


## RESEARCH ARTICLE

# Use of allied-health services and medication among adults with ASD in Latin America

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## Abstract

ASD is a neurodevelopmental disorder that affects people across the entire lifespan, yet most of the research identifying the health and medical needs for autistic individuals have been among minors. As individuals with ASD transition to emerging adulthood, the services, already limited, become less available. This study aimed to identify the use of services for Latin American adults on the spectrum. We surveyed 295 caregivers of adults with ASD from six Latin American countries. Comparing the results for all the possible services observed in this study, the adults in our sample were primarily underserved: 84.4%–95.9% were receiving zero hours per week, 3.7%–12.9% 1%–10 h, 0%–1.7% 11–20, and only 0%–1% above 20 h of services. Almost half of the sample used medication, and neurologists were the most consulted health providers. Next to inexistent health care usage in Latin American adults with ASD highlights socioeconomic and health disparities in service provision for ASD in the region. The lack of services places adults with ASD in Latin America at a higher risk of worse symptom severity than autistic adults from regions with broader access to services.

## Lay Summary

This study aimed to identify the quantity of services received by adults with autism in Latin America. Most of our sample was not receiving health services yet almost half had access to medication. This could mean that adults with autism in Latin America are at higher risk for poorer health.

## KEYWORDS

allied health, autism, autism medication, health disparities, Hispanics, Latin America

## INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder primarily characterized by socio-communication deficits and the presence of restricted, repetitive patterns of behavior and interests (American Psychiatric Association, 2013). Adults with ASD are not only at a higher risk for poorer health outcomes and medical complications, but also have a shorter life expectancy compared to the general population (Hirvikoski et al., 2016; Jokiranta-Olkonemi et al., 2020; Mandell, 2018). ASD is thus a disability that requires

external support throughout adulthood for many of those affected by the condition (Roux et al., 2015; Croen et al., 2015; Nicolaidis et al., 2014; Murphy et al., 2016; Brugha et al., 2011). As individuals with ASD transition to emerging adulthood, the services, already limited, become less available (Platos & Pisula, 2019; Shattuck et al., 2012).

Symptom expression in both verbal and non-verbal individuals with ASD is displayed heterogeneously throughout the population, making it imperative that service provision for adults with ASD be tailored to their individual needs (Mason et al., 2019). Barriers to

accessing healthcare services for adults might vary from a combination of factors such as policy restrictions set forth by insurance companies, limited availability of services, and lack of ASD knowledge by providers and the public (Raymaker et al., 2017; Shattuck et al., 2020; Day et al., 2020; Lake, Perry & Lunsky, 2014; Day et al., 2020; Friedman et al., 2013). Navigating medical care is more cumbersome for autistic adults given the reported limited awareness of various healthcare system aspects such as insurance coverage, billing, or medical benefits (Brugha et al., 2011; Shattuck et al., 2012). Such barriers and challenges could be partially influenced by limited knowledge of transitioning services from families and caregivers of autistic adults as they might not be able to advocate for such services or help their relatives navigate the healthcare system (Cheak-Zamora & Thullen, 2017; Croen et al., 2015; Raymaker et al., 2017). Incorrect assumptions about needs or skills adults with ASD and inappropriate language use by the provider toward the ASD adult can decrease future patient autonomy and treatment seeking behavior (Kinnear et al., 2016; Obeid et al., 2015).

Autism symptoms, mental and physical health issues, and behavioral challenges are often left untreated in adulthood due to insufficient medical coverage or lack thereof after transitioning (Hansel, 2013; Friedman et al., 2013; Richards et al., 2012). Moreover, those autistic adults with medical problems may experience more barriers to service use than those with no medical problems (Vogan et al., 2017). Among the barriers, the high coverage costs, both out-of-pocket and deductible fees, remain temporally constant during the developmental trajectory of individuals with ASD (Buck et al., 2014; Kennedy-Hendricks et al., 2018; LeClerc & Easley, 2015).

On the other hand, medication use in individuals with ASD also increases with age (Buck et al., 2014; Fusar-Poli et al., 2019). The most-reported medications include neuroleptics, anticonvulsants, and antidepressants (Buck et al., 2014; Daniels et al., 2008). Because of adults' various health conditions with autism, medication for those co-occurring conditions can be helpful. However, delays in diagnosing and problems recognizing symptoms might cause some of these conditions to be over or under-treated. (Espadas et al., 2020; Mandell et al., 2008).

