

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

Autism

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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 Latinoamerica* 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 Latinoamerica* 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

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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.

## Keywords

autism, economic costs, healthcare utilization, stigma, treatment barriers

## Introduction

Most people with developmental disorders and mental health problems face several challenges and do not receive adequate treatment (Brondino et al., 2015; Lopez et al., 2020; Sweetland et al., 2014). Moreover, some studies reveal that among the population with disability, people with autism spectrum disorders (ASDs) living in high-income countries have the highest percentage of unmet healthcare needs in terms of treatment and support in comparison with individuals with other developmental disabilities and special healthcare needs (Chiri & Warfield, 2012; Krauss et al., 2007; Lindly et al., 2016). Unmet needs, lack of infrastructure, and stigma have been highlighted as important issues in access to service for this population (Kinneer et al., 2016; Lopez et al., 2019). The costs related to treatment are one of the biggest barriers to access to services among individuals with ASD (Buescher et al., 2014; Järbrink & Knapp, 2001; Roddy & O'Neill, 2019).

In most low- and middle-income countries (LMIC), successful public policies for individuals with ASD are largely lacking (Durkin et al., 2015). To the best of our knowledge, no data on the costs of access to services are available, while stigma has been described in LMIC in different regions (Daniels et al., 2017; Tilahun et al., 2016). Studies covering other barriers to care for the population with ASD in LMIC are rare (Daniels et al., 2017) and nonexistent in Latin America. One important step forward is learning from family members about the main priorities and challenges of individuals with ASD in each region of the globe.

Although Latin American countries still have a long way to go in terms of public policy, several countries in the region have been pursuing the aim of achieving universal health coverage. Recently, they have set clear priorities to define health benefit plans in the search for more effective, equitable, transparent, and efficient practices (Vega & Frenz, 2015), resulting in significant improvements in access to care (Atun et al., 2015; Báscolo et al., 2018; Cotlear et al., 2015). While the region is still behind in a number of areas related to providing adequate support to the ASD population and their families, there has been some progress over the past 5–10 years. This has included the use of better instruments to gather more reliable data

(including prevalence data), the establishment of awareness programs, and improvements in services.

Several questionnaires designed to collect information from caregivers (Modified Checklist for Autism in Toddlers (M-CHAT), Autism Screening Questionnaire (ASQ/SCQ), Autism Behavior Checklist (ABC), Social Responsiveness Scale (SRS), and/or Autism Detection in Early Childhood (ADEC)) now have official translations in Spanish and Brazilian Portuguese, and have already been validated in Argentina, Brazil, Chile, and Mexico (Backes et al., 2014; Coelho-Medeiros et al., 2019; Manzone, 2013; Soto et al., 2015; Stewart & Lee, 2017). In addition, three observational screening tools, the Childhood Autism Rating Scale (CARS), the Structured Observation for Autism Screening (OERA), and the Autism Mental Status Examination (AMSE), have been validated in Argentina, Brazil, Chile, and Mexico (Galdino et al., 2020; Paula et al., 2018; Pereira et al., 2008; Stewart & Lee, 2017; Cukier et al., 2019 and Saffre et al., 2019 [October 17, 2019; in press—personal communication]). The “gold standard” diagnosis instruments for ASD, the Autism Diagnostic Interview-Revised (ADI-R) (Becker et al., 2012) and the Autism Diagnostic Observation Schedule (ADOS; Pacifico et al., 2019) now have official Spanish and Brazilian Portuguese versions, and in Brazil both of them have preliminary validation data.

Prevalence estimates are available from five Latin American countries, some with a reliable robust methodology, while others have important methodological limitations (Elsabbagh et al., 2012). Since 2008, a pioneering clinic-based data-review survey from Venezuela (Montiel-Nava & Pena, 2008), a pilot study in Brazil (Paula et al., 2011), and the most reliable study, with a large representative sample of the city of Leon in Mexico (Fombonne et al., 2016) have been completed. There has also been an estimate of ASD prevalence based on a non-representative sample of service users from Argentina in a study designed to identify broad developmental problems, using instruments not specific to the ASD population (Lejarraga et al., 2008), and another study based on schools referring children suspected to have ASD for treatment in Quito, Ecuador (Dekkers et al., 2015)

Awareness programs, the development of guidelines, and improvements in service provision are also noticeable in the region (Ceballos et al., 2018). In Brazil, for example,

the rights of individuals with ASD were improved after ASD was recognized by the Ministry of Health and Social Development as a disability in 2012. The same rights guaranteed to Brazilians were achieved by Chilean individuals with ASD in 2010. In addition, in 2014 the Brazilian Ministry of Health launched, for the first time, two open-access protocols about identifying individuals with ASD and how to provide assistance to people with the condition (Ministry of Health, 2014a, 2014b). In 2019, the Argentine Ministry of Health and Social Development published a consensus on ASD in the National Bulletin as part of the National Law on Autism (27.043) sanctioned in 2014 (Ministry of Health and Social Development, 2014). In Chile, in 2008, the Ministry of Education launched a guide for teachers on how to support students with ASD, while in 2011, the Ministry of Health published for the first time a guideline for the detection of ASD (Ministry of Health, 2011). Moreover, in 2015, in Argentina, the *Mirame* autism awareness campaign won the first prize in a competition organized by *Fundación La Nación*, a leading newspaper in the country. This campaign had a significant public impact, with many families being directed to the website ([www.mirame.org.ar](http://www.mirame.org.ar)) to access information about early signs, an autism screening questionnaire, and contact information about local organizations.

