## THE ROLE OF EARLY INTERVENTIONS IN SUPPORTING FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER: A STUDY OF WEST DELHI

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## ABSTRACT

Autism Spectrum Disorder (ASD) is a growing public health concern in India, with an estimated prevalence of 1 in 100 children (Arora et al., 2018). Early intervention has proven effective in enhancing cognitive, behavioural, and communication outcomes for affected children (Dawson et al., 2010). Despite these benefits, families in urban regions such as West Delhi face multiple barriers in accessing timely and effective intervention. This study investigates the accessibility, effectiveness, and challenges of early intervention services for children with ASD, with a specific focus on the influence of socio-economic factors. Using a thematic analysis approach, semi-structured interviews were conducted with 50 parents of children diagnosed with ASD. The study explores their lived experiences across five major thematic areas: accessibility and awareness, effectiveness and impact, financial and government support, social challenges, and professional support. Additionally, a socio-economic analysis was integrated to assess variables such as household income, parental education, employment status, and family structure. Findings reveal significant gaps in public healthcare infrastructure, financial strain due to expensive therapies, and limited availability of trained professionals. While early intervention programs positively impacted children's development, access remained highly uneven across socio-economic lines (Jose et al., 2023). Social stigma and emotional distress further compounded the burden on families. The study underscores the urgent need for policy reforms to expand public intervention services, increase awareness, and provide targeted financial and psychological support for parents. It advocates for a more inclusive, community-based approach to bridge disparities in autism care in urban India.

**Keywords:** Autism Spectrum Disorder, Early Intervention, Thematic Analysis, West Delhi, Socio-Economic Factors

## **INTRODUCTION**

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent deficits in social communication and interaction, along with restricted, repetitive patterns of behaviours, interests, or activities (American Psychiatric Association, 2013). Globally, the prevalence of autism has seen a notable increase over the past two decades. According to the World Health Organization (2023), approximately 1 in every 100 children worldwide is diagnosed with ASD, although regional variations exist based on diagnostic criteria, awareness, and healthcare infrastructure.

In India, estimates suggest a prevalence of roughly 1 in 68 children, although the true figure may be higher due to underreporting and limited diagnostic access in rural and urban areas alike (Arora et al., 2018) (Mukherjee et al., 2020). Despite the growing incidence, awareness of autism remains low, especially outside metropolitan centres. While India has seen a gradual improvement in special education policies and inclusive education, early diagnosis and timely intervention continue to pose major challenges (Kumar et al., 2021). The lack of trained professionals, societal stigma, and inadequate public healthcare support structures have left many families struggling to access essential services.

Early intervention is a critical factor in improving developmental outcomes for children with ASD. Evidence from international and Indian studies alike underscores that interventions initiated before the age of five can result in measurable improvements in language, cognitive ability, social interaction, and adaptive behaviour.

These interventions typically involve a multidisciplinary approach, including behavioural therapy, speech and language therapy, occupational therapy, and social skills training. Neuroplasticity research supports the notion that earlier interventions are more effective due to the heightened flexibility of young children's brains (Zwaigenbaum et al., 2015).

While theoretically more resource-rich due to proximity to healthcare and educational institutions, systemic issues such as overcrowded facilities, unequal access, lack of trained personnel, and socio-cultural barriers hinder effective autism care. Families in West Delhi often encounter long wait times, high therapy costs, and inadequate government support, contributing to emotional and financial stress.

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This study focuses on West Delhi, where rising ASD cases highlight the need to understand barriers and opportunities for early intervention. While detection rates are higher in urban areas, an estimated 15,000-22,000 (1-1.5%) of West Delhi's 1.5 million children (0-18 years) are estimated to have ASD (Arora et al., 2018; Delhi Statistical Handbook, 2022). By exploring family experiences, this research aims to inform policies to enhance support for children with ASD and their families.

## **OBJECTIVES**

- To explore how early interventions help children with ASD in developing essential skills such as communication, social interactions and behavioural regulation.
- To examine the ways in which early intervention programs impact the emotional and psychological wellbeing of families, along with their overall caregiving experience
- To explore the financial, social and structural challenges that families encounter while trying to access early intervention services
- To analyse different intervention approaches and highlight the most beneficial strategies for children with ASD and their families.
- To analyse the participant's socioeconomic background.

