

National Profile of Caregivers' Perspectives on Autism Spectrum Disorder Screening and Care in Primary Health Care the Need for Autism Medical Home

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Abstract

Although autism spectrum disorder (ASD) is a common developmental disorder, primary healthcare providers show a deficit in providing early diagnosis. To understand parents' experience and perspective in the diagnosis and intervention process of their children, a survey was deployed through social media to parents' with at least one child diagnosed with ASD. The survey included parents experience, satisfaction and perception in the diagnosis process and services provided for their children, stigma and type of support received. A total of 223 participants were enrolled. Although 62% of ASD patients were diagnosed by three years old, most diagnoses (66%) were non-physician initiated. Additionally, 40.8% of the parents reported that the services required for their child are available in their area of residence, but only 7.9% were satisfied with these services. Parents who received psychological support (9.9%) started early intervention, and their children have a better prognosis ($p \leq 0.005$). Stigmatized parents were more likely to delay intervention. ($p \leq 0.005$). Parents' perception is to have qualified healthcare and educational professionals experienced in ASD. Our findings suggest that a specialized family-centred medical home for ASD patients would significantly benefit ASD patients, increase parents' satisfaction, reduce parents' stress, and ease their children's transition to adolescents.

Keywords:

Autism, Autism Spectrum Disorder, Medical Homes, Primary Healthcare.