Finally, in order to strengthen ASD research collaborations and awareness in the region, the *Red Espectro Autista Latinoamerica* (REAL; Latin American Autism Spectrum Network) was constituted in 2015. The REAL network comprises researchers and clinicians from 6 of the 37 Latin America countries (Brazil, Argentina, Chile, Uruguay, Venezuela, and the Dominican Republic), which represents approximately half of the total of 623 million people living in the region.

The present study is the first collaborative work by REAL. It aimed to provide a broad picture of the main needs and challenges faced by families with autistic children in Latin America and was recently completed. The study will help to enhance awareness of ASD, seek to pave the way for further improvement in services, and support the development of long-term policy solutions related to ASD in the region. The objective of this article is to present the results from this study which aimed to (1) detect the main challenges and priorities for individuals with ASD in six Latin American countries, (2) identify barriers to access to care in this population, and (3) describe the stigma and financial impacts of ASD in families in the same sample.

## Method

### Participants

It initially comprised a convenience sample of 2965 caregivers of individuals with ASD. From this total, 23 cases were excluded (11 were “empty cells” and 12 had missing data specifically related to the goals of the current study),

resulting in a final sample of 2942 families. A specific diagnosis was provided by the caregiver in most cases, but 137 cases had a nonspecific ASD diagnosis: 108 classified as “other category” and 29 without the type of diagnosis. More details about the REAL study methods have been previously published elsewhere (Rattazzi et al., 2016).

### Instrument

Informants/caregivers answered the questionnaire “Caregiver Needs Survey” developed by Amy Daniels and the national coordinators of The Southeast European Autism Network (SEAM), as a part of the Global Autism Public Health Initiative of Autism Speaks, to assess the needs of families/caregivers of individuals with ASD. The questionnaire was designed to be used by parents or primary caregivers of individuals with a diagnosis of ASD. This instrument includes several domains such as the demographics of the respondents; characteristics of the individual with ASD; access and barriers to services; and caregiver needs and perceptions adapted from previous scales (Daniels et al., 2017). The questionnaire also covers stigma, particularly a proxy of family/courtesy/associative stigma toward the caregiver through mocking or blaming for the child’s disabilities (Ali et al., 2012; Mitter et al., 2019).

The original questionnaire was translated into both Spanish and Brazilian Portuguese and then back-translated to assure the integrity of the translation. Authors from each country made modifications to items related to educational modalities and levels, insurance coverage types, service types/treatments (such as the inclusion of psychoanalyses, an approach not covered in previous surveys), and informed consent details to ensure validity for cultural contexts. Following the authors’ review, questions regarding access to services and the costs related to each country involved in the study were considered. After this was completed, the Spanish and Brazilian Portuguese versions were piloted in 10 families per country in all six countries to study the reaction of caregivers to the instrument in terms of length, the language used, and the user-friendliness of the website. There were no modifications needed at this stage.

The current study examines the caregiver’s answers regarding the main challenges and priorities for individuals with ASD, barriers to access to care, perception of stigma, and financial impact. The question regarding perceived stigma or self-stigma was extracted from the affective dimension items of the Affiliate Stigma Scale which has been previously shown to present high reliability (Cronbach’s alpha  $r = 0.95$  for intellectual disability and  $r = 0.94$  for mental illness) in caregivers of children with intellectual disability or mental illness (Mak & Cheung, 2008). In addition, the scale had already been used in a Brazilian population of caregivers of children with ASD with good content validity according to three experts in the

field, who had a high level of agreement among themselves ( $W = 0.337$ ;  $\chi^2 = 81.503$ ;  $p$  value  $< 0.001$ ; Rubinho, 2015).

Moreover, internal consistency was evaluated within the sample, showing low to acceptable Cronbach's alpha. More specifically, Cronbach's alpha was  $r = 0.74$  for the five items related to access to services (waiting list, costs, services not available, not eligible for services, and no information available), it was  $r = 0.49$  for the four items for stigma by caregivers, and it was  $r = 0.60$  for the three items of the financial impact on the family (Raykov, 1997).

### Procedures and ethics

The final Spanish and Brazilian Portuguese versions of the Caregiver Needs Survey were made available for online access. No age restriction was established to give a first broad picture of the situation in Latin America. Data collection was made online between December 2015 and April 2016. Online data collection has been growing dramatically in the past decade enabling researchers to deliver surveys to participants in a convenient, low-cost, and expeditious manner (Buchanan & Hvizdak, 2009). This methodological strategy was crucial for the current study to reach a high number of families of individuals with ASD, especially given the lack of any funding specific for this research.

National coordinators oversaw survey implementation in their respective countries and attainment of clearance from an accredited ethical review board. All caregivers had to sign an informed consent for her or his country before participating in the study. The anonymity of all participants was preserved, as well as the confidentiality of the obtained information.

### Data analysis

Online data was collected through the MySQL program and stored in a database in the Excel program. Data from the six countries were merged in a single Excel dataset. The final database was converted into the SAV format of the Statistical Package for Social Sciences Version 17.0 (SPSS 17.0) for descriptive and inferential statistical analyses.

Data analysis included descriptive statistics, such as measures of central tendency and dispersion (means and standard deviation), and frequency distributions for each measure for the whole sample and by country. We also ran inferential statistics to compare distribution between countries using chi-square tests.