## LITERATURE REVIEW

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is described by enduring social communication and interaction difficulties, with limited, repetitive behaviour or interest (American Psychiatric Association, 2013). The word "spectrum" indicates the broad range of severity in symptoms, from having minimal need for support to those with a lifetime need for care (Lord et al., 2020). Study emphasizes unusual neural connectivity between brain areas associated with social cognition and sensory processing as a central element in ASD (Baron-Cohen et al., 2009).

Early intervention is essential to enhance the developmental outcomes in children with ASD. Intervention models across the world depend on available resources and culture context. In the US, evidence-based interventions such as the Early Start Denver Model (ESDM) and Applied Behaviour Analysis (ABA) have yielded dramatic gains in IQ, language, and adaptive behaviour (Dawson et al., 2010). The UK uses multidisciplinary interventions, such as TEACCH and parent-mediated interventions such as the Preschool Autism Communication Trial (PACT), which improve communication (Pickles et al., 2016). In India, limited resource and cultural stigma pose obstacles to implementation on a large scale, although parent-mediated and community-based interventions parents are becoming increasingly aware about this. (Daley et al., 2013). Emerging developments include the creation of "6BIO," a compound which has the potential to enhance learning and memory in ASD (Department of Science & Technology, India, 2021).

Theoretical frameworks highlight ASD interventions such as the Theory of Mind (ToM), describing challenges in understanding others' mental states (Baron-Cohen et al., 1985); Behavioural Theories such as ABA, founded on reinforcement principles (Lovaas, 1987); Social Learning Theory (SLT), focusing on observational learning (Bandura, 1977); and Piaget's Cognitive Development Theory, informing interventions to target cognitive development (Piaget, 1952). Genetic research shows high heritability, with genes involved in synapse function and neural connectivity being implicated in ASD (Sandin et al., 2014).

Empirical data testify to the effectiveness of early intervention. ESDM has reported important cognitive and adaptive gains (Dawson et al., 2010), whereas Family-Centered Early Intervention (FCEI) and Parent-Mediated Interventions (PMIs) empower families with resultant better communication and social competence (Mahoney et al., 2020; Green et al., 2010). In India, PMIs are of special relevance owing to a dearth of professional expertise. Speech and occupational therapy also advance verbal skills and lower sensory sensitivity.

In the Indian scenario, ASD prevalence is increasing, but low awareness, poor healthcare infrastructure, and cultural stigma are barriers to early intervention (Daley et al., 2013). Delayed diagnosis is prevalent because of misconceptions regarding developmental disorders (Ravindran & Myers, 2012). The Indian Scale for Assessment of Autism (ISAA) supports diagnosis, but international screening tools are not readily available in rural settings (Juneja et al., 2014). Government programs, for instance, the Rights of Persons with Disabilities Act (2016) and Developmental Disabilities Act (1999), acknowledge ASD and support individuals with it under schemes such as Samarth and Niramaya (Singh et al., 2017; Ghosh et al., 2020). Community intervention such as Project Impact proves helpful in bridging the gaps in services (Sengupta et al., 2020). The Sarva Shiksha Abhiyan (SSA) favours inclusive education but shows variance in its implementation.

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Challenges remain, such as socioeconomic barriers, restricted access to online programs, and a lack of trained staff. Steep intervention costs and restricted government funding worsen access gaps (Mukherjee et al., 2020). Technology, in the form of mobile health (mHealth) applications, provides scalable solutions through accessible, tailored therapy solutions (Smith et al., 2020). Apps such as Autism & Beyond and Cognoa enable early screening and intervention, and resources such as Proloquo2Go enable communication for non-verbal children (Schaefer et al., 2020; Fletcher-Watson et al., 2016). Gamified apps such as Otsimo educate children in daily living skills (Whyte et al., 2015). Nevertheless, digital divides and cultural suspicion circumscribe their applicability in India.

