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## **From Diagnosis to Intervention: Lived Experiences of Parents and Professionals in Early Autism Services in Punjab**

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### **ABSTRACT**

This study explored the lived experiences of parents and professionals regarding early therapeutic services for children with Autism Spectrum Disorder (ASD) in Punjab, Pakistan. Guided by a qualitative research design within an interpretivist paradigm and hermeneutic phenomenology, the study aimed to understand how individuals construct meaning around diagnosis, intervention, and service delivery within a sociocultural context. Data were collected through semi-structured in-depth interviews with five parents of children with ASD and five professionals, including speech and language therapists, special education teachers, behavior therapists, and clinical psychologists across selected districts of Punjab. Thematic analysis revealed five interconnected patterns shaping ASD intervention experiences: emotional transition from diagnosis to acceptance, parental empowerment through active therapeutic involvement, persistent barriers to accessibility and service equity, systemic and institutional gaps in service delivery, and emerging narratives of transformation and hope. Findings indicated that parents initially experienced shock, denial, and self-blame, but gradually moved toward acceptance through therapy engagement and observable developmental progress in their children. A significant outcome was the transformation of parents into co-therapists, enhancing their confidence and involvement in home-based intervention. However, major challenges such as financial constraints, shortage of trained professionals, lack of standardized protocols, and urban–rural disparities continued to hinder service accessibility. Despite these limitations, both parents and professionals reported meaningful child progress, reduced stigma, and increasing awareness of autism within society. The study concludes that early intervention services in Punjab are shaped by a dynamic interaction of emotional, structural, and social factors, highlighting the need for policy reforms, expansion of community-based services, structured parent-training programs, and strengthened interdisciplinary collaboration to ensure equitable and effective ASD support systems in Pakistan.

**Keywords:** Autism Spectrum Disorder (ASD), Early Intervention, Parental Experiences, Hermeneutic Phenomenology, Therapeutic Services, Accessibility Barriers, Qualitative Study, Parent-Mediated Intervention, Pakistan.

### **Introduction**

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition marked by persistent difficulties in social communication and interaction, along with restricted and repetitive behaviors. These symptoms usually appear in early childhood and can significantly affect language, learning, and adaptive functioning. Communication



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impairment is especially important because early language delays are strongly linked with later educational, social, and independence outcomes. Early social communication difficulties are therefore considered key predictors of developmental progress, making early identification and intervention essential for children with ASD (Landa, 2018).

Globally, ASD affects approximately 1% of children, although prevalence varies according to diagnostic practices, awareness, and healthcare systems. Recent meta-analyses estimate prevalence between 0.6% and 1%, with rising figures mainly linked to improved awareness and broader diagnostic criteria rather than an actual increase in incidence (Talantseva et al., 2023; Zeidan et al., 2022). In South Asia, prevalence appears broadly similar to global estimates, but access to diagnosis and intervention remains limited. In Pakistan, reliable data are scarce due to underdiagnosis, weak surveillance, and stigma. Although many children are believed to be affected, only a small number receive formal diagnosis or structured support.

Awareness of ASD in Pakistan remains low among both the public and healthcare professionals. Studies from Karachi and Lahore show that many people have heard of autism, but understanding of symptoms, early warning signs, and referral pathways is limited (Rahbar et al., 2016). Families often consult general physicians or non-specialist providers first, causing delays in diagnosis and intervention. Misconceptions, stigma, and weak referral systems further reduce timely access to services (Minhas et al., 2015).

Early therapeutic intervention is widely recognized as the most effective approach for improving communication and social outcomes in children with ASD. Evidence suggests that interventions beginning in the preschool years lead to stronger developmental gains due to early neuroplasticity (Sandbank et al., 2020). Approaches focusing on joint attention, play, early language, and social communication produce lasting benefits (Landa, 2018). Parent-mediated and naturalistic developmental behavioral interventions are especially useful because they involve caregivers and embed learning into daily routines, improving both child outcomes and parental confidence (Schreibman et al., 2015; Fuller & Kaiser, 2020).

However, implementing such interventions in Pakistan remains difficult. Intensive therapies such as ABA require trained professionals and financial resources, which are often unavailable. Families, particularly mothers, face emotional stress, financial burden, and social isolation (Minhas et al., 2015). Services are concentrated in major cities such as Lahore, Karachi, and Islamabad, while rural areas remain underserved. Although recent policy initiatives in Punjab, including autism schools and resource centers, show progress, their impact is limited by workforce shortages and uneven service distribution.

In this context, the present study explores how parents and professionals in Punjab experience early therapeutic services for children with ASD. It examines diagnosis, access to intervention, therapy engagement, and communication development, while highlighting emotional adjustment, parental empowerment, and systemic barriers in resource-constrained settings.

### Research Objectives

To explore parents lived experiences from autism diagnosis to acceptance in the context of early intervention services in Punjab.

To examine how therapy involvement contributes to parental empowerment and active participation in supporting children with ASD.

To identify key barriers, facilitators, and systemic gaps in accessing and delivering autism services from both parental and professional perspectives.



