# Appendix B

## Extraction Table of Selected Articles

<table>
<thead>
<tr>
<th>No.</th>
<th>Authors/Year, Title, Country</th>
<th>Purpose</th>
<th>Study Design</th>
<th>Method</th>
<th>Main Findings</th>
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</table>
| 1   | Dababnah et al. (2018). “We Had to Keep Pushing”: Caregivers’ Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care Baltimore, Maryland, USA | To investigate the perspectives of parents and other primary caregivers of Black children with ASD on barriers and facilitators to ASD screening and referrals in primary care | Qualitative study, grounded theory approach | **Sample and setting:** A sample of 22 female caregivers (mother - grandmother - aunt) of young children in urban areas in Baltimore, Maryland who self-identified themselves as black or indicated their child was black.  
**Data collection:** Semi-structured individual interviews were used to collect information. | • Primary healthcare providers ignore parents’ concerns regarding their children’s behavioral developmental delays.  
• Parents expressed need for a more respectful individual communication with their child's provider.  
• Caregivers described denial, shame, and stigma relating to ASD in the Black community |
| 2   | Elder et al. (2016). Identifying the Barriers to Early Diagnosis and Treatment in Underserved Individuals with Autism Spectrum Disorders (ASD) and Their Families: A qualitative study United States of America (USA) | To build capacity and engage the community in research related to individuals with Autism Spectrum Disorders (ASD) and their families. | Qualitative Study – participatory action research | **Sample and setting:** Purposive sample of 35 community members including parents of children with ASD, healthcare providers, service providers, and schoolteachers participated in the focus groups.  
**Data collection:** Focus group sessions were audio-recorded, transcribed verbatim, and analyzed by three trained independent coders. Focus group participants also completed a short demographic survey | • Unclear path to obtain ASD services.  
• Lack of parents' knowledge about ASD.  
• Lack of professionals' knowledge about ASD.  
• Lack of professionals to do screening test.  
• Parental fear of social stigma associated with an ASD diagnosis.  
• Inadequate insurance coverage  
• Inadequate time to screen |
| 3   | Fenikilé, T. et al. (2015). Barriers to autism screening in family medicine | To explore potential barriers to adoption of recommended | Qualitative study | **Sample and setting:** Convenience sample of 15 family physicians | • Lack of physicians' time to screen autism  
• Lack of adequate training for pediatricians to perform early screening tests.  
• Limited availability of community resources to manage |
<table>
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<tr>
<th>Practice</th>
<th>Screening</th>
<th>Data Collection</th>
<th>Sample and Setting</th>
<th>Challenges</th>
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<tbody>
<tr>
<td>A qualitative study USA</td>
<td>screening for autism by family physicians at 18- and 24-month well-child visits.</td>
<td>Three focus groups and six semi-structured interviews</td>
<td>A purposive sampling of 39 parents of children with a presumptive diagnosis of autism and 11 professionals who included special needs services teachers, clinicians, social workers, occupational therapists, speech therapists, and religious and lay leaders who work with children with autism</td>
<td>Professionals lacked understanding about ASD. lack of parents’ awareness about ASD. Social stigma, isolation and broken families were factors in missing early diagnosis. Lack of the autism professionals made ASD diagnosis more difficult for parents. Lack of government or private insurance to cover the costs of autism treatment</td>
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<td>Kamau (2017). Autism Spectrum Disorders (ASD) in Kenya: Barriers Encountered in Diagnosis, Treatment and Management. Kenya</td>
<td>To understand the difficulties that parents, caregivers, and special needs providers encounter as they experience the diagnosis, and treatment of autism</td>
<td>Qualitative study- An exploratory research design and used a general inductive analysis approach</td>
<td>Focus groups and individual in-depth, semi-structured and open-ended interviews. Interviews were audio-recorded digitally and transcribed immediately after each interview by the researcher</td>
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<td>Khowaja et al. (2014). Sociodemographic barriers to early detection of autism: screening and evaluation using the M-CHAT, M-CHAT-R, and Follow-Up USA</td>
<td>To examine the difficulties that parents, caregivers, and special needs providers encounter as they experience the diagnosis, and treatment of autism</td>
<td>Quantitative study</td>
<td>Parents of autistic children (n = 11,845) at well-child pediatric appointment who completed either the M-CHAT (n = 5,035) or M-CHAT-R (n = 6,810)</td>
<td>There was significant correlation between parents’ educational level and their knowledge about ASD. Mothers with low educational level were less likely to continue to ASD screen. Financial burden was barrier to ASD screening and diagnosis. Participants reported telephone difficulties and lack of transportation were barrier to reach some families.</td>
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<td>Mahapatra et al. (2019). Parental care-seeking pathway and challenges for autistic spectrum disorders</td>
<td>To decipher parents’ perception regarding ASD and to understand</td>
<td>A cross-sectional facility-based study (using parallel)</td>
<td>Sample and setting: 76 parents of children with ASD at four centers that provide service.</td>
<td>lack of knowledge among parents about early signs of ASD. Level of education had no significant impact on parents’ knowledge about ASD. Parents were looking for affordable centers with excellent</td>
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| Children: A mixed method study from Bhubaneswar, Odisha India | The early signs of ASD recognition among parents, treatment-seeking pathways adopted their experiences and challenges in the overall process. | A semi-structured questionnaire was used to collect information about participants' demographics and treatment paths with time intervals. The second part of the questionnaire consists of an in-depth and open interview to capture parents' general experiences during the treatment process which included facilitators and barriers to the treatment-seeking pathway. | Services.  
