

Use of Health Services among Children and Adults with Autism Spectrum Disorder in Puerto Rico

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Abstract

Background: Data about health services use among children and adults with Autism Spectrum Disorders (ASD) in middle-low-income countries are limited, particularly with epidemiological samples. The objective of this paper is to show a brief perspective about sociodemographic characteristics and access to care between a sample with ASD children compared with a sample of ASD adults in Puerto Rico.

Methods: The current study is based on an island-wide probabilistic multistage cluster sample of individuals living in Puerto Rico.

Results: Approximately 89% of the children with ASD and 50% of adults were receiving some kind of treatment. Most of the associated costs of these services in children are paid by the Department of Education of Puerto Rico. However, in the adult ASD group, most treatment cost are covered by other funders.

Conclusion: Use of services by ASD children and adults as reported by parents and relatives in this middle-low-income epidemiological sample, was slightly different between these two developmental stages. Policies and programs should focus on the development and provisions of services provided by government agencies in Puerto Rico, aiding to pay the bill for ASD services, especially of adults.

Keywords: Autism Spectrum Disorder; Epidemiological Study; Use of Health Services; Middle-Low-Income Country

Abbreviation

ASD: Autism Spectrum Disorders

Introduction

The World Health Organization [1] estimated a worldwide prevalence of Autism Spectrum Disorder (ASD) to be one person in 160 people, 62/10,000 individuals [2]. The ASD ratio between male and female is closer to 3:1 [3]. When taking into account rates of ASD in different ethnic or racial groups, some studies have found variations in the number of people affected, the age of disorder diagnosis and access to services [4]. However, other studies [2,5] have found no differences between these groups, and thus the debate continues over

whether belonging to a particular racial/ethnic group leads to greater difficulty gaining access to ASD mental health care, particularly in low-income countries [2,6].

Knowledge about health services is still more limited in low-income societies where Epidemiological studies are scarce (i.e. Latin America, Africa and the Caribbean), and where the health care services are limited [1,7]. There is a need for additional well-designed epidemiological studies to understand the relevant demographic, service use patterns and barriers to care associated to ASD in such countries, to be able to develop efficient mental health policies, both from an individual and organizational point of view [6].

Latino individuals living in the United States with ASD experience many disadvantages compared to non-Latino white individuals; for instance, delayed diagnosis [8], or less spending services such as community care facilities, day care programs, support services or supplemented employment work [9]. Reasons for this ethnic variation are that Latino parents, relatives and providers, find it more difficult to identify ASD, there is limited access to care and services to diagnose and treat the disorder, and higher levels of poverty. Racial/ethnic individuals (particularly Latinos) living in poverty, have less access to all types of health care, particularly from specialists. They also receive lower quality care, and experience more barriers to care even after adjusting socioeconomic factors [8-10]. Similar data is not available for Puerto Rican children or adults diagnosed with ASD. It is also of relevance to highlight that after the age of 21 years old most ASD individuals experience a considerable reduction in specialized financial assistance for a great part of their chronic condition [11]. This is compounded by the fact that medical expenses of ASD adults are increased due to the fact that, inpatient and long term care increase with age [12]. In a recent study Dudley, *et al.* [13], suggest that adults with ASD living with their family reported less health service use, higher unmet need, and more obstacles for accessing services. Moreover, the mean spending services related to employment support, community care facilities, day care, transportation and in/out home respite are more elevated in persons over 18 years old [9]. However, similar research is not available for Puerto Rican ASD adults, and it is unknown how the decrease in government financial support after reaching adulthood affects the health care utilization of this population.

Materials and Methods

Participants and data collection

The sample utilized in this study comprised a sub-sample of households in which the selected household member said he/she had a child diagnosed with autism. The original sample from which this sub-sample was obtained was a household probability sample of individuals (N = 3,062) aged 18 to 64 years old living in Puerto Rico between May 2013 and October of 2014. The methods for this study are described in more detail elsewhere [14]. Briefly, the study used a multi-stage probability sample of the island of Puerto Rico. Trained interviewers, after screening for eligibility, used a Kish table in order to select randomly the eligible individual. Eligibility was based on age (18 - 64 years), ability to speak Spanish, no incapacitating cognitive impairment, and self-identification as Puerto Rican. Excluded from the sample were homeless or transient adults and those living in institutions lacking family in the community. A total of 3,062 interviews were completed based on 3,654 eligible subjects, for a response rate of 83.8% in the original survey. Of the 3,062 participants who responded to the survey [14] said they had a child with autism. Sex participation in the autism study sub-sample was (approximately 58% women vs. 42% man), 35% with a family monthly income less than \$1000.