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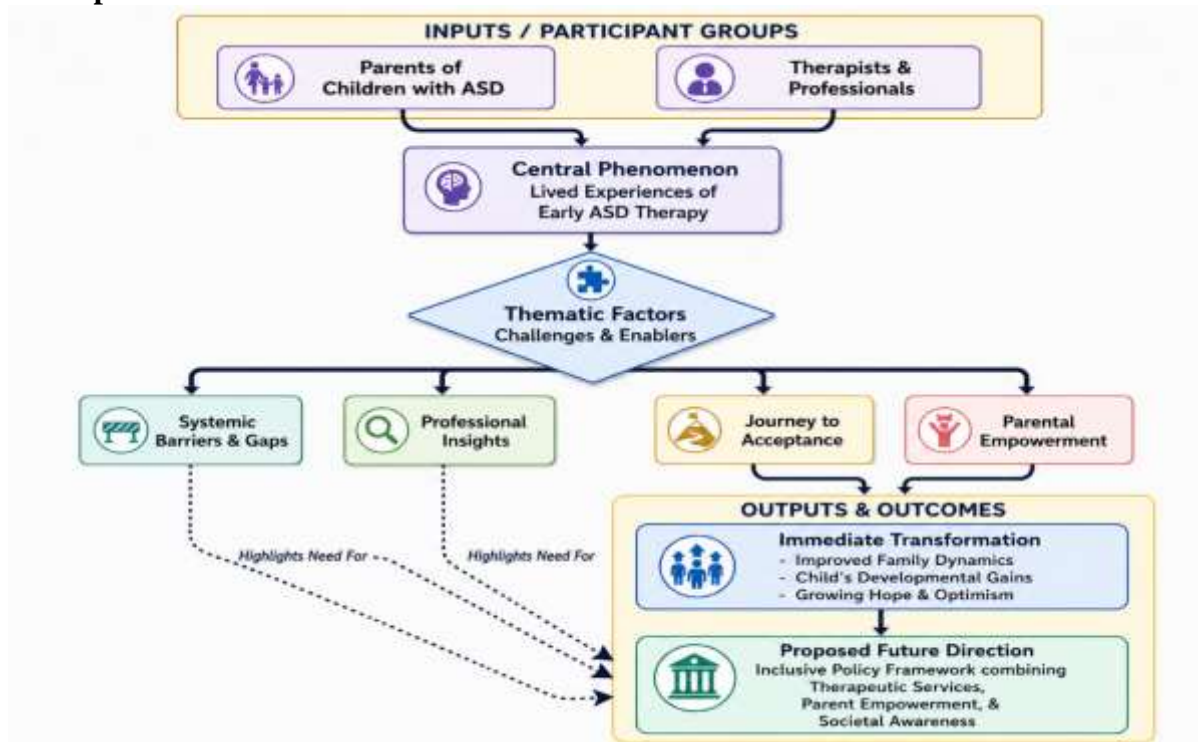
**Research Questions**

How do parents experience the journey from autism diagnosis to acceptance within the context of early intervention services in Punjab?

How does involvement in therapy influence parental empowerment and their role in supporting children with ASD?

What barriers, facilitators, and systemic gaps affect access to and delivery of autism services from parents’ and professionals’ perspectives?

**Conceptual Framework:**



**Figure 1: Conceptual Framework**

The conceptual framework of this study is grounded in the interpretivist paradigm and hermeneutic phenomenology. Interpretivism supports the framework because it views reality as socially constructed through participants’ experiences, meanings, and interactions (Creswell & Poth, 2023). Therefore, the framework begins with two key participant groups: parents of children with ASD and therapists/professionals. Their experiences provide the main source of understanding regarding early therapeutic services. The central phenomenon in the framework is the lived experience of early ASD therapy. This is linked with hermeneutic phenomenology, which focuses not only on describing experiences but also on interpreting how individuals make meaning from those experiences within their social and cultural context (Heidegger, 1962; van Manen, 2023). In this study, parents’ experiences of diagnosis, acceptance, emotional struggle, and empowerment are interpreted alongside professionals’ experiences of service delivery, institutional gaps, and therapeutic challenges.

The framework is also supported by existing ASD and early intervention literature, which emphasizes the importance of early diagnosis, family involvement, parent-mediated support, and interdisciplinary collaboration in improving developmental outcomes for children with ASD (National Research Council, 2001; Schreibman et al., 2015). The themes of parental empowerment, professional insight, systemic barriers, and



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journey to acceptance reflect these established ASD intervention principles. For example, parent participation is linked with improved family dynamics and stronger continuity of therapy at home, while professional collaboration is essential for effective service delivery. The framework further recognizes that access to ASD services is shaped by broader social and structural factors. Financial burden, urban–rural inequality, lack of trained professionals, and limited public awareness influence how families experience therapy. This aligns with ecological perspectives, which suggest that child development and family experiences are affected by multiple systems, including family, institutions, community, and policy structures (Bronfenbrenner, 1979).

### Literature Review

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition marked by persistent difficulties in social communication and interaction, along with restricted and repetitive behaviors. These features usually appear in early childhood and may affect language, learning, adaptive functioning, and social participation. Communication impairment is especially significant because early language delays are closely linked with later educational, social, and independence outcomes. Therefore, early social communication difficulties are not only symptoms of ASD but also important predictors of long-term developmental progress. Early identification and intervention are essential to support communication development and improve overall functioning in children with ASD (Landa, 2018).