### Results

The characteristics of the individuals with ASD and types of health system used by families are presented by country and overall in Table 1 ( $N = 2942$ ). The mean age in years

was 9.06 ( $SD \pm 6.86$ ) and 82.9% were male. Only 36.3% of the participants used complex sentences. Most of the families exclusively used the private health system (73.9%). The following differences were identified: (1) the Brazilian sample was older, while the Venezuelan was younger ( $p < 0.01$ ); (2) Individuals with ASD from Brazil and the Dominican Republic were less verbal ( $p < 0.01$ ); and (3) those from the Dominican Republic used the private sector exclusively more than other countries ( $p < 0.01$ ).

The inference statistics presented in Tables 1 to 4 ( $F$ ,  $\chi^2$ , and  $p$  values) represent the results of comparisons between the six countries.

The main concerns reported by the caregivers were communication difficulties (55.4%), social interaction deficits (52.2%), and making sure that the person with ASD received adequate education (52.3%). Regarding priorities, the need for greater community awareness (54.4%) and improvements in the educational system (55.2%) were the most frequently cited (Figure 1).

As a whole, 80.7% of the total sample had received some type of service during their lifetime. The most common type was speech therapy (63.7%), followed by occupational therapy (44.7%) and behavior therapy/behavior modification (39.2%); 38.7% reported using medication. The least reported services included psychoanalyses (18.1%) and biomedical treatments (14.0%).

Distribution of the treatments was slightly different among countries, except in regard to speech therapy, which was the most commonly offered therapy in all the countries. Occupational therapy was lower in Uruguay (11.1%) and higher in Venezuela (66.4%); behavior therapy/behavior modification was lower in Chile (28.4%) and higher in Venezuela (52.0%); while medication was lower in Dominican Republic (28.1%), but higher in Chile (53.1%) and Uruguay (54.7%). Psychoanalyses was higher in Argentina (31.2%) but lower in the Dominican Republic (6.9%) and Venezuela (4.6%), while biomedical treatments were higher in Chile (27.6%) and Venezuela (21.9%).

Families felt more satisfied with the services received from behavior therapy/behavior modification (73.0%), occupational therapy (68.7%), and speech therapy (65.2%) than with medication (57.5%), psychoanalyses (56.7%), and biomedical treatments (52.3%). This sequence is similar all six countries.

The main barriers to receiving treatment were related to structure, including long waiting lists (50.2%), high costs (35.2%), and lack of services (26.1%). This sequence was similar in the six countries, although some differences among them were observed. For example, *waiting lists* were reported as a problem more frequently in Brazil (56.5%) and less in Argentina (42.4%) and Chile (43.0%), while costs were more reported in the Dominican Republic (41.4%;  $p < 0.01$ ; Table 2).

Only 17.8% of families reported difficulties obtaining information about services and treatments for ASD, except

**Table 1.** Caregiver-reported characteristics of individuals with ASD in Latin America, by country and total sample (N = 2942).

Country/Characteristic	Chile (N = 291)	Argentina (N = 786)	Brazil (N = 1232)	Dominican Republic (N = 147)	Uruguay (N = 375)	Venezuela (N = 111)	All countries (N = 2942)	F; P-value <sup>a</sup>
Child age in years, mean (SD) <sup>b</sup>	10.44 (6.1)	8.33 (5.7)	9.33 (8.1)	7.8 (5.6)	9.13 (6.2)	8.76 (4.4)	9.06 (6.86)	5.625; <0.01
Child gender, N (%) <sup>b</sup>								$\chi^2$ ; p value <sup>a</sup>
Male	259 (89)	650 (82.7)	1009 (81.9)	122 (83)	302 (80.5)	97 (87.4)	2439 (82.9)	11.601; 0.41
Female	32 (11)	136 (17.3)	223 (18.1)	25 (17)	73 (19.5)	14 (12.6)	503 (17.1)	
Current verbal ability, N (%) <sup>b</sup>								102.883; <0.01
Does not talk	38 (13.1)	113 (14.4)	292 (23.8)	34 (23.1)	63 (16.8)	18 (16.4)	558 (19.0)	
Uses single words only	28 (9.6)	111 (14.1)	171 (13.9)	29 (19.7)	54 (14.4)	4 (3.6)	397 (13.5)	
Uses 2- or 3-word phrases	35 (12)	115 (14.6)	158 (12.9)	23 (15.6)	50 (13.4)	21 (19.1)	402 (13.7)	
Uses sentences with >4 words	35 (12)	138 (17.6)	219 (17.8)	25 (17)	66 (17.6)	31 (28.2)	514 (17.5)	
Uses complex sentences	155 (53.3)	309 (39.3)	389 (31.7)	36 (24.5)	141 (37.7)	36 (32.7)	1066 (36.3)	
Type of health system								222.755; <0.01
Only private	177 (65.8)	671 (87.6)	781 (64.0)	124 (91.9)	262 (78.4)	80 (72.1)	2095 (73.9)	
Only public	87 (32.3)	55 (7.2)	327 (26.8)	9 (6.7)	68 (20.4)	17 (15.3)	563 (19.9)	
Both public and private	5 (1.9)	40 (5.2)	112 (9.2)	2 (1.5)	4 (1.2)	14 (12.6)	177 (6.2)	

ASD: autism spectrum disorder.

<sup>a</sup>Between the six countries.<sup>b</sup>Significance difference between columns (t-test).

