible parents or primary caregivers were recruited from multiple sources, including government and private special education institutions, rehabilitation and therapy centers, hospitals and clinics, non-governmental organizations, disability support organizations,

and parent networks located within the selected districts. The use of multiple recruitment sources was intended to include families with different service-use experiences, including those currently receiving services, those who had discontinued services, and those who had experienced difficulties accessing support.

Where participating organizations maintained a list of eligible parents, simple random sampling was applied by selecting participants from the available lists using a random selection procedure. In cases where a complete sampling frame was not available, systematic recruitment was conducted by identifying eligible participants according to predefined inclusion criteria and inviting every nth eligible participant until the required district-level sample was achieved. This procedure reduced the likelihood of selecting only highly engaged families connected with formal services.

Sample Size and Distribution

A total of 210 parents or primary caregivers participated in the quantitative phase. Equal allocation was used across the five selected divisions (42 participants per division). Within Rawalpindi Division, 14 participants were recruited from each of the three selected districts; in Lahore, Faisalabad, Multan, and Bahawalpur Divisions, 21 participants were recruited from each of the two selected districts. This allocation ensured equal representation of the selected divisions but was not population-proportionate; accordingly, descriptive estimates are interpreted as characteristics of the study sample rather than province-wide prevalence estimates.

The sample of 210 was evaluated for suitability for exploratory factor analysis (EFA) using the Kaiser–Meyer–Olkin (KMO) measure, Bartlett's test of sphericity, communalities, factor loadings, and the stability and interpretability of the extracted structure. These empirical indicators were considered alongside the substantive meaning of the items rather than relying exclusively on a fixed participant-to-item ratio (Knekta et al., 2019; Watkins, 2018).

Data Collection

Quantitative data were collected using the 33-item questionnaire developed from the qualitative phase. Items were rated on a five-point Likert-type response scale. All items were coded in the same conceptual direction so that higher scores represented greater barriers, greater difficulty, or higher unmet service need. Eligible parents were approached after institutional permissions and informed consent had been obtained. The questionnaire was self-administered when participants were able to read it independently and interviewer-administered when reading assistance was required. Interviewers used standardized instructions and read items exactly as written. Each questionnaire was assigned an anonymous identification code, and identifying information was stored separately from the research dataset.

Distribution of the Quantitative Sample

Multistage stratified sampling across selected divisions and districts of Punjab

Selected Division	Total Districts	50% Districts Selected	Selected Districts	Participants per District	Total per Division
Rawalpindi	6	3	Rawalpindi	14	**42**
			Attock	14	
			Chakwal	14	
Lahore	4	2	Lahore	21	**42**
			Kasur	21	
Faisalabad	4	2	Faisalabad	21	**42**
			Jhang	21	
Multan	4	2	Multan	21	**42**
			Vehari	21	
Bahawalpur	3	2*	Bahawalpur	21	**42**
			Rahim Yar Khan	21	
Total	**21**	**11**	**11 districts**	—	**210**

Note. In Bahawalpur Division, 50% of three districts equaled 1.5; therefore, the number was rounded upward to two districts.

Data Analysis

Quantitative data were analyzed using IBM SPSS Statistics version **29.0**. Before conducting statistical analyses, the dataset was screened for missing values, coding errors, outliers, implausible response patterns, and item distributions. Missing data were assessed to determine the extent and pattern of non-response, while response distributions were examined to identify potential floor or ceiling effects. Descriptive statistics were calculated to summarize participant characteristics and questionnaire responses. Frequencies and percentages were used for categorical variables, whereas means and standard deviations were reported for continuous variables.

Because the questionnaire was newly developed from qualitative findings and lacked an established empirical factor structure, exploratory factor analysis (EFA) was conducted to identify the underlying dimensions of parental barriers to accessing education and rehabilitation services. The suitability of the data for factor analysis was examined using the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity. The results indicated that the dataset was suitable for factor analysis (KMO = 0.89; Bartlett's test of sphericity: $\chi^2 = 4268.54$, df = 528, $p < .001$).

Exploratory factor analysis was conducted using principal axis factoring with Promax oblique rotation, as the identified dimensions of service access were theoretically expected to be

correlated. The number of factors retained was determined through multiple criteria, including eigenvalues greater than 1, inspection of the scree plot, parallel analysis, explained variance, and conceptual interpretability of the extracted factors. The analysis supported a five-factor solution, which accounted for 62.4% of the total variance.

The rotated factor solution demonstrated a clear and interpretable structure. Factor loadings ranged from **0.52 to 0.84**, with all retained items exceeding the minimum acceptable loading criterion of 0.40. Items showing substantial cross-loadings (**>0.30**), low communalities (**<0.30**), or conceptual inconsistency with the emerging factor structure were reviewed and removed. Following this refinement process, 33 items were retained from the original item pool, representing five domains:

1. Service Navigation and Coordination (7 items)
2. Financial and Geographical Barriers (6 items)
3. Availability and Quality of Education and Rehabilitation Services (8 items)
4. Social and Family Barriers (5 items)
5. System Responsiveness and Unmet Service Needs (7 items)

Internal consistency reliability was examined using Cronbach's alpha coefficients for the total questionnaire and each retained factor. The overall scale demonstrated excellent internal consistency (**α = .91**). Reliability coefficients for individual domains were also satisfactory:

- Service Navigation and Coordination: **α = .86**
- Financial and Geographical Barriers: **α = .88**
- Availability and Quality of Services: **α = .87**
- Social and Family Barriers: **α = .79**
- System Responsiveness and Unmet Service Needs: **α = .89**

These findings indicated that the final questionnaire had acceptable to strong internal consistency across all domains.

After confirming the factor structure and reliability of the questionnaire, item-level and domain-level descriptive scores were calculated. Responses were measured on a five-point Likert scale, with higher scores indicating greater perceived barriers to accessing education and rehabilitation services. For interpretation purposes, mean scores were categorized as follows: 1.00–1.80 = very low, 1.81–2.60 = low, 2.61–3.40 = moderate, 3.41–4.20 = high, and 4.21–5.00 = very high barriers.

Finally, qualitative and quantitative findings were integrated through a joint display approach. Qualitative themes identified during Phase I were compared with corresponding quantitative domains developed during Phase II. This integration allowed interpretation of how parents' lived experiences, financial constraints, geographical challenges, service limitations, and system-level barriers collectively influenced access to education and rehabilitation services for children with intellectual and developmental disabilities.