The limited research on autism in low-and-middle-income countries complicates the understanding of whether individuals with ASD do not receive services because what they need is not available or because they require different or more services (Montiel-Nava et al., 2020). Uneven distribution of social, economic, political, and environmental resources, like those experienced in Latin American countries, are risk factors for health disparities (Rubin et al., 2011). This paper presents data on six different Latin American countries considered as upper-middle or high-income countries according to the World Bank classification (World Bank, 2017). However, people in these countries hardly ever have access to

services and trained specialists since there is a shortage of mental health professionals, and government mental health expenditure is below standard (World Health Organization, WHO, 2017). Most of the participating countries reports universal health coverage for mental health services (WHO, 2005, 2017). However, this universal health coverage implies mainly overbooked urban facilities, few trained professionals, and long waiting lists (Kohn et al., 2005; Saldivia et al., 2004).

Systematic data about ASD in adulthood is limited for Latin American countries (Baxter et al., 2015; Paula et al., 2020) and U.S. populations. For instance, most of the literature on ASD in Latin America (Paula et al., 2011; (Montiel-Nava & Pena, 2008) (Bagaiolo et al., 2017; Bordini et al., 2020) and for Hispanics living in the U.S. focuses on children. (Zuckerman et al., 2014). Although the symptom severity is similar regardless of race or ethnicity (Magaña & Smith, 2006), other factors like psychological well-being and/or adaptive function could be considered a disadvantage. Latin American families with an autistic member exhibit health inequality in the form of long periods of wait time to access services, inability to pay for the costs of services, and overall limited availability of ASD services (Paula et al., 2020). Therefore, existing socioeconomic disparities affect the initial identification and diagnostic process of ASD in Latinos (Montiel-Nava et al., 2017) but also prevents the access or continuation of ASD services, which can have adverse physical health outcomes for the adult with ASD (Shattuck et al., 2020). The overall health of Latin American adults with ASD is likely to be significantly poorer than autistics from developing countries, as is the limited ASD-services encounters among Latin American children and adolescents (Montiel-Nava et al., 2020).

In summary, adults with ASD living in Latin American countries are at a higher risk of being under-diagnosed, underserved, and experience a lower quality of services than adults with ASD living in developed countries. This study aimed to identify the usage of health services and medication by adults with ASD in Latin America.

## METHODS

This study was carried out in six different countries in South and Central America: Argentina, Brazil, Chile, Dominican Republic, Uruguay, and Venezuela. Advertisement of the study was disseminated through social networking platforms, parent and professional associations, institutions that provide services for individuals with ASD. A sample of convenience was drawn from each country. This study is part of a multisite study of Caregivers Needs in Latin America sponsored by the REAL network (Red Espectro Autista Latinoamerica, Montiel-Nava et al., 2020). Due to the disparity in ages, data on caregivers of adult children were analyzed separately.

## Participants

This study, an online anonymous survey, was carried out in six different countries in South and Central America: Argentina, Brazil, Chile, Dominican Republic, Uruguay, and Venezuela. Advertisement of the study was disseminated through social networking platforms, parent and professional associations, institutions that provide services for individuals with ASD. A sample of convenience was drawn from each country. This study is part of a multisite study of Caregivers Needs in Latin America sponsored by the REAL network (Red Espectro Autista Latinoamerica, Montiel-Nava et al., 2020). Due to the disparity in ages, data on caregivers of adult children were analyzed separately.

## Instruments

Caregivers completed the questionnaire “Caregiver Needs Survey” (Daniels et al., 2017). This survey was designed to be used by parents or primary caregivers of individuals diagnosed with ASD. The survey contained four sections: family demographics, affected individual characteristics, service encounters, and parent/caregiver perceptions. Questions for the section on service encounters included past and current service use for a variety of ASD-specific and non-ASD-specific services as well as education and educational supports (adapted from the Survey of Pathways to Diagnosis and Services; CDC, 2011). For this study, REAL translated the questionnaire into both Spanish and Portuguese; and translated it back to the original language (English) to assure that the instrument’s integrity was preserved through translation. After the backtranslation was completed, each country made modifications to items related to educational modalities and levels, insurance coverage types, and informed consent details to ensure validity for cultural contexts. In general, language adjustments were responsible for most changes and adaptations to the survey.

Caregivers entered the website and were asked to choose the country of residence from a cascading menu. The selection opened a separate window with informed consent for their country, and initials were requested as a signature. Once participants signed the informed consent, they received a random computer-generated ID, which offered caregivers the opportunity to come back any time to complete the survey without losing the entered data. No personal information was required (i.e., name, phone number, email address, etc.), preserving the anonymity of all participants and confidentiality of the data. Ethics approval was granted by the ethics board of the different agencies to which the national coordinator was affiliated.

