

PARENTAL EXPERIENCES AND SERVICE EXPECTATIONS FOR CHILDREN WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE CASE STUDY FROM SAMASTIPUR

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ABSTRACT

This qualitative case study explores parental experiences and service expectations for children with Autism Spectrum Disorder (ASD) in Samastipur, Bihar. Using in-depth interviews and case-based analysis, the study examines parents' perspectives on diagnosis, access to educational and therapeutic services, social acceptance, financial challenges, and caregiving responsibilities. The findings reveal significant barriers, including limited awareness, inadequate specialized services, delayed intervention, and emotional stress experienced by families. Parents expressed the need for affordable, accessible, and inclusive support systems, along with improved collaboration among schools, healthcare professionals, and community agencies. The study highlights the importance of family-centered interventions and policy measures to enhance the quality of life of children with ASD and their caregivers.

Keywords: Autism Spectrum Disorder, Parental Expectations, Inclusive Education, Qualitative Case Study.

Introduction

Education is globally recognized as a fundamental human right essential to personal development and societal progression. Every child possesses distinct intellectual abilities, communication patterns, learning styles, and emotional needs. However, children presenting with neurodevelopmental, physical, cognitive, or behavioral challenges require specialized educational, therapeutic, and environmental adaptations to achieve functional autonomy and educational equity. Among neurodevelopmental conditions, Autism Spectrum Disorder (ASD) has emerged as one of the most critical challenges within special education, clinical psychology, pediatric rehabilitation, and social policy. ASD is characterized by persistent impairments in social communication and interaction across multiple contexts, alongside restricted, repetitive patterns of behavior, interests, or activities. Because ASD manifests along a wide biological and clinical spectrum, no two individuals exhibit identical symptom profiles or functional capacities.

Globally, the reported prevalence of ASD has risen dramatically over recent decades, driven by expanding diagnostic criteria, enhanced clinical awareness, and improved early screening instruments. Diagnostic and Statistical Manual of Mental Disorders (DSM) formulations historically categorized conditions like Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) as distinct entities, whereas current diagnostic consensus conceptualizes these presentation patterns within a unified spectrum. Etiological research indicates that ASD is a highly heterogeneous neurodevelopmental condition driven by complex interactions between genetic susceptibility and environmental, prenatal, and neurobiological influences. High concordance rates among identical twins and identified genetic variations highlight strong hereditary underpinnings. Concurrently, prenatal risk factors—such as advanced parental age, maternal

immune activation, metabolic dysregulation like gestational diabetes, and environmental teratogen exposures—interact with genetic vulnerabilities to alter early neurodevelopment, synaptic connectivity, and sensory processing mechanisms.

The onset of ASD in early childhood initiates a profound, lifelong transformation in family dynamics. Primary caregivers, particularly mothers, experience elevated levels of parenting stress, psychological distress, financial strain, and existential anxiety regarding their child's ultimate functional independence and long-term care. While timely evidence-based interventions—such as speech and language therapy, occupational therapy, applied behavior analysis, and parent-mediated developmental approaches—significantly improve long-term functional trajectories, access to such resources remains deeply inequitable.

In developing nations like India, the burden of ASD is further complicated by systemic challenges. Low awareness, pervasive social stigma, inadequate diagnostic infrastructure, and a severe shortage of trained rehabilitation professionals create major barriers for families. While Tier-1 metropolitan centers in India have seen a growing concentration of specialized developmental clinics and private inclusive schools, semi-urban and rural districts—such as Samastipur in Bihar—continue to face structural service deficits. Families in these regions encounter late diagnoses, lack of post-diagnostic counseling, non-existent or fragmented therapeutic facilities, financial strain, and resistance to inclusive educational placement in local mainstream schools. Understanding the lived experiences, daily caregiving burdens, and expectations regarding educational and therapeutic services among parents in semi-urban contexts is critical for formulating contextually appropriate, family-centered policy interventions and equitable service delivery frameworks.

Literature Review

Literature on Autism Spectrum Disorder spans epidemiological studies, clinical etiologies, intervention methodologies, and caregiver experiences. Elsabbagh et al. (2012) examined global autism prevalence, highlighting wide variations across geographic regions driven primarily by diagnostic criteria availability, screening methodologies, and public health awareness, while emphasizing early identification as a critical determinant of developmental outcomes. Matson and Kozlowski (2013) documented the rapidly shifting epidemiology of ASD, emphasizing the high co-occurrence of intellectual disabilities, sensory processing alterations, and adaptive deficits that necessitate comprehensive, individualized assessment frameworks. Lord et al. (2018) synthesized clinical evidence regarding ASD diagnosis and management, concluding that the extreme heterogeneity of the spectrum demands tailored educational and therapeutic intervention strategies.