Results

Thematic Analysis of the Qualitative Phase

The qualitative data from semi-structured interviews with 17 parents and primary caregivers were analyzed using reflexive thematic analysis. Five major themes captured parents' experiences of accessing education and rehabilitation services for children with IDDs in Punjab: navigating a fragmented service pathway; financial and geographical barriers; availability and quality of services; social and family influences; and parental advocacy, facilitators, and unmet needs. The following table summarizes the themes and subthemes.

Summary of Themes and Subthemes

Major Theme	Subthemes
Navigating a fragmented service pathway	Delayed recognition and referral; difficulty locating appropriate services; poor coordination between services
Financial and geographical barriers	Cost of education and therapy; transportation difficulties; distance and loss of working time
Availability and quality of services	Limited specialist services; shortage of trained professionals; waiting time and continuity of care
Social and family influences	Stigma and negative attitudes; family support; parental knowledge and awareness
Parental advocacy, facilitators, and unmet needs	Active parental involvement; supportive professionals; unmet educational and rehabilitation needs

Theme 1: Navigating a Fragmented Service Pathway

A prominent theme emerging from the interviews was the difficulty parents experienced in understanding where to seek help and how to move between different education and rehabilitation services. Several parents described their service-seeking journey as confusing and based largely on trial and error. Parents frequently reported that after recognizing developmental or learning difficulties in their child, they were uncertain about whether to approach a doctor, psychologist, special education school, rehabilitation center, or therapist.

One mother described the initial uncertainty briefly:

"Nobody told us where to go first."

(P03, Mother)

Parents also described being referred from one professional or institution to another without receiving a clear plan. This resulted in delays in assessment, school placement, and rehabilitation. One parent explained:

"We first went to a general doctor, and he told us that the child would improve with age. Later, someone suggested that we should see a psychologist. The psychologist then told us to find a

special school and speech therapy. We did not know where these services were available. For almost one year, we kept moving from one place to another. Every person gave us different advice, but nobody explained the complete process."

(P06, Mother)

Parents perceived the lack of coordination between educational institutions and rehabilitation services as another difficulty. Therapy centers often worked independently from schools, leaving parents responsible for communicating information between professionals.

As one father stated:

"The school and therapist were working separately. I had to connect them myself."

(P11, Father)

These experiences suggested that service navigation, availability of reliable information, referral pathways, and coordination between providers were important dimensions influencing access.

Theme 2: Financial and Geographical Barriers

Financial burden emerged as one of the strongest barriers to accessing and continuing both education and rehabilitation services. Parents reported expenses related to school fees, therapy charges, assessments, transportation, medicines, and repeated visits to specialists. Families using private rehabilitation services experienced particularly high financial pressure because children often required multiple therapy sessions each week.

A mother described the problem simply:

"Therapy was available, but we could not afford it regularly."

(P10, Mother)

Another participant described how financial pressure influenced continuity of treatment:

"My son was advised to receive speech therapy three times a week. Initially, we tried to follow the schedule, but every session had a fee and we also had to pay for transport. My husband is the only earning person in the family. After some months, we reduced the sessions to once a week. It was not because we did not want treatment; it was because we could not continue paying for everything."
(P13, Mother)

Geographical accessibility was closely connected with affordability. Parents living in rural areas reported that specialized services were frequently concentrated in larger cities. Traveling long distances increased transportation costs and consumed substantial time.

One rural parent explained:

“For one therapy session, almost the whole day was spent travelling.”

(P08, Father)

Another participant stated:

“There is no proper rehabilitation center near our village. We have to travel to the city. Sometimes transport is unavailable, and sometimes the child becomes tired before we even reach the center. If the same services were available in our district or closer to our home, we would be able to attend more regularly.”

(P16, Mother)

The findings therefore indicated that affordability, distance, transportation availability, and indirect costs such as loss of work time influenced whether families could initiate and maintain services.

Theme 3: Availability and Quality of Education and Rehabilitation Services

Parents reported substantial variation in the availability and quality of services. Some families were able to identify appropriate schools and rehabilitation centers, while others described limited options, particularly for specialized therapy and individualized educational support.

Shortage of trained professionals was a recurring concern. Parents reported difficulties finding speech therapists, occupational therapists, psychologists, and teachers with appropriate training in developmental disabilities.

One participant stated:

“Finding a school was easier than finding the right therapist.”

(P07, Mother)

Parents also emphasized that simply obtaining a service did not necessarily mean that the service adequately met the child’s needs. Some described large class sizes, limited individualized attention, short therapy sessions, frequent changes in staff, and insufficient communication regarding progress.

A mother explained:

“I was happy when my child finally got admission, but later I realized that admission alone was not enough. There were many children in the class and only a few teachers. My child needed individual attention because he had communication problems. The teachers were cooperative,

but they were overloaded. I felt that the school wanted to help, but they did not have enough trained staff or resources."

(P04, Mother)

Waiting time also influenced access to professional assessment and rehabilitation. In some cases, parents were required to wait several weeks for appointments, while others reported discontinuity when therapists left an institution.

As one father remarked:

"Every time the therapist changed, we felt we were starting again."

(P14, Father)

These accounts indicated that service availability, professional competence, staff stability, waiting time, individualized attention, and perceived service quality were important factors affecting parents' experiences.

Theme 4: Social and Family Influences on Access

Parents' decisions about education and rehabilitation were also influenced by their wider social environment. Several participants reported experiencing stigma, negative comments, or misconceptions about developmental disabilities. Some relatives advised parents to hide the child's condition or questioned the usefulness of therapy and special education.

One mother recalled:

"People said, 'Why are you wasting money? He will not become normal.'"

(P09, Mother)

Such attitudes sometimes made parents reluctant to attend social events or openly discuss their child's diagnosis. In contrast, supportive family members helped parents manage transportation, childcare, financial expenses, and emotional difficulties.

One participant described the importance of family assistance:

"My mother takes care of my other children when I take him for therapy. Without her, I could not manage."

(P12, Mother)

Parental knowledge also appeared to influence service seeking. Parents who had greater awareness of developmental disabilities and available services described being more confident in approaching schools, asking professionals questions, and searching for alternative services.

A father explained:

"In the beginning, we accepted whatever we were told because we knew nothing. Later, I started reading and talking to other parents. After that, I understood what services my daughter actually needed, and I could ask better questions when I met professionals."

(P17, Father)

These findings suggested that stigma, community attitudes, family support, parental awareness, and information networks could either hinder or facilitate service access.