The caregiver completed all items about the person with ASD. The sociodemographic measures included sex of the individual with ASD, insurance coverage (private, public, or both), and country. Clinical variables referred

to the diagnosis of the affected individual (autism/autistic disorder, Asperger’s disorder, PDD, PDD-NOS, ASD, and other), and the presence of medical comorbidities at the time of the study. The survey contains diagnosis options based on the DSM-IV-TR (APA, 2000) and the DSM-5 (APA, 2013).

Participating caregivers indicated (a) current service encounters from a list of allied- health services for their children and (b) the number of hours per week for each current service for their children at the time of the study. The original survey included eight allied- health services, Speech Therapy, Occupational Therapy, Physical Therapy, Behavioral Therapy, Cognitive Rehabilitation, Sensory Integration, Social Skills Training, Psychoanalytic Therapy, and medication frequency. The original survey also contains Relational Therapies (e.g., Floortime, SUNRISE) but was excluded from the analysis due to low numbers ( $n = 1$ ).

The survey used three different questions to inquire about the autistic adults’ language, adaptive function, and intellectual level. The questions were, (1) What is the verbal ability of your child? With response options including “(a) Does not speak, (b) uses single words, (c) uses 2–3-word phrases, (d) uses sentences of four or more words, and (e) uses full sentences.” (2) In your opinion, how is the level of functionality and severity of your child? The response options were, (a) mild symptomatology/high function), (b) moderate symptomatology/moderate function, (c) severe symptomatology/low function, and (d) I do not know. The final question, (3) Based on the professionals’ information, what is the intellectual level (IQ/intelligence) of your child? with response options including “(a) severe, (b) mild, (c) average, (d) above average, and (e) I do not know.” The caregivers responded to the questionnaire about individuals ranging from nonverbal to verbally fluent. However, different individuals’ verbal and intellectual development and functioning level scores may not be directly comparable. For that purpose, the three variables (language, severity, and adaptive function) were transformed to severity scores combining the three variables to achieve comparability across the subjects.

## Data analysis

Data sets were reviewed for duplicate or missing cases, which were excluded from the analysis. Duplicates were verified by comparing initials used in the consent form, country and region of residence indicated in the survey, and the caregivers’ IP addresses (Montiel-Nava et al., 2020; Paula et al., 2020).

Data analysis included calculations of central tendency and frequency. Country, sex of the individual with ASD (male or female), another family member with ASD, insurance type, current diagnosis, medical comorbidities, and type of service were treated as

nominal; severity index and usage of services were treated as ordinal. Age and age of diagnosis were treated as continuous variables. Group comparisons (based on age groups) were conducted using chi-square tests for categorical variables and independent sample T-tests for continuous variables.

Usage of services, our main dependent variable, was measured as the current (at the time of participation) number of hours received of health service (or the current medication frequency).

## Age group

As emerging adults transition to higher education from secondary education (Elias & White, 2018; Liptak et al., 2011) and into the workforce (Griffiths et al., 2016; Rogers & Vismara, 2008), they are faced with new challenges related to their independence (Friedman et al., 2013). In contrast, middle-aged adults face a new set of challenges associated with the aging process (Stuart-Hamilton & Morgan, 2011). Those changes might include neuroanatomy (Courchesne et al., 2011; Zielinski et al., 2014), neurocognitive function (Braden et al., 2017), and worsening health and well-being. Therefore, we categorize autistic adults by age groups into emerging adults (18–25 years) and middle-aged adults (26–50 years).

## Symptom severity

A four-step procedure was used to derive the severity score: (a) normalization of data using  $z$ -scores; (b) addition of the  $z$ -scores [(score-mean)/ $SD$ ]; (c) defining the severity range:  $+3 SD$  p 99.9 (severe),  $+2 SD$  p 98 (moderate), and  $+1 SD$  p 84 (low); and (d) performance of  $z$ -score transformation up to three ranks: low/medium/high severity. The index is directly proportional, that is, a higher severity index indicates a higher severity in symptoms.

## RESULTS

### Sample characteristics

The total sample was 295 caregivers from the different participant countries, and most of the caregivers were from Brazil 56.3% ( $n = 166$ ). The mean age of their children (adults) was 24.3 years ( $SD$  6.6 years), and ages ranged from 18 to 50 years. In terms of adulthood stage, 68.13% ( $n = 201$ ) were emerging adults (18–25 years old), and 31.87% ( $n = 94$ ) were middle-aged adults (26–50 years old). Caregivers were primarily mothers (73.9%), with undergraduate (55.5%) or graduate (33.6%) degrees. While most of the caregivers were mothers (73.9%,  $n = 218$ ), most of their adult children were identified as males 75.6% ( $n = 223$ ) (Table 1). From the total

sample of caregivers, 95.9% ( $n = 283$ ) had health insurance, 68.5% ( $n = 202$ ) had only private, 22.7% ( $n = 67$ ) had only public, 4.7% ( $n = 14$ ) had both private and public, and 4.1% ( $n = 12$ ) did not respond the item. There was no relationship between type of coverage and age groups ( $\chi^2 = 0.94$ ,  $p > 0.05$ ).

