

Section: SOCIAL SCIENCES AND HUMANITIES

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Mothers' perspectives on children with autism spectrum disorder

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INTRODUCTION: Mothers of children with suspected Autism Spectrum Disorder (ASD) frequently face long journeys through public health services until diagnostic confirmation. Lack of knowledge among health professionals and limited access to the Brazilian Unified Health System (SUS) significantly contribute to diagnostic delays. This process, marked by uncertainties and bureaucracy, has a substantial impact on the lives of these families. Therefore, the present study aimed to analyze the barriers faced by mothers seeking an ASD diagnosis for their children. **METHOD:** This is a qualitative study conducted with mothers affiliated with the Notea NGO, an organization that supports autistic children. Data was collected through semi-structured interviews and analyzed using content analysis. The project was approved by the Research Ethics Committee (CEP) under opinion No. 8.010.760 and carried out at the FMABC University Center during a university extension social action for the group through semi-structured interviews. **RESULTS:** Of the 12 interviewed mothers, approximately 64% reported that health professionals attributed suggestive signs of ASD to “normal” behaviors, “spoiled” or “whining behavior.” Additionally, obtaining a diagnosis through the SUS was described as exhausting due to long waiting lists and limitations of the public service. Access to rights, such as the Continuous Cash Benefit (BPC), was also reported as slow and highly bureaucratic. **DISCUSSION:** These results demonstrate the social and structural vulnerability experienced by atypical families, forcing many to resort to the private healthcare network - an unfeasible option for a large portion of the Brazilian population. Moreover, the lack of professional training for ASD screening not only contributes to family overload but also reveals limitations in the country's Primary Health Care. **CONCLUSION:** The study shows that barriers to ASD diagnosis amplify the overload and vulnerability of atypical families. The findings suggest the need to strengthen Primary Health Care services through professional training and reduction of SUS bureaucracy. Although the proposed Line of Care for ASD signals an institutional advance, its practical implementation has not yet been achieved, and access inequalities persist.

KEYWORDS: Health services accessibility; Delayed diagnosis; Unified Health System; Autism Spectrum Disorder.