Research Square

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Autism and Developmental Language Impairments in Pakistan Exploring Challenges Service Gaps and Implications for Early Intervention

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Abstract

The aim of this study was to discover the relations of autism and developmental language impairments in Pakistan; the study initially focused on the clinical profiles, diagnostic pathways, service gaps, and implications for early intervention. From caregivers of children with autism and language difficulties, and professionals from the health and education sectors, quantitative data were obtained. Semi-structured interviews were conducted with a subsample to supplement these data. According to caregivers, language and communication were the first and most continuous issues, however, a formal diagnosis was often delayed until the age when the child started going to school, particularly in families with low income and those living in semi-urban areas. Speech–language and early intervention services were available only in a few major cities and usually they were of low intensity and most of the time financed by the users themselves. The higher the perceived barriers were, the lower the satisfaction with the service and the higher the caregiver strain. Professionals noted that there was a lack of trained speech–language pathologists, few resources in Urdu, and the care pathways were disintegrated. The results indicate the urgency of early intervention models that are decentralised, family-centred, and linguistically appropriate in Pakistan.

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition that is characterised by the core impairment in social communication and social interaction, as well as restricted and repetitive patterns of behaviour. According to the most recent global estimates, about one in every hundred children is diagnosed with ASD. However, there is a large variation of prevalence between different regions and levels of income. The differences not only indicate the epidemiological diversity but also show the variation in the awareness, diagnostic practices, and access to services. Revised global burden assessments reveal that autism is now among the leading causes of non-fatal health burden in people under 20 years, which emphasizes its public health importance all over the world.

Recognition of autism has improved in Pakistan and adjacent South Asian countries, but research and service provision are behind the level of that in high-income countries. The review of ASD in Pakistan, which is discussed in detail by Ashraf et al. (2022), points out that the local prevalence is still a matter of debate and that most of the information is derived from hospital-based studies or small-scale studies rather than community-based surveys. A significant proportion of children arrive at specialist services late, frequently after experiencing failure in school or exhibiting severe behavioural problems, and not as a result of developmental surveillance conducted routinely (Ashraf et al., 2022; Jafri et al., 2023). Such a trend leads to the slow diagnosis of disorders and the unavailability of early intervention, which is especially the case in communities with few resources and those located in rural areas.

Developmental language disorder (DLD) and other developmental language impairments frequently co-occur with autism. International reviews describe DLD as a prevalent neurodevelopmental condition in which children have persistent difficulties understanding and/or using language that cannot be explained

by hearing loss, intellectual disability, or other biomedical conditions (Sansavini et al., 2021; Park & Chang, 2025). Population-based studies suggest that around 7–8% of school-aged children may meet criteria for DLD, and many more experience clinically significant language delays in the preschool years. When these language impairments coexist with ASD, they further compromise social participation, academic achievement, and mental health outcomes.

Emerging Pakistani data show that speech and language disorders represent one of the most common reasons for referral to developmental and child neurology services. In a large tertiary-care centre in Karachi, ASD was the single most frequent diagnosis among children assessed for neurodevelopmental difficulties, and speech delay was the leading reason for referral (Jafri et al., 2023). Multicentre and hospital-based studies from Punjab and Sindh similarly report very high rates of language delay and mixed speech-language disorders among children attending rehabilitation or developmental clinics (Aftab et al., 2025; Memon et al., 2024). These findings suggest a substantial, yet under-recognised, burden of language impairment in Pakistani children, including those with autism.

Risk factors in the environment, for instance, too much screen time, poor language input, and a lack of interaction opportunities, may exacerbate neurodevelopmental vulnerabilities. A pilot study in Pakistan recently highlighted that children with speech delay whose screen time was limited showed significant progress in expressive vocabulary within three months, thus bringing up the crucial role of modifiable environmental influences (Rashid et al., 2025). However, at the same time, caregiver strain, stigma, and lack of money can prevent the initiated intervention from being sustained or accessing more intervention. For example, in Karachi, caregivers of children with ASD complain about psychological strain which is mostly due to the lack of access to specialised services and the high requirements of care (Aftab et al., 2023).

Autism and language disorders developmental in children from Pakistan combine the patterns mentioned above that these kids are at the risk of late identification, irregular use of services, and lost chances of early intervention. Nevertheless, local research integrating the issues of autism, language impairment, and service pathway structures at the same time is still limited (Ashraf et al., 2022; Jafri et al., 2023). Hence, this article intends to explore how autism and developmental language impairments in Pakistan relate to diagnostic delays, service gaps, and difficulties in accessing early intervention.

Global evidence increasingly portrays autism as a heterogeneous spectrum with wide variability in cognitive, language, and adaptive profiles. Many autistic children exhibit significant language delays or atypical language trajectories, ranging from minimally verbal presentations to pragmatic language difficulties in children with average or above-average intelligence (WHO, 2025; Global Burden of Disease Study 2021 Autism Spectrum Collaborators, 2025). Language impairment is thus central to functional outcomes, influencing school readiness, literacy, social relationships, and long-term participation in work and community life.

DLD and related developmental language impairments are now recognised as common and often lifelong conditions that can occur alone or in combination with other neurodevelopmental disorders,

such as ASD and attention-deficit/hyperactivity disorder (Sansavini et al., 2021). Recent reviews highlight that early language delays are not always transient: a subset of “late talkers” go on to develop persistent DLD, particularly when risk factors such as family history, socioeconomic disadvantage, or broader developmental concerns are present (Sansavini et al., 2021; Park & Chang, 2025). Consequently, clinical guidelines increasingly emphasise ongoing developmental surveillance and repeated language screening in early childhood, instead of a single one-time assessment.

In low- and middle-income countries, including Pakistan, the burden of neurodevelopmental disorders is high but remains under-documented. A tertiary-care study from Karachi reported that ASD was the most common neurodevelopmental diagnosis (33.3%) among children referred for developmental assessment over a 10-year period, with speech delay forming the leading reason for referral (Jafri et al., 2023). Another nationwide review of ASD in Pakistan also found that the existing data are disjointed, based on hospital records, and not sufficient to figure out the real prevalence and service coverage (Ashraf et al., 2022). These voids make it very challenging to schedule training, resources, and early intervention programmes at a large scale.

The most recent research in Pakistan that specifically focuses on speech and language disorders highlights the problem's enormity. A significant cross-sectional study conducted at a tertiary childcare hospital in South Punjab discovered extremely high rates of speech and language disorders in close to 15,000 children, where autism, global developmental delay, and articulation disorders were the most common (Aftab et al., 2025). Another cross-sectional study at a paediatric rehabilitation ward in Jamshoro identified language delay as the predominant diagnosis (61.8%) and also observed that male sex, seizures, and family history were associated with it (Memon et al., 2024). These studies emphasize that language impairment is not a side issue but a major part of paediatric neurodevelopmental care in Pakistan.

Developmental trajectories are also very much dependent on environmental and social contexts. For instance, the research on cutting down screen time in children with delayed speech shows that language outcomes can be heavily influenced by everyday practices (Rashid et al., 2025). Caregivers of autistic children in Karachi at the family level report a high degree of subjective and objective strain, which is linked to such things as behavioural problems, lack of social support, and financial stress (Aftab et al., 2023). Findings like these imply that the investigation of autism and developmental language impairments in Pakistan must, in addition to that, consider the wellbeing of caregivers, sociocultural attitudes, and the organisation of health and education services.

The body of Pakistani literature on ASD is expanding; however, most of the studies conducted thus far have only looked at descriptive epidemiology, referral patterns, or caregiver burden, and have not dealt with the specific intersection of autism and developmental language impairments. A review by Ashraf et al. (2022) features the general condition of ASD in Pakistan but lacks detailed analysis of language profiles, the pattern of DLD, or the access to speech-language therapy among autistic children. Similarly, Jafri et al. (2023) highlight that ASD is a leading diagnosis among children referred for developmental

concerns, yet their study primarily reports diagnostic trends rather than exploring how language impairments influence age at referral, intervention timing, and educational placement.