### Clinical characteristics

The most prevalent diagnosis of the adult child was Asperger Disorder (34.90%,  $n = 103$ ), followed by Autism/Autistic Disorder (28.8%,  $n = 85$ ). The least common diagnosis was PDD (4.1%,  $n = 12$ ). Medical comorbidities analysis shows epilepsy is the most frequent condition among the sample (18.6%,  $n = 55$ ). Most adults (73.2%,  $n = 201$ ) had at least one comorbid diagnosis (besides the autism-related diagnosis). The comorbid disorders included Epilepsy (18.6%,  $n = 55$ ), Down Syndrome (0.7%,  $n = 2$ ), Fragile X (2.4%,  $n = 7$ ), and others (22.4%,  $n = 66$ ). For the “Other” category, the survey had a blank space for caregiver to fill. Responses included depression, ADHD, genetic and congenital disorders, and respiratory/allergy-related conditions. The sample was equally distributed between Moderate (40%,  $n = 118$ ) and High (40%,  $n = 118$ ) severity. None of the clinical variables reached significant differences across age groups. (Table 2).

### Allied-health services and medication

Behavior therapy was the most frequently used allied-health service; however, 84.4% ( $n = 249$ ) were not receiving this service. For those receiving behavior therapy, only 2.7% ( $n = 8$ ) received 11+ hours per week. The least frequent service was Sensory Integration Therapy, where 95.9% ( $n = 283$ ) did not receive this service, and for those that did receive it, none were in the 11+ hours per week category (Table 3). Only one of the services showed a significant difference among the two age groups; emerging adults were more likely than middle-aged adults to receive Social Skills Training ( $X^2 = 7.1$ ,  $p < 0.05$ ). On the other hand, 48.6% ( $n = 143$ ) of participants were using medication at the time of the study, with no significant differences across age groups (Table 3). Regarding the overall number of utilized health services, 58% ( $n = 171$ ) of participants were receiving zero types of services, while 16.9% ( $n = 50$ ) were receiving at least one type of allied-health service. There were no significant differences in the number allied-health services utilized by the two age groups (Table 3).

The chi-square analysis of the relationship between medication and medical comorbidities showed that most of those receiving medication had only one comorbid diagnosis (57.8%,  $n = 170$ ) (Table 4). Finally, the most utilized health providers were Neurologists



**TABLE 1** Distribution of demographic characteristics of the sample

	Emerging adults (Age: 18–25) <i>n</i> = 201	Middle-aged adults (Age: 26–50) <i>n</i> = 94	Total <i>n</i> = 295
<i>Who completed the survey</i>			
Mother	79.5 (158)	63.8 (60)	218 (73.9)
Father	11 (22)	10.6 (10)	32 (10.9)
Grandparents	0.5 (1)	1.1 (1)	2 (0.7)
Other	9 (18)	24.5 (23)	41 (14.5)
<i>Highest educational level</i>			
Elementary or less	11.5 (23)	9.7 (9)	10.9 (32)
High School Diploma	19 (38)	12.9 (12)	17.1 (50)
Undergraduate Degree	36.5 (73)	43 (40)	38.6 (113)
Graduate Degree	33 (66)	34.4 (32)	33.4 (98)
<i>Country</i>			
Argentina	21.4 (43)	11.7 (11)	18.3 (54)
Brazil	52.2 (105)	64.9 (61)	56.3 (166)
Chile	10 (20)	7.4 (7.4)	9.2 (27)
Dominican Republic	2.5 (5)	0 (0)	1.7 (5)
Uruguay	11.4 (23)	12.8 (12)	11.9 (35)
Venezuela	2.5 (5)	0 (0)	1.7 (5)
<i>Type of insurance coverage</i>			
Only private	70.8 (136)	72.5 (66)	71.4
Only public	24 (46)	23.1 (21)	23.7 (67)
Both private and public	5.2 (10)	4.4 (4)	4.9 (14)
<i>Family member with an ASD diagnosis <i>n</i> (%)</i>			
	77.6 (156)	89.4 (84)	90.8 (268)
<i>Adults with ASD demographics gender [<i>N</i> (%)]</i>			
Male	96.5 (194)	94.7 (89)	95.9 (283)
Female	3 (6)	5.3 (5)	3.7 (11)
<i>Age, Mean ± SD</i>	20.58 ± 2	31.1 ± 6.2	24.3 ± 6.6

(44.3%, *n* = 129), followed by dietitians (35.7%, *n* = 104). The least used professionals were psychiatrists and (14.6, *n* = 42), and audiologists (6.3%, *n* = 18). There were no significant differences by age group in any of our identified medical and health service providers. (Table 5).