### Global and Regional Context of ASD

Globally, ASD affects approximately 1% of children, although prevalence varies due to differences in diagnostic criteria, awareness, screening practices, and healthcare systems. Recent meta-analyses report prevalence estimates between 0.6% and 1%, with rising figures mainly attributed to improved awareness and broader diagnostic recognition rather than a confirmed increase in incidence (Talantseva et al., 2023; Zeidan et al., 2022). However, global estimates conceal major inequalities. High-income countries generally have more developed systems for screening, diagnosis, and early intervention, whereas low- and middle-income countries face underdiagnosis, limited professional capacity, weak surveillance, and poor access to services.

### ASD Awareness and Diagnosis in Pakistan

In Pakistan, reliable data on ASD remain limited because of underdiagnosis, weak monitoring systems, stigma, and lack of trained professionals. Although many children are likely affected, only a small proportion receive formal diagnosis or structured intervention. Studies from Karachi and Lahore show that public and professional awareness of autism is increasing, but understanding of early signs, symptoms, and referral pathways remains inadequate (Rahbar et al., 2016). Families often consult general physicians or non-specialist providers first, which delays diagnosis and reduces opportunities for timely intervention. These delays reflect broader systemic weaknesses, including poor developmental screening, limited referral mechanisms, and insufficient family guidance (Minhas et al., 2015).

### Importance of Early Therapeutic Intervention

Early therapeutic intervention is strongly associated with improved communication and social outcomes in children with ASD. Intervention during the preschool years is especially effective because early childhood is a period of heightened neuroplasticity



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(Sandbank et al., 2020). Strategies targeting joint attention, play, imitation, early language, and social engagement can support long-term communication development (Landa, 2018). Parent-mediated and naturalistic developmental behavioral interventions are particularly valuable because they integrate therapy into everyday routines and actively involve caregivers. Research shows that when parents are trained in modelling, prompting, reinforcement, and responsive communication, children receive more consistent learning opportunities, while parents gain confidence and self-efficacy (Schreibman et al., 2015; Fuller & Kaiser, 2020).

### **Service Gaps and Structural Barriers in Pakistan**

Despite strong evidence supporting early intervention, access to ASD services in Pakistan remains limited and unequal. Intensive therapies such as Applied Behavior Analysis require trained professionals, regular sessions, and financial resources, making them inaccessible for many families. Services are mostly concentrated in major urban centers such as Lahore, Karachi, Islamabad, and Rawalpindi, while rural areas remain underserved. Families from remote areas often travel long distances or rely on unqualified providers, resulting in delayed or inconsistent care. Caregiving responsibilities also fall heavily on mothers, who frequently experience stress, financial pressure, and social isolation (Minhas et al., 2015). Although recent initiatives in Punjab, including autism schools and resource centers, show policy progress, their impact remains restricted by workforce shortages, weak implementation, and uneven service distribution.

Within this context, the present study explores how parents and professionals in Punjab experience early therapeutic services for children with ASD. It examines diagnosis, access to intervention, therapy engagement, and communication development, while also considering emotional adjustment, parental empowerment, stigma, and systemic barriers. The study views parents not as passive recipients of services but as active participants in intervention, particularly in resource-constrained settings where formal support remains limited. Overall, the literature shows that early ASD intervention is most effective when it is timely, family-centered, evidence-based, and accessible; however, in Pakistan, these conditions remain difficult to achieve due to social, financial, and structural constraints.

### **Population and Sample**

The population of the study consisted of two groups:

Parents of children diagnosed with Autism Spectrum Disorder (ASD) who were receiving or had received early therapeutic services in Punjab, Pakistan.

Professionals working in the field of ASD and early intervention, including special education teachers, speech and language therapists, and behavior therapists working in autism centers and special education institutions.

These participants were selected because they were directly involved in or affected by early therapeutic service delivery for children with ASD. A purposive (criterion-based) sampling technique was used to select information-rich participants who had direct experience with early ASD intervention services.

### **Inclusion Criteria:**

Parents of children formally diagnosed with ASD and receiving at least six months of therapeutic intervention.

Professionals with a minimum of one year of experience working in ASD-related therapeutic or educational settings.



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Participants willing to share detailed lived experiences.

A total of 10 participants were included in the study, comprising five parents of children with autism and five professionals working in autism centres and special education institutions across Lahore, Gujranwala, Faisalabad, Multan, and Sargodha. This sample size was considered appropriate for a phenomenological qualitative study because the purpose was to explore participants lived experiences in depth rather than to generalize the findings to a larger population. Data saturation was achieved after 10 interviews, as no new themes emerged in the final two interviews, indicating that the collected data were sufficient to address the research objectives.