**Table 2.** Past 12 months' access to services and unmet needs as reported by caregivers of individual with ASD in Latin America, by country and total sample ( $N = 2942$ ).

Country/ question	Chile N (%)	Argentina N (%)	Brazil N (%)	D. Republic N (%)	Uruguay N (%)	Venezuela N (%)	All countries N (%)	$\chi^2$ ; $p$ value <sup>a</sup>
<i>In the past 12 months, did you have any difficulties or delays in getting services for your child because of the following reasons?</i>								
Waiting list (N (%))								99.35; <0.01
Yes	101 (43.0)	253 (43.4)	480 (56.5)	61 (53.5)	151 (51.5)	46 (46.0)	1092 (50.2)	
No	119 (50.6)	315 (54.0)	287 (33.8)	51 (44.7)	136 (46.4)	52 (52.0)	960 (44.2)	
Don't know	15 (6.4)	15 (2.6)	82 (9.7)	2 (1.8)	6 (2.0)	2 (2.0)	122 (5.6)	
Costs (N (%))								19.84; 0.03
Yes	105 (36.2)	248 (33.2)	456 (37.3)	60 (41.1)	101 (27.7)	46 (41.4)	1016 (35.2)	
No	180 (62.1)	489 (65.4)	744 (60.8)	85 (58.2)	260 (71.2)	63 (56.8)	1821 (63.2)	
Don't know	5 (1.7)	11 (1.5)	23 (1.9)	1 (0.7)	4 (1.1)	2 (1.8)	46 (1.6)	
Services not available (N (%))								13.20; 0.21
Yes	76 (26.2)	198 (26.7)	358 (29.3)	53 (36.3)	89 (24.5)	29 (26.1)	803 (27.9)	
No	208 (71.7)	518 (69.8)	823 (67.4)	89 (61.0)	264 (72.7)	76 (68.5)	1978 (68.8)	
Don't know	6 (2.1)	26 (3.5)	40 (3.3)	4 (2.7)	10 (2.8)	6 (5.4)	92 (3.2)	
Not eligible for services (N (%))								11.00; 0.36
Yes	69 (23.8)	137 (18.4)	252 (20.6)	39 (26.5)	77 (20.9)	20 (18.0)	594 (20.6)	
No	210 (72.4)	574 (77.3)	935 (76.5)	104 (70.7)	280 (76.1)	86 (77.5)	2189 (76.0)	
Don't know	11 (3.8)	32 (4.3)	35 (2.9)	4 (2.7)	11 (3.0)	5 (4.5)	98 (3.4)	
No information available (N (%))								44.2; <0.01
Yes	44 (15.2)	133 (18.2)	261 (21.4)	14 (9.6)	50 (13.9)	8 (7.2)	510 (17.8)	
No	238 (82.1)	573 (78.3)	936 (76.8)	131 (89.7)	308 (85.3)	100 (90.1)	2286 (80.0)	
Don't know	8 (2.8)	26 (3.6)	22 (1.8)	1 (0.7)	3 (0.8)	3 (2.7)	63 (2.2)	
How often have you been frustrated in your efforts to get services for your child? (N (%))								103.1; <0.01
Never	56 (21.5)	115 (16.5)	101 (9.8)	28 (20.9)	64 (18.5)	22 (20.8)	386 (15.0)	
Sometimes	123 (47.1)	339 (48.7)	428 (41.6)	56 (41.8)	161 (46.5)	69 (65.1)	1176 (45.7)	
Usually	56 (21.5)	147 (21.1)	301 (29.3)	28 (20.9)	80 (23.1)	10 (9.4)	622 (24.2)	
Always	21 (8.0)	82 (11.8)	172 (16.7)	18 (13.4)	37 (10.7)	4 (3.8)	334 (13.0)	
Don't know	5 (1.9)	13 (1.9)	26 (2.5)	4 (3.0)	4 (1.2)	1 (0.9)	53 (2.1)	

ASD: autism spectrum disorder.

<sup>a</sup>Between the six countries.

in Brazil, where almost a quarter of families stated that a lack of information was associated with difficulties or delays in receiving ASD treatment. The main sources of information were the Internet (80.4%), followed by professionals (64.0%), and then other parents (50.4%). This sequence was exactly the same in all countries.

More than one-third of all caregivers (37.2%) felt usually or always *frustrated when seeking treatment*. This was particularly challenging in Brazil (46.0%), but less problematic in Venezuela (4.7%;  $p < 0.01$ ; Table 2).

Among the three items related to *family/courtesy/associative stigma*, the most common was "feeling helpless for having a child with autism" (overall sample 39%). Moreover, 34.0% of the whole sample reported that *other people would discriminate against them* because they had a child with autism, and 17.6% of the caregivers in this sample stated that having a child with autism imposed a negative impact on them. Significant differences related to stigma were found in all countries, particularly in "feeling helpless for having a child with ASD," which was highest

among Brazilian families and lowest among Venezuelan families ( $p < 0.01$ ), and the item "other people would discriminate against me because I have a child with autism," also being the lowest among Venezuelan families ( $p < 0.01$ ; Table 3).

The financial familial impact of ASD was evident in the six Latin America countries. Overall, half of the sample reported some sort of financial problem (48.8%), with even higher percentages in the Dominican Republic (62.6%;  $p < 0.01$ ). A significant number of caregivers had to *cut down work hours* (47.4%), and one-third of caregivers (35.5%) had to stop working because of the child's autism (Table 4).