Supplemental analysis to look for possible predictors of use of service were all non-significant (Tables S1 and S2). There were no significant differences in allied-health usage by either country, gender, caregivers' educational level, diagnosis, or insurance coverage type. While social skills training revealed to have a significant difference by countries in the Chi-Square analysis, post-hoc testing revealed non-significant differences, as the standardized residuals all fail to reach statistical significance (adj. Standardize values <1.96).

## DISCUSSION

In the current study, we examined the frequency of use of allied-health services among emerging and middle-aged

adults with ASD from six Latin American countries, according to a sample of highly educated, computer literate parents almost all with insurance coverage. According to these parents, between 84.4%–95.9% were receiving zero hours of services per week. Moreover, for those having some services, 3.7%–12.9% receive between 1 and 10 h per week, and only 0%–2.7% 11 or more hours per week. Parents in our sample reported a very different experience than a prior parallel study of young people (Montiel-Nava et al., 2020). This is an unfortunate reality for adults with ASD in Latin America regarding the use of health services.

Although behavioral therapy was the most frequently used service in our sample, most participants were receiving none. Even considering that developed countries also report widely underserving adults with ASD (Dietz et al., 2020; Friedman et al., 2013; Platos & Pisula, 2019; Shattuck et al., 2011; Vogan et al., 2017), the lack of services in Latin America is striking, bordering the total absence of services.

Families with an autistic adult member also confront health providers who are vastly unaware of ASD and its

TABLE 2 Clinical features

	Emerging adults (age 18–25) <i>n</i> = 201	Middle-aged adults (age 26–50) <i>n</i> = 94	Total <i>n</i> = 295	$\chi^2$	<i>T</i>
<i>Autism diagnosis</i>					
ASD % (n)	21.9 (44)	23.4 (22)	22.4 (66)	0.1	
Asperger % (n)	36.3 (73)	31.9 (30)	34.9 (103)	0.6	
Autism/autism spectrum % (n)	26.4 (53)	34 (32)	28.8 (85)	1.8	
PDD-NOS % (n)	10.9 (22)	7.4 (7)	9.8 (29)	0.9	
PDD % (n)	4.5 (9)	3.2 (3)	4.1 (12)	2.7	
Age of diagnosis mean + SD	8.6 + 6.0	10.43 + 11.4	9.18 + 8.1		−1.8
<i>Medical comorbid diagnoses</i>					
Down syndrome % (n)	1.0 (2)	0 (0)	0.7 (2)	0.9	
Epilepsy % (n)	16.4 (33)	23.4 (22)	18.6 (55)	2.1	
Fragile—X % (n)	2 (4)	3.2 (3)	2.4 (7)	0.4	
Other % (n)	23.4 (47)	20.2 (19)	22.4 (66)	0.4	
Missing	56.2 (115)	53.2 (44)	55.9 (134)	—	
<i>Count of medical comorbid disorders % (n)</i>					
Only autism diagnosis/es	58.2 (117)	56.4 (53)	57.6 (170)		1.9
One comorbid diagnosis	40.8 (82)	40.4 (38)	40.7 (120)		
Two comorbid diagnoses	1 (2)	3.2 (3)	1.7 (5)		
<i>Severity index</i>					
Low % (n)	18.4 (37)	23.4 (22)	20 (59)		
Moderate % (n)	40.8 (82)	38.3 (36)	40 (118)		
High % (n)	40.8 (82)	38.3 (36)	40 (118)		

<sup>a</sup>Variable included missing cases.

manifestations during adulthood, leading to incorrect assumptions about their service needs (Shattuck et al., 2020; Zerbo et al., 2015). Such inaccurate clinical assumptions and inappropriate language might decrease their future autonomy (Kinnear et al., 2016; Nicolaidis et al., 2015). As adults with ASD are not offered enough services, they face long-term repercussions, including housing and employment opportunities (Butler & Gillis, 2011), relationships (Link & Phelan, 2001) denial of other types of services. Furthermore, it may lead to adverse health outcomes, limited self-efficacy, social isolation, which in turn makes it difficult accessing available services (Link & Phelan, 2001; Obeid et al., 2015; Martínez-Hidalgo et al., 2018; Muñoz et al., 2011; Stronach et al., 2019).