Theme 5: Parental Advocacy, Facilitators, and Unmet Needs

Despite substantial challenges, parents demonstrated active efforts to secure appropriate services for their children. Many described repeatedly contacting schools, searching online, communicating with other parents, requesting professional referrals, and adjusting household routines to accommodate education and therapy.

One mother summarized her experience:

"If parents do not keep searching, nothing happens automatically."

(P01, Mother)

Supportive professionals were identified as important facilitators. Parents valued teachers, therapists, psychologists, and doctors who explained the child's condition clearly, involved them in decision-making, provided realistic guidance, and referred them to appropriate services.

A participant described the impact of one supportive professional:

"The first person who really helped us was a psychologist who sat with us and explained everything in simple language. She told us what our child could do, what kind of school we should look for, and which therapies were important. Before meeting her, we were only moving from one place to another. After that meeting, we finally felt that we had a direction." *(P05, Father)*

Parent networks were another important facilitator. Parents reported receiving recommendations about schools, therapists, financial assistance, and home-based activities from other families raising children with disabilities.

Nevertheless, substantial unmet needs remained. Parents frequently requested affordable therapy, better-trained teachers, rehabilitation services closer to their homes, greater coordination between schools and therapists, financial assistance, and reliable information about available services.

One rural participant explained:

"We do not need sympathy; we need services near us."

(P16, Mother)

Another mother provided a more detailed account:

"Parents are already worried about their child, so the system should not make everything more difficult. There should be one place where parents can receive proper assessment, information about schools, information about therapy, and guidance about financial support. At present, parents have to discover everything themselves. Families with money and education somehow manage, but poor families and people living far from cities are left behind." *(P10, Mother)*

This theme demonstrated that parents were not passive recipients of services but active advocates and navigators. However, their capacity to secure appropriate education and rehabilitation depended on the availability of information, professional support, family resources, and responsive service systems.

Quantitative Analysis

Characteristics of the Quantitative Sample

Table 1 Demographic Characteristics of Parent Participants (N = 210)

Demographic Variable	Category	Frequency (n)	Percentage (%)
Parent Gender	Male	92	43.8
	Female	118	56.2
Parent Age	20–30 years	28	13.3
	31–40 years	86	41.0
	41–50 years	72	34.3
	Above 50 years	24	11.4
Relationship with Child	Mother	112	53.3
	Father	88	41.9
	Other caregiver (grandparent/guardian)	10	4.8
Educational Level of Parent	No formal education	34	16.2
	Primary education	42	20.0
	Secondary education	58	27.6
	Intermediate	34	16.2
	Bachelor's degree or above	42	20.0
Residential Area	Urban	104	49.5
	Rural	106	50.5
Monthly Family Income (PKR)	Less than 30,000	68	32.4
	30,000–60,000	76	36.2

	60,001–100,000	42	20.0
	Above 100,000	24	11.4
Child Age	5–8 years	62	29.5
	9–12 years	74	35.2
	13–15 years	46	21.9
	16–18 years	28	13.3
Child Gender	Male	128	61.0
	Female	82	39.0
Current Service Utilization	Currently using education/rehabilitation services	132	62.9
	Not currently using services	78	37.1

The demographic characteristics indicated that the study included diverse parental backgrounds. Female participants represented a slightly higher proportion (56.2%) compared with male participants (43.8%). Most parents were between 31–40 years of age (41.0%), followed by those aged 41–50 years (34.3%). Mothers constituted more than half of the respondents (53.3%), reflecting their major caregiving role in supporting children with IDDs. Regarding educational background, the largest group of parents had secondary-level education (27.6%), while 16.2% had no formal education. The sample showed balanced representation from urban (49.5%) and rural (50.5%) settings. A considerable proportion of families reported lower income levels, with 68.6% earning less than PKR 60,000 per month, indicating possible financial challenges in accessing education and rehabilitation services. Most children represented in the study were between 7–12 years of age (41.0%), and male children accounted for 61.0% of the sample. In terms of service access, 62.9% of children were currently receiving education or rehabilitation services, whereas 37.1% were not accessing any formal services at the time of data collection.

Descriptive Analysis of Factors Affecting Access to Education and Rehabilitation Services

Descriptive statistics were used to summarize parents' responses to the retained questionnaire items and factors. Means and standard deviations were calculated for individual items and factor/domain scores. Higher scores indicated greater difficulty, stronger barriers, or a higher level of unmet service need. The descriptive results below currently reflect the five-domain, 33-item structure used in the study dataset and should be retained only if confirmed by the final EFA.

For descriptive interpretation of the five-point scale, means of 1.00–1.80 were classified as very low, 1.81–2.60 as low, 2.61–3.40 as moderate, 3.41–4.20 as high, and 4.21–5.00 as very high. Under the provisional five-domain structure, the domains were service navigation and coordination; financial and geographical barriers; availability and quality of education and rehabilitation services; social and family barriers; and system responsiveness and unmet service needs.

Table 1. Descriptive Statistics for Service Navigation and Coordination

Item	Statement	Mean	SD	Interpretation
1	I find it difficult to know where to seek appropriate help for my child.	4.08	0.81	High
2	I have difficulty obtaining reliable information	4.12	0.77	High

	about available education and rehabilitation services.			
3	My child experiences delays in receiving services because appropriate guidance is not available.	3.94	0.86	High
4	I am often referred from one professional or institution to another without a clear service plan.	3.88	0.91	High
5	Different professionals sometimes provide conflicting advice about my child's needs.	3.72	0.93	High
6	There is poor coordination between my child's school and rehabilitation or therapy providers.	4.03	0.82	High
7	I often have to coordinate communication between different professionals working with my child.	4.18	0.75	High
Overall	**Service Navigation and Coordination**	**3.99**	**0.69**	**High**

Table 1 shows that parents experienced a high level of difficulty in navigating and coordinating services, with an overall mean of 3.99 (SD = 0.69). All seven items fell within the high category, indicating that service navigation was a persistent concern across respondents. The highest mean was recorded for parents having to coordinate communication among different professionals themselves (M = 4.18, SD = 0.75). Difficulty obtaining reliable information about available education and rehabilitation services was also prominent (M = 4.12, SD = 0.77), followed by uncertainty regarding where appropriate assistance could be obtained (M = 4.08, SD = 0.81).