Barriers including unawareness, delayed diagnosis, exorbitant expenses, and cultural stigma persist in India. Parents and professionals alike do not identify early signs of ASD, and routine screening is lacking, as opposed to Western nations (Srivastava et al., 2020). Lack of trained therapists and the expense of therapy, with limited insurance cover, render interventions inaccessible to most. Cultural beliefs such as considering ASD as a curse or temporary situation discourage the seeking of assistance (Reddy et al., 2019).

Future plans involve incorporating early interventions into public health systems, training additional professionals, and utilizing digital technologies to increase accessibility. The creation of Autism Centres of Excellence and studies of toddlers' reactions to "baby talk" highlight the significance of early detection and intervention (NIMH, 2025). Policy-driven interventions to offer financial assistance to lower socioeconomic families may improve access to intervention programs (Patra & Kar, 2021).

## **RESEARCH METHODOLOGY**

This study employs a mixed-method research design, predominantly qualitative, to investigate the significance of early interventions for families with children diagnosed with autism spectrum disorder (ASD) in West Delhi, India. The methodology integrates semi-structured interviews with quantitative demographic data to provide a comprehensive understanding of the challenges and benefits of early intervention programs, addressing a critical research gap in the Indian context.

## **Research Design**

The mixed-method approach combines qualitative depth with quantitative context to capture both subjective experiences and broader trends. Qualitative data, derived from semi-structured interviews, provide rich, descriptive insights into families lived experiences, while demographic data offer socio-economic context (Bryman, 2016). This design enhances the validity of findings by cross-verifying qualitative themes with quantitative patterns (Creswell & Plano Clark, 2022).

## **Participant Selection**

Fifty participants, selected via snowball sampling, are parents of children aged 0-14 diagnosed with ASD by a certified professional, residing in West Delhi, and engaged in early intervention programs (e.g., behavioural, occupational, or speech therapy). Exclusion criteria include families outside West Delhi or unwilling to participate in interviews. This sample size ensures sufficient depth for thematic analysis while capturing diverse perspectives (Guest et al., 2006; Braun & Clarke, 2019).

## **Data Collection**

Semi-structured interviews, conducted in Hindi or English based on participant preference, last 25-30 minutes and are held in neutral settings (e.g. clinics) or via telephone. Audio-recorded with consent and transcribed verbatim, the interviews follow a guide covering five themes: accessibility and awareness, effectiveness and impact, financial and government support, social challenges, professional support. Open-ended questions allow participants to share experiences, ensuring systematic coverage of key topics. Supplementary demographic data—age, gender, education, employment, income, marital status, number of children, and family dependents—are collected to identify socio-economic patterns influencing access to interventions.

#### Data Analysis

Thematic analysis, a flexible qualitative method, is used to identify, examine, and report patterns in the interview data (Braun & Clarke, 2006). The process involves six steps: familiarizing with the data, generating initial codes, searching for themes (e.g., accessibility issues, financial burden), reviewing themes, defining and naming them, and writing a report contextualized within existing literature.

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#### **Ethical Considerations**

Ethical integrity is maintained through strict adherence to guidelines protecting participants' rights and wellbeing. Informed consent is obtained, detailing the study's purpose, procedures, and participants' right to withdraw without repercussions. Confidentiality and anonymity are ensured by anonymizing transcripts (e.g., using codes like P1, P2). To minimize psychological distress, participants can skip uncomfortable questions, particularly those involving emotional topics.

#### Supplementary Data

Demographic data contextualize qualitative findings by highlighting how socio-economic factors, such as income and education, influence access to and experiences with early interventions. This analysis helps identify disparities and inform targeted policy recommendations.

#### Study Aim

By combining qualitative depth with quantitative context, the study aims to provide a multifaceted perspective on early interventions for ASD in West Delhi. The findings are expected to offer valuable insights for policymakers, educators, and social workers, addressing barriers like financial constraints and limited professional support to enhance intervention accessibility and effectiveness.

#### FINDINGS AND DISCUSSIONS

The demographic characteristics of the participants in this study were systematically collected to understand their socio-economic and personal backgrounds, which may influence their perceptions, experiences, and access to resources concerning autism spectrum disorder (ASD).