A unique result from this study is identifying the neurologists as the most frequently used service provider, even more regularly than psychiatrists or family doctors. The reported comorbidity with epilepsy in this sample could partially explain the high frequency of use of neurologists. According to the World Health Organization (2017), public expenditure on mental health and mental health specialists are scarce and unevenly distributed in Latin American and Caribbean countries (WHO, 2017), directly affecting access to services. Thus, a shortage of mental health specialists who attend to the adult

population with ASD might be somewhat responsible for reported services' paucity. On the other hand, in Brazil's health system neurologist rank as the second most available medical specialists in the country (Scheffer et al., 2018). Surprisingly, dietitians ranked second in the list of service providers. Without regional data to use as a baseline, we can only assume that non-healthy weight was the reason for this consultation. Reports of a significant association between obesity and ASD considered that autistic adults are more likely to be in non-healthy weight categories than non-autistic adults (i.e., underweight, overweight, or obese; Sedgewick et al., 2020; Zheng et al., 2017). In children, parents had reported the use of specialty diets to promote immune system function, increase quality and duration of sleep, and promote sociability among others (Trudeau et al., 2019). Thus, it might be possible that parents in our sample sought dietitians to develop food strategies or use dietary supplements to reduce symptoms or behaviors (e.g., specialty diets such as the ketogenic diet, low-carb diet, gluten free diet, and multivitamins). In general, lack of trained professionals, as it is the case of Latin American countries, is in the roots of delayed referral for services.

The medication in ASD is used for non-core symptoms (i.e., irritability, aggression), being the most used

**TABLE 3** Usage of allied health services and use of medication

	Emerging adults (age: 18–25) <i>n</i> = 201	Middle-aged adults (age: 26–50) <i>n</i> = 94	Total <i>n</i> = 295	<i>T</i>	$\chi^2$
<b>Type of service (8 total)</b>					
<i>Speech therapy</i>		—			0.1
0 h/wk % (n)	94 (189)	94.7 (89)	94.2 (278)		
1–10 h/wk % (n)	6 (12)	5.3 (5)	5.8 (17)		
11+ h/wk % (n)	0 (0)	0 (0)	0 (0)		
<i>Occupational therapy</i>					4.4
0 h/wk % (n)	92.5 (186)	86.2 (81)	90.5 (267)		
1–10 h/wk % (n)	7 (14)	11.7 (11)	8.5 (25)		
11+ h/wk % (n)	0.5 (1)	2.2 (2)	1.0 (3)		
<i>Physical therapy</i>					0.1
0 h/wk % (n)	95.5 (192)	95.7 (90)	95.6 (282)		
1–10 h/wk % (n)	4.5 (9)	4.3 (4)	4.4 (13)		
11+ h/wk % (n)	0 (0)	0 (0)	0 (0)		
<i>Behavior therapy</i>					1.4
0 h/wk % (n)	85.6 (172)	81.9 (77)	84.4 (249)		
1–10 h/wk % (n)	11.4 (23)	16 (15)	12.9 (38)		
11+ h/wk % (n)	3.0 (6)	2.2 (2)	2.7 (8)		
<i>Cognitive rehabilitation</i>					3.3
0 h/wk % (n)	91.5 (184)	89.4 (84)	90.8 (268)		
1–10 h/wk % (n)	6.5 (13)	10.6 (10)	7.8 (23)		
11+ h/wk % (n)	2.0 (4)	0 (0)	1.3 (4)		
<i>Sensory integration therapy</i>					1.4
0 h/wk % (n)	96.5 (194)	94.7 (89)	95.9 (283)		
1–10 h/wk % (n)	3 (6)	5.3 (5)	3.7 (11)		
11+ h/wk % (n)	0.5 (1)	0 (0)	0.3 (1)		
<i>Social skills training</i>					7.1*
0 h/wk % (n)	92 (185)	81.9 (77)	88.8 (262)		
1–10 h/wk % (n)	7 (14)	17 (16)	10.2 (30)		
11+ h/wk % (n)	1 (2)	1.1 (1)	1 (3)		0.5
<i>Psychoanalytic services</i>					
0 h/wk % (n)	90 (181)	92.6 (87)	88.8 (262)		
1–10 h/wk % (n)	10 (20)	7.4 (7)	10.2 (30)		
11–20 h/wk % (n)	0 (0)	0 (0)	0 (0)		
<i>Medication received (Yes) % (n)</i>	47.3 (95)	51.1 (48)	48.6 (143)	−0.57	
<i>Total amount of allied health services % (n)<sup>a</sup></i>					6.6
No services	57.7 (116)	58.5 (55)	58 (171)		
One service	18.4 (37)	13.8 (13)	16.9 (50)		
Two services	9 (18)	9.6 (9)	9.2 (27)		
Three services	8.5 (17)	8.5 (8)	8.5 (25)		
Four services	2 (4)	2.1 (2)	2 (6)		
Five+ services	4.5 (9)	7.4 (7)	5.4 (16)		