## Discussion

The present study is the first collaborative work by the REAL network. It aimed to provide a broad picture of the main needs and challenges faced by families with autistic children in Latin America.

**Table 3.** Stigma as reported by caregivers of individuals with ASD in Latin America, by country and total sample (N = 2942).

Country/question	Chile	Argentina	Brazil	D. Republic	Uruguay	Venezuela	All countries	$\chi^2$ ; p value <sup>a</sup>
I feel helpless for having a child with autism								
Agree/strongly agree (N (%))	82 (31.4)	200 (28.8)	526 (51.2)	50 (37.6)	120 (34.7)	18 (17.0)	996 (38.8)	176.23; <0.01
Strongly disagree/disagree (N (%))	179 (68.6)	494 (71.2)	501 (48.8)	83 (62.4)	226 (65.3)	88 (83.0)	1571 (61.2)	
I worry if other people know that I have a child with autism								
Agree/strongly agree (N (%))	28 (10.7)	46 (6.7)	105 (10.3)	10 (7.5)	21 (6.1)	7 (6.6)	217 (8.5)	24.48; 0.06
Strongly disagree/disagree (N (%))	233 (89.3)	644 (93.3)	913 (89.7)	123 (92.5)	325 (93.9)	99 (93.4)	2337 (91.5)	
Other people would discriminate against me because I have a child with autism								
Agree/strongly agree	92 (35.4)	235 (34.1)	350 (34.4)	40 (30.1)	133 (38.3)	18 (17.0)	868 (34.0)	69.76; <0.01
Strongly disagree/disagree	168 (64.6)	455 (65.9)	667 (65.6)	93 (69.9)	214 (61.7)	88 (83.0)	1685 (66.0)	
Having a child with autism imposes a negative impact on me								
Agree/strongly agree	48 (18.5)	114 (16.5)	205 (20.1)	23 (17.3)	51 (14.8)	8 (7.6)	449 (17.6)	21.54; 0.12
Strongly disagree/disagree	212 (81.5)	576 (83.5)	817 (79.9)	110 (82.7)	293 (85.2)	97 (92.4)	2105 (82.4)	

ASD: autism spectrum disorder.

<sup>a</sup>Between the six countries.

Almost 3000 participants were involved in the six REAL countries (Argentina, Brazil, Chile, Uruguay, Venezuela, and the Dominican Republic), helping to better understand the needs of families affected by ASD and to pave the way to build data-driven strategies at a national and regional level.

More than half of the caregivers stated that communication and social interaction deficits were the main challenges for individuals with ASD. These results are similar to those found in families from other cultures and countries, such as Serbia (Pejovic-Milovancevic et al., 2018). These challenges were, however, different from the mental and physical health, distress and sensory issues usually reported in high-income countries (McConachie et al., 2018). Despite the challenges being different in LMIC compared to high-income countries, in the end, all these difficulties are closely related to the adaptability, acceptability, and demandingness of the everyday activity of individuals with ASD, and these three factors are usually indicated as the main concerns of the parents of children with ASD (Hoffman et al., 2009; Pejovic-Milovancevic et al., 2018).

The main priority for most of the participants was “to make sure that the child with ASD received adequate education,” highlighting parental concerns about the socialization and independence of their sons/daughters. Again, this finding has been previously revealed from studies conducted in Southeast European countries using the same measurements and a similar methodology (Daniels et al., 2017; Pejovic-Milovancevic et al., 2018), as well as in a recent review about the main indicators of progress and outcomes among young children with ASD (McConachie et al., 2018). These results reflect a general frustration about current educational systems. Parents from high-income countries also complain that schools are not able to handle ASD special needs (Bitterman et al., 2008), and that the number of hours spent at school is insufficient (McIntyre & Zemantic, 2017). Caregiver frustration is in agreement with teacher reports of lack of support, training, and knowledge about ASD, even in early school years (Fontil et al., 2020). Thus, policymakers from Latin America and other regions must be aware of these challenges and priorities when developing programs for people with autism.

On the contrary, unlike studies from high-income countries (Hoffman et al., 2009; McConachie et al., 2018), the current study indicated that the main priority was improvements in community awareness. This can be interpreted as result of the fact that although there has been a great deal of progress in the past 5–10 years in Latin America, there is still much that needs to change, especially in relation to people’s attitudes toward ASD, and minimizing related social stigma.