Trained interviewers conducted Computer Assisted Personal Interviews at the respondents' homes. Respondents provided written informed consent and received a \$30 for participation. The study was conducted in accordance with the Declaration of Helsinki, and the survey was approved by the Committee for the Protection of Human Subjects of the Medical Sciences Campus of the University of Puerto Rico.

Instruments and call-backs

Sociodemographic data. A survey was created ad hoc to gather demographic data such as age, sex, income, occupation, education, employment and marital status.

Autism spectrum variables. Several questions about autism spectrum variables were included in the survey. As a proxy for the diagnosis of ASD, each selected respondent was asked the following question: “Has a doctor or other health professional ever told you that someone in your home has autism, Asperger or pervasive developmental disorder?” Any affirmative response to this question was considered as positive for ASD [15]. We also asked whether the identified person was a son/daughter; their age and sex, the age at which he/she received a diagnosis, and the age at which the first symptoms appeared. Parents were also asked: which of the following medical specialists the child or adult with ASD had visited for autism: developmental pediatricians, Neurologists, psychiatrists, geneticists, or other professionals (including psychologists, family doctor, dentist and otolaryngologist). In the original survey, relatives were not asked the service use questions in regards to the individuals with autism. For this reason, a call-back was conducted during summer 2018 with the relatives to obtain the service use data. Of the 34 relatives, a total of 28 (82.35%) were located and completed the ASD service use questions. Of the latter, 15 reported having at least one family member with ASD younger than 21 living in the household. In total 51 children and adults with autism were identified in these households among the parents and relatives that completed the questionnaire. No significant differences in demographic variables were found between the subgroup of informants not responding (Call-backs 2018; n = 17) compared with the final subgroup for analysis at the present study (n = 51). Decisions for inclusion or exclusion are summarized in a flow chart according STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) recommendations (See figure 1).

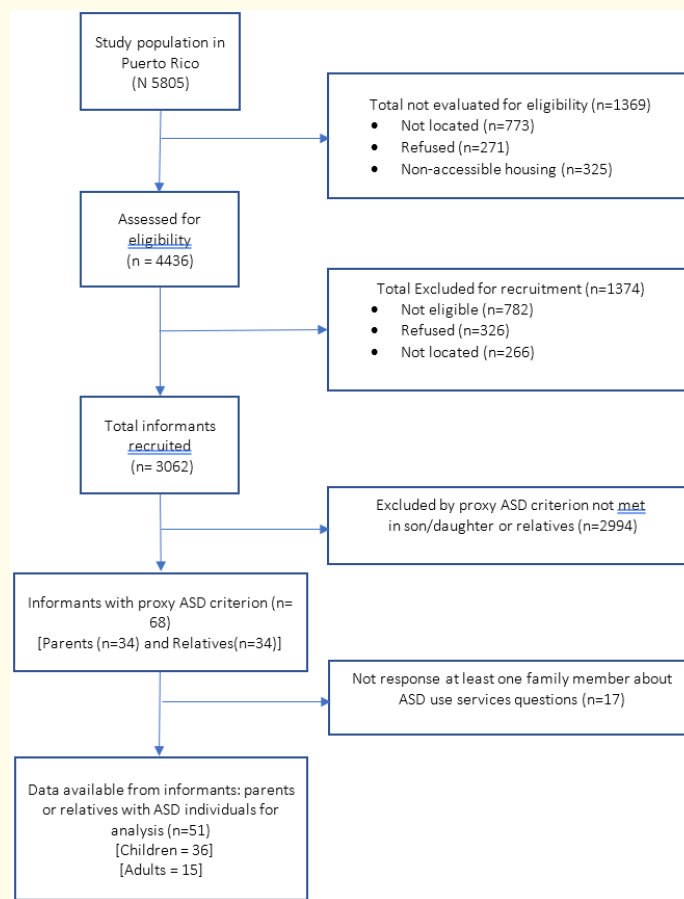


Figure 1: STROBE flowchart of the study selection process.