In the Indian context, Divan et al. (2020) conducted a scoping review of autism research, revealing that while literature on clinical profiles and screening tools has expanded, empirical research remains heavily concentrated in urban tertiary care hospitals, leaving semi-urban and rural populations underrepresented. Parental stress and family adaptation have also been extensively documented. Hayes and Watson (2013) conducted a meta-analysis showing that parents of children with ASD experience significantly higher stress levels than parents of neurotypical children or children with other developmental disabilities, with child behavioral problems and communication deficits serving as primary stress predictors. Karst and Van Hecke (2014) highlighted that long-term family adaptation depends heavily on available informal social support, functional family dynamics, and access to professional intervention services. Similarly, Ilias et al. (2018)

documented high rates of anxiety, depression, and caregiver burden among parents facing inadequate support infrastructure in low- and middle-income contexts.

Recent Indian research has highlighted the necessity and efficacy of parent-mediated and digital interventions. Kalorath et al. (2022) conducted a systematic review demonstrating that parent-mediated intervention programs in India significantly enhance children's communication, language, and adaptive behavior while improving parental competence. Yadav et al. (2026) developed the CARER program, a play-based, parent-mediated intervention designed for resource-constrained Indian settings, noting that caregivers expressed urgent unmet needs for psychoeducation, behavioral management training, and structured skill-building. Ravichandran et al. (2026) demonstrated that symptom severity directly predicts parental stress, underscoring the protective role of family-centered support frameworks. Furthermore, Chakkaraiappan et al. (2026) reviewed e-health and digital caregiver supports, concluding that telehealth solutions offer promising pathways to bridge service gaps in underserved regions where specialist healthcare professionals are scarce.

Research Gap

Despite the growing body of literature on ASD in India, existing studies present notable geographical and methodological limitations. Most Indian studies are quantitative, clinical, or epidemiological investigations conducted in major urban centers. There is a lack of qualitative empirical research examining the concurrent profiles of autistic children alongside the lived experiences, service access pathways, unmet needs, and expectations of parents in semi-urban and rural districts such as Samastipur, Bihar. Furthermore, few studies integrate both parental narratives and professional special educator perspectives within a localized district ecosystem. This study addresses these empirical gaps by exploring parental experiences and service expectations

in Samastipur

Objectives

1. To analyze the developmental, behavioral, communication, and functional profiles of children with Autism Spectrum Disorder in Samastipur.
2. To map the current landscape of educational, therapeutic, and support services available to autistic children and their families in Samastipur.
3. To examine parental experiences, emotional coping mechanisms, challenges, and unmet needs regarding diagnostic, therapeutic, and educational access.
4. To evaluate parental expectations and attitudinal stances regarding inclusive mainstream education versus specialized residential/group care provisions.
5. To propose evidence-based measures and policy recommendations for enhancing multi-sectoral service delivery based on parental and professional insights.

Methodology

Research Design

This study utilized a qualitative descriptive-exploratory multiple case study design. Qualitative methodology was selected as it allows for an in-depth examination of participants' lived experiences, emotional responses, and nuanced contextual realities. The multiple case study approach allowed the researcher to investigate each child-family unit within its real-world context, documenting individual heterogeneity across developmental traits, socioeconomic backgrounds, diagnostic pathways, and service experiences.

Sampling and Participants

Participants were selected using purposive sampling to ensure the inclusion of information-rich cases. The final sample comprised 20 distinct case studies involving primary caregivers (mothers, fathers, extended family relatives) of children diagnosed with ASD, alongside key informant interviews with special educators, speech-language therapy.

Data Analysis

Transcribed interviews and field notes were analyzed using inductive thematic analysis. Transcripts were coded

line-by-line to identify recurrent primary codes. Codes were organized into broader sub-themes and collated into five primary themes.

Findings

Theme 1: Diagnostic Delays, Initial Misdirection, and Post-Diagnostic Guidance Vacuum

Analysis across the 20 case studies reveals that initial parental recognition of developmental concerns typically occurred between 18 and 36 months of age. The most frequent triggering symptoms were speech delays or total speech regression (e.g., Arpit, Case 10; Priti, Case 11), lack of social responsiveness/eye contact (e.g., Shivansh, Case 06; Yuvan, Case 12), and extreme social aloofness (e.g., Aarav, Case 01; Navya, Case 09).