Participant ID	Category	Gender	Age Range	Role Profession	Experience / Child Details	Location
P1	Parent	Female	30–40	Mother of child with ASD	Child receiving early intervention (3 years)	Lahore
P2	Parent	Male	35–45	Father of child with ASD	Child in speech & ABA therapy (5 years)	Faisalabad
P3	Parent	Female	28–38	Mother of child with ASD	Child receiving speech therapy (4 years)	Multan
P4	Parent	Female	32–42	Mother of child with ASD	Child in multiple therapies (ABA, OT)	Gujranwala
P5	Parent	Male	36–46	Father of child with ASD	Child receiving early intervention (6 years)	Sargodha
PR1	Professional	Female	30–40	Speech Language Therapist	5 years experience in ASD intervention	Lahore
PR2	Professional	Female	28–38	Special Education Teacher	4 years experience in autism classroom	Faisalabad
PR3	Professional	Male	35–45	Behavior Therapist ABA Practitioner	6 years experience in ASD therapy center	Multan
PR4	Professional	Female	32–42	Clinical Psychologist	7 years experience in ASD assessment & therapy	Gujranwala
PR5	Professional	Male	33–43	Special Education	5 years' experience in	Sargodha



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Participant ID	Category	Gender	Age Range	Role Profession	/ Experience Child Details	/ Location
				Teacher	autism resource center	

### Research Tool / Instrument

Data were collected through **semi-structured in-depth interviews**. An interview guide was developed based on literature review and research objectives, focusing on:  
 Parents' emotional and experiential journey from diagnosis to intervention engagement  
 Accessibility and perceived effectiveness of therapeutic services  
 Professionals' experiences with service delivery and evidence-based practices  
 Barriers and facilitators in early intervention implementation  
 The interview guide allowed flexibility to explore emerging themes while ensuring alignment with research objectives.

### Data Collection Procedure

Interviews were conducted in person at autism centers and special education institutions, while some were held in quiet, convenient locations selected by participants. Each interview lasted approximately 30 to 60 minutes.  
 Participants were informed about the purpose of the study, and written informed consent was obtained prior to data collection. Interviews were conducted in Urdu and/or English depending on participant preference. All interviews were audio-recorded with permission and supplemented with field notes to capture non-verbal cues and contextual details.

### Data Analysis

Data were analyzed using **thematic analysis following the hermeneutic phenomenological approach**. The analysis followed a systematic process inspired by Braun and Clarke, including:

**Familiarization with data:** Repeated reading of transcripts to gain an overall understanding of participants' experiences.

**Initial coding:** Systematic identification of meaningful units of text relevant to the research questions.

**Theme development:** Grouping of codes into broader categories representing shared meanings.

**Reviewing themes:** Refinement of themes to ensure coherence and distinctiveness.

**Defining and naming themes:** Finalization of five overarching themes representing participants' lived experiences.

**Interpretation:** Themes were interpreted in relation to existing literature and the sociocultural context of ASD services in Punjab.  
 To enhance rigor, coding was conducted manually and reviewed multiple times by the researcher to ensure consistency and depth of interpretation.



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### **Trustworthiness of the Study**

The trustworthiness of the study was ensured through established qualitative rigor criteria, including credibility, transferability, dependability, and confirmability (Polit & Beck, 2021; Bradshaw et al., 2021).

**Credibility** was achieved through prolonged engagement with participants and member checking, where participants verified summarized interpretations to ensure that their experiences were accurately represented.

**Dependability** was ensured by maintaining a detailed audit trail of data collection, coding, and theme development, which supported transparency and consistency in the research process (Nowell et al., 2020).

**Confirmability** was maintained through reflexive journaling and continuous self-reflection to reduce researcher bias and ensure that findings were grounded in participants' narratives rather than personal assumptions (Korstjens & Moser, 2021).

**Transferability** was supported through rich contextual descriptions of participants' lived experiences, service settings, and therapeutic environments in Punjab, allowing readers to assess relevance to similar contexts (Bradshaw et al., 2021).

### **Ethical Considerations**

Ethical approval was obtained from the Institutional Review Board of the University of Education, Lahore before data collection, ensuring adherence to ethical standards (Barrow, 2022). Participation was voluntary, and informed consent was obtained from all participants after explaining the study purpose, procedures, and their rights (Xiao et al., 2023). Confidentiality and anonymity were maintained by assigning participant codes instead of real names. Participants were also assured of their right to withdraw at any stage without consequences. All data were securely stored and used strictly for academic purposes (Dougherty, 2021).

### **Data Analysis**

Hermeneutic phenomenological analysis was used to interpret the lived experiences of parents and professionals involved in early therapeutic services for children with Autism Spectrum Disorder (ASD) in Punjab. This interpretive qualitative approach focuses on understanding how individuals make meaning of their experiences within social and cultural contexts. It goes beyond description by emphasizing interpretation through participants' narratives and the researcher's reflexive engagement with the data (Creswell & Poth, 2023; Bradshaw et al., 2021). Data analysis followed an iterative process of repeated transcript reading, coding meaningful segments, and organizing codes into broader interpretive themes. As a result, five interrelated themes were developed, reflecting participants' experiences of emotional struggle, empowerment, systemic barriers, and emerging hope within early ASD service delivery in Punjab.

### **Theme 1: Journey from Diagnosis to Acceptance**

Parents described the journey from diagnosis to acceptance as an emotionally challenging but gradually transformative process. The initial diagnosis of autism often created feelings of shock, confusion, denial, and self-blame. However, over time, professional counselling, repeated explanations, therapy sessions, and visible developmental progress helped parents understand autism more clearly. This gradual understanding supported their emotional adjustment and encouraged them to participate more actively in their child's therapeutic journey.