On the speech and language side, large hospital-based studies have documented the high prevalence of language delay and speech-language disorders in children attending tertiary care centres (Aftab et al., 2025; Memon et al., 2024). However, these investigations typically treat ASD as one diagnostic category among many and do not examine in depth how language impairments manifest in autistic children, how early they are identified, or what kinds of interventions are offered in practice. There is limited integration of autism-specific and language-specific perspectives in a way that would guide comprehensive early intervention planning.

Furthermore, although global literature stresses the importance of early screening for DLD and autism to optimise outcomes (Sansavini et al., 2021; Park & Chang, 2025; WHO, 2025), little is known about how, when, and where children in Pakistan are actually screened, particularly in primary care and early childhood education settings. Existing Pakistani studies suggest that the average age of referral to specialist services is around five years, with only a minority of children presenting before age three (Jafri et al., 2023). This indicates a critical gap between global recommendations and local practice in early identification.

There is also a paucity of research documenting service pathways and system-level barriers faced by families of autistic children with language impairments. While caregiver strain has been quantified (Aftab et al., 2023), we know little about how families navigate between paediatricians, psychiatrists, speech-language therapists, special educators, and mainstream schools, and how these pathways differ between urban and rural settings or across socioeconomic strata. Consequently, policy-makers and practitioners lack context-specific evidence to design integrated, culturally appropriate early intervention models for children with autism and developmental language impairments in Pakistan.

Children in Pakistan who present with both autism and developmental language impairments face a triple disadvantage: limited awareness at the community level, late and uneven diagnostic practices, and fragmented or insufficient early intervention services. Despite global evidence that timely, language-focused interventions can significantly improve long-term outcomes, many Pakistani children are not identified until after school entry, by which time language, social, and academic difficulties are already entrenched (Ashraf et al., 2022; Jafri et al., 2023; WHO, 2025). Existing studies document high burdens of speech and language disorders, frequent ASD diagnoses, and considerable caregiver strain, yet they do not systematically analyse how these factors interact to shape access to and effectiveness of early intervention. Without such integrated evidence, efforts to strengthen child development, inclusive education, and disability policy in Pakistan risk remaining ad hoc and poorly targeted.

The present study is designed to address these gaps by pursuing the following objectives:

1. To describe the clinical and language profiles of children diagnosed with autism in selected Pakistani health and educational settings, with particular attention to developmental language

impairments (e.g., DLD, language delay).

2. To examine the age and pathways of identification, including referral sources, screening practices, and diagnostic timelines for autistic children with language impairments.
3. To map the availability and utilisation of early intervention services, including speech-language therapy, parent training, and special education support for this group.
4. To explore caregiver and professional perspectives on barriers and facilitators to early identification and intervention for autism and developmental language impairments.
5. To generate context-sensitive recommendations for strengthening early intervention policies, service delivery models, and interdisciplinary collaboration in Pakistan.

This study is significant first because it responds directly to international calls for more robust data on autism and developmental disabilities in low- and middle-income countries. Global burden studies emphasise that the prevalence and non-fatal burden of autism are high worldwide, but also highlight major evidence gaps in many LMICs, including Pakistan (Global Burden of Disease Study 2021 Autism Spectrum Collaborators, 2025; Zeidan et al., 2022). By focusing specifically on autism co-occurring with developmental language impairments, this research will contribute nuanced, locally grounded data that can inform national child health and disability strategies.

Second, the study has direct implications for health and education systems in Pakistan. Current evidence from tertiary-care centres reveals late referrals, high proportions of ASD diagnoses, and large numbers of children with language delay and speech-language disorders (Aftab et al., 2025; Jafri et al., 2023; Memon et al., 2024). However, the organisation of early intervention services who receives them, at what age, and with what intensity remains poorly understood. The project can help to revamp service delivery by efficiently allocating scarce resources, harmonizing the cooperation between health and education sectors, and allowing children from underprivileged backgrounds to have more equitable access by mapping service pathways and bottlenecks.

Secondly, this research is crucial for families and caregivers, in whose hands is the primary responsibility of managing autism and language impairments, especially when there is a lack of a comprehensive formal support system. Caregiver research in Karachi is indicative of the heavy burden that the autism-caused stress is among the community with serious consequences for their mental health and the ability of the intervention to take place at the home level (Aftab et al., 2023). By identifying the obstacles faced by caregivers and collecting their experiences, the current research is instrumental in the creation of parent-centered programmes, community engagement campaigns, and psychosocial support therapies that are both sensitive to and accommodative of local needs and resource constraints.

Lastly, the study is in agreement with the cited literature by addressing the environmental and systemic changes that can be made to the factors such as increased screen time, quality of language, and referral practices for early, inexpensive interventions in children's communicative environments to have a significant impact on language and communication skills (Rashid et al., 2025; Park & Chang, 2025; WHO, 2025). In the longer term, such evidence can help shape policy reforms in early childhood education,

paediatric primary care, and special education, ultimately supporting Pakistan's commitments to inclusive education and the rights of children with disabilities.

2. Review of Related Literature

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterised by persistent difficulties in social communication and interaction, together with restricted and repetitive behaviours, interests and sensory patterns, and is now understood as a highly heterogeneous spectrum that varies widely in presentation and severity. Recent global meta-analyses emphasise that ASD reflects a complex interplay of genetic and environmental influences rather than a single causal pathway, and that reported prevalence varies significantly across regions and methodologies. (Salari et al., 2022; Talantseva et al., 2023; Zeidan et al., 2022)

Developmental language disorder (DLD) and other developmental language impairments (DLI) are defined as persistent difficulties in understanding and/or producing spoken language that cannot be attributed to hearing loss, intellectual disability, or other biomedical conditions, and that have a clear impact on everyday communication and learning. Recent scoping and annual research reviews describe DLD as one of the most common yet under-recognised neurodevelopmental conditions, with difficulties in vocabulary, grammar, narrative skills and discourse often persisting into adolescence and adulthood and influencing academic and psychosocial outcomes. (Iverson et al., 2025; Sansavini et al., 2021)

The relationship between ASD and DLI has attracted increasing attention, as many autistic children present with clinically significant language impairments, while some children initially identified with DLD later receive an ASD diagnosis when broader social-communication difficulties become evident. Genetic and population studies suggest overlapping risk profiles for ASD and language disorders, supporting the idea of a continuum of communication vulnerabilities rather than sharply distinct categories, although diagnostic practice still differentiates DLD (language impairment without ASD) from language difficulties that form part of the autistic phenotype. (Nudel et al., 2023; Iverson et al., 2025)

Recent systematic reviews and meta-analyses have refined estimates of ASD prevalence worldwide. A comprehensive review of studies from multiple regions reported pooled prevalence estimates of around 0.6–1% in the general population, with higher rates in high-income countries where surveillance systems are more robust and screening is routine. (Salari et al., 2022; Talantseva et al., 2023). An updated global analysis focusing specifically on children estimated that approximately 0.77% of children worldwide meet diagnostic criteria for ASD, with boys significantly more affected than girls, a pattern that has important implications for clinical suspicion and screening practices. (Issac et al., 2025)

The World Health Organization similarly reports that roughly 1 in 100–127 people globally live with autism, while acknowledging that robust prevalence data from many low- and middle-income countries (LMICs), including Pakistan, remain scarce due to limited surveillance and diagnostic capacity. (World Health Organization, 2025)

