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Building Autism Research Capacity and Policy in Latin America: The REAL Network

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Abstract

Over the past decade, the Latin American Autism Spectrum Network (REAL) has played a key role in advancing autism research, training, and policy in low- and middle-income countries across the region. Established in 2013, the network unites researchers from seven countries to generate collaborative, cross-cultural evidence on diagnosis, service access, stigma, caregiver needs, and mental health in autism. Its first large-scale study, involving nearly 3,000 caregivers, revealed major gaps in service provision, late diagnosis, and high levels of unmet needs. Subsequent investigations addressed the impact of COVID-19 on autistic individuals and families, and validated culturally adapted tools such as the Emotional Outburst Questionnaire. With dozens of published articles, book chapters, and sustained dissemination through conferences and advocacy, REAL has strengthened regional capacity and informed policy discussions. The network continues to expand its scientific agenda, developing new collaborative studies that respond to the persistent and emerging priorities of autistic people and their families in Latin America.

In most low- and middle-income countries (LMICs), public policies specifically addressing the needs of individuals with autism spectrum disorder (ASD) remain scarce (Paula et al., 2020; Torres et al., 2021). Stigma toward autism has been consistently documented across these settings (Daniels et al., 2017; Tilahun et al., 2016). Until 2013, this knowledge gap was particularly evident in Latin America, where virtually no studies had examined aspects such as age at diagnosis, service priorities, or barriers to care. Despite ongoing challenges — such as socioeconomic disparities and the absence of comprehensive national strategies — the past two decades have witnessed growing regional collaboration and research capacity in autism (Divan et al., 2021). Advancing this progress requires incorporating the perspectives of family members to better understand the priorities and challenges faced by individuals with ASD within diverse regional contexts (Paula et al., 2020).

During the 2000s, a severe shortage of services, training, validated tools, and research infrastructure was evident in LMICs (Amaral, 2019; Durkin, 2015). In response to these challenges, the Latin American Autism Spectrum Network (REAL) was formally created in 2013 with the mission of promoting cooperation in awareness-raising, research, training, and policy influence related to ASD in Latin America and the Caribbean. The foundation for this initiative had been laid through earlier collaborations in international projects and informal meetings. Two landmark studies provided opportunities to include data from Latin America and further strengthened regional ties: a systematic review of epidemiological surveys of autistic disorder and pervasive developmental disorders (PDDs, precursors of the current ASD terminology), which analyzed the influence of geographic, cultural, and socioeconomic factors on prevalence and clinical presentation (Elsabbagh et al., 2012); and a global overview that identified the grand challenges in ASD research in LMICs, offering strategies for bridging knowledge gaps to improve quality of life worldwide (Khan et al., 2012).

The REAL network was also shaped by Latin American researchers' increasing presence at the annual conferences of the International Society for Autism Research (INSAR). Since the 2006 meeting in Montreal, Canada, these events provided an informal but important venue for exchanging ideas about ASD in the Latin American context and laid the groundwork for the network's consolidation. The REAL network was initially formed with representatives from Argentina, Brazil, Chile, the Dominican Republic, Uruguay, and Venezuela, and more recently welcomed a representative from Mexico. In addition, one member has established their work in Spain, further broadening opportunities for studies across Latin America and the Spanish-speaking world.

The mission of the REAL network is to investigate the needs of individuals with autism and their families across Latin America, with a particular focus on:

a) assessing community-specific needs and priorities;
b) mapping the availability, accessibility, and quality of health and educational services;
c) developing, delivering, and evaluating training programs while promoting high-quality service provision;

d) estimating and analyzing the socioeconomic, psychological, and developmental impact of raising a child with ASD across the region; and
e) examining stigma and advocating for inclusive practices, cultural norms, and public policies.

After several informal initiatives, the team recognized that the most effective way to establish a stronger and more sustainable network was through joint studies. Given the scarcity of regional data, the natural starting point was a situational mapping. From this broader initial effort, building on this foundation, we progressively moved toward more specific research, exploring the manifestations of autism in real-world contexts, identifying regional patterns and cultural factors to provide evidence-based insights for clinicians and policymakers. Since 2019, the REAL network has produced 14 collaboratively published papers and two book chapters (Manrique et al., 2019; Montiel-Nava et al., 2019), in English or Spanish, distributed across the projects listed below.

The objective of this invited commentary is therefore to provide an overview of autism research in Latin America by summarizing the scientific contributions of the REAL network and outlining directions for future research.