The diagnostic pathway in Samastipur is characterized by significant structural friction. Primary healthcare professionals and health visitors often lacked specialized neurodevelopmental training, leading to misdiagnoses, delayed referrals, or dismissive reassurances. For example, in Case 05 (Suryansh), the primary health worker who evaluated the child was perceived by the mother as lacking sufficient knowledge about autism. Formal diagnoses were typically confirmed late—frequently between ages 2.5 and 4—by doctors or specialists outside the primary health infrastructure.

A critical finding is the pervasive post-diagnostic guidance vacuum. In most cases (e.g., Case 03, Riaza; Case 08, Nayan; Case 10, Arpit; Case 12, Yuvan), parents reported receiving a clinical label without structured post-diagnostic counseling, educational planning, or guidance on behavioral management. Parents expressed feelings of grief, confusion, and isolation upon receiving the diagnosis, leaving them to navigate fragmented, unverified treatment avenues independently.

Theme 2: Severe Communication Deficits, Adaptive Dependencies, and Co-occurring Behaviors

The functional profiles of the children demonstrate significant cross-case heterogeneity alongside widespread deficits in functional communication and adaptive autonomy. A high proportion of children across the sample

were non-verbal or exhibited severe speech limitations (e.g., Case 01, Aarav; Case 03, Riaza; Case 06, Shivansh; Case 09, Navya; Case 18, Advik Yadav). Echolalia, atypical vocalizations, squealing, and speech regression were frequently documented (e.g., Case 01, Case 10).

Adaptive functioning and self-care independence showed wide variation. While an isolated case demonstrated complete ADL autonomy (Case 09, Navya—independent in brushing, bathing, toileting, dressing, and feeding), the vast majority exhibited profound dependency. Children frequently required full assistance or remained entirely dependent on primary caregivers for basic activities of daily living, including toileting, dressing, bathing, and feeding (e.g., Case 01, Case 03, Case 06, Case 07, Case 14, Case 16, Case 17, Case 20).

Behavioral challenges were reported as major sources of daily family strain. These included repetitive motor mannerisms (hand flapping, face fanning, body rocking; Cases 01, 03, 20), hyperactivity and severe temper tantrums (Case 01), sensory hypersensitivities such as auditory distress (Case 18), uncontrollable giggling without context (Cases 02, 03, 20), resistance to routine changes (Case 01), and non-compliance with commands (Case 20).

Theme 3: Institutional Fragmentation, Professional Shortages, and Generalization Barriers

Mapping the service landscape in Samastipur highlights extreme institutional fragmentation and a severe deficit of specialized resources. The public education and healthcare infrastructure lacks specialized autism units, early intervention centers, or multi-disciplinary allied health teams. Families rely almost exclusively on a small number of private setups—such as local branches of the Centre for Hearing and Speech.

Interviews with special educators and therapists (e.g., Jaya Kumari, Priya Kumari, Radha Kumari, Kumar Suyash, Aaditya Kumar Jha, Akhilesh Kumar, Nidhi Kumari) highlighted structural obstacles within these centers:

- Shortage and Retention of Qualified Personnel: Institutions face difficulties recruiting and retaining

qualified professionals holding specialized credentials (e.g., D.Ed Special Education, DHLS, DOT, BPT).

- **Extreme Clinical Heterogeneity:** Practitioners note that meeting the distinct sensory, behavioral, communication, and learning needs of each child under 1:1 or 8:10 ratios is demanding without adequate institutional funding or specialized equipment (Cases 01, 02, 04, 05, 06, 09, 16).
- **Inadequate Efficacy across Alternative Therapies:** Families frequently turn to unstandardized modalities—such as general physical exercises, acupressure, or yoga—due to a lack of evidence-based speech and occupational therapy, reporting little to no positive outcome (e.g., Case 03, Case 07, Case 08).
- **The Generalization Gap:** A major challenge identified by special educators (e.g., Aaditya Kumar Jha, Cases 13 & 15) is the failure of children to generalize functional communication and behavioral self-regulation from structured therapy settings to home and community environments. This gap is exacerbated by a lack of structured parent training programs.