The majority of the respondents (66%) belonged to the age group of 30 to 40 years, indicating that most participants were in their early to mid-parenting years a critical period for early diagnosis and intervention in children with ASD.

In terms of gender distribution, 54% of the participants were female and 46% were male. This near-equal gender representation reflects a balanced perspective from both mothers and fathers, although mothers slightly outnumbered fathers, which may also indicate their increased involvement in caregiving responsibilities.

Regarding educational qualifications, 60% of the participants were graduates. This suggests a relatively educated respondent base, potentially facilitating better awareness, access to information, and understanding of developmental disorders such as ASD.

Employment status data revealed that 40% of the participants were employed, while 24% identified as homemakers. This highlights a mix of working and non-working parents, with a significant portion dedicating their time exclusively to household and caregiving roles, which may influence the time and resources they can allocate to the care of a child with ASD.

In terms of monthly household income, 26% of the respondents reported earning between  $\gtrless 20,000$  and  $\gtrless 30,000$  per month. This indicates that a notable proportion of the sample falls within the lower-middle income bracket, which could impact affordability and accessibility of private therapy or specialized interventions for their children.

Finally, 58% of the participants reported having one child and are diagnosed with autism spectrum disorder. This is a key statistic, as it underlines the direct relevance of the study's focus and the lived experiences of the respondents.

Demographic	Details
Age Range	30–40 years (66%)
Gender	54% Female, 46% Male
Education	60% Graduates
Employment	40% Employed, 24% Homemakers
Income (INR)	26% earned ₹20,000–₹30,000 monthly
Number of Children	58% parents had one child

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## THEMATIC ANALYSIS OF INTERVIEW RESPONSES

This thematic analysis synthesizes responses from 50 semi-structured interviews with parents or guardians of children aged 0-14 with autism spectrum disorder (ASD) in West Delhi, India. Conducted in Hindi or English, the interviews explored experiences with early interventions, revealing five key themes: Accessibility and Awareness, Effectiveness and Impact, Financial and Government Support, Social Challenges, and Professional Support with their respective sub-themes.

Theme	Sub-Themes
Accessibility and	When Children Were Diagnosed: Delayed diagnosis reasons are due to
Awareness	limited awareness among parents and healthcare providers, cultural
	misconceptions, and lack of screening protocols.
	Challenges in Accessing Services: Financial constraints, scarcity of
	specialized services, long waiting lists, cultural stigma, and lack of reliable
	information about available services.
Effectiveness and	Communication and Interaction Skills: Improvements in speech and social
Impact	engagement (e.g., eye contact), with varying outcomes based on autism
	severity.
	Changes in Daily Functioning: Gains in self-care (e.g., dressing, eating)
	and adaptive behaviours (e.g., managing routines), though complex tasks
	remain challenging for some.
<b>Financial and</b>	Cost of Intervention Services: High therapy and diagnostic costs,
Government	transportation expenses, and limited insurance coverage create financial
Support	burdens.
	Availability and Awareness of Government Support: Low awareness of
	programs like Niramaya, inconsistent funding, and long wait times for
	government services.
Social Challenges	Stigma and Exclusion: Social isolation due to cultural misconceptions (e.g.,
	autism as a result of poor parenting or spiritual punishment), leading to
	exclusion from community activities.
	Parents' Mental and Emotional Well-Being: Anxiety, depression, and
	loneliness from caregiving stress, stigma, and lack of social support.
Professional	Availability of Trained Professionals: Shortage of therapists and special
Support	educators, long waiting lists, and variable care quality due to limited autism-
	specific training.
	Role of Parent Support Groups: Emotional support, information sharing,
	advocacy, and workshops empower parents to manage their child's needs.

#### Accessibility and Awareness

The diagnosis of ASD is a pivotal moment, shaping families' intervention strategies and emotional adjustments. In West Delhi, many children were diagnosed after age three, later than the recommended window for early intervention (American Academy of Paediatrics, 2019). Parents attributed delays to limited awareness of ASD signs among themselves and healthcare providers, who often dismissed symptoms like delayed speech as behavioural or temperamental. Cultural attitudes in India, which may to developmental delays, further delayed professional help.