Study participants who responded affirmative to the ASD gate question, were also asked about therapies received by the ASD family member, with different providers such as speech, occupational, psychological, physical therapy or individualized physical education. For each endorsed therapy, they were asked to indicate who paid for the therapy among the following: private assurance, Medicaid, State Department of Education, other public programs, or family support.

Statistical analyses

To take into account the multistage, multi-cluster design used in the survey sampling frame, all analyses were conducted using SUDAAN software 10.0. [16]. Rates of ASD health service use were determined using data weighted to correct for unequal probabilities of inclusion in the sample. In addition, a post-stratification weight was applied, which corrected for nonresponse and adjusted the sample to the population distributions of the US Census [17] based on demographic variables such as age and sex. Because of the small sample of children and adults with ASD (n = 51), only descriptive data are presented. The chi-squared or Fisher exact and t-student test were used to estimate differences between children and adults with ASD.

Results

Sociodemographics

The demographic data of children (n = 36) and adults (n = 15) with ASD and their respective parents or relative information is described in table 1. As can be seen, no significant differences were observed in age of first symptoms, formal diagnosis or sex between ASD children or adults regarding these variables. Furthermore, no significant differences were observed between both groups in level of education, employment or marital status, and family income. The age of first symptoms was over 3 and 8 years old (respectively to children and adult group) and the formal diagnosis was confirmed almost one year later. The sex ratio was twofold for females (68%) as compared to males (32%) in the children group and fourfold (82% female to 18% male) in the adult group.

Characteristics	Children with ASD (n = 36)		Adults with ASD (n = 15)	
	M (SE)	Weighted (95% CI)	M (SE)	Weighted (95% CI)
Age M (SE)*	9.5 (0.8)	(7.8 - 11.2)	31.2 (3.0)	(25.3 - 37.0)
Age of first ASD symptoms	3.1 (0.4)	(2.2 - 3.9)	8.0 (2.8)	(2.5 - 13.6)
Age of formal diagnosis	4.1 (0.5)	(3.1 - 5.1)	9.4 (3.4)	(2.8 - 16.0)
	N	% Weighted (95% CI)	n	% Weighted (95% CI)
Sex				
Male	10	31.5 (18.5 - 48.3)	3	82.3 (54.8 - 94.7)
Female	26	68.5 (51.7 - 81.5)		
Parent/Relative's Level of education				
Less than high school	< 5	2.0 (0.3 - 13.0)	3	18.0 (6.0 - 42.9)
High school	8	19.9 (9.3 - 36.9)	4	32.7 (13.2 - 60.9)
Some college	20	54.3 (36.9 - 70.6)	4	24.9 (9.1 - 52.5)
More than college	7	23.8 (11.6 - 42.8)	3	24.4 (7.9 - 54.7)
Parent/Relative's Employment status				
Employed	18	47.3 (29.9 - 65.3)	4	29.1 (11.1 - 57.3)
Unemployed	5	12.2 (4.0 - 31.3)	0	-- (-- --)
Not in workforce	13	31.8 (18.3 - 49.3)	10	65.9 (40.1 - 84.8)

Parent/Relative's Marital status				
Married or living with someone	26	78.0 (62.0 - 88.5)	8	57.3 (30.9 - 80.2)
Separated, divorced	6	14.5 (6.1 - 30.5)	3	16.3 (5.4 - 40.0)
Or Widowed		1.4 (0.2 - 9.9)	0	-- (-- --)
Never married/single	< 5	6.1 (2.0 - 16.8)	4	26.4 (9.9 - 53.9)
Monthly family income				
Less than \$1,000	11	22.3 (11.1 - 39.9)	5	27.2 (10.1 - 55.3)
\$1,000 - \$1,999	7	20.3 (10.1 - 36.8)	4	32.1 (12.2 - 61.7)
\$2,000 - \$2,999	10	36.4 (21.7 - 54.3)	2	12.6 (3.1 - 39.8)
\$3,000 or more	6	1.9 (9.8 - 39.2)	4	28.1 (10.6 - 56.3)

Table 1: Sociodemographic characteristics in children and adults with autism spectrum disorder (ASD) and their respective parents or relatives.