Theme 4: Parental Psychological Distress, Existential Vulnerability, and Informal Coping

Caregivers, particularly mothers, bear a heavy emotional, psychological, and financial burden. Across nearly all case studies, mothers reported chronic emotional distress, feelings of anxiety, frequent crying spells, and intrusive existential anxiety regarding their child's long-term future.

The primary source of parental anxiety centers on long-term dependency, reflected in the recurring caregiver phrase: "What will happen to my child when I am gone?" (e.g., Cases 01, 03, 05, 06, 07, 08, 09, 10, 11, 16, 17, 19, 20). Parents struggle to accept the permanent nature of the diagnosis, continuous non-verbal presentation, and lack of emotional reciprocity or affection (Cases 03, 05, 19).

Socioeconomic disparities significantly influence parental coping capacity. High-income households (e.g., Case 05, ₹1,00,000/month; Case 14, ₹1,00,000/month) absorb high therapy costs and loss of income from caregiving, whereas low-income families (e.g., Case 03, ₹10,000/month; Case 07, ₹25,000/month) experience severe financial distress. Social

stigma remains pervasive. Relatives and neighbors often view the child with pity, offer misinformed advice, or blame parents for the condition (e.g., Cases 16, 17, 20). Formal support groups or peer networks are absent. As a result, families rely primarily on internal coping mechanisms, including spousal support, adjusting daily routines, practicing unconditional acceptance, and prioritizing the child's care over personal and professional goals.

Theme 5: Aspirations for Inclusion, Systemic Resistance, and Structural Expectations

A striking divergence emerged regarding educational expectations and inclusive schooling. Out of the 20 cases evaluated, 15 children were completely out of school and not enrolled in any formal educational institution. Only 5 children attended specialized centers

Despite this non-enrollment rate, the majority of parents (~85%) expressed strong support for mainstream inclusive education. Parents articulated well-developed arguments for inclusion, asserting that learning alongside neurotypical peers would:

1. Promote social adaptation and functional interaction skills;
2. Provide naturalistic language models to stimulate clearer speech;
3. Foster a sense of societal belonging; and
4. Educate neurotypical peers, building community-wide empathy, tolerance, and acceptance.

Conversely, a minority of parents (e.g., Case 07, Adhya; Case 08, Nayan) opposed mainstream inclusion. Their resistance stemmed from fear of regular classroom environments. They expressed concern that mainstream teachers lack special education training, that large class sizes preclude individualized attention, and that their children would face bullying, teasing, or social exclusion from neurotypical peers.

Regarding long-term adult care, parents voiced clear structural expectations. Recognizing the likelihood of lifelong support needs, most parents favored the establishment of community-based group homes,

structured adult residential facilities, or combined residential-sheltered workshop environments. These models were viewed as essential for ensuring dignity, safety, continuous care, and vocational engagement after parents pass away.

Discussion

The qualitative findings of this study provide critical insights into how Autism Spectrum Disorder is experienced, managed, and perceived in semi-urban contexts like Samastipur. The results align with and expand upon recent global and national literature published between 2022 and 2026. The finding regarding diagnostic friction and the lack of post-diagnostic guidance mirrors global observations in low- and middle-income regions. Similar to findings by Samadi and McConkey (2014) and Divan et al. (2020), families in non-metropolitan Indian districts encounter significant delays in securing a formal diagnosis. This delay stems from limited pediatric psychiatric infrastructure and insufficient developmental training among primary healthcare workers. The lack of post-diagnostic psychoeducation exacerbates caregiver trauma, driving families toward unverified alternative treatments. This structural gap underscores the urgent need to integrate standardized screening tools—such as the Modified Checklist for Autism in Toddlers (M-CHAT)—into community healthcare frameworks.

The high level of caregiver distress, centered on the existential dread of long-term dependency, aligns with findings by Ravichandran et al. (2026) and Hayes and Watson (2013). Child symptom severity, particularly the absence of functional speech and co-occurring behavioral difficulties, serves as a primary driver of caregiver stress. However, this study demonstrates that this stress is further intensified by socioeconomic pressures, social isolation, and the absence of localized support systems. In line with Ilias et al. (2018), the lack of parent support groups and professional counseling in semi-urban districts leaves primary caregivers vulnerable to anxiety, burnout, and depression.