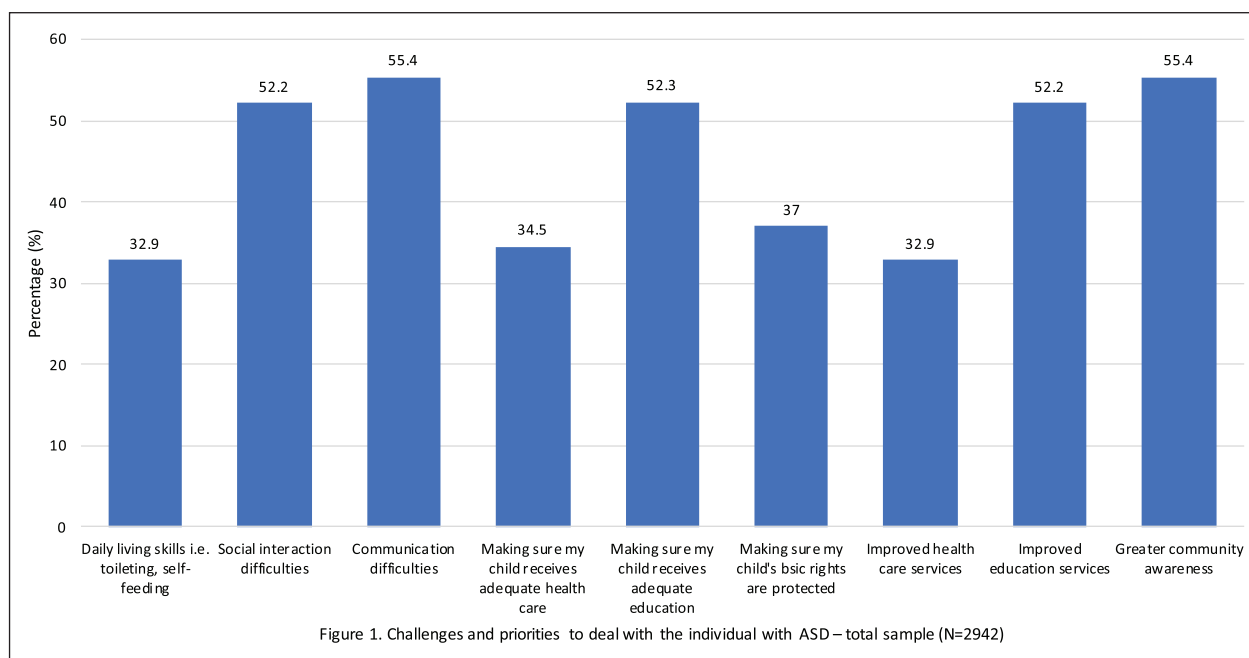
The study showed that 80.7% of the participants in Latin America had received some type of service at some

**Table 4.** Financial impact on the family, by country and total sample ( $N = 2942$ ).

Country/question	Chile	Argentina	Brazil	D. Republic	Uruguay	Venezuela	All countries	$\chi^2$ ; $p$ value <sup>a</sup>
Has your child's autism caused financial problems for your family?								
Yes	156 (53.8)	332 (42.8)	596 (48.6)	92 (62.6)	199 (53.2)	52 (46.8)	1427 (48.8)	41.35; <0.01*
No	132 (45.5)	424 (54.6)	620 (50.5)	52 (35.4)	172 (46.0)	59 (53.2)	1459 (49.9)	
Don't know	2 (0.7)	20 (2.6)	11 (0.9)	3 (2.0)	3 (0.8)	0 (0.0)	39 (1.3)	
Have you or other family members cut down on the hours your work because of your child's autism?								
Yes	134 (46.2)	387 (50.0)	539 (43.9)	68 (46.3)	197 (52.8)	60 (54.1)	1385 (47.4)	14.77; 0.13*
No	155 (53.4)	384 (49.6)	682 (55.6)	76 (51.7)	175 (46.9)	50 (45.0)	1522 (52.1)	
Don't know	1 (0.3)	3 (0.4)	6 (0.5)	3 (2.0)	1 (0.3)	1 (0.9)	15 (0.5)	
Have you or other family members stopped working because of your child's autism?								
Yes	102 (35.2)	269 (34.6)	452 (36.8)	41 (27.9)	132 (35.2)	44 (39.6)	1040 (35.5)	22.42; 0.017*
No	188 (64.8)	505 (65.0)	768 (62.6)	103 (70.1)	242 (64.5)	66 (59.5)	1872 (64.0)	
Don't know	0 (0.0)	3 (0.4)	7 (0.6)	3 (2.0)	1 (0.3)	1 (0.9)	15 (0.5)	

<sup>a</sup>Between the six countries.

\*Based on 10,000 sampled tables with starting seed at 2,000,000.

**Figure 1.** Challenges and priorities to deal with the individual with ASD—total sample ( $N = 2942$ ).

time; however, this is lower in comparison to reports from high-income European countries where, in some examples, the level of support reached over 90% (Daniels et al., 2017; Salomone et al., 2015). An encouraging finding was that the three types of treatment most frequently offered,

speech therapy, occupational therapy, and behavior therapy/behavior modification, are in accordance with the recommendations of international guidelines and evidence-based interventions (Anagnostou et al., 2014; Manning-Courtney et al., 2013; The National Autism



Center's, 2011; Reichow, 2012; Schoen et al., 2018; Volkmar et al., 2014; C. Wong et al., 2015).

There were some differences between the six countries in the types of treatments provided. Families from Venezuela received more behavior therapy/behavior modification, and occupational therapy. Recruitment for the sample in Venezuela was conducted through institutions that offer these kinds of treatments, which may have impacted this finding. The fact that both of these approaches are among the most recommended treatments for ASD may explain, at least partially, why in the whole sample the lowest levels of frustration and stigma were found in Venezuelan families. Another possible reason for these low levels is that participants from Venezuela were younger, mostly preschoolers, when stigma tends to be lower and symptoms have not become chronic.