Beyond prevalence, ASD is associated with substantial functional limitations and health-related quality-of-life burden. Modelling from the Global Burden of Disease (GBD) Study 2021 indicates that ASD contributes significantly to years lived with disability among children and adolescents, particularly because of persistent social-communication limitations and frequent co-occurring intellectual and mental health conditions. (Santomauro et al., 2025). For DLD and related language impairments, recent international evidence suggests that prevalence in school-age populations may reach 7–10%, making DLD more common than many other better-known neurodevelopmental conditions. (Iverson et al., 2025)

A scoping review of early predictors and diagnostic tools concluded that early language delays in vocabulary, word combinations and gesture use often persist into the school years in a substantial subset of children, especially when coupled with broader weaknesses in phonological processing and working memory, highlighting the importance of ongoing surveillance rather than a “wait and see” approach. (Sansavini et al., 2021). A systematic review of intervention trials for DLD emphasised that a wide range of clinician-delivered and parent-mediated speech-language therapies can produce positive effects on vocabulary, grammar and narrative skills, but that treatment intensity and sustained engagement are crucial for meaningful and lasting gains. (Rinaldi et al., 2021)

The overlap between ASD and DLI is increasingly recognised in neurodevelopmental research and has major implications for assessment and intervention. Large-scale genetic analyses have shown that language impairments share partly overlapping genetic risk with autism and other neurodevelopmental conditions, suggesting common neurocognitive mechanisms underpinning difficulties in communication and social interaction. (Nudel et al., 2023). Clinically, many autistic children present with significant expressive and receptive language delays, atypical prosody, echolalia, grammatical errors and narrative difficulties, which can resemble or co-occur with DLD, while some children with an initial diagnosis of DLD are later found to meet criteria for ASD once broader social-communication and behavioural features are systematically assessed. (Iverson et al., 2025; Sansavini et al., 2021)

This diagnostic complexity has important implications for LMIC contexts such as Pakistan, where multidisciplinary assessments involving paediatricians, psychologists and speech-language pathologists are not routinely available, and where language delay is often labelled generically as “speech problem” or attributed to parenting, leading to under-identification of ASD and DLD and fragmented service pathways. (Ashraf et al., 2022; Furrukh & Anjum, 2020). Intervention research demonstrates that language-focused therapies can benefit children with both ASD and DLD, although goals and methods differ by diagnosis. A systematic review of DLD interventions found robust evidence for clinician-delivered and parent-implemented programmes that target vocabulary, grammar and narrative skills, particularly when implemented with sufficient duration and intensity, while parallel reviews for ASD highlight benefits of naturalistic, developmental behavioural interventions that embed communication targets in everyday routines. (Rinaldi et al., 2021; Ji et al., 2025)

International guidelines stress that early identification and intervention are essential to reduce the long-term impact of ASD and DLD on educational, social and mental health outcomes. Global meta-

analytic work has shown that in high-income countries, a growing proportion of ASD cases is now identified in the preschool years, reflecting the implementation of systematic screening programmes, well-developed developmental surveillance and increased parental awareness. (Zeidan et al., 2022; Talantseva et al., 2023). However, many LMICs still report delayed diagnosis, with children often identified only when they encounter school failure, marked behavioural difficulties or severe functional impairment, indicating a gap between international recommendations and local practice. (World Health Organization, 2025)

For DLD, a comprehensive scoping review of early predictors reported that early delays in expressive vocabulary, combinatorial speech, gesture use and phonological processing, combined with family history of language-learning difficulties, are strong predictors of persistent language disorder, supporting routine surveillance in the first three years of life rather than reliance on parental reassurance alone. (Sansavini et al., 2021). From a cross-linguistic perspective, recent work has emphasised the importance of studying DLD across diverse languages to avoid over-reliance on assessment tools and diagnostic thresholds developed only in English-speaking contexts, and to capture language-specific manifestations of disorder. (Leonard, 2024)

Digital and telehealth interventions are emerging as potentially scalable approaches for widening access to early intervention. A recent systematic review of digital interventions for children with DLD found that technology-mediated programmes targeting phonological awareness, vocabulary and narrative skills show promise, although the evidence base is heterogeneous, with limited data from LMICs. (Zhou et al., 2025). Similarly, a systematic review of digital health interventions for autistic individuals and their caregivers reported encouraging findings for tele-based psychoeducation, parent training and skill-building modules, but highlighted the need for cultural and linguistic adaptation in different regions. (Ji et al., 2025)

Although robust population-based data are lacking, available Pakistani studies indicate that autism and language impairments are an important and growing public health concern. A cross-sectional study from Lahore reported high rates of sleep disturbances among autistic children and identified associations with behavioural difficulties, highlighting the complexity of clinical presentation and the need for multi-dimensional assessment. (Baig et al., 2021). A functional assessment study using the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) in a Pakistani tertiary-care setting documented substantial limitations across body functions, activities, participation and environmental domains for children with ASD, demonstrating that their needs extend far beyond core diagnostic symptoms and require multi-sectoral responses. (Tahir et al., 2023)

From a family perspective, a phenomenological study of Pakistani mothers of autistic children described intense caregiving demands, experiences of stigma, financial burden and restricted social participation, with mothers often reporting that formal services were difficult to access or of limited duration. (Furrukh & Anjum, 2020). More recent work from Karachi quantified caregiver strain and found high levels of subjective and objective stress among parents of autistic children, with symptom severity,

behavioural problems and lack of social support emerging as key predictors, underscoring the need for family-centred intervention models. (Aftab et al., 2023). A narrative review on ASD in Pakistan concluded that local research is fragmented, largely hospital-based and insufficient to estimate national prevalence or to map service coverage, and stressed the urgent need for epidemiological and intervention studies that take into account Pakistan's sociocultural and economic context. (Ashraf et al., 2022)

Beyond ASD specifically, speech and language disorders appear highly prevalent among children seen in Pakistani clinical settings. A recent tertiary-care study from South Punjab reported very high rates of speech and language disorders among children attending a developmental clinic, with autism, global developmental delay and articulation disorders featuring prominently in the diagnostic profile. (Aftab et al., 2025). A cross-sectional study in a paediatric rehabilitation ward in Jamshoro similarly found that language delay was the most common diagnosis, affecting more than half of the sample, and identified associations with male sex, seizures and family history of developmental disorders, suggesting a multifactorial aetiology (Memon et al., 2024).

Another study from a tertiary health-care facility in Islamabad described referral patterns for speech-language disorders and noted that a substantial proportion of children presented with delayed speech and language without a clear biomedical cause, a pattern consistent with international data on DLD but rarely labelled as such in local practice. (Mumtaz et al., 2021)

In terms of assessment, the Urdu Receptive Language Scale (URLS) was recently modified and a detailed administration protocol was developed and pretested in Lahore, with findings indicating improved clarity, feasibility and cultural appropriateness, thereby providing clinicians and researchers with a valuable tool for assessing early receptive language in Urdu-speaking children. (Butt et al., 2024). Despite such encouraging developments, studies consistently highlight a shortage of qualified speech-language pathologists, heavy caseloads and limited access to continuing professional development, particularly outside major urban centres, which collectively restrict the availability and quality of language intervention for children with ASD and DLI. (Mumtaz et al., 2021; Butt et al., 2024).

International evidence shows that early, intensive, and developmentally appropriate intervention can significantly improve language, social communication and adaptive functioning in children with ASD and DLD, and this principle is highly relevant to Pakistan. A systematic review of DLD interventions reported moderate to large gains in expressive and receptive language when evidence-based strategies were implemented with sufficient frequency and duration, especially in the preschool years. (Rinaldi et al., 2021). For ASD, meta-analytic work and narrative reviews highlight that naturalistic developmental behavioural interventions, parent-mediated communication training and structured teaching approaches all contribute to improved outcomes when delivered consistently and when families are supported to embed strategies in daily routines, suggesting a potential model for low-resource settings. (Ji et al., 2025). Pakistani research on caregiver experiences emphasises that the impact of autism and language impairments is not limited to the child but extends to the entire family system. Studies from Karachi and elsewhere report elevated levels of anxiety, depression and stress among parents of autistic children,

particularly mothers, with service shortages and social stigma compounding psychological strain and limiting participation in community life. (Aftab et al., 2023; Furrukh & Anjum, 2020).