*"When the doctor told me my son might have autism, I felt my whole world collapse. For*



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*weeks, I searched for second opinions, hoping someone would say it was a mistake. But after joining therapy sessions and seeing how small improvements came, I finally accepted that this is part of our life journey. Acceptance brought peace and strength to move forward.” (Parent 3)*

A professional respondent also supported this finding by explaining that denial and guilt are common early responses among parents.

*“In my experience working with families, I have observed that most parents initially struggle with denial and guilt. However, when they are consistently guided and shown small developmental progress in their child, their perception gradually shifts from emotional distress to acceptance and active participation in therapy.” (PR5)*

This statement highlights the important role of professional support in helping parents move from emotional distress toward acceptance. It also shows that acceptance is closely linked with guidance and evidence of progress. When professionals explain the condition clearly and involve parents in therapy, parents become more confident and emotionally prepared to support their child.

### **Emotional Shock, Denial, and Self-Blame After Diagnosis**

At the time of diagnosis, many parents experienced disbelief, fear, and emotional pain. Some parents questioned the accuracy of the diagnosis, while others blamed themselves for their child’s condition. These reactions show that diagnosis is not only a medical event but also an emotional turning point for the family.

*“Most parents initially respond to the diagnosis with denial and emotional shock, and many begin by questioning the accuracy of the diagnosis or blaming themselves for their child’s condition.” (PR1)*

This quote indicates that denial and self-blame are common psychological responses among parents after diagnosis. Instead of immediately accepting autism, parents may first try to reject or reinterpret the diagnosis. This stage reflects their emotional struggle and lack of preparedness. Therefore, early counselling and sensitive communication by professionals are important to help parents process the diagnosis in a healthier way.

### **Emotional Struggle Transforming Through Professional Guidance**

Professional guidance played a key role in reducing parental guilt and confusion. Parents gradually began to understand autism when therapists explained the condition patiently and showed progress through small, achievable goals.

*“The therapist explained autism patiently and showed me progress through small goals. Over time, I stopped feeling guilty and started focusing on her happiness and learning.” (Parent 1)*

This quote shows how professional explanation helped the parent shift from guilt to constructive involvement. The parent initially viewed the child’s condition through self-blame, but therapy helped reshape this understanding. By focusing on small goals, the parent became more aware of the child’s abilities and progress. This reduced emotional burden and encouraged a more positive and supportive approach toward the child.

### **Acceptance Through Developmental Progress and Therapy Engagement**

Acceptance became stronger when parents observed gradual improvements in communication, behavior, and learning. These small developmental gains gave parents hope and helped them become more engaged in therapy.

*“When parents begin to observe even small developmental gains during therapy, their emotional resistance reduces significantly, and they gradually move toward acceptance*



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*and active participation in intervention.” (PR3)*

This quote suggests that progress, even when small, has a strong emotional impact on parents. Observing improvement helps parents understand that therapy can support their child’s development. As a result, parents move from fear and resistance toward hope, cooperation, and active participation. Therefore, acceptance can be understood as a gradual process shaped by professional support, therapy engagement, and visible developmental change.

### **Theme 2: Parental Empowerment through Therapy**

A recurring theme in the data was the sense of empowerment parents experienced when they became actively involved in their child’s therapy. Initially, many parents felt helpless and dependent on professionals, believing that only therapists could support their child’s development. However, through professional guidance, structured training, and participation in therapy sessions, parents gradually learned communication and behavior-management strategies. This involvement helped them move from passive observers to active contributors in their child’s progress.

*“Before therapy, I was helpless—I just waited for someone to fix my child. But when the therapist trained me to use play and gestures to teach words, everything changed. I now feel like a teacher at home. When he calls me ‘Amma’ during playtime, I know I am making a difference every single day.” (Parent 5)*

*“Parents are the most powerful part of therapy. When they participate, the progress doubles. I have seen mothers who were anxious and unsure become confident educators of their own children. Empowering parents is not an option; it is the heart of early intervention.” (PR3)*

These responses show that therapy not only supports the child’s development but also transforms the parents’ role and confidence. Parents began to understand that their involvement at home was essential for reinforcing therapeutic goals. The use of play, gestures, repetition, and daily interaction allowed them to support communication development in natural settings. As a result, parents developed emotional resilience and a stronger belief in their own ability to contribute meaningfully to their child’s learning.

### **Skill Development and Confidence Building**

Parents developed practical skills through continuous guidance from professionals. These skills included using play-based communication, encouraging verbal responses, managing behavior, and supporting learning through daily routines. As parents became familiar with these strategies, their confidence increased, and they felt more capable of helping their child outside formal therapy sessions.

*“When parents are actively trained in intervention strategies, they gain confidence and become more capable of supporting their child’s communication and learning at home.” (PR4)*

This finding suggests that professional training plays an important role in reducing parental helplessness. Instead of depending entirely on therapists, parents started applying learned strategies in the home environment. This shift strengthened their confidence and allowed therapy to continue beyond the clinical setting.