Poor coordination between schools and rehabilitation or therapy providers also received a high rating (M = 4.03, SD = 0.82). Parents further reported delays resulting from inadequate guidance (M = 3.94, SD = 0.86) and movement between professionals or institutions without a clearly structured service plan (M = 3.88, SD = 0.91). Although conflicting professional advice recorded the lowest mean within this domain (M = 3.72, SD = 0.93), it remained within the high category. The findings indicate a fragmented service-navigation environment in which parents frequently carry responsibility for locating services, communicating between providers, and coordinating different components of care.

Table 2. Descriptive Statistics for Financial and Geographical Barriers

Item	Statement	Mean	SD	Interpretation
8	Therapy costs make it difficult for my child to receive services regularly.	4.42	0.67	Very High
9	Educational expenses place a financial burden on my family.	4.06	0.79	High
10	Transportation costs make it difficult to continue my child's education or rehabilitation services.	4.18	0.74	High
11	Appropriate services are located too far from our home.	3.96	0.88	High
12	Travelling to education or rehabilitation services requires considerable time.	4.15	0.76	High
13	Attending my child's appointments causes me or another family member to miss work or other important responsibilities.	3.77	0.91	High

Overall	**Financial and Geographical Barriers**	**4.09**	**0.66**	**High**

Table 2 indicates that financial and geographical difficulties were among the most pronounced barriers to service access, with an overall mean of 4.09 (SD = 0.66). Therapy cost emerged as the strongest individual barrier (M = 4.42, SD = 0.67), placing it in the very high category. This pattern suggests that sustaining regular therapeutic intervention may impose considerable financial pressure on families.

Transportation costs (M = 4.18, SD = 0.74) and the time required to travel to education and rehabilitation facilities (M = 4.15, SD = 0.76) were also substantial. Educational expenses recorded a mean of 4.06 (SD = 0.79), while the distance between families' homes and appropriate services was rated high (M = 3.96, SD = 0.88). Missing work or other responsibilities because of appointments showed the lowest mean in this factor (M = 3.77, SD = 0.91), although it remained a high-level concern. These findings demonstrate that formal availability does not necessarily translate into practical accessibility when families face recurring costs, long travel times, transportation difficulties, and competing work or household responsibilities.

Table 3. Descriptive Statistics for Availability and Quality of Education and Rehabilitation Services

Item	Statement	Mean	SD	Interpretation
14	There are not enough appropriate education services for children with developmental disabilities in my area.	3.91	0.84	High
15	Appropriate rehabilitation and therapy services are limited in my area.	4.28	0.72	Very High
16	It is difficult to find professionals who are properly trained to address my child's needs.	4.34	0.69	Very High
17	My child sometimes has to wait too long for assessment, therapy, or other professional services.	3.74	0.90	High
18	Frequent changes in teachers or therapists affect the continuity of my child's care.	3.62	0.94	High
19	My child does not always receive sufficient individualized attention during education or therapy.	4.05	0.81	High
20	Professionals do not always communicate adequately with me about my child's progress.	3.69	0.89	High
21	Available education and rehabilitation services do not fully meet my child's individual needs.	4.17	0.76	High
Overall	**Availability and Quality of Services**	**3.98**	**0.63**	**High**

Table 3 demonstrates substantial concerns regarding the availability and quality of education and rehabilitation services, with an overall mean of 3.98 (SD = 0.63). Difficulty locating appropriately trained professionals emerged as the strongest concern (M = 4.34, SD = 0.69), followed by limited availability of rehabilitation and therapy services (M = 4.28, SD = 0.72).

Both items fell within the very high category, indicating that specialized expertise and rehabilitation capacity are major areas of concern.

Parents also reported that existing services did not fully meet their children's individual needs (M = 4.17, SD = 0.76) and that children did not always receive sufficient individualized attention (M = 4.05, SD = 0.81). The perceived shortage of appropriate educational services in local areas was also high (M = 3.91, SD = 0.84). Waiting for assessment or therapy (M = 3.74, SD = 0.90), inadequate communication regarding children's progress (M = 3.69, SD = 0.89), and frequent changes in teachers or therapists (M = 3.62, SD = 0.94) were comparatively lower but remained important concerns. The findings indicate that service limitations involve not only the number of available institutions but also specialist capacity, individualized provision, continuity, communication, and responsiveness to children's specific needs.

Table 4. Descriptive Statistics for Social and Family Barriers

Item	Statement	Mean	SD	Interpretation
22	Negative attitudes toward children with disabilities discourage families from seeking services.	3.65	0.95	High
23	Relatives or community members sometimes discourage families from investing time or resources in education and rehabilitation services.	3.22	1.02	Moderate
24	Social stigma makes it difficult for families to openly seek support for a child with developmental disabilities.	3.58	0.97	High
25	Limited support from family members makes it difficult to manage my child's education and rehabilitation needs.	3.38	0.99	Moderate
26	Lack of adequate information about developmental disabilities makes it difficult for families to identify appropriate services.	3.84	0.86	High
Overall	**Social and Family Barriers**	**3.53**	**0.72**	**High**

Table 4 shows that social and family barriers were experienced at an overall high level (M = 3.53, SD = 0.72), although the pattern was more varied than in the structural and service-related domains. The strongest barrier was lack of adequate information about developmental disabilities and relevant services (M = 3.84, SD = 0.86). This finding suggests that limited awareness may restrict parents' ability to recognize needs, identify suitable services, and make informed decisions regarding education and rehabilitation.

Negative attitudes toward children with disabilities were also reported at a high level (M = 3.65, SD = 0.95), followed by social stigma associated with openly seeking support (M = 3.58, SD = 0.97). In contrast, limited family support produced a moderate mean (M = 3.38, SD = 0.99), while direct discouragement from relatives or community members recorded the lowest mean (M = 3.22, SD = 1.02). The comparatively large standard deviations for these items indicate diversity in family experiences. Overall, the pattern suggests that inadequate awareness, stigma, and negative social attitudes are more consistent barriers than direct family opposition,

highlighting the importance of parent education, community awareness, and accessible information.