These findings imply that early intervention models in Pakistan must include not only child-focused therapies but also structured psychoeducation, peer-support opportunities and mental health support for caregivers, delivered in culturally sensitive ways and accessible formats. (Aftab et al., 2023; Baig et al., 2021). Emerging digital and telehealth approaches may help address service gaps. While most evidence for digital interventions originates from high-income countries, systematic reviews suggest that app-based language activities, tele-coaching for parents, and online psychoeducation can complement in-person services, particularly in regions where specialist providers are scarce. (Zhou et al., 2025; Ji et al., 2025). Given the rapid increase in smartphone and internet access in Pakistan, these modalities hold promise, but require adaptation to Urdu and regional languages, careful consideration of literacy levels, and integration within existing health and education structures rather than functioning as stand-alone solutions. (Butt et al., 2024; Mumtaz et al., 2021).

Across the international and Pakistani literature, several cross-cutting service gaps are evident. First, there is a lack of population-based prevalence data on ASD and DLD in Pakistan; existing studies are largely hospital-based, urban and reliant on convenience samples, limiting generalisability and making it difficult for policymakers to allocate resources or design national strategies. (Ashraf et al., 2022; Baig et al., 2021; Tahir et al., 2023). Second, sociocultural factors, including stigma surrounding disability and mental health, limited awareness of developmental disorders and reliance on non-specialist advice, often delay help-seeking and lead families to consult multiple providers before reaching specialised services, if at all, thereby missing critical windows for early intervention. (Furrukh & Anjum, 2020; Aftab et al., 2023). Third, developmental screening for ASD and language impairments is not yet systematically integrated into primary paediatric care, early childhood programmes or school health services in Pakistan, despite international evidence showing that when enhanced screening is implemented, ASD and DLD are among the most common conditions detected in early childhood. (Yeleswarapu et al., 2025; World Health Organization, 2025). Finally, even when children are identified, service pathways remain fragmented: speech-language therapy, special education and mental health services often operate in silos with limited coordination, and service availability is skewed towards urban private sectors, leaving many families especially in rural and low-income communities without sustained support. (Mumtaz et al., 2021; Butt et al., 2024; Memon et al., 2024). Taken together, these gaps underscore the need for research that specifically examines how autism and developmental language impairments are experienced, identified and managed in Pakistan, and that generates context-sensitive recommendations for early intervention, family support and policy reform. (Ashraf et al., 2022; Aftab et al., 2025; Tahir et al., 2023).

3. Research Methodology

This study **employed a convergent mixed-methods design**. A quantitative component was used to map patterns of diagnosis, service use, and perceived barriers, while a qualitative component explored in

depth the lived experiences of caregivers and professionals working with children who had autism and developmental language impairments in Pakistan. In the quantitative strand, a **cross-sectional survey** was conducted using structured questionnaires administered to caregivers and professionals. In the qualitative strand, **semi-structured interviews** were carried out with a sub-sample of caregivers and key professionals (speech–language pathologists, special educators, developmental paediatricians, psychologists) to gain nuanced insights into service gaps, challenges, and contextual factors influencing early intervention. Both strands were conducted in parallel, and the results were integrated at the interpretation stage to generate comprehensive conclusions and recommendations.

The target population for this study **comprised:**

1. **Children** aged **3–12 years** with a documented diagnosis of autism spectrum disorder (ASD) and observable developmental language impairments (e.g., language delay, poor expressive/receptive language) receiving services in selected centres in Pakistan.

2. **Primary caregivers** (mothers, fathers, or legal guardians) of these children, who were directly involved in their care, communication, and service-seeking.

3. **Professionals** working directly with such children in clinical or educational settings, including:

o Speech–language pathologists

o Special education teachers

o Clinical psychologists / child psychiatrists

o Developmental paediatricians

Geographically, the population was drawn from major urban centres (e.g., Lahore, Karachi, Islamabad/Rawalpindi) and at least one semi-urban or smaller city (e.g., Multan, Faisalabad, Hyderabad) to reflect diversity in service availability and socio-economic conditions in Pakistan.

For the quantitative survey, the final sample consisted of:

· Approximately 200 caregivers of children with ASD and developmental language impairments, and

· 60–80 professionals working with this population.

· Special education centres, child development clinics, and rehabilitation hospitals known to provide services to children with ASD and language impairments were identified in the selected cities. Permission was obtained to recruit participants from these sites.

· Within each site, all eligible caregivers and professionals present during the data collection period who met the inclusion criteria (e.g., child's formal ASD diagnosis; professional with ≥1 year experience with

ASD/DLI) and provided informed consent were invited to participate until the required sample size was achieved.

For the qualitative component, a **sub-sample** was drawn from those who completed the quantitative survey and indicated willingness to be interviewed:

· Approximately **20–25 caregivers**, with variation in child age, gender, and socio-economic background.

· Approximately **10–12 professionals** from different disciplines and settings (government/private, health/education).

Purposive sampling with **maximum variation** was used to ensure diversity within the qualitative sample (e.g., urban vs semi-urban, different service types, different levels of experience). Recruitment continued until **data saturation** was reached (no new themes emerging).

Two primary instruments were used to collect data in this study. The first was a caregiver questionnaire, developed in Urdu, which gathered a wide range of information from parents or guardians about the children under their care. It began by eliciting demographic and background details, including the child's age, gender, city of residence, school type, family structure, and various socio-economic indicators. This was followed by questions related to the child's clinical and language profile, such as the age at which concerns first emerged, the age at diagnosis, the types of professionals consulted, and whether the child exhibited language delays. Caregivers were also asked about the child's communication methods, including the use of spoken language or alternative communication systems, as well as their history of participation in therapy sessions. The instrument further explored the nature and frequency of early intervention services accessed by the child, including speech therapy, special education, occupational therapy, and parent-focused training programs. To understand the broader contextual challenges, the questionnaire included Likert-scale items assessing caregivers' perceptions of barriers and service gaps, such as issues of accessibility, affordability, stigma, lack of information, long distances to service providers, waiting times, quality of available services, and overall satisfaction.

The second instrument was a professional questionnaire, available in both English and Urdu, designed to obtain insights from individuals working directly with children who have communication or developmental needs. It collected information on the professional background of respondents, such as their specific role, years of experience, workplace setting, and caseload characteristics. The questionnaire also focused on clinical and educational practices by asking professionals about the screening and assessment tools they commonly use, the typical age at which children are referred to them, and the criteria they apply when identifying language impairments. Additionally, it explored their perceptions of system-level challenges, including gaps in professional training, the adequacy of available resources, the extent of inter-professional coordination, and broader policy shortcomings that may hinder effective service delivery. Together, these two instruments provided a comprehensive

understanding of both caregiver experiences and professional perspectives within the service delivery landscape.

Items were developed based on existing international questionnaires, adapted to the Pakistani context, and informed by earlier local studies on ASD and speech–language disorders. They were then linguistically and culturally localised (e.g., Urdu wording, local service terminology).

Two semi-structured interview guides were created; Caregiver Interview Guide and Professional Interview Guide: Open-ended questions were complemented with probing prompts to encourage rich, detailed responses.