### **Becoming Co-Therapists**

Parental involvement also helped parents see themselves as co-therapists in their child’s developmental journey. By participating in therapy sessions and practicing strategies at home, parents felt emotionally connected to the child’s progress. Small improvements,



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such as learning a word or responding during play, became meaningful achievements for the whole family.

*“Now I feel like I am part of my child’s therapy. Every small word he learns at home feels like my achievement too.” (Parent 4)*

*“Parents become co-therapists when they are actively involved in intervention, which not only improves child outcomes but also strengthens parental engagement and emotional investment.” (PR5)*

Collectively, these quotations indicate that therapy empowered parents by giving them knowledge, practical tools, and emotional strength. Parents no longer viewed themselves as powerless or separate from the therapeutic process. Instead, they became active partners who could support communication and behavioral development at home. This transformation from helplessness to active participation reflects the central role of parental empowerment in early intervention.

### **Theme 3: Barriers to Accessibility and Service Equity**

Participants consistently identified financial limitations, shortage of trained therapists, and the urban–rural service gap as major barriers to accessing autism-related therapeutic services. These challenges were more severe for families living in rural areas, where specialized services, diagnostic facilities, and professional guidance were either limited or completely unavailable. In addition, lack of awareness and social stigma often delayed diagnosis and intervention, causing children to miss the benefits of early support.

*One parent described the financial and travel burden of accessing therapy:*

*“We travel almost three hours from our village to Lahore twice a week for therapy. The transport alone costs more than what we earn in a day. Sometimes I skip sessions because we cannot afford them. If centres were in smaller towns, many children like mine could get help sooner.” (Parent 3)*

A professional participant also highlighted the unequal distribution of autism services in Punjab:

*“In Punjab, services are concentrated in cities. Rural families face immense difficulties—no specialists, no screening tools, and no guidance. Parents often come after years of delay, when early improvement could have been possible if interventions were accessible at the right time.” (PR5)*

Collectively, these responses show that access to therapy is not only a clinical issue but also a social and economic concern. Families from rural or low-income backgrounds face multiple layers of difficulty, including travel costs, long distances, limited availability of professionals, and lack of local support systems. These barriers often interrupt therapy and reduce the chances of consistent intervention, which is essential for developmental progress.

### **Financial Burden of Therapy**

Families reported that the high cost of therapy sessions, transportation, and related expenses made regular access to services difficult. For many parents, therapy required not only money but also time, travel arrangements, and emotional effort. One parent explained:

*“Sometimes I skip sessions because we cannot afford them.” (Parent 3)*

This statement reflects how financial pressure directly affects continuity of therapy. Even when parents understand the importance of intervention, economic hardship may force them to miss sessions. As a result, children from financially weaker families may receive irregular support, which can slow their developmental progress.



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### Urban–Rural Service Gap

Participants highlighted a clear difference between urban and rural access to autism services. Most specialized services are located in major cities, while smaller towns and villages often lack trained therapists, screening facilities, and diagnostic support. One parent shared:

*“We live in a village where there is no proper therapist nearby. Every visit means travelling to the city, which takes the whole day. Because of distance and lack of transport, we sometimes miss sessions, even though we know how important regular therapy is for our child.”*

*(Parent 2)*

This response shows that distance and transport difficulties create major obstacles for rural families. The absence of local therapy centres forces parents to depend on urban facilities, making intervention irregular and stressful. The urban–rural gap therefore contributes to unequal access and delays in receiving timely support.

### Lack of Awareness and Delayed Intervention

Another important barrier was limited awareness about autism, especially at the community level. Parents often misunderstood early signs, assuming that delayed speech or unusual behavior would improve naturally with time. In some cases, families consulted general practitioners or local healers before reaching specialized services.

One professional participant explained:

*“Many families in rural areas do not recognize early signs of autism and often consult general practitioners or local healers first. By the time they reach specialized services, valuable early intervention time has already been lost, which affects the child’s developmental progress significantly.”* *(PR1)*

Similarly, one parent stated:

*“At first, we thought our child was just slow in speaking and would improve with time. We did not know it could be autism, and no one in our area guided us properly. We only realized the seriousness when he did not start speaking even after several years.”*

*(Parent 2)*

Another parent added:

*“We kept visiting different doctors and trying different treatments because no one clearly explained autism to us. If we had been told earlier, we could have started therapy much sooner and helped our child in a better way.”* *(Parent 5)*

Taken together, these quotations indicate that delayed intervention is strongly connected to lack of awareness, poor professional guidance, and limited community-level screening. Parents were not unwilling to seek help; rather, they lacked timely information and access to appropriate services. This finding highlights the need for affordable therapy centres, trained professionals in smaller towns, public awareness campaigns, and early screening systems to ensure more equitable access for children with autism.

### Theme 4: Professional Perspectives on Systemic Gaps

Therapists and special educators identified several systemic gaps that affect the quality of autism-related services. These included the absence of standardized protocols, limited professional training, lack of certification systems, inconsistent funding, and weak coordination among professionals. They emphasized the need for government-supported structures, autism-specific programs, and interdisciplinary collaboration.