The institutional challenges identified by special

educators—specifically the difficulty of achieving skill generalization between clinical and home environments—reinforce the conclusions of Kalorath et al. (2022) and Yadav et al. (2026). Contemporary research demonstrates that center-based therapy isolated from family routines yields limited functional generalization. Parent-mediated intervention programs (such as the CARER model developed by Yadav et al., 2026) offer a promising framework to address these barriers. By training primary caregivers as co-therapists within daily home routines, parent-mediated models enhance skill generalization while improving parental self-efficacy. Furthermore, given the shortage of qualified special educators and therapists in districts like Samastipur, leveraging digital health platforms and e-health caregiver supports—as advocated by Chakkaraiappan et al. (2026)—presents a scalable strategy to deliver training and tele-rehabilitation directly to underserved families.

Finally, the contrast between parents' strong desire for inclusive education and the high rate of school non-enrollment exposes a critical policy-implementation gap. Although rights-based frameworks—such as India's Rights of Persons with Disabilities (RPwD) Act 2016 and the National Education Policy (NEP) 2020—mandate inclusive schooling, local reality in Samastipur is characterized by structural exclusion. Mainstream schools frequently lack resource rooms, special education personnel, modified curricula, and peer sensitization initiatives. Addressing parental fears regarding bullying and inadequate attention requires moving beyond physical mainstreaming toward comprehensive structural accommodations, professional professional development for regular teachers, and enforceable inclusion standards.

Implications

Theoretical Implications

- De-Centering Metropolitan Models: Contributes to neurodevelopmental literature by providing empirical qualitative data from a semi-urban Indian district, challenging dominant metropolitan-centered assumptions regarding service access and family dynamics.

- **Systemic Ecological Framework:** Demonstrates that caregiver adaptation and child developmental trajectories are shaped by interlinked systemic factors, including primary healthcare diagnostic capacity, institutional rehabilitation infrastructure, socioeconomic safety nets, and local educational attitudes.

Practical and Clinical Implications

- **Decentralized Early Screening:** Primary health centers, Anganwadi workers, and Accredited Social Health Activists (ASHAs) must be trained in basic neurodevelopmental screening tools (e.g., M-CHAT) to enable early identification.
- **Parent-Mediated Tele-Rehabilitation:** Rehabilitation centers should adopt parent-mediated intervention models (e.g., CARER program), utilizing digital platforms and hybrid tele-consultations to build caregiver capacity and bridge professional shortages.
- **Formal Post-Diagnostic Counseling:** Public healthcare facilities must institute mandatory post-diagnostic counseling protocols to provide families with structured guidance, behavioral management strategies, and local resource mapping.

Policy Implications

- **Enforceable Inclusive Education Standards:** Educational authorities must mandate resource rooms, special educators, and individualized education plans (IEPs) across mainstream public and private schools, accompanied by peer sensitization programs to eliminate bullying.
- **Subsidized Allied Health Infrastructure:** Local government bodies should establish subsidized, public-private multi-disciplinary therapy hubs providing speech therapy, occupational therapy, and behavioral interventions at regulated rates.
- **Adult Social Security Frameworks:** Policymakers must establish long-term care provisions—including community-based group homes, supported living facilities, and vocational sheltered workshops—to address parental concerns regarding lifelong care.

Limitations

1. **Geographic Localization:** Data were collected exclusively within Samastipur district, Bihar; caution should be

exercised when generalizing findings to culturally or socioeconomically different regions.

2. **Qualitative Sample Size:** While appropriate for qualitative case study methodology, the sample size of 20 case studies limits quantitative generalizability.

3. **Selection Bias:** Case recruitment was partially facilitated through private special educational setups, potentially underrepresenting families who have never accessed formal services due to severe poverty or extreme isolation.

4. **Cross-Sectional Timeframe:** Data collection occurred across a single time period; longitudinal research is needed to track evolving parental expectations and child trajectories over time.

Conclusion

This qualitative case study illustrates the complex realities faced by autistic children and their families in Samastipur, Bihar. Findings reveal a fragmented support ecosystem characterized by diagnostic delays, a post-diagnostic guidance vacuum, non-affordability or unavailability of evidence-based therapies, severe caregiver distress, and systemic exclusion from formal schooling. Despite these structural barriers, families demonstrate remarkable resilience, with a majority advocating strongly for inclusive education and seeking long-term adult care frameworks. Addressing these challenges requires systemic policy reforms, including decentralized early diagnostic screening, parent-mediated tele-rehabilitation models, subsidized therapeutic services, enforceable inclusive schooling standards, and adult community residential provisions. Bridging the gap between legislative mandates and local implementation is essential to ensure that children with ASD in semi-urban India achieve functional autonomy, educational equity, and long-term societal inclusion.

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