Study 1: Mapping Autism in Latin America – Needs, Service Gaps, and Stigma

The REAL's first large-scale investigation began in 2015 and involved almost 3,000 caregivers of individuals with ASD across Argentina, Brazil, Chile, the Dominican Republic, Uruguay, and Venezuela. The study aimed to identify the needs of autistic individuals from the perspective of their caregivers. Participants completed the Caregiver Needs Survey (Daniels, 2017), adapted to Spanish and Portuguese, as well as additional questions about local health and education systems. Data collection was approved by ethics committees, conducted online, and analyzed with descriptive and inferential statistics (SPSS 17.0).

This project generated eight peer-reviewed articles. Findings showed that although caregivers reported developmental concerns by 22 months of age, formal diagnosis typically occurred nearly two years later, often coinciding with school entry (Montiel-Nava et al., 2023). Across the region, 19–37% of individuals received no treatment, and service use was substantially below international recommendations. While access to speech, occupational, and behavioral therapies declined with age, psychotropic medication use increased (Montiel-Nava et al., 2020). Families identified community awareness and improvements in education as top priorities, while the most significant barriers to care included waiting lists (50.2%), treatment costs (35.2%), and lack of specialized services (26.1%) (Paula et al., 2020).

Results also highlighted profound disparities in adult services: between 84.4% and 95.9% of autistic adults received no weekly intervention, and 58% accessed no health service at all (Torres et al., 2021). Stigma was another major theme, with caregivers of autistic adults reporting greater feelings of helplessness than those of younger children. Perceived stigma was further associated with contextual factors such as caregiver frustration, challenging behaviors, gender, and country of residence (Montenegro et al., 2022a).

Two additional studies analyzed data from specific countries. The first quantitatively examined changes over five years in Argentina regarding the age at which caregivers first noticed developmental concerns and obtained an autism diagnosis for their children, revealing earlier identification, improved service access, and greater community awareness, while still highlighting persistent gaps in support and in the protection of autistic individuals' rights (Montenegro et al., 2022b) The second study identified patterns of service use and barriers to care among Brazilian families of children with autism, showing significant regional and socioeconomic disparities in access – particularly to behavioral interventions –driven by caregivers' education level and the type of health care system used (Araripe et al., 2022).

Together, these findings provided the first systematic evidence on autism in Latin America, underscoring gaps in diagnosis, treatment, and service provision, and establishing a foundation for subsequent REAL research initiatives.

Study 2: COVID-19 and Autism in Latin America – Behavioral, Emotional, and Service Impacts

In response to the COVID-19 pandemic, the REAL group investigated its effects on autistic individuals and their families across the region. An online survey was conducted with 1,826 participants, including caregivers of autistic individuals, autistic adults, teachers, and therapists, from eight countries: Argentina, Brazil, Chile, Mexico, Peru, the Dominican Republic, Uruguay, and Venezuela. The study aimed to assess the impact of the COVID-19 pandemic and social isolation on behavior, mood, sleep, and diet. Four peer-reviewed articles were derived from this project.

Overall, results indicated that mandatory confinement exacerbated irritability, wandering, anxiety, and difficulties with eating, sleeping, and concentrating. Families reported developmental setbacks, while also noting the positive effects of outdoor activities such as walks. Service provision was heavily disrupted, though remote interventions were often evaluated positively (Valdez et al., 2021).

Country-specific analyses provided further insights. In Uruguay, among 269 caregivers who reported on behavioral changes, externalizing behaviors worsened more in males, while internalizing difficulties were greater among adolescents aged 13–18 (Garrido et al., 2021). In Mexico, among 126 caregivers, 38.9% reported the suspension of at least one service; however, no significant association was found between symptom worsening and the modality of service delivery (Perez Liz et al., 2023).

Study 3: Understanding Emotional Outbursts in Autism – A Cross-Cultural Perspective with the EOQ

Emotional outbursts (EOs) are among the most disruptive challenges for autistic individuals, presenting as heterogeneous patterns of behavior that vary across individuals and contexts. Cultural factors are likely to influence their expression, yet these influences remain understudied, despite well-documented global differences in emotional processes (e.g., higher motivation to suppress emotions in interdependent cultures). Addressing this gap requires reliable, cross-culturally valid measures.

To this end, we conducted a series of studies to carry out the translation and cultural adaptation of an English tool: the Emotional Outburst Questionnaire (EOQ) into Brazilian Portuguese and Spanish. The EOQ captures multiple dimensions of EOs, including frequency, duration, intensity, associated behaviors, recovery time, triggers, and the effectiveness of calming strategies.