Accessing early intervention services was fraught with challenges. Financial constraints were significant, with therapy sessions costing at least ₹2,000, often requiring multiple weekly sessions. The scarcity of specialized services in West Delhi led to long waiting lists for therapies like Applied Behaviour Analysis (ABA). Cultural stigma deterred some families, fearing social judgment. Many parents struggled to find reliable information about services, leading to delayed or inappropriate interventions. But there some effective results of early interventions services which were felt by many parents. One participant said "Before therapy my son wasn't

able to express himself, but now he's able to say what he wants and interact with his friends in a meaningful way."

Systemic barriers, such as the lack of ASD screening in primary care and limited specialists creating some problems. The World Health Organization notes a shortage of trained healthcare personnel in India, particularly in semi-urban areas like West Delhi, hindering timely interventions (WHO, 2017).

## **Effectiveness and Impact**

Despite barriers, early interventions showed significant benefits. Parents reported improvements in communication and social interaction skills, particularly after speech therapy and social skills training. Children with limited verbal abilities began expressing needs and engaging with peers. One parent said "Before socialization therapy, my son hardly said two words, and now, he is talking in full sentences and can request whatever he wants." Progress varied by autism severity, on the one hand with milder cases showing faster gains whereas on the other hand severe cases showed slower progress.

Daily functioning also improved, with children gaining independence in self-care tasks like dressing and eating. "Before the therapy, my daughter was dependent on someone to help her with everything, now she brushes her teeth and eats by herself." Adaptive behaviors, such as managing routines, also advanced, though some children struggled with complex tasks, indicating the need for ongoing support. Parents expressed dissatisfaction when interventions lacked personalization, advocating for tailored plans.

## **Financial and Government Support**

The cost of early interventions was a major burden. Therapies, diagnostic assessments, and specialized education strained family budgets, particularly for low- to middle-income households. Many parents felt financial burden as in some families there is only single person who is earning and the whole family depends on him. One parent said "The cost of therapy is too much," other parent said, "Each session costs us at least ₹2000, and we need multiple sessions a week. That simply isn't sustainable for most families." Additional costs, like transportation to distant therapy centres, compounded the strain.

Government support, such as the National Trust Act (1999) and Niramaya Health Insurance Scheme, offers financial aid and healthcare coverage, but awareness and accessibility remain low National Trust, India. When participants were asked about the government policies related to ASD many of them were not aware about this. One response was "I didn't even know there were any government programs for families like ours until I met another parent at the therapy centre."

In the education sector programs like Sarva Shiksha Abhiyan (SSA) promote inclusive education, but inconsistent implementation limits their impact (Ministry of Education, India) Long wait times at government facilities and inadequate funding further restricted access and making families vulnerable in accessing these services for their children diagnosed with ASD.

## **Social Challenges**

Stigma and exclusion were pervasive. Misconceptions about autism led to social isolation, with families often shunned by communities. Many parents reported experiencing social exclusion, noting that societal attitudes often led them to feel that their child, due to being diagnosed with autism spectrum disorder (ASD), was perceived as problematic. One parent stated that "When we explained to our neighbours that my son was autistic, they started avoiding our family. We were no longer invited, and people began to avoid us in public places." Such stigma, rooted in cultural beliefs that autism reflects poor parenting or spiritual punishment, increased parental guilt and isolation. Several parents also shared that their own family members began treating them differently upon learning about the diagnosis. Instead of offering support or seeking appropriate interventions, some relatives advised them to consult spiritual healers or priests.

The emotional toll of caregiving, compounded by social and financial pressures, impacted parents' mental health, leading to anxiety and depression. Response from one of the parents "I feel like I'm under stress all the time. I simply can't sleep at night because I'm constantly thinking about how I can support my son, and the criticism from others only makes the situation worse." Parents also reported that schools, particularly teachers, contributed to their sense of distress by implying that their child was not 'normal' and incapable of keeping up with peers academically and socially. Limited access to counselling or support groups exacerbated feelings of loneliness.

