

Challenges, priorities, barriers to care, and stigma in families of people with autism: Similarities and differences among six Latin American countries

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Abstract

Lack of access to services and support is an important issue for people with autism, but in low- and middle-income countries there is a lack of data on this problem. The aims of this study were to describe the challenges and priorities, identify barriers to care, and map stigma among families of individuals with autism in Latin America. This survey was undertaken by the Red Espectro Autista Latinoamericano network, a coalition of researchers/clinicians from six Latin American countries; it comprised 2942 caregivers of children with autism from Brazil, Argentina, Chile, Uruguay, Venezuela, and the Dominican Republic, who completed the Spanish/Portuguese version of the Caregiver Needs Survey. The survey showed that the main priorities were greater community awareness and improvements in education. The main barriers to care were waiting lists (50.2%), treatment costs (35.2%), and lack of specialized services (26.1%). Stigma experienced by families was frequent: one-third reported feeling discriminated against and helpless for having a child with autism, 48.8% reported some type of financial problem, 47.4% had to reduce work hours, and 35.5% had to stop working because of their child's autism. This survey describes the main needs/challenges faced by individuals with autism in Latin America, helping to build data-driven strategies at a national/regional level. Lay abstract Approximately 6 million individuals with autism spectrum disorder live in Latin America. In order to strengthen autism spectrum disorder research collaborations and awareness in the region, the Latin American Autism Spectrum Network (Red Espectro Autista Latinoamerica) was constituted in 2015, comprising researchers and clinicians from the following six countries: Brazil Argentina, Chile, Uruguay, Venezuela, and the Dominican Republic. This first multisite study from the Red Espectro Autista Latinoamericano network aims to describe the challenges and priorities to identify barriers to care and to map stigma among families of individuals with autism spectrum disorder living in Latin America. A total of 2942 caregivers from these six countries completed an online survey showing that the main

priorities were greater community awareness and improvements in the educational system for individuals with autism spectrum disorder. In addition to that, the main barriers to care were related to lack of structure, mainly waiting lists (50.2%), high treatment costs (35.2%), and lack of specialized services (26.1%). Stigma experienced by families was frequent: one third reported feeling discriminated against and helpless for having a child with autism spectrum disorder. Also, 48.8% of the caregivers declared financial problems, 47.4% of them had to cut down work hours, and 35.5% had to leave their jobs because of their child's autism spectrum disorder. This is a pioneer study providing a description of the needs and challenges faced by families affected by autism spectrum disorder in Latin America, helping to build data-driven strategies at the national and regional levels.

Palabras clave

Palabras clave de autor:[autism](#); [economic costs](#); [healthcare utilization](#); [stigma](#); [treatment barriers](#)

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