First, we performed a cross-cultural adaptation of the EOQ into Brazilian Portuguese. The translation process confirmed strong content validity, requiring only minor adjustments. We then assessed predictive validity in a sample of 25 Brazilian caregivers of individuals with developmental disabilities (ASD, Down syndrome, and intellectual disability). Results indicated a significant increase in the frequency and duration of severe EOs during a period of mental health service interruption caused by COVID-19, demonstrating the EOQ's sensitivity to contextual changes and its potential utility as an outcome measure (Teixeira et al., 2024b).

Second, we implemented the EOQ in a large-scale, cross-cultural study involving 689 autistic children (mean age 8.7 ± 2.6) across five countries in the REAL network: Argentina, Brazil, Chile, Uruguay, and the Dominican Republic. Caregivers completed the EOQ in its Spanish and Portuguese versions. The most frequently reported indicators of EOs were "behavioral indicators of emotion" (52.0%), followed by "increased motor activity" (28.3%), "non-speech vocalizations" (27.6%), "mild verbal aggression" (23.8%), and "avoidance" (21.5%). Emotional states such as irritability or having a "bad day" emerged as significant triggers, underscoring the importance of monitoring irritability as a key marker of mental health in autistic children (Teixeira et al., 2024a)..

Together, these findings establish the EOQ as a valid and cross-culturally applicable tool for characterizing EOs and evaluating interventions in autism across diverse Latin American contexts (Teixeira et al., 2024b).

Dissemination and Capacity Building in the Latin American Region

Another key function of the scientific events promoted by the REAL Network has been to disseminate research findings and to bring knowledge directly to local audiences, fostering awareness, training, and collaboration across Latin American countries. Another central component of the network's mission has been the organization of major conferences and extensive dissemination activities, both in academic settings and through the media.

The First Latin American Conference on Autism Spectrum Disorder, organized by REAL members, was held in Santiago, Chile, in 2013. In 2015, a roundtable with REAL representatives took place during the *International Congress on Autism in Adulthood* in São Paulo, Brazil. Subsequent international meetings with REAL members in the organizing committees were hosted in Argentina (in 2016) and Uruguay (in 2018).

Regarding the dissemination of the network's findings, more than 40 studies have already been presented as posters or oral communications at 10 scientific conferences, including the Autism-Europe International Congress, the European Network for Mental Health Service Evaluation (ENMESH), World Psychiatric Association (WPA); Asociación Española de Profesionales del Autismo(AETAPI); International Developmental Pediatrics Association (IDPA), and especially the INSAR Meeting.

The studies covered a wide range of themes, such as access to health and education services for individuals with autism in Latin America; barriers experienced by children, adolescents, and adults; the impact of the COVID-19 pandemic on individuals with ASD and their families; caregivers' experiences of stigma, burden, and unmet needs; and the development and cross-cultural adaptation of assessment instruments.

Future Directions

Our group remains active, holding regular virtual meetings and annual in-person gatherings at the INSAR congresses, where the REAL Network has been officially recognized for the past five years. At the 2025 INSAR Annual Meeting in Seattle, USA, the network received the Cultural Diversity Research Award.

In addition, four of our members were selected as national representatives of INSAR, joining the Global Senior Leaders committee that includes participants from 30 countries, with Latin American representation from Argentina, Brazil, and Uruguay. Further expansion is expected in 2026. Two REAL Network members have also served as South America representative to INSAR[1] (AR – term until 2025, and CSP – term from 2025 to 2027).

Recognizing that it is known that autistic individuals experience significantly increased suicide risk and that most existing literature has focused on children, there remains a lack of population-based studies on mental health and suicidality among autistic youth and adults in Latin America. To address this gap, in 2025 we initiated a cross-country study exploring suicidality rates and interpersonal risk factors in autistic and non-autistic adults across Argentina, Brazil, Chile, Uruguay, Spain, Mexico, Venezuela and the Dominican Republic through a large survey-based project. In Brazil, data collection will also include adults with ADHD to allow broader comparisons across neurodevelopmental profiles.

We aim to recruit approximately 1,000 autistic adults and an equivalent number of non-autistic participants to test the following hypotheses:

1) Autistic adults will report higher levels of suicidal thoughts and behaviors than non-autistic adults;
2) Suicidality will correlate with autistic traits, thwarted belongingness, perceived burdensomeness, and childhood polyvictimization;
3) Autistic trait severity will moderate will moderate the relationship between thwarted belongingness, perceived burdensomeness, and suicidality; and
4) Childhood victimization experiences will mediate the association between autistic traits and suicidal behaviors.

Together, these initiatives demonstrate the REAL Network's ongoing commitment to advancing collaborative, cross-cultural research that informs policies and interventions to improve the mental health and well-being of autistic individuals in Latin America and beyond.

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[1] https://www.autism-insar.org/page/GSLReps

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