\**p* < 0.05;<sup>a</sup>Variable included missing cases.

treatment for coexisting psychiatric conditions (Buck et al., 2014; Gotham et al., 2015; Fusar-Poli et al., 2019), and its use increases with age. In line with previous

studies, almost half of the sample used medication. The difference in medication usage between children and adults in Latin America (37% vs. 49%) is not as alarming

**TABLE 4** Use of medication and comorbid disorders

	No medication ( <i>n</i> = 151)	Medication ( <i>n</i> = 143)	Total	$\chi^2$
<i>Comorbid disorders % (n)<sup>a</sup></i>				4.3
Only an autism-related diagnosis	63.6(96)	51.7 (74)	57.8 (170)	
One comorbid diagnosis	35.1 (53)	46.2 (66)	40.5 (119)	
Two comorbid diagnoses	1.3 (2)	2.1 (3)	1.7 (5)	
<i>Medication usage by epilepsy (most common comorbid DX) % (n)<sup>a</sup></i>	13.9 (21)	23.8 (34)	18.7 (55)	4.8*

\**p* < 0.05;<sup>a</sup>Variable included missing cases.**TABLE 5** Medical and health providers

	Emerging adults (Age: 18–25) <i>n</i> = 151	Middle-aged adults (Age: 26–50) <i>n</i> = 143	Total <i>n</i> = 295	$\chi^2$
<i>Medical &amp; health providers % (n)<sup>a</sup></i>				
Audiologist <sup>a</sup>	7.7 (15)	3.3 (3)	6.3 (18)	2.0
CBT therapist <sup>a</sup>	15.7 (31)	14.1 (13)	15.2 (44)	0.1
Dietician <sup>a</sup>	37.2 (74)	32.5 (30)	35.7 (104)	0.6
Psychiatrist <sup>a</sup>	12.2 (24)	19.6 (18)	14.6 (42)	2.7
Neurologist <sup>a</sup>	46.2 (91)	40.4 (38)	44.3 (129)	0.9
School psychologist <sup>a</sup>	7.2 (14)	11 (12)	8.7 (25)	1.8

<sup>a</sup>Variable included missing cases.

as the difference in allied health services (Montiel-Nava et al., 2020). The survey did not inquire about type of medication used, preventing further analysis. However, medication might have also been tailored for the medical comorbidities included in the “Other” category (i.e., ADHD, genetic, and congenital disorders). As families in Latin America frequently face a lack of services and trained professionals, medication might be seen as an alternative to help their members on the spectrum. Moreover, doctors could use medication as a palliative measure to help adults cope with the daily challenges associated with autistic symptoms and comorbid conditions (Fusar-Poli et al., 2019).

Current evidence, along with these new data, highlights the many systemic barriers experienced by adult autistic individuals and their families in low and middle-income countries, hindering their ability to access and benefit from health services (Durkin et al., 2015; Montiel-Nava et al., 2020; Paula et al., 2020). One of the main barriers refers to policy restrictions set by insurance companies (; Day et al., 2020; Friedman et al., 2013; Hansel, 2013; Lake et al., 2014; Raymaker et al., 2017; Shattuck et al., 2020; Vogan et al., 2017). Our sample was highly educated, with private insurance and access to the internet to complete the online survey, which might be related to the sampling method’s nature. Despite these advantages over the included countries’ general population, most participants were in the “Zero Hours of Services per week” category, highlighting the current lack of health services for adults with ASD in Latin America.

Enrollment in private insurances allows families with high or middle income to have another option on top of the public health system. However, our results show they are still not receiving services. Significant areas of concern in adulthood might remain unaddressed due to insufficient insurance coverage (Hansel, 2013; Friedman et al., 2013; Richards et al., 2012) or to the increasing costs of services (Friedman et al., 2013). As we described earlier in this paper, even with universal health care, families face overbooked facilities, long waitlists, scarcity of medicines, and a lack of trained professionals (Kohn, Saxena, Levav, & Saraceno, 2004; Paula et al., 2020; Saldivia et al., 2004)). In summary, having universal coverage is not a warranty for access to services in participant countries. Moreover, less affluent families might have no choice but to wait to be serviced at public institutions delaying possible diagnosis and treatment of ASD.