One professional participant stated:

*“Most of us learned on the job; there is no proper certification system for autism therapy*



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*in Pakistan. We try our best, but without continuous professional development, it is hard to maintain quality. The system must invest in structured training and supervision.” (PR 1)*

Another professional explained:

*“There are government schools for special education, but autism-specific programs are missing. We need national guidelines, a referral system, and coordination among pediatricians, speech therapists, and psychologists who truly help these children. Right now, everyone works in isolation.” (PR5)*

Collectively, these views show that autism services in Pakistan require stronger institutional support. The lack of formal training and national guidelines may lead to inconsistent service quality. Similarly, weak coordination among professionals limits comprehensive care for children with autism. Therefore, structured training, supervision, referral systems, and autism-specific policies are essential to improve service delivery.

### **Theme 5: Transformation and Hope for the Future**

Despite many challenges, parents and professionals shared experiences of transformation, hope, and gradual social acceptance. Parents described how small developmental improvements in their children restored their confidence and motivated them to continue therapy. Professionals also observed that families are now becoming more open about autism, which reflects a slow but positive shift from stigma toward acceptance.

One parent shared an important moment of progress:

*“My son spoke his first clear word after one year of therapy. That single moment changed everything for us. I felt like all the sleepless nights were worth it. Now, I help new parents at the centre to believe that progress may be slow, but it comes if you stay consistent and hopeful.” (Parent 2)*

A professional participant also explained the importance of small developmental gains:

*“Even small improvements such as better eye contact, responding to name, or initiating basic communication are very meaningful milestones for parents. These gradual changes rebuild their hope and motivate them to remain consistent with therapy despite long challenges.” (PR1)*

Collectively, these responses show that progress in autism therapy may be gradual, but even small achievements can have a powerful emotional impact on families. Such improvements help parents regain hope and strengthen their commitment to regular intervention.

### **Growing Acceptance and Social Transformation**

Participants also highlighted a gradual change in family and community attitudes toward autism. Increased awareness helped reduce shame, fear, and social isolation. One professional participant observed:

*“Earlier, families used to hide children with autism, but now they come openly to our centers. I see mothers sharing tips, fathers joining sessions, and siblings getting involved. This is a transformation, when awareness becomes acceptance, and acceptance turns into collective action.” (PR 3)*

Similarly, one parent stated:

*“At first, I used to feel ashamed when taking my child outside, but with time and therapy support, I realized there is nothing to hide. Now I openly participate in sessions and even talk to other parents to encourage them.” (Parent 3)*

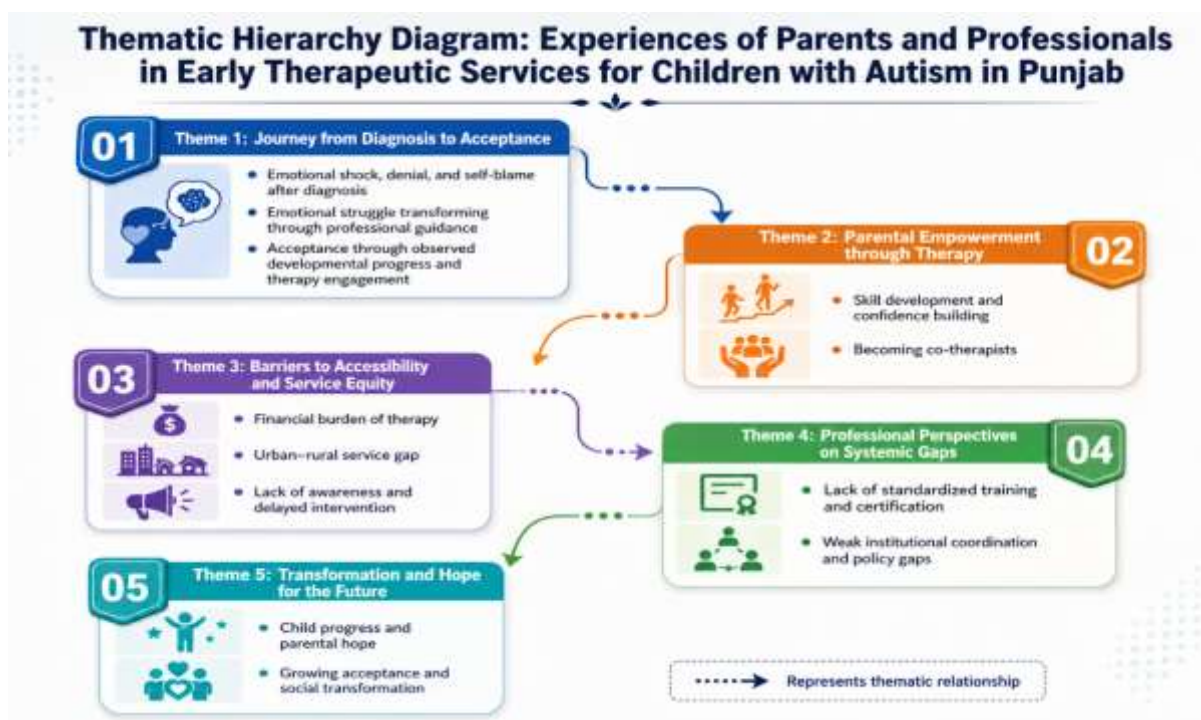
Another parent added:



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*“When we started therapy, I was very conscious about people’s reactions. But slowly I noticed that awareness is increasing in society, and people have started to understand autism better, which has reduced my fear of judgment.” (Parent 1)*

Together, these quotations indicate that awareness and therapy support are gradually changing how families and communities respond to autism. Parents are becoming more confident, families are participating more actively, and communities are slowly moving toward acceptance. This theme reflects hope for the future, where autism is understood with greater empathy and children receive more inclusive support.