#### **Professional Support**

The shortage of trained professionals in West Delhi hindered effective interventions. Parents faced long waiting lists for therapies due to limited specialists. "We were fortunate that we found a special educator for my son, but there are so few of these professionals available that we had to wait for months." Care quality varied, with some therapists lacking autism-specific expertise.

Parent support groups were a vital resource, offering emotional support, information sharing, and advocacy opportunities. "Joining a parent group really helped me understand how to respond to some of my child's behaviours. It was nice to speak to people who understand it." These groups also hosted workshops, empowering parents to manage their children's needs and advocate for better services.

The findings from this study highlight the multifaceted challenges and disparities surrounding early intervention for children with autism spectrum disorder (ASD) in West Delhi. A complex interplay between access to services, parental awareness, and socio-economic status significantly shapes the outcomes for these children. Families from higher socio-economic backgrounds, particularly those with greater educational attainment, tend to have better access to both public and private diagnostic and therapeutic services. This access enables them to secure timely diagnoses and high-quality interventions, and their enhanced awareness about autism makes them more proactive in seeking appropriate support.

In contrast, families from lower socio-economic strata face considerable barriers. These include limited availability of specialized diagnostic centres, high costs of private therapies, and a general lack of awareness regarding autism and the services available. Consequently, children from these backgrounds often encounter delays in diagnosis and intervention, leading to developmental challenges that could have been mitigated with timely support.

Stigma further complicates the situation. In many conservative communities, autism is still poorly understood and heavily stigmatized. Parents shared experiences of being socially excluded, often made to feel that their child was problematic due to the diagnosis. Some even reported that their extended families began treating them differently and, rather than suggesting evidence-based interventions, advised consulting spiritual healers. Schools and teachers were also cited as sources of discouragement, with some parents reporting that educators implied their children were not "normal" and incapable of coping with their peers. These experiences of social stigma and exclusion intensify the psychological burden on parents and caregivers, especially in the absence of strong community support networks.

Despite these challenges, the study reaffirms that early intervention plays a vital role in improving communication, social interaction, and daily functioning in children with ASD. However, systemic barriers such as delayed diagnosis, financial constraints, social stigma, and a shortage of trained professionals continue to hinder equitable access to these services. Addressing these issues through greater public awareness, enhanced implementation of government schemes, stigma reduction initiatives, and improved professional training is essential for ensuring better outcomes for children with autism and their families in West Delhi.

## CONCLUSION

This research on autism spectrum disorder (ASD) in West Delhi highlights the gaps in awareness, access, and affordability of early intervention services, especially among marginalized families. Even as awareness about ASD is slowly rising in India, support mechanisms are still remained fragmented. There is a need for a multi-sectoral, inclusive, and integrated approach to enhance outcomes, foster social inclusion, and achieve long-term developmental gains for children with ASD.

Major suggestions include reinforcing government structures through enhanced budgets for subsidized early intervention centres and universal autism screening in government hospitals and Anganwadi centres. Funding assistance towards therapy and early diagnosis is very important, especially in low-income areas. Special education must take centre stage through hiring special educators, implementing sensory-friendly classrooms, and incorporating ASD-based teacher training under initiatives like Samagra Shiksha Abhiyan.

Community-level action is also crucial. Autism-friendly public spaces and public awareness campaigns can help decrease stigma and promote social inclusion. Digital platforms and mobile apps in local languages can fill access gaps, while peer support groups can provide emotional and practical support to newly diagnosed families.

Social workers are key players as advocates, counsellors, mediators, and facilitators. They not only offer emotional support to families but also act as bridges between service providers and recipients, making

interventions inclusive and context-relevant. Their mobilization and stigma-reduction role make them invaluable change agents.

This research not only contributes to the knowledge base regarding early intervention and family problems in West Delhi but also paves the way for further studies. There is an urgent need for longitudinal research to determine long-term consequences of early interventions on children's cognition, behaviour, and socialization. Urban-rural comparative research can ascertain gaps in access and services. Subsequent research must analyse the efficacy of parent-based, community-based, and online interventions, and cross-cultural perceptions. The changing role of social workers in multidisciplinary teams also needs to be analysed to build collaborative action for inclusive development in the Indian context.

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