Suppose that the described lack of services is the reality of adults on the spectrum in Latin American countries with some advantaged socioeconomic background (private insurance, access to internet and computer, highly educated caregivers). What would be the actual use of services in the vast majority of the population? Following this analysis, we conclude that adults with ASD living in Latin America and disadvantaged socioeconomic backgrounds would confront additional barriers to services (lack of awareness, financial burden, transportation problems, stigma, etc.). Furthermore, they would be at an increased risk of receiving low service standards (Broder Fingert et al., 2019). As a result, their outcomes,



including autonomy, health, quality of life, and caregivers' burden, might be impacted. Although ASD is typically diagnosed in childhood, it is a long-life neurodevelopmental disorder with different symptom expression depending on the developmental trajectory. Developing an agenda for practice, policymaking, and research about health disparities in ASD would identify further needs or modify existing policies to benefit the expanding needs of the aging ASD adult (Bishop-Fitzpatrick & Kind, 2017). Legal and special education advocates could also assist this population by requesting transitioning services to late adolescents and emerging adults with ASD within educational settings. Both emerging and middle-aged adults were highly underserved; however, allocating these services and educating autistic individuals about their options at an early age could reduce this health inequality. As Bailey (2012) aptly expressed, the challenge lies in ensuring that legislation, resource allocation, and research studies reflect the reality of adults with ASD. This is the first study in Latin America attempting to show the barriers to accessing services for families with an adult autistic member.

Identifying health service usage among adults is of utmost relevance, given the prevailing nature of this condition. As adults with ASD experience different challenges than children, they will encounter the absence of individualized treatments, uncertainty about employment opportunities or vocational development, and challenges navigating the health system. Also, comorbid symptomatology might appear due to the difficulties mentioned above (Cheak-Zamora et al., 2018). In that way, any standard of care should consider the heterogeneous needs of services by age groups regarding type and number of services.

To our knowledge, this is the first study identifying service-use among adults with ASD in Latin America. Our Latin American sample demonstrated next to inexistent health care usage highlighting socioeconomic and health disparities in service provision for ASD symptoms and related conditions in the region. Even when diagnosed during childhood, ASD is a lifelong neurodevelopmental condition, and adults with ASD will likely continue to exhibit the triad of symptoms across the lifespan. The lack of services places adults with ASD in Latin America at a higher risk of worse symptom severity than autistic adults from regions with broader access to services.

Our study contains limitations. First, being an online survey, the sampling framework excluded those without internet access, hindering generalization of the results to all caregivers of adults on the spectrum in Latin America. Such a research design needed a sampling framework that, by definition, left out those without internet even before the study started. Internet access is far from universal in the participant countries, ranging from 23% (Chile) to 48.2% (Uruguay) at the time of the study (Internet Live Stats, 2016). This sampling bias is also

evident in the proportion of caregivers with a college degree or higher (89.1) and the proportion using only private insurance to cover services for their children with ASD (71.4%). Second, despite an overall large sample size, there was a marked difference in the sample size among countries, with limited participants from the Dominican Republic and Venezuela. Third, since there is no published consensus concerning the number of hours adults should receive for ASD-related health services, we generated categories by the total hours of weekly service hours. Besides, data from use of service providers could not contribute to the calculation of hours of services. Fourth, by following the same format as the original Caregivers Need Survey (Daniels et al., 2017), this study did not inquire about each medication's name or classification reported by the participants. Such information could have allowed us to investigate further if the medication received is related to autism, a comorbid disorder to autism, or untreated medical conditions. Another limitation of the survey is that the data from the use of service providers could not contribute to the calculation of hours of services. The survey only asked caregivers to check from a list with different service providers the ones they have used, with no information about the number of hours received from each provider.

## Conclusion

Since most research on ASD has focused on children's populations, the study of health services' uses and needs on adults with ASD is in its infancy. Our findings indicated that both emerging adults and middle-aged adults living in Latin America are highly underserved across all the examined health services, with between 86% and 95% receiving zero hours of services per week.

Adults with ASD living in Latin America are significantly at higher risk for low utilization of health services, which we speculate could lead to worse outcomes for their quality of life. Before this study, we knew next to nothing about adults on the spectrum living in Latin America. It is of utmost relevance to develop culturally sensitive best practices to address the adults' needs on the spectrum and their families living in low- and middle-income countries. By taking into account caregivers' perspectives, we have valuable information to guide subsequent research studies and match our goals with those needs of the autism community in Latin America, specifically those with less access to services.

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## SUPPORTING INFORMATION

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