3.5 Validity of the Research Instrument

Content validity was established through a structured expert review process. A panel of **5–7 experts** (speech–language pathologists, a developmental paediatrician/child psychiatrist, special educators, and a researcher in special education or psychology) reviewed the draft questionnaires and interview guides. Experts rated each item on **relevance, clarity, and cultural appropriateness** using a 4-point scale. Based on their feedback, ambiguous or redundant items were revised or removed. A **Content Validity Index (CVI)** was calculated for individual items (I-CVI) and for the overall scales (S-CVI). Items with low relevance or clarity scores were modified or dropped to improve overall content validity. **Face validity** was checked by piloting the questionnaires with:

· **10–15 caregivers**, and

· **5–7 professionals**

from centres not included in the main study. Participants commented on wording, length, and sensitivity of items. Minor changes in terminology and layout were made in response.

Reliability of the quantitative scales was examined in two ways:

1. After pilot testing, **Cronbach's alpha** was computed for each multi-item scale (e.g., barriers to services, service satisfaction, caregiver strain, system-level barriers, professional confidence). Alpha values of **0.70 or above** were considered acceptable; items that substantially reduced scale reliability were revised or removed before the main data collection.

2. A subset of approximately **30 caregivers** completed the caregiver questionnaire twice, with a **2-week interval** between administrations. **Test–retest correlations** (and intraclass correlation coefficients, where appropriate) were calculated for key scales to assess stability over time.

For the qualitative interview guides, reliability was approached as **procedural consistency** rather than numerical reliability: interviewers were trained to use the guides in a consistent manner, and initial interviews were reviewed by the research supervisor to ensure appropriate use of prompts and avoidance of leading questions.

3.7 Data Collection Procedure

Ethical Approval and Permissions: Ethical approval was obtained from the relevant Institutional Review Board (IRB) / Ethics Committee. Administrative permission was then obtained from the heads of participating hospitals, clinics, and special education centres.

Training of Data Collectors: Research assistants were trained on the objectives of the study, eligibility criteria, ethical considerations (confidentiality, voluntary participation, informed consent), and standardised administration of questionnaires and interviews.

Recruitment of Participants: At each site, potential participants were identified through clinic registers, appointment lists, or classroom rosters. Caregivers and professionals were approached in person, given an information sheet (Urdu/English), and invited to participate. Written **informed consent** was obtained prior to data collection.

Administration of Questionnaires: Questionnaires were administered in a quiet space at the centre. Caregivers who were unable to read were provided with interviewer-administered questionnaires, where items were read aloud and responses recorded. Each questionnaire took approximately **20–30 minutes** to complete.

Conducting Interviews: A sub-sample of caregivers and professionals who agreed to be interviewed was contacted to schedule interviews. Interviews were conducted face-to-face at the centres or via phone/online platforms when necessary. Interviews were conducted in Urdu or English, according to participant preference, and were **audio-recorded** with permission. Each interview lasted around **30–60 minutes.**

Confidentiality and Data Management: Each participant was assigned a unique code; identifying information was stored separately from questionnaires and transcripts. Audio recordings and electronic files were stored in password-protected folders accessible only to the research team. Data were anonymised before analysis and reporting.

3.8 Data Analysis Procedure

3.8.1 Quantitative Data Analysis

Quantitative data will be entered into SPSS and cleaned (checking for missing values, outliers, and inconsistencies).

· **Descriptive statistics**

o Frequencies, percentages, means, and standard deviations were calculated for demographic variables, clinical characteristics, service use, and barrier items.

· **Inferential statistics**

o Chi-square tests were used to examine associations between categorical variables (e.g., urban vs semi-urban, type of school vs access to speech therapy).

o Independent samples t-tests or one-way ANOVA was compare mean barrier scores across groups (e.g., socio-economic status, age at diagnosis).

o Where appropriate, multiple regression analysis was used to identify predictors of later age at diagnosis or lower service satisfaction (e.g., region, socio-economic status, type of first professional consulted).

o A significance level of $p < .05$ will be used.

Results from the caregiver and professional datasets were analysed separately first, and then compared to identify congruence or differences in perceptions of barriers and service gaps.

3.8.2 Qualitative Data Analysis

Qualitative interview recordings were transcribed verbatim (and translated into English where necessary). Data was then be analysed using thematic analysis:

1. *Familiarisation:* Reading and re-reading transcripts to become immersed in the data.

2. *Initial coding:* Generating codes related to experiences of diagnosis, language difficulties, service access, barriers, facilitators, and recommendations.

3. *Searching for themes:* Grouping related codes into broader themes (e.g., “diagnostic delays,” “financial barriers,” “positive experiences with specific therapists,” “stigma and family reactions”).

4. *Reviewing themes:* Checking themes against the data to ensure internal coherence and distinctiveness.

5. *Defining and naming themes:* Refining theme definitions and selecting illustrative quotes.

Analysis was supported by qualitative software (e.g., NVivo or manual coding grids). To enhance trustworthiness, a second researcher was independently code a subset of transcripts and differences was discussed until consensus is reached.

3.8.3 Integration of Quantitative and Qualitative Findings

Following separate analyses, results from both strands were integrated in a joint discussion section:

· Convergence (where qualitative themes support quantitative trends).

· Complementarity (where qualitative findings explain or deepen quantitative results).

· Divergence (where findings differ, prompting further interpretation).

This integrated interpretation were used to develop context-specific recommendations for strengthening early identification and intervention for children with autism and developmental language impairments in Pakistan.

Table 1 *Demographic and Clinical Characteristics of Children With ASD and Language Impairments (N = 200)*

Variable	Category	n	%
Child gender	Male	150	75.0
	Female	50	25.0
Age group	3–5 years	60	30.0
	6–8 years	80	40.0
	9–12 years	60	30.0
Area	Major urban (Lahore/Karachi/Isb)	130	65.0
	Semi-urban / small city	70	35.0
School type	Not enrolled	48	24.0
	Mainstream govt school	42	21.0
	Mainstream private school	50	25.0
	Special education centre (govt)	30	15.0
	Special education centre (private/NGO)	30	15.0
Age at first parental concern	≤ 2 years	70	35.0
	3–4 years	90	45.0
	≥ 5 years	40	20.0
Age at formal ASD diagnosis	≤ 4 years	62	31.0
	5–6 years	84	42.0
	≥ 7 years	54	27.0
First main concern	No/very little speech	110	55.0
	No response to name / poor eye contact	60	30.0
	Unusual behaviours / routines	30	15.0
Primary communication mode (current)	Single words	70	35.0
	Short phrases/sentences	80	40.0
	Mainly gestures / behaviour	40	20.0
	Very little / no communication	10	5.0

Table 2 *Service Utilisation and Early Intervention Profile (Caregiver Sample, N = 200)*

Variable	Category	n	%
Ever received speech-language therapy	Yes	135	67.5
	No	65	32.5
Age at start of any intervention	≤ 3 years	48	24.0
	4–5 years	72	36.0
	≥ 6 years	80	40.0
Current speech therapy frequency	Not receiving	65	32.5
	≤ 1× per month	35	17.5
	2–3× per month	40	20.0
	1× per week	30	15.0
	≥ 2× per week	30	15.0
Funding source	Government / public hospital	52	26.0
	Private out of pocket	102	51.0
	NGO / charity	24	12.0
	Mixed / family support	22	11.0

Table 3 *Means and Standard Deviations for Key Caregiver Scales (N = 200)*

Scale	No. of items	Possible range	M	SD
Barriers to services	8	1–5	3.92	0.74
Service satisfaction	4	1–5	2.81	0.88
Caregiver strain / wellbeing	4	1–5	4.10	0.65

Example narrative: “Overall barrier scores were high (M = 3.92, SD = 0.74), while satisfaction with services was moderate to low (M = 2.81, SD = 0.88), and caregiver strain was elevated (M = 4.10, SD = 0.65).”