Medication was also reported as a prevalent treatment. There are no available drugs to treat the core symptoms of ASD and medication is mainly used to help minimize behavioral problems (such as aggression, irritability, and self-injurious behavior), hyperactivity, and coexisting psychiatric and/or medical conditions (Santosh & Singh, 2016; Venkat et al., 2012). However, few psychotropic interventions have strong empirical evidence (Huffman et al., 2011; Siegel & Beaulieu, 2012). Therefore, pharmacotherapy should not be an isolated choice, but part of an integrated multidisciplinary intervention (Bertelli et al., 2016; Volkmar et al., 2014). Considering the limited research support for psychopharmacology, our results identify a possible cause for concern, particularly among families from Chile and Uruguay where medication use was more frequent than in the other four Latin American countries (53.1% and 54.7%, respectively), and more similar with the high rates identified in the United States, ranging from 45% (Aman et al., 2003) to 56% (Logan et al., 2012). This is a pioneer study of medication use in Latin America, and further studies are recommended to better understand the local context.

Our survey becomes original in terms of showing some light on such comparative frequencies in Latin America, describing the distribution of mainstream treatments in the region and describing therapeutic approaches not usually covered in previous studies, such as psychoanalyses.

Biomedical therapy, including restrictive diets, supplements, and hormone interventions has been classified as a type of complementary/alternative medicine (CAM) treatment but with limited evidence of efficacy (Huffman et al., 2011). In our study, only 14.0% of families reported using biomedical therapy (highest in Venezuela [21.9%] and Chile [27.6%]) while previous studies reported rates of between 30% and 50% for any type of CAM use among families with ASD, including biomedical therapy (Akins et al., 2014; H. H. L. Wong & Smith, 2006). This is another positive result from the study, as it is, to the best of our knowledge, the first to present findings in relation to CAM

treatment for the ASD population in Latin America. Therefore, it should be of interest to families, providers, and policymakers.

Interestingly, families felt more satisfied with evidence-based treatments for ASD, such as behavior therapy/behavior modification (Linstead et al., 2017; Reichow, 2012), occupational therapy (Jasmin et al., 2009), and speech therapy (Manning-Courtney et al., 2013), than with other treatments with less evidence in the literature (Huffman et al., 2011; The National Autism Center's, 2011).

In addition, most of the caregivers in this survey consider that they have information about services and treatments for ASD, mainly obtained from the Internet, and providers—the same pattern identified in other samples (Daniels et al., 2017; Pejovic-Milovancevic et al., 2018). This is another positive result from our study, showing that information is reaching caregivers.

Lack of infrastructure was identified as the main barrier to access to care among individuals with ASD, specifically waiting lists, costs, and lack of specialized services. Over a third of caregivers felt frustrated when seeking treatment, with half of the sample having to face waiting lists, and a quarter of them not having services available. The evidence suggests that most people with ASD do not receive enough evidence-based and intensive treatment as recommended by international guidelines (Krauss et al., 2007; Lindly et al., 2016; McIntyre & Zemantic, 2017; Myers & Johnson, 2007; Nguyen et al., 2016).

Brazilian families reported significantly more problems associated with waiting lists, more frustration when seeking treatment, and more difficulties in obtaining information. Although the Brazilian Unified National Health System (SUS) provides universal care to the entire population, a lack of financial and human resources limits what can be provided. In addition, unequal distribution of resources among different regions of the country, and high levels of individual income inequality make access to care a significant challenge for the Brazilian population (Paula et al., 2012). The quality of service provided is also unequal, with some specialized services being provided exclusively in the public or in the private system, mainly in urban areas, particularly in big cities in the most developed regions of the country (Paim et al., 2011). This may explain why Brazilian families struggle with infrastructural barriers and frustration when seeking treatment. In addition, the Brazilian sample is slightly older and with more severe ASD (more nonverbal individuals), and, therefore, probably requiring more specialized and intensive treatments.

As far as the authors know, this is the first comprehensive data on barriers to access to services for ASD individuals in Latin America, including some proxy of service satisfaction. Thus, it is not possible to compare these results with previous ones, but it is possible to speculate

that difficulties in accessing services are not exclusive to ASD, as already shown in other populations from the same regions, such as those with emotional/behavioral problems and neurodevelopmental disorders (Eaton et al., 2011; Fatori et al., 2019; Paula et al., 2014).

More recently, researchers have started to highlight the importance of cultural influences on parental beliefs, attitudes, and knowledge toward help-seeking patterns (Greenwood et al., 2015; Lopez et al., 2020), including in relation to the specificities of the ASD population (Ravindran & Myers, 2012; Zuckerman et al., 2014). Studies conducted in high-income countries highlight that ASD caregivers from racial or ethnic minorities have even less access to services, due not only to a lack of services, but also to parental beliefs and different help-seeking patterns. In a nationally representative sample of the U.S. population, while ASD caregivers from minority families were significantly less likely to perceive a need for prescription medication, English-speaking Hispanic and Black non-Hispanic caregivers reported more need for therapy than White non-Hispanic caregivers (Benevides et al., 2016). Taking this into consideration, it is important that professionals are culturally aware of parental feelings so that they can help the ASD population to achieve the best course of care (Ravindran & Myers, 2012).

The perception of stigmatizing situations was also high among caregivers, with a third of the sample fearing discrimination for having a child with ASD. Families of individuals with mental illness, intellectual disability, and ASD are mainly exposed to two kinds of stigma: courtesy stigma, when the stigma associated with the disorder extends to the caregiver, and affiliate stigma, when negative judgments associated with the disorder are incorporated within the caregiver identity (Mak & Cheung, 2008; Mitter et al., 2019). In Latin America, a recent review revealed that studies with relatives of individuals with mental disorders focused mostly on stigma “from” the family, not stigma “toward” the family (Mascayano et al., 2016). Thus, results from this article contribute to this gap in the scientific literature and should be examined in future research. In addition, stigma brings emotional consequences to members of families with individuals with ASD, including sadness, embarrassment, shame, guilt, and fear (Mitter et al., 2019; Papadopoulos et al., 2019). In addition, there are consistent findings indicating overall financial impact and lower rates of help-seeking among the victims of stigma (Clement et al., 2015; Evans-Lacko et al., 2015).

