Implementation of the Latin American Autism Spectrum Network Caregiver Needs Survey

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Background

ASD knowledge, services and research infrastructure in Latin America are limited and unevenly distributed. In 2015, researchers from Argentina, Brazil, Chile, Uruguay, Venezuela and Dominican Republic constituted the Latin American Autism Spectrum Network (Red Espectro Autista Latinoamericana - REAL) in order to conduct international research collaborations related to ASD. The first project undertaken by REAL was the translation, adaptation and implementation of the AS Caregivers Needs Survey. The AS Caregivers Needs Survey was developed by Autism Speaks to assess the needs of families affected by autism in partner countries of its Global Autism Public Health Initiative. It is intended for parents or primary caregivers of individuals with a professional diagnosis of autism spectrum disorder. After translation, adaptation, back translation and pilot testing of the survey, REAL researchers reached a final version by consensus, taking into account caregiver suggestions collected during the pilot phase.

Objectives

To provide a comprehensive picture of the major needs and challenges faced by families affected by ASD in REAL countries with the purpose of successfully enhancing awareness, improving services, and developing long-term policy solutions related to ASD.

Methods

The Caregivers Needs Survey was broadly disseminated via social networks in REAL countries during a period of 4 months (December 2015-April 2016) so that caregivers could complete it online, either assisted by a clinician or not. The survey solicited information about family demographics, affected individual characteristics, service encounters and parent/caregiver perceptions, including stigma. A total of 2905 surveys were completed. After data cleaning and data analysis, REAL researchers will draft a country and regional report.

Quality of life

Unmet needs, Caregiver impact, and Stigma

Demographics of individuals with ASD

Service encounters and school enrollment

Results

General information

Conclusions

The assessment of needs and challenges faced by families affected by ASD in different Latin American countries is essential for the identification of knowledge gaps, service needs, and stigma. Demographic variables showed a similar picture among countries. As expected, males were more prevalent than females in all countries. ASD was the most common diagnosis for all the countries but Argentina. Worrisome the fact that among the least mentioned professionals involved in diagnosis were pediatricians. A 16 to 37 months difference was found between the age of parents first concerns and the age of diagnosis. More than 25% of interviewed families participated in parent organizations, with Argentina and Uruguay having the highest proportion, and Brazil and Venezuela having the lowest. Across countries, communication and social interaction difficulties were rated as the greatest challenges for caregivers, showing that the core symptoms of ASD were of primary concern to families in the study, as opposed to associated challenges such as eating and sleep difficulties. While there is some variability in priorities across countries, each country considers improving educational services and health care services to be the most important priorities. About half of the caregivers who completed the survey had sometimes experienced frustration to get services, reported that the condition of autism had impacted them financially and that they had to cut down work hours because of the child’s condition. Although quality of life variables showed a high level of importance to caregivers in all countries, the level of satisfaction with these was low, especially regarding school support. This study is important in the development of culturally relevant strategies for raising autism awareness, guiding the implementation of successful and improved ASD clinical and educational services at the national and regional levels and setting priorities for future national and regional research collaborative efforts. In this era of globalization, REAL is an attempt to generate a collaborative workforce in order to readily identify the best ways to approach issues related to ASD in Latin America.