**Figure 1;** *Thematic Hierarchy Diagram*

## Discussion

The findings show that parents and professionals in Punjab experience early ASD therapeutic services as emotionally challenging, socially influenced, and structurally limited. Parents initially reported shock, denial, guilt, and self-blame after diagnosis, gradually moving toward acceptance. This pattern reflects evidence that parents often experience grief-like responses, especially where awareness and counselling are limited (Papadopoulos & Kalyva, 2018). Delayed diagnosis and lack of professional guidance further increase distress in low-resource settings (Bashir et al., 2018). However, acceptance in this study developed mainly through continued therapy and visible child progress, supporting Karst and Van Hecke’s (2017) view that adaptation improves through psychoeducation and observable developmental gains.

Therapy also transformed parents from passive observers into active participants. By learning communication and behavior strategies, parents gained confidence in supporting their children at home. This aligns with evidence that parent-implemented interventions improve child outcomes and parental self-efficacy (Oono, Honey, & McConachie, 2017). Fuller and Kaiser (2020) similarly found that parent-mediated interventions improve expressive language and social communication when used consistently in natural settings. Parents’ role as co-therapists reflects empowerment through information, involvement, and increased control (Meadan et al., 2016; Peltekova et al., 2021).



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Despite these gains, major barriers remained, including financial burden, shortage of trained professionals, long travel distances, and unequal urban–rural service distribution. Such barriers are common in low- and middle-income countries (Divan et al., 2021). In Pakistan, ASD services remain concentrated in urban centers, leaving rural families with limited support (Haider et al., 2024). This delays intervention despite evidence that early support improves developmental outcomes (Zwaigenbaum et al., 2019). Limited awareness and reliance on non-specialist advice further delay diagnosis and care, as seen across South Asia (Daniels & Mandell, 2020).

Professionals highlighted systemic weaknesses, including absence of standardized diagnostic protocols, limited training pathways, and weak interdisciplinary coordination. These findings align with Hossain et al. (2020), who note that informal training systems create uneven service quality in developing countries. Effective ASD intervention requires collaboration among therapists, educators, and medical professionals, yet this remains limited in resource-constrained settings (Lord et al., 2018). Stronger governance and training systems are therefore essential for sustainable ASD services in South Asia (Divan et al., 2021; Khan et al., 2019).

Despite these challenges, parents reported meaningful progress such as first words, improved eye contact, and better social responsiveness. These outcomes are consistent with evidence that early intervention improves communication, adaptive behaviour, and family well-being (Sandbank et al., 2020; Fuller & Kaiser, 2020). Many parents also moved from stigma and isolation toward advocacy, supporting research that awareness reduces stigma and improves family engagement (Cai et al., 2021).

### **Conclusion**

In conclusion, this study highlights that early therapeutic services for children with Autism Spectrum Disorder (ASD) in Punjab are shaped by a continuous interaction between emotional adjustment, parental empowerment, systemic constraints, and gradual social transformation. Parents move from initial shock and denial toward acceptance primarily through therapeutic engagement and visible developmental progress in their children, while professionals emphasize the critical role of structured guidance in facilitating this transition. Although significant barriers such as financial limitations, limited availability of trained professionals, and urban–rural disparities continue to restrict access to timely intervention, the study also demonstrates that involving parents as active co-therapists significantly enhances both child outcomes and parental confidence. Despite systemic gaps, emerging signs of hope, improved awareness, and gradual reduction in stigma indicate a positive shift toward inclusion and acceptance of autism in society. Overall, the findings underscore the urgent need for policy-level reforms, expansion of community-based services, standardized training frameworks, and stronger interdisciplinary collaboration to ensure equitable, sustainable, and effective ASD intervention services in Pakistan.

### **Recommendations & Future Directions**

Building upon the findings and discussion, several practical and research-oriented recommendations are proposed to enhance early therapeutic intervention for children with autism spectrum disorder (ASD) in Punjab, Pakistan.

Early therapeutic services should include parent-training, Urdu/Punjabi visual aids, and refresher sessions to support home-based therapy.

Community-based services, satellite centers, mobile outreach units, and trained community workers should be introduced to reduce the urban–rural service gap.



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A standardized certification and training system is needed for ASD therapists, speech-language pathologists, and behavior technicians.

Universities, NGOs, and government departments should promote evidence-based practices such as ABA, ESDM, and PECS.

Provincial autism initiatives should be regularly monitored and supported through dedicated budget lines for therapy, transport, and parent support.

Awareness campaigns through media, schools, mosques, and community leaders should reduce stigma and encourage early help-seeking.

Tele-therapy, parent webinars, progress-tracking tools, and local-language mobile apps should be used to improve access for remote families.

Future research should assess long-term outcomes, compare public and private service models, examine cost-effectiveness, and support a national ASD database.

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