• Stigmatization identified as a social issue among parents in community  
• Diagnostic path took a long time until children was confirmed with autism  
• Financial issues delayed parents to access ASD services early.  
• Distance of treatment centers was another contributed factor to delay diagnosis. |
|---|---|---|---|
| Ribeiro et al. (2017). Barriers to early identification of autism in Brazil. Brazil | To evaluate the pathway between initial parental concerns about atypical child development and ASD diagnosis in Brazil. | Qualitative | Sample and setting:  
19 mothers whose children had been diagnosed with ASD participated and completed in-depth interviews. The ASD children were two girls and 17 boys at interview time. The families were middle-class in Brazil. All children were recruited from a specialty clinic for ASD.  
Data collection:  
The semi-structured interview was based on Mandell’s semi-structured questionnaire.  
Pediatricians dismissed Mothers' concerns about the atypical development of their children.  
Parents reported that failure to take parental concerns into account delayed four to five years formal ASD diagnosis of their children.  
parents reported long and complexity path to access autism services. |
| Schelly et al. (2019). Barriers to an Information Effect on Diagnostic Disparities of Autism Spectrum Disorder in Young Children. Costa Rica | To identify and describe barriers to an “information effect” in diagnosis | Qualitative study | Sample and setting:  
Interviews were conducted with the parents of 54 children with ASD. Parents were recruited from the hospital in 2013 when the parents attended a follow-up appointment for a previous ASD diagnosis or arrived for an informing interview after their children underwent an Autism Diagnostic Observation Schedule assessment.  
Parents lacked knowledge about early symptoms of ASD.  
Parents' knowledge about ASD affected by their educational level  
Most parents seeking advice from friends and family, who encouraged them to wait. |
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<tr>
<th></th>
<th>Study Title</th>
<th>USA</th>
<th>Data collection:</th>
<th>Sample and setting:</th>
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| 9 | Stahmer et al. (2019). Caregiver Voices: Cross-Cultural Input on Improving Access to Autism Services | To identifying developmental concerns, obtaining an ASD diagnosis, and accessing ASD-related services. | Qualitative study | 58 caregivers of children with ASD, and 55 ASD service providers and administrators ASD service settings in Los Angeles, CA, Sacramento, CA, Rochester, NY, and Philadelphia, PA | 19 focus groups and 15 interviews were conducted | Lack of knowledge among caregivers and healthcare providers.  
Parents who expressed concern about their children's behaviors were often told to "wait and see".  
Stigma related to ASD leads to isolation and delayed acceptance.  
Parents were blamed for poor parenting.  
The ASD system of care is complex and confusing for access to service.  
Caregivers often receive conflicting information from different providers. |
| 10| Zuckerman et al. (2014). Latino Parents' Perspectives of Barriers to Autism Diagnosis | To qualitatively describe community, family, and health care system barriers to ASD diagnosis in Latino children. | Qualitative study | 33 parents of Latino children previously diagnosed with an ASD | Five focus groups and four qualitative interviews.  
Sessions were audio recorded and transcribed. Transcripts were coded by two researchers, and data were analyzed using thematic analysis. | Lack of parents and community knowledge about ASD  
Stigma among parents around ASD in Latino community  
Parents believe that ASD is embarrassing issues  
Mothers have found a diagnosis of ASD to be a particular problem for their male fathers.  
Lack of attention to ASD in media  
Lack information resources to navigate ASD services  
Financial burden among low-income families made seeking care more difficult. |