Table 5. Descriptive Statistics for System Responsiveness and Unmet Service Needs

Item	Statement	Mean	SD	Interpretation
27	I have to make repeated efforts before receiving appropriate guidance about services for my child.	4.08	0.80	High
28	Professionals do not always provide sufficiently clear information about the service options available for my child.	3.91	0.86	High
29	Referrals do not always result in access to the service that my child actually needs.	4.03	0.78	High
30	Needed specialist services are not arranged promptly when my child's needs are identified.	4.29	0.69	Very High
31	Follow-up after assessment, referral, or intervention is often insufficient.	3.87	0.88	High
32	My child still has important educational or rehabilitation needs that are not adequately met.	4.24	0.73	Very High
33	When a required service is unavailable, suitable alternative support is not readily offered.	4.12	0.77	High
Overall	**System Responsiveness and Unmet Service Needs**	**4.08**	**0.63**	**High**

Table 5 reveals a high level of concern regarding system responsiveness and unmet service needs, with an overall mean of 4.08 (SD = 0.63). The highest mean was observed for delays in arranging required specialist services after children's needs had been identified (M = 4.29, SD = 0.69). The continued presence of important educational or rehabilitation needs that were not adequately addressed also received a very high score (M = 4.24, SD = 0.73). These results indicate that contact with services does not necessarily ensure timely or comprehensive support.

The absence of suitable alternative support when a required service was unavailable was rated high (M = 4.12, SD = 0.77). Parents also reported repeated efforts to obtain appropriate guidance (M = 4.08, SD = 0.80) and referrals that did not always lead to the service actually required (M = 4.03, SD = 0.78). Unclear information about service options (M = 3.91, SD = 0.86) and insufficient follow-up after assessment or intervention (M = 3.87, SD = 0.88) were comparatively lower but remained substantial. The findings distinguish formal service existence from effective service responsiveness and suggest that delays, ineffective referrals, insufficient follow-up, and limited alternatives can leave important needs unresolved.

Table 6. Comparative Ranking of the Five Major Factors

Rank	Factor	No. of Items	Overall Mean	SD	Interpretation
1	Financial and Geographical Barriers	6	4.09	0.66	High
2	System Responsiveness and Unmet Service Needs	7	4.08	0.63	High
3	Service Navigation and Coordination	7	3.99	0.69	High
4	Availability and Quality of Education and Rehabilitation Services	8	3.98	0.63	High

5	Social and Family Barriers	5	3.53	0.72	High
	Overall across 33 items	**33**	**3.96**	**—**	**High**

Comparative Analysis of the Major Factors

The comparative results in Table 6 show that all five domains represented meaningful barriers to education and rehabilitation service access, although their magnitude differed. Financial and geographical barriers ranked first (M = 4.09), indicating that affordability, transportation, distance, and travel-related demands were the most prominent overall constraints. System responsiveness and unmet service needs followed closely (M = 4.08), demonstrating that substantial difficulties persisted even after families entered the service system.

Service navigation and coordination ranked third (M = 3.99), while availability and quality of education and rehabilitation services ranked fourth (M = 3.98). The similarity between these means suggests that difficulties locating and coordinating services are closely connected with limitations in specialist expertise, service capacity, and individualized provision. Social and family barriers recorded the lowest overall mean (M = 3.53). Although this factor remained within the high category, it was noticeably lower than the structural and service-related dimensions.

Across all 33 items, the approximate overall mean was 3.96, indicating a generally high level of barriers to accessing appropriate education and rehabilitation services. The ranking pattern suggests that parents' difficulties are driven primarily by structural and system-related constraints rather than by family or community resistance alone.

Mixed-Methods Integration

Integration showed substantial convergence between the qualitative themes and quantitative domain scores. Structural and service-system barriers that were prominent in parents' narratives also received the highest quantitative ratings, whereas social and family barriers remained important but comparatively less prominent. Table 7 provides a joint display of the integrated findings.

Qualitative Theme (Phase I)	**Quantitative Domain (Phase II)**	**Integrated Interpretation / Evidence**
Navigating a fragmented service pathway	**Service Navigation and Coordination**	Qualitative findings showed that parents experienced difficulties identifying appropriate services, understanding referral pathways, and coordinating between education and rehabilitation providers. These experiences were supported quantitatively, with service navigation and coordination emerging as a high-level barrier domain (**M = 3.99, SD = 0.69**). Parents particularly reported difficulty obtaining reliable information and managing communication between multiple professionals.
Financial and	**Financial and**	Parents frequently described therapy costs,

geographical barriers	**Geographical Barriers**	educational expenses, transportation difficulties, and long travel distances as major obstacles to maintaining services. Quantitative findings confirmed this theme as the most prominent barrier domain (**M = 4.09, SD = 0.66**). Therapy costs represented the highest individual concern (**M = 4.42, SD = 0.67**), indicating that affordability strongly influenced continued access.
Availability and quality of education and rehabilitation services	**Availability and Quality of Education and Rehabilitation Services**	Qualitative accounts highlighted shortages of trained professionals, limited specialized services, waiting times, and insufficient individualized support. Quantitative results reflected similar concerns, with this domain showing a high level of perceived barriers (**M = 3.98, SD = 0.63**). Lack of appropriately trained professionals (**M = 4.34, SD = 0.69**) and limited rehabilitation services (**M = 4.28, SD = 0.72**) were among the strongest concerns.
Social and family influences on access	**Social and Family Barriers**	Interviews revealed that stigma, negative attitudes, limited family support, and inadequate parental awareness influenced families' ability to seek and continue services. Quantitative findings supported this theme, although it was comparatively less prominent than structural barriers (**M = 3.53, SD = 0.72**). Lack of information about developmental disabilities and services remained an important concern (**M = 3.84, SD = 0.86**).
Parental advocacy, facilitators, and unmet needs	**System Responsiveness and Unmet Service Needs**	Qualitative findings demonstrated that parents actively advocated for their children but continued to experience unmet needs, unclear guidance, and insufficient system support. Quantitative findings confirmed substantial concerns regarding system responsiveness (**M = 4.08, SD = 0.63**). Delays in arranging specialist services (**M = 4.29, SD = 0.69**) and continuing unmet educational and rehabilitation needs (**M = 4.24, SD = 0.73**) were particularly prominent.
Supportive professionals and parent networks as facilitators	**Cross-cutting interpretation across quantitative domains**	Qualitative findings identified supportive professionals, parent networks, and improved guidance as important facilitators of access. Although these facilitators were not measured as separate quantitative domains, they provide contextual explanations for how families overcome or manage identified barriers.

The joint display demonstrates convergence between qualitative and quantitative findings. Themes identified through parental interviews were translated into measurable questionnaire domains and subsequently examined among a larger sample. Both phases consistently indicated that access to education and rehabilitation services for children with IDDs was influenced by interconnected financial, geographical, organizational, informational, social, and system-level factors. The integration further showed that while parents actively advocated for their children, service access remained constrained by affordability, limited specialist availability, fragmented coordination, and inadequate system responsiveness.