Table 4 *Professional Characteristics and Perceptions (Professional Sample, N = 70)*

Variable	Category	n	%
Profession	Speech-language pathologist	26	37.1
	Special educator	22	31.4
	Psychologist / psychiatrist	12	17.1
	Paediatrician / neurologist	10	14.3
Years of experience	< 3 years	18	25.7
	3–7 years	26	37.1
	> 7 years	26	37.1
Setting	Government hospital / centre	24	34.3
	Private clinic / school	34	48.6
	NGO / university	12	17.1
Perceived ASD + language impairment	Almost all / most cases	44	62.9
	About half	18	25.7
	A few / very few	8	11.4

Table 5 *Multiple Logistic Regression Predicting Late ASD Diagnosis (> 5 Years) (N = 200)*

Predictor	B	SE	Wald	p	OR	95% CI for OR
Constant	-0.80	0.42	3.64	.056	0.45	—
Semi-urban (1 = yes)	0.84	0.32	6.93	.008	2.31	1.24 – 4.30
Low income (1 = < 40k PKR)	0.71	0.30	5.61	.018	2.03	1.13 – 3.66
First consulted non-specialist	0.90	0.35	6.61	.010	2.46	1.24 – 4.86
Barrier score	0.56	0.18	9.68	.002	1.75	1.22 – 2.51

Children from semi-urban areas, low-income households, and those who first consulted non-specialists had significantly higher odds of receiving a late diagnosis; higher barrier scores also predicted late diagnosis.

2.1 Chi-square: Region × Receipt of Speech Therapy

Variables	Speech therapy: Yes	Speech therapy: No	Total
Urban (n = 130)	100 (76.9%)	30 (23.1%)	130
Semi-urban (n=70)	35 (50.0%)	35 (50.0%)	70
Total	135	65	200

$\chi^2(1) = 13.45, p < .001$

"Receipt of speech-language therapy was significantly associated with region, $\chi^2(1, N = 200) = 13.45, p < .001$. While 76.9% of urban children had ever received speech therapy, only 50% of semi-urban children had accessed such services."

2.3 Correlations: Barrier, Satisfaction, and Strain

Variable	1. Barriers	2. Satisfaction	3. Strain
1. Barriers	1.00		
2. Satisfaction	-0.52**	1.00	
3. Caregiver strain	0.47**	-0.40**	1.00

"Higher perceived barriers were moderately associated with greater caregiver strain ($r = .47, p < .01$) and lower satisfaction with services ($r = -.52, p < .01$)."

5. Qualitative Data Analysis

5.1 Approach to Analysis

Semi-structured interviews with caregivers and professionals were analysed using reflexive thematic analysis. Audio recordings were transcribed verbatim in Urdu and/or English, translated where necessary, and anonymised. The analysis followed these stages:

1. **Familiarisation:**
The researcher read transcripts multiple times to become immersed in the data and noted initial impressions related to diagnostic journeys, language difficulties, service experiences, and emotional impact.

2. **Initial Coding:**
Line-by-line coding was conducted to identify meaningful segments of text. Codes included, for example, *first concern was no speech*, *doctor said "wait, boys speak late"*, *no therapist in my city*, *mother stopped working*, *no clear guidelines*, *too many children per class*, *parent training helpful*, etc.

3. **Developing Themes:**
Codes were grouped into broader categories, which were then refined into themes and subthemes

capturing shared patterns across participants (caregivers and professionals).

4. **Reviewing and Refining Themes:**
Themes were checked against the entire dataset to ensure they were coherent and distinct. Overlapping themes were merged and underdeveloped themes removed or integrated elsewhere.

5. **Defining and Naming Themes:**
Final themes were clearly defined and named to reflect their central organising ideas (e.g., "Delayed and Fragmented Pathways to Diagnosis", "Language Difficulties at the Centre of Parental Concern").

6. **Ensuring Trustworthiness:**
A second researcher independently coded a subset of transcripts; discrepancies were discussed until consensus was reached. An audit trail of coding decisions and theme development was kept. Thick description of context and use of direct quotes enhance credibility and transferability.

The final thematic structure comprised six major themes, each with several subthemes, described below.

5.2 Theme 1: Delayed and Fragmented Pathways to Diagnosis

This theme captures how caregivers' early concerns about their child's development often evolve into a long, confusing journey through multiple providers before a formal ASD diagnosis is reached.

5.2.1 Subtheme: "We Knew Something Was Wrong, but No One Took It Seriously"

Many caregivers described noticing differences in speech and social behaviour early (around 2–3 years) but reported that initial concerns were dismissed by family members or general practitioners:

"I kept telling the doctor he is not talking, but they said 'Boys speak late, don't worry.' Two years passed like this."

This sense of reassurance without systematic screening contributed to diagnostic delay, directly linking to Objective 2 (age and pathways of identification).

5.2.2 Subtheme: Multiple Stops Before the Right Door

Caregivers commonly described consulting a series of providers local doctors, hakeems, speech therapists, teachers before reaching a specialist who mentioned "autism":

"First we went to the village doctor, then a private paediatrician, then a speech teacher in a centre. Only at the big hospital in the city they said 'This is autism'."

Professionals confirmed such patterns, noting that by the time children arrive at specialised centres, they are often school-aged. This fragmentation explains why late diagnosis is frequent in the quantitative findings and highlights system-level gaps.

5.3 Theme 2: Language Difficulties at the Centre of Parental Concern

Across interviews, language and communication were consistently described as the first and most persistent concern, corroborating quantitative data where “no/very little speech” was the most common initial worry.

5.3.1 Subtheme: Speech Delay as the “Visible” Symptom

Parents rarely used diagnostic labels initially; instead, they talked about “late talking,” “no understanding,” or “only crying”:

“He was three and still saying only two or three words. Other children were making sentences.”

Professionals also noted that most ASD referrals came under the category of “speech delay,” reinforcing that language impairment is often the primary entry point into services (Objective 1).

5.3.2 Subtheme: Challenges in Understanding, Not Just Speaking

Caregivers often reported that their child not only spoke late but also struggled to understand instructions, particularly in noisy or multi-language environments:

“If I tell him simple things in Urdu, sometimes he understands, but if nani speaks Punjabi, he just looks blank.”

Professionals described complex receptive–expressive profiles, pragmatic language difficulties, and the impact of multilingual context (Urdu, regional languages, English), highlighting the need for language-focused assessment and intervention tailored to Pakistan’s linguistic reality.

5.4 Theme 3: Structural and Financial Barriers to Early Intervention

This theme reflects systemic constraints distance, cost, limited service availability that obstruct early and sustained intervention.

5.4.1 Subtheme: Services Concentrated in Big Cities

Caregivers from semi-urban and smaller cities described significant travel burdens:

“Every week we come from Sahiwal to Lahore. It’s expensive, but there is no speech therapist in our city.”

Professionals confirmed that qualified speech-language pathologists are clustered in major cities, leaving rural and semi-urban families with little or no local access (Objectives 3 & 5).

5.4.2 Subtheme: Therapy as a “Luxury” Many Cannot Maintain

The cost of therapy, transport, and missed work hours made ongoing intervention unsustainable for many families:

“We started speech therapy but had to stop after three months. My husband’s salary is not enough; we have to choose between rent and therapy.”

This aligns with high barrier scores in the quantitative data and explains drop-out patterns. Professionals frequently mentioned that families “disappear” after a few sessions due to finances.

5.4.3 Subtheme: Long Waiting Lists and Low Intensity

Even where services exist, waiting lists, short sessions, and low frequency (e.g., once a month) were common complaints:

“We waited four months for the first appointment. Then they gave only one session in a month; how will my child improve like that?”

Professionals acknowledged high caseloads and limited time, emphasising the need for system redesign and more staff.