In the current study, affiliate stigma was particularly strong among caregivers living in Brazil, especially in relation to its affective component. This resulted in greater emotional strain on Brazilian caregivers (Bos et al., 2013) who reported the highest level of “feeling helpless for having a child with ASD.” This may be due to the fact ASD in the Brazilian sample was more severe than in the samples from the other countries. This result is in line with a literature

review indicating that parental emotional overload was the main challenge faced by families of children with ASD in Brazil (Gomes et al., 2014), and reinforces the need for expanding assistance to family members of individuals with ASD to minimize psychological distress related to the disorder.

Finally, almost half of the caregivers in the sample were facing financial challenges derived from having a child with ASD, which is not surprising since most of the families are exclusively using private health system users. Thus, these financial impacts highlighted the great vulnerability of the families in the Latin America region, especially knowing that this situation tends to be chronic, since most of the adults with ASD are not economically independent, and need parental financial support (Burke et al., 2019). In addition, employment impacts were detected in the participants of the current study, with a large percentage of caregivers having to stop work, or to reduce working hours because of the child’s autism. This unfortunate consequence of lacking adequate services has previously been described by Cidav et al. (2012), with the time required for taking care of children with ASD and the high cost of specialized care possibly reducing parents’ ability to sustain paid employment, resulting in extensive productivity losses for the families (Cidav et al., 2012).

In our sample, families from the Dominican Republic experienced significantly more financial problems, and faced more difficulties/delays in getting services due to costs. One can hypothesize that this may be due to low investment in the public health system, with health expenditure being only 2.5% of the national gross domestic product (GDP) in 2015 (Ministerio de Economía, Planificación y Desarrollo, [Ministry of Education, Planning, and Development], 2016). This lack of investment probably impacts the quality of the services provided, forcing families to seek help from private services where costs are higher. In our sample, 91.9% of the caregivers from the Dominican Republic exclusively used the private system, the highest percentage among the six countries.

Our findings are consistent with the international literature, which shows that caregivers of individuals with ASD face a high financial burden (Horlin et al., 2014). There are no data about ASD costs in Latin America, but studies conducted in high-income countries, such as the United States and Great Britain, indicate high costs to families and society (Buescher et al., 2014; Horlin et al., 2014; Penner et al., 2015). A recent large population-based survey in the United States found that 41% of caregivers had financial problems due to the child’s ASD condition and almost 40% reported they either stopped working or reduced working hours to take care of their children (Benevides et al., 2019). Because health and education services are essentially lifelong for people with ASD (Burke et al., 2019), costs, which normally increase over time, place a significant burden on public health systems and the

families who have to pay for services (Cidav et al., 2013; Roddy & O'Neill, 2019). Moreover, increased out-of-pocket costs are linked to higher unmet needs and delayed care due to cost (Karaca-Mandic et al., 2014).

This is the first study of this type in Latin America and its results provide a description of families and children with ASD in the region, but some limitations should be noted: (1) the results are based on a convenience sample, and lack of access to the Internet may have limited the participation of individuals with lower socioeconomic status, so the results cannot be generalized to all families with autistic children in the region; (2) the sample is unbalanced among countries, so data from the total sample analysis may have some bias and must be interpreted with care. Although we cannot be sure why the sample sizes differed so much between countries, the most obvious reason is the fact that the countries have significantly different population sizes; Brazil has the largest population (209 million inhabitants), followed by Argentina (44 million), Venezuela (31 million), Chile (18 million), the Dominican Republic (10 million), and Uruguay (3 million). Contributions to the research sample in general followed a pattern reflecting the population size, except in the case of Uruguay and Venezuela. Brazil contributed 41.9% of the total sample, followed by Argentina (26.7%), Uruguay (12.7%), Chile (9.9%), the Dominican Republic (5.0%), and Venezuela (3.8%). The proportionally smaller sample size from Venezuela may be due to limited access to the Internet related to media restrictions because of the political situation. As for Uruguay, we believe the country's proportionally higher sample size is due to the high capacity of researchers there to disseminate the survey. The local research team comprises members of the Child/Adolescent Attention Unit for ASD, the main reference service for autism for the entire country and is well connected with the National ASD Parents Association, which promotes regular talks to families and providers and helped to disseminate the survey among different towns in Uruguay. Moreover, the (3) diagnosis of ASD was reported by the caregivers but was not verified by direct evaluation, and all families were included, regardless of the specificity of the diagnosis within the spectrum of autism. In addition, (4) two sections of the questionnaire presented less than acceptable internal consistency, and (5) the current study did not investigate the role of parental beliefs as a barrier in relation to help-seeking patterns. Further studies should address this aspect to understand better the situation of families living in Latin America.

Our findings expand the knowledge about the challenges, priorities, barriers to care, stigma, and impact on families of individuals with ASD in LMIC. ASD treatment is expensive and requires well-trained professionals. It would, therefore, be interesting for future studies to explore the possibility of collaborative programs between parents, teachers, and professionals, to provide improved

support and care for individuals with ASD and their families.

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