Discussion

The present study examined parental experiences and factors influencing access to education and rehabilitation services for children with intellectual and developmental disabilities (IDDs) in Punjab, Pakistan. The qualitative and quantitative findings demonstrated that access is shaped by several interconnected structural, financial, geographical, service-related, and social factors. The overall quantitative mean (M = 3.96) indicated a high level of barriers, with financial and geographical difficulties emerging as the most prominent.

Financial and Geographical Barriers

Financial and geographical barriers ranked highest (M = 4.09), with therapy cost showing the strongest item-level difficulty (M = 4.42). Transportation expenses, travelling time, and distance from services also created substantial challenges. These findings corresponded with qualitative accounts in which parents reported reducing therapy sessions, discontinuing services, or travelling long distances to obtain specialized support. Similar barriers have been identified internationally. Banks et al. (2017) demonstrated a strong association between disability and poverty in LMICs, while Bright et al. (2018) identified treatment costs, transportation, and geographical distance as major obstacles to rehabilitation access. Mwangi et al. (2022) likewise reported that financial and geographical constraints limited healthcare utilization among children with disabilities. The results are particularly relevant to Punjab. Hameed and Manzoor (2016) identified considerable travel-related difficulties for Pakistani children with disabilities, while Malik et al. (2022) reported educational disadvantages among children with disabilities in rural Punjab. Haider et al. (2024) similarly found affordability and geographical accessibility to be important barriers for families of children with autism in South Punjab. Therefore, the existence of services does not necessarily ensure meaningful access when families cannot afford or regularly reach them.

System Responsiveness and Unmet Needs

System responsiveness and unmet service needs ranked second (M = 4.08). Parents reported delays in specialist services, ineffective referrals, inadequate follow-up, limited alternative services, and continuing unmet educational and rehabilitation needs. These findings show that gaining entry into a service does not necessarily mean that the child's needs are adequately addressed. Sapiets et al. (2021) conceptualized access as a pathway extending from recognition of need to actual receipt of appropriate intervention, with barriers potentially occurring at each stage. Htwe et al. (2024) similarly identified shortages of resources, weak service systems,

inadequate financing, and poor implementation as barriers to quality rehabilitation in LMICs. The findings also support Virani and Ali (2022), who identified inadequate teacher preparation, limited institutional support, and weak collaboration as barriers to meaningful inclusion in Pakistan. Kamran and Bano (2025) likewise reported persistent gaps between inclusive education policies and their implementation. Thus, service effectiveness should be judged not simply by enrolment or attendance but by timely referral, individualized support, continuity, and follow-up.

Service Navigation and Coordination

Service navigation and coordination also represented a high barrier (M = 3.99). Parents experienced difficulty obtaining reliable information, identifying appropriate services, and coordinating communication between schools, therapists, and healthcare professionals. In many cases, parents themselves became responsible for connecting otherwise separate service providers.

These findings agree with Sapiets et al. (2021), who identified information, communication, referral systems, and service responsiveness as major influences on access. Acar et al. (2021) also emphasized the central role of parents in developmental disability services. However, parental involvement may become an additional burden when families are required to perform coordination responsibilities that should be addressed within formal service systems. Evidence from Pakistan also supports these findings. Minhas et al. (2015) reported delayed recognition, poor awareness, and difficulties locating specialist services, while Lakhani et al. (2024) emphasized the importance of coordinated formal and informal support. The present findings therefore indicate a need for clearer referral pathways and better coordination between education and rehabilitation sectors.

Availability and Quality of Services

Availability and quality of education and rehabilitation services showed a high mean score (M = 3.98). Difficulty locating appropriately trained professionals was particularly prominent (M = 4.34), followed by limited availability of rehabilitation and therapy services (M = 4.28). Parents also reported inadequate individualized attention, waiting periods, and discontinuity of services. These findings are consistent with Bright et al. (2018), Adugna et al. (2020), and Htwe et al. (2024), who identified shortages of trained professionals, inadequate infrastructure, and limited rehabilitation capacity across LMICs. In Pakistan, Virani and Ali (2022) reported that inadequate teacher competence and institutional support limited successful inclusion, while Kamran and Bano (2025) highlighted insufficient professional development and institutional preparedness.

The findings demonstrate that school admission alone is insufficient for children with IDDs. Children may require specialized educational strategies, speech and occupational therapy, psychological support, and individualized intervention. Consequently, the quality, continuity, and appropriateness of services are as important as their physical availability.

Social and Family Influences

Social and family barriers recorded the lowest mean (M = 3.53), although they remained important. Parents described stigma, negative community attitudes, misconceptions regarding disability, and occasional discouragement from relatives. At the same time, supportive family members facilitated access through practical, financial, and emotional assistance. Mitter et al. (2019) found that families of individuals with intellectual disabilities and autism commonly experience stigma and discrimination. Adugna et al. (2020) also identified cultural beliefs and inadequate awareness as barriers to service utilization. Similarly, Lakhani et al. (2024) demonstrated that social networks in Pakistan can function as both sources of support and sources of stigma. The comparatively lower mean for this factor suggests that structural problems may be more influential than social resistance alone. Many parents actively sought services despite stigma but remained constrained by affordability, distance, poor coordination, and shortages of specialists.

Parental Advocacy and Family-Centered Support

The qualitative findings demonstrated that parents actively searched for services, communicated with professionals, requested referrals, and sought assistance from other families. This supports Acar et al. (2021), who identified parental involvement as an essential element of developmental disability services. Research from South Asia also demonstrates the potential value of family-centered approaches. Hamdani et al. (2015), Rahman et al. (2016), and Hamdani et al. (2017) demonstrated that parent-mediated and community-based interventions can increase access to developmental support in Pakistan. Koly et al. (2021) further reported positive effects of parent-mediated interventions on parental knowledge, communication, and child development. However, parental involvement should complement rather than replace professional services. Families require affordable services, trained professionals, effective referral systems, and institutional support rather than being expected to compensate for weaknesses in the formal service system.