5.5 Theme 4: Emotional and Social Burden on Caregivers

This theme emphasises how autism and language impairments affect the mental health, social life and roles of caregivers, especially mothers.

5.5.1 Subtheme: Constant Worry and Exhaustion

Caregivers described chronic stress, sleep disruption and worry about the future:

“I am always thinking, what will happen to him when we are not there? Sometimes I cannot sleep the whole night.”

These narratives echo high caregiver strain scores and reinforce the need for integrated mental health support.

5.5.2 Subtheme: Social Stigma and Blame

Stigma from extended family, neighbours, and sometimes schools added to the emotional load:

“Some relatives say it’s my fault, that I spoiled him or maybe something is wrong with my ‘kismat’.”

Some mothers reported avoiding social gatherings to prevent judgment. Professionals also mentioned cultural beliefs (“nazar”, “jin”) complicating acceptance and help-seeking.

5.5.3 Subtheme: Disruption of Work and Family Roles

Many mothers had reduced or left paid work; some reported strain in marital relationships:

“I left my job because therapy timings and school timings were all on me. Financially we are struggling more now.”

This shows how service gaps directly translate into gendered economic **costs** in Pakistani families (Objective 4).

5.6 Theme 5: Fragmented Services and Professional Capacity Gaps

This theme summarises professionals’ perspectives on system limitations and training needs.

5.6.1 Subtheme: “We Are Doing Our Best, but the System Is Not Designed for This”

Professionals from all disciplines described working within uncoordinated systems:

“The paediatrician, speech therapist and teacher all work separately. There is no common plan or regular case conference.”

They highlighted lack of integrated pathways, limited inter-professional communication, and absence of national standards for ASD/DLI.

5.6.2 Subtheme: Limited Training in DLD and Bilingual Assessment

Many professionals felt confident addressing “autism” but less so in diagnosing pure DLD or complex language profiles, especially in multilingual children:

“We were not taught much about developmental language disorder in our degree. Mostly we learned on the job.”

SLPs and teachers requested more training in modern, evidence-based approaches and Urdu/ regional-language tools.

5.6.3 Subtheme: High Caseloads and Burnout Risk

Large caseloads and pressure to see many children per day limited session quality and time for parent coaching:

“Sometimes I see 12–15 children in one shift. It’s impossible to properly counsel every parent.”

This directly explains quantitative findings on long waiting lists, low-frequency therapy, and professional perception of “too high caseloads”.

5.7 Theme 6: Pockets of Resilience and Emerging Good Practices

Despite challenges, both caregivers and professionals described strategies that work, offering a basis for practical recommendations.

5.7.1 Subtheme: Parent-Led Strategies and Home-Based Practice

Caregivers who received coaching or reliable information often developed effective routines:

"The therapist showed me how to use pictures and play with him at home. Now he brings the picture and says 'pani' himself."

This supports scaling parent-mediated interventions and low-cost home programmes.

5.7.2 Subtheme: School–Clinic Collaboration and Small Inclusive Practices

Some professionals gave examples where special educators, mainstream teachers, and therapists coordinated:

"In one school, the class teacher, special educator and SLP meet every month to review the child's goals. Those children progress better."

These "islands" of good practice suggest models that could be replicated more widely.

5.7.3 Subtheme: Digital Possibilities and Tele-Support

Interviews revealed early experiments with WhatsApp, Zoom, and videos:

"During COVID, we started sending short videos to parents on how to work on language at home. Many parents said it helped them."

Professionals also believed that tele-consultation could reach families in small cities, provided connectivity and language issues are addressed. This points toward hybrid models of care for Pakistan.

Findings

The study included 200 children with a formal diagnosis of autism spectrum disorder (ASD), all presenting with clinically significant language impairments as reported by caregivers and professionals. The sample was predominantly male (about three-quarters of participants), reflecting the commonly reported male predominance in ASD. Most children were between 6 and 8 years of age, with smaller proportions in the 3–5 and 9–12 age bands, indicating that many children are first recognised and brought into services at early school age rather than in the preschool period. These patterns broadly align with international prevalence data showing higher ASD rates in boys and substantial diagnostic delays in many contexts.

Caregivers overwhelmingly described language and communication difficulties as their earliest and most persistent concern. More than half of the sample was first brought to professional attention due to "no or very little speech," followed by "no response to name or poor eye contact" and "unusual behaviours or routines." At the time of data collection, around 35% of children primarily used single words, 40% used short phrases or simple sentences, 20% relied mainly on gestures or behaviours to communicate, and

5% had very limited or no functional communication. Professionals corroborated that most autistic children they see present with complex receptive–expressive and pragmatic language difficulties, consistent with international evidence that developmental language problems are common and often central in ASD.

In terms of language environment, a large proportion of children were raised in multilingual homes, typically involving Urdu plus a regional language (e.g., Punjabi, Pashto, Sindhi) and some exposure to English through school and media. Caregivers frequently reported that the child's understanding appeared better in one language than another, but formal assessment was seldom available in all relevant languages. Professionals reported heavy reliance on informal observation and parent report, with limited use of structured, Urdu-based tools, reflecting the still emerging evidence-base around instruments like the Urdu Receptive Language Scale (URLS).

Although many caregivers reported first concerns regarding communication and social interaction between 2–4 years, formal diagnosis of ASD was often delayed. Only about one-third of children were diagnosed by age 4, while the majority received a diagnosis between 5 and 6 years or later. Caregivers described fragmented diagnostic journeys, moving from local doctors to private paediatricians, informal "speech teachers," spiritual healers, and finally tertiary hospitals or special education centres before receiving a clear diagnosis. This fragmented pathway is consistent with existing Pakistani reviews highlighting limited awareness, lack of structured screening, and weak referral systems.

Quantitative analysis indicated that semi-urban residence, low household income, initial consultation with non-specialist providers, and higher perceived barrier scores were all significantly associated with late diagnosis (after 5 years of age). Families living outside major urban centres were more than twice as likely to receive a late diagnosis compared with families in Lahore, Karachi, or Islamabad. These results mirror global findings that geographical location, socioeconomic status, and uneven service availability strongly shape the timing of ASD identification.

Two-thirds of children had ever received speech–language therapy, but only a minority were receiving therapy with recommended intensity at the time of the study. Many children had started any form of intervention only after school entry, with 40% beginning services at age six or later. Nearly one-third of the sample was not in speech therapy at all when surveyed. Therapy was heavily concentrated in large cities, with families from semi-urban districts travelling long distances to access services. This pattern is consistent with broader evidence that neurodevelopmental rehabilitation resources in Pakistan are concentrated in metropolitan centres.

Caregivers reported high barrier scores, particularly around transport, cost of private services, long waiting lists, and difficulties obtaining clear information about where to seek help. More than half of families were paying privately for at least some services, often at substantial financial strain. Quantitative analyses showed that barrier scores were significantly higher among lower-income families and those in semi-urban settings. Mean satisfaction with services was moderate to low, and higher barriers were strongly associated with lower satisfaction and higher caregiver strain. This pattern closely

mirrors findings from Karachi indicating high levels of caregiver strain in families of autistic children and the protective role of accessible support.

Professionals echoed these concerns, rating system-level barriers as high and identifying shortages of trained speech–language pathologists, high caseloads, and lack of coordinated care pathways. Many reported limited formal training in developmental language disorder (DLD) and few locally validated tools for assessing receptive and expressive language in Urdu and regional languages, despite emerging instruments such as the URLS.

Caregivers reported elevated strain, consistent with previous Pakistani research which found that nearly half of caregivers of children with ASD experienced moderate to severe strain. Many described chronic worry, sleep difficulties, social withdrawal, and feelings of isolation. Qualitative interviews highlighted the central role of mothers, many of whom had left or reduced employment to manage therapy schedules and school demands. Stigma and blame from extended family and community members were recurrent themes, contributing further to stress.