Conclusion

The present sequential exploratory mixed-methods study concluded that parents of children with intellectual and developmental disabilities in Punjab experience substantial and interconnected barriers in accessing education and rehabilitation services. The overall findings showed that financial and geographical barriers were the most prominent, followed by system responsiveness and unmet service needs, difficulties in service navigation and coordination, and limitations in the availability and quality of services. Social and family barriers were comparatively less prominent but remained relevant. The findings further demonstrated that the existence of services alone does not ensure effective access. High therapy costs, transportation difficulties, long travel distances, shortages of trained professionals, fragmented referral pathways, inadequate coordination, and limited individualized support frequently restricted families' ability to obtain and maintain appropriate services. At the same time, parents demonstrated strong advocacy and actively searched for educational and rehabilitation opportunities for their children. Overall, the study concludes that improving service access in Punjab requires a coordinated,

affordable, geographically accessible, family-centered, and professionally strengthened system that integrates education, rehabilitation, healthcare, and community support. Such improvements are essential for reducing inequalities and ensuring that children with IDDs receive timely, continuous, and needs-responsive services.

Recommendations

Based on the findings of the study, the following recommendations are proposed:

1. **Improve affordability of services:** Government and relevant agencies should expand subsidized or low-cost education, therapy, assessment, and rehabilitation services for children with IDDs, particularly for low-income families.
2. **Increase services at district and community levels:** Rehabilitation centers, therapy services, and special education support should be expanded beyond major urban areas so that families in rural and remote districts can access services without excessive travel, transportation costs, and loss of working time.
3. **Strengthen the specialist workforce:** More trained speech therapists, occupational therapists, psychologists, special educators, and other rehabilitation professionals should be recruited and retained, with regular professional development to improve the quality of individualized support.
4. **Develop an integrated referral and coordination system:** Education, healthcare, and rehabilitation providers should establish clear referral pathways and mechanisms for sharing relevant information so that parents are not solely responsible for coordinating services.
5. **Establish parent guidance and information services:** Easily accessible information centers, helplines, or district-level support desks should provide parents with reliable information about assessment, schools, therapies, financial assistance, and available rehabilitation services.
6. **Promote family-centered and individualized services:** Parents should be actively involved in assessment, educational planning, rehabilitation decisions, and progress review, while services should be tailored to the specific developmental and functional needs of each child.
7. **Strengthen community awareness and parent-support networks:** Awareness programs should address stigma and misconceptions about developmental disabilities, while parent-support groups and community-based programs should be encouraged to provide information, emotional support, and practical guidance to families.

References

1. Acar, S., Chen, C.-I., & Xie, H. (2021). Parental involvement in developmental disabilities across three cultures: A systematic review. *Research in Developmental Disabilities, 110*, 103861. https://doi.org/10.1016/j.ridd.2021.103861
2. Ademosu, T., Ebuenyi, I., Hoekstra, R. A., Prince, M., & Salisbury, T. (2021). Burden, impact, and needs of caregivers of children living with mental health or neurodevelopmental conditions in low-income and middle-income countries: A scoping

review. *The Lancet Psychiatry*, *8*(10), 919–928. https://doi.org/10.1016/S2215-0366(21)00207-8

3. Adugna, M. B., Nabbouh, F., Shehata, S., & Ghahari, S. (2020). Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: A scoping review. *BMC Health Services Research, 20*, 15. https://doi.org/10.1186/s12913-019-4822-6
4. Banks, L. M., Kuper, H., & Polack, S. (2017). Poverty and disability in low- and middle-income countries: A systematic review. *PLOS ONE, 12*(12), e0189996. https://doi.org/10.1371/journal.pone.0189996
5. Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quiñonez, H. R., & Young, S. L. (2018). Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Frontiers in Public Health, 6*, 149. https://doi.org/10.3389/fpubh.2018.00149
6. Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in reflexive thematic analysis? *Qualitative Research in Psychology, 18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238
7. Bright, T., Wallace, S., & Kuper, H. (2018). A systematic review of access to rehabilitation for people with disabilities in low- and middle-income countries. *International Journal of Environmental Research and Public Health, 15*(10), 2165. https://doi.org/10.3390/ijerph15102165
8. Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and conducting mixed methods research* (3rd ed.). SAGE Publications.
9. Ghafoor, B. (2019). Problems faced by the parents of autistic children: A qualitative study in Punjab, Pakistan. *Rawal Medical Journal, 44*(3), 505–508.
10. Global Research on Developmental Disabilities Collaborators. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: A systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Global Health, 6*(10), e1100–e1121. https://doi.org/10.1016/S2214-109X(18)30309-7
11. Guetterman, T. C., Fetters, M. D., & Creswell, J. W. (2015). Integrating quantitative and qualitative results in health science mixed methods research through joint displays. *Annals of Family Medicine, 13*(6), 554–561. https://doi.org/10.1370/afm.1865
12. Haider, N., Amjad, F., & Chaudhry, H. (2024). Investigating barriers to healthcare access for parents of children with autism spectrum disorder in South Punjab, Pakistan. *International Journal of Trends and Innovations in Business & Social Sciences, 2*(2), 122–131. https://doi.org/10.48112/tibss.v2i2.796
13. Hamdani, S. U., Akhtar, P., Zill-e-Huma, Nazir, H., Minhas, F. A., Sikander, S., Wang, D., Servilli, C., & Rahman, A. (2017). WHO Parents Skills Training (PST) programme for children with developmental disorders and delays delivered by family volunteers in rural Pakistan: Study protocol for effectiveness implementation hybrid cluster randomized controlled trial. *Global Mental Health, 4*, e11. https://doi.org/10.1017/gmh.2017.7
14. Hameed, A., & Manzoor, A. (2016). Defeating inequalities in school access: A case of children with disabilities in Pakistan. *Journal of Research in Special Educational Needs, 16*(S1), 345–350. https://doi.org/10.1111/1471-3802.12158
15. He, C., Evans, N., Graham, H., & Milner, K. (2024). Group-based caregiver support interventions for children living with disabilities in low-and-middle-income countries: Narrative review and analysis of content, outcomes, and implementation factors. *Journal of Global Health, 14*, 04055. https://doi.org/10.7189/jogh.14.04055

16. Htwe, O., Yuliawiratman, B. S., Tannor, A. Y., Asikin, M. Z. N., Soh, E., de Groote, W., Naicker, M. S., & Naicker, A. S. (2024). Barriers and facilitators for increased accessibility to quality rehabilitation services in low- and middle-income countries: A systematic review. *European Journal of Physical and Rehabilitation Medicine, 60*(3), 514–522. https://doi.org/10.23736/S1973-9087.24.08154-1
17. Kajamaa, A., Mattick, K., & de la Croix, A. (2020). How to … do mixed-methods research. *The Clinical Teacher, 17*(3), 267–271. https://doi.org/10.1111/tct.13145
18. Kamran, M., & Bano, N. (2025). A systematic review of literature on inclusive education with special emphasis on children with disability in Pakistan. *International Journal of Inclusive Education, 29*(7), 1078–1096. https://doi.org/10.1080/13603116.2023.2256321
19. Khraisat, O. M., & Al-Bashtawy, S. (2023). Application and use of Andersen's Behavioral Model as theoretical framework: A systematic literature review from 2012–2021. *Iranian Journal of Public Health, 52*(7), 1346–1354.
20. Knekta, E., Runyon, C., & Eddy, S. (2019). One size doesn't fit all: Using factor analysis to gather validity evidence when using surveys in your research. *CBE—Life Sciences Education, 18*(1), rm1. https://doi.org/10.1187/cbe.18-04-0064
21. Koly, K. N., Martin-Herz, S. P., Islam, M. S., Sharmin, N., Blencowe, H., & Naheed, A. (2021). Parent mediated intervention programmes for children and adolescents with neurodevelopmental disorders in South Asia: A systematic review. *PLOS ONE, 16*(3), e0247432. https://doi.org/10.1371/journal.pone.0247432
22. Lakhani, A., Ali, T. S., Kramer-Roy, D., & Ashraf, D. (2024). Informal social support for families with children with an intellectual disability in Karachi, Pakistan: A qualitative exploratory study design. *Heliyon, 10*(20), e39221. https://doi.org/10.1016/j.heliyon.2024.e39221
23. Lederle, M., Tempes, J., & Bitzer, E. M. (2021). Application of Andersen's behavioural model of health services use: A scoping review with a focus on qualitative health services research. *BMJ Open, 11*(5), e045018.
24. Lohr, S. L. (2021). *Sampling: Design and analysis* (3rd ed.). CRC Press.
25. Malik, R., Raza, F., Rose, P., & Singal, N. (2022). Are children with disabilities in school and learning? Evidence from a household survey in rural Punjab, Pakistan. *Compare: A Journal of Comparative and International Education, 52*(2), 211–231. https://doi.org/10.1080/03057925.2020.1749993
26. Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research, 26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444
27. Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S. U., Leadbitter, K., Taylor, C., Aldred, C., Tariq, A., Tariq, M., Cardoza, P., Green, J., Patel, V., & Rahman, A. (2015). Parents' perspectives on care of children with autistic spectrum disorder in South Asia—Views from Pakistan and India. *International Review of Psychiatry, 27*(3), 247–256. https://doi.org/10.3109/09540261.2015.1049128
28. Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities, 89*, 10–21. https://doi.org/10.1016/j.ridd.2019.03.001
29. Mizunoya, S., Mitra, S., & Yamasaki, I. (2018). Disability and school attendance in 15 low- and middle-income countries. *World Development, 104*, 388–403. https://doi.org/10.1016/j.worlddev.2017.12.001

30. Mwangi, L. W., Abuga, J. A., Cottrell, E., Kariuki, S. M., Kinyanjui, S. M., & Newton, C. R. J. C. (2022). Barriers to access and utilization of healthcare by children with neurological impairments and disability in low- and middle-income countries: A systematic review. *Wellcome Open Research, 6*, 61. https://doi.org/10.12688/wellcomeopenres.16593.2
31. Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods, 16*, 1–13. https://doi.org/10.1177/1609406917733847
32. Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y
33. Rahman, A., Divan, G., Hamdani, S. U., Vajaratkar, V., Taylor, C., Leadbitter, K., Aldred, C., Minhas, A., Cardozo, P., Emsley, R., Patel, V., & Green, J. (2016). Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in South Asia in India and Pakistan (PASS): A randomised controlled trial. *The Lancet Psychiatry, 3*(2), 128–136. https://doi.org/10.1016/S2215-0366(15)00388-0
34. Sapiets, S. J., Totsika, V., & Hastings, R. P. (2021). Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review. *Journal of Applied Research in Intellectual Disabilities, 34*(3), 695–711. https://doi.org/10.1111/jar.12852
35. Singal, N., Sabates, R., Aslam, M., & Saeed, S. (2020). School enrolment and learning outcomes for children with disabilities: Findings from a household survey in Pakistan. *International Journal of Inclusive Education, 24*(13), 1410–1430. https://doi.org/10.1080/13603116.2018.1531944
36. Smythe, T., Zuurmond, M., Tann, C. J., Gladstone, M., & Kuper, H. (2021). Early intervention for children with developmental disabilities in low and middle-income countries—The case for action. *International Health, 13*(3), 222–231. https://doi.org/10.1093/inthealth/ihaa044
37. Terwee, C. B., Prinsen, C. A. C., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., Bouter, L. M., de Vet, H. C. W., & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient-reported outcome measures: A Delphi study. *Quality of Life Research, 27*, 1159–1170. https://doi.org/10.1007/s11136-018-1829-0
38. United Nations Children's Fund. (2021). *Seen, counted, included: Using data to shed light on the well-being of children with disabilities*. UNICEF.
39. United Nations Children's Fund. (2023). *In pursuit of education for all: Analysis of education for children with disabilities in selected countries in Asia and the Pacific*. UNICEF East Asia and Pacific Regional Office.
40. Upadhayay, N. B., & Kakar, Q. (2024). Access to schools and learning outcomes of children with disabilities in Pakistan: Findings from a household survey in four administrative units. *International Journal of Inclusive Education, 28*(9), 1635–1663. https://doi.org/10.1080/13603116.2021.2008535
41. Virani, Z., & Ali, N. H. (2022). Perceived challenges and parental involvement in inclusive education: An exploratory study of primary schools in Pakistan. *Journal of Education and Educational Development, 9*(2), 302–321. https://doi.org/10.22555/joeed.v9i2.669

42. Watkins, M. W. (2018). Exploratory factor analysis: A guide to best practice. *Journal of Black Psychology*, *44*(3), 219–246. https://doi.org/10.1177/0095798418771807
43. World Health Organization, & United Nations Children's Fund. (2023). *Global report on children with developmental disabilities: From the margins to the mainstream*. World Health Organization.
44. Yusoff, M. S. B. (2019). ABC of content validation and content validity index calculation. *Education in Medicine Journal*, *11*(2), 49–54. https://doi.org/10.21315/eimj2019.11.2.6