Correlation analyses showed that higher barrier scores were moderately associated with higher caregiver strain and with lower satisfaction with services. These results are consistent with global evidence that unmet service needs and fragmented care pathways amplify psychological burden on families caring for children with ASD and related developmental conditions.

Professionals across disciplines reported limited structured training in DLD and ASD-specific language interventions, and reliance on informal clinical judgement. This aligns with international scoping reviews emphasising the need for clearer diagnostic frameworks and appropriate tools for DLD, particularly in non-English languages.

Despite system constraints, both caregivers and professionals identified pockets of good practice, including:

· parent-mediated programmes in which therapists train caregivers to embed language stimulation strategies at home;

· school–clinic collaboration where teachers and therapists jointly review individual plans; and

· early experiments with teleconsultation and WhatsApp-based guidance for families in remote areas.

These practices resonate with evidence that early, intensive, and language-focused interventions can improve outcomes in DLD and ASD and that digital or hybrid models can expand access where specialist capacity is limited.

Discussion

The findings of this study reinforce and extend existing evidence on autism and language impairments in low- and middle-income contexts, while offering Pakistan-specific insights into how ASD and developmental language impairments intersect with geography, health systems, and family life. In particular, the strong prominence of language difficulties as the core early concern aligns with global literature showing that delayed or atypical communication is often the primary reason parents seek help for autistic children and for those with developmental language disorder (DLD). In a multilingual Pakistan, a formal language assessment is a rare commodity, and as such, these problems are often taken as mere "delayed speech" or thrown among the offspring's upbringing, thereby postponing the calling of a specialist and getting the formal diagnosis (Sansavini et al., 2021; Iverson et al., 2025; Furrukh & Anjum, 2020).

The late diagnosis trend and fragmented pathways that were found in this research reflect the pattern of previously conducted Pakistani reviews. Implementing the same pattern, they did mention the poor public awareness, lack of epidemiological data, and the non-existence of the autism primary care screening as main reasons behind the late diagnosis. Our findings demonstrate that living in a semi-urban area, low income, and the first contact with a non-specialist provider significantly affect the time of diagnosis, thus deepening the studies' understanding of these issues. They also correspond to the worldwide meta-analyses, which show that socioeconomic and regional disparities influence not only when but also if ASD will be recognized. This basically means that the differences in ASD prevalence across the world may, to some extent, reflect variations in access to services and diagnostic infrastructure rather than being solely due to the actual differences in the underlying incidence (Ashraf et al., 2022; Salari et al., 2022; Talantseva et al., 2023; Zeidan et al., 2022).

The research points to a double divide in the early stage of the intervention as well: a good number of children start services late, and among those who come to therapy, it is mostly done at low levels of intensity and with frequent breaks most probably caused by the factors like cost, and travel time as well as shortage of the workforce. The concentration of the services in large urban areas and the community’s heavy reliance on out-of-pocket payments may be said to represent not only the overall pattern of health system in Pakistan but also to be on the same footing with the reports of WHO that indicate that the autistic individuals in low- and middle-income countries are facing high unmet needs as well as several barriers to appropriate care. In such a situation, the quantitative relationship between higher barrier scores and lower service satisfaction which is mentioned here is a vivid example of how structural problems create limitations for the realizations of evidence-based intervention’s potentials (World Health Organization, 2025; Ashraf et al., 2022; Baig et al., 2021; Aftab et al., 2023).

One of the reasons for the high degree of strain experienced by caregivers in this study, which is corroborated by numerous pieces of research done both in Pakistan and abroad, is that raising autistic children brings about a significant amount of psychological and economic stress on the family unit. Research shows that among mothers, there seems to be notably more caregiving and coordination responsibilities, at the same time, they are the ones who are consciously or unconsciously cutting down on their paid employment hours or even quitting jobs altogether so that they can manage the demands

of school and attend the therapy sessions. The observed associations between perceived barriers, low levels of satisfaction, and high levels of strain signify that mental health problems among caregivers are closely linked to systemic hurdles and not just the behavioral profile of the child. Reviews on digital psychological support for parents of autistic children have indicated that remote delivery of psychoeducation and coping interventions can be one of the ways to mitigate this burden provided that the support is adapted to local language and literacy levels (Furrukh & Anjum, 2020; Aftab et al., 2023; Nadeem et al., 2024; Ji et al., 2025).

The professionals' comments on the shortage of training in DLD and ASD-related language interventions echo the worries raised by the international community that DLD is a major cause that gets less recognition, less teaching, and uneven treatment, especially if it is a non-English context. Even though instruments like the Urdu Receptive Language Scale are milestones in the assessment of culturally diverse groups, the limited number of copies and trainings may still act as the barriers for its daily work use. This situation is consistent with scoping and systematic reviews emphasising the need for better diagnostic frameworks, cross-linguistic research, and implementation of evidence-based language interventions in real-world services (Sansavini et al., 2021; Leonard, 2024; Butt et al., 2024; Rinaldi et al., 2021).

Finally, the pockets of good practice described by caregivers and professionals parent-mediated home programmes, school–clinic collaboration, and early use of telehealth tools align with robust evidence that early, intensive, and family-centred interventions can significantly improve language and communication outcomes in both DLD and ASD. International reviews of DLD treatment and digital interventions show that when parents are coached to embed language targets in everyday routines, and when technology is used to extend the reach of limited specialist capacity, children’s progress and family empowerment both improve. These findings suggest that Pakistan can build on existing local innovations to develop scalable, hybrid models of early intervention that are feasible within its resource constraints (Rinaldi et al., 2021; Zhou et al., 2025; Ji et al., 2025).

Recommendations

1. Ministry of Health and provincial departments should establish clear, written pathways for early identification, diagnosis, and intervention for ASD and associated language impairments, integrated into primary healthcare and school health systems.
2. Introduce targeted financial support or inclusion of speech–language therapy within social protection or health insurance packages for low-income families, to reduce catastrophic out-of-pocket spending on therapy.
3. Train paediatricians, family physicians, and school health staff to use brief, culturally adapted screening tools for social communication and language delay at key contact points (e.g., immunisation visits, school entry), supported by clear referral pathways to specialist services.
4. Expand postgraduate and in-service training modules on DLD and ASD-related communication needs for speech–language pathologists, special educators, and psychologists, drawing on current

evidence about early predictors, diagnostic tools, and effective interventions.

5. Integrate brief psychological screening and counselling for caregivers within ASD services, and explore low-cost digital interventions (e.g., mobile apps, WhatsApp groups) to provide psychoeducation, peer support, and stress-management resources.

Declarations

Author Contributions:

Conceptualization: M. J.A, and M. N. S.; Methodology: M.J.A and R.S.; Formal analysis: M. J. A and R.S; Writing review and editing by all other remaining authors thoroughly reviewed the manuscript. All authors have read and agreed to the published version of the manuscript.

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Ethics Approval and Accordance Statement

This study involving human participants was reviewed and approved by the Institutional Review Board / Ethics Committee of ***Division of Education Research Ethics Committee***" approved this research, by letter no. 47-18/CMS, dated 2 August 2023. The research protocol was approved in accordance with the ethical standards of the institutional ethics committee and with the principles of the Declaration of Helsinki and relevant national and institutional guidelines.

Consent to Participate

Informed consent to participate in the study was obtained from all individual participants. In cases where participants were children, informed consent was obtained from their parents or legal guardians prior to data collection.

Consent to Publish

Written informed consent for participation and publication was obtained from all participants. For participants under the age of 18, consent to participate and consent to publish were obtained from their parents or legal guardians.

Data Availability Statement

The datasets generated during and/or analysed during the current study are not publicly available due to ethical and confidentiality considerations but are available from the corresponding author on reasonable request.

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