*: $p < .05$.

Use of health and educational services

With regard to health services (Table 2), around 89.1% of children with ASD and 50.5% of adults, were receiving some type of treatment or educational service with significant difference between groups. Of those in the group of children with ASD, 72.4% were enrolled in special education schools or specialized day care centers, and 95% had an individualized education plan. However, in the adult group 62.9% were enrolled in day care centers and only 12.1% had an individualized education plan. The health specialists most consulted by parents/relatives were neurologists (84.1% for children - 73.8% for adults), psychiatrists (49.5% for children - 81.3% for adults) and pediatricians (45.2% - for children 35.4% for adults). More than half of respondents (60.9% for children- 74.9% for adults) indicated that they saw other specialists, among them psychologists.

Health and Educational Services	Children with ASD (n = 36)		Adults with ASD (n = 15)	
	N	% Weighted (95% CI)	n	% Weighted (95% CI)
Current treatment*	32	89.1 (73.1 - 96.1)	8	50.5 (26.8 - 73.9)
Day care centers ¹	23	72.4 (48.6 - 87.9)	5	62.9 (28.3 - 87.9)
Individualized Education Plan ^{1**}	25	95.0 (70.9 - 99.3)	1	12.1 (1.7 - 53.1)
Specialist				
Neurologist ¹	17	84.1 (64.4 - 93.9)	5	73.8 (34.7 - 93.7)
Psychiatrist ¹	10	49.5 (26.1 - 73.2)	6	81.3 (34.2 - 97.3)
Developmental Pediatric ¹	10	45.2 (25.7 - 66.4)	2	35.4 (8.7 - 75.9)
Geneticist ¹	8	44.0 (24.0 - 66.1)	1	21.9 (3.1 - 70.8)
Other professionals ^{1,2}	12	60.9 (37.1 - 80.5)	5	74.9 (35.9 - 94.1)

Table 2: Health and educational services used among individuals with ASD.

¹: The basis of persons receiving this service is variable in each health service; ²: This category includes (psychologists, family doctors, dentists and ear-nose specialists); * $p < .05$; ** $p < .01$.

The types of therapeutic treatment (Table 3) accessed by the parents/relatives were, in order of frequency: speech therapy, psychological treatment, occupational services, individualized physical education and physical therapy. In the children group, the majority of these services were paid by the public Department of Education (between 61 to 100% depending on the type of service). However, sometimes psychological services (44%) and physical therapy (57.5%) were financed in part by the parents’ private health insurance. On the other hand, in the adult group, financial support from the State Education Department was inexistent. Other public programs, own private insurance and Medicaid were the main payers of ASD related health services.

Type of Health/Educational Service	N	ASD individuals Receiving any Service (n = 40) % Weighted (95% CI)	Financial Support				
			State Education Department [†] % (95% CI)	Own Private Insurance [†] % (95% CI)	Other Public Programs [†] % (95% CI)	Own Family Support [†] % (95% CI)	Medicaid [†] % (95% CI)
Language							
Children	22	75.8 (56.6 - 88.2)	90.5 (67.2 - 97.8)	6.7 (0.9 - 35.9)	7.2 (1.0 - 37.7)	0.0 (-)	14.7 (3.4 - 45.8)
Adult	<5	12.5 (1.7 - 54.1)	0.0 (-)	0.0 (-)	0.0 (-)	0.0 (-)	100.0 (-)
Occupational							
Children	19	66.7 (46.6 - 82.1)	93.0 (63.3 - 99.0)	7.9 (1.1 - 40.0)	8.5 (1.2 - 42.2)	0.0 (-)	12.2 (1.8 - 51.8)
Adult	<5	9.9 (1.3 - 47.9)	0.0 (-)	0.0 (-)	100.0 (-)	0.0 (-)	0.0 (-)
Psychological							
Children	19	68.9 (46.7 - 84.8)	60.8 (36.1 - 81.0)	44.0 (18.3 - 73.4)	17.2 (4.1 - 50.2)	23.1 (8.5 - 49.5)	7.0 (1.3 - 30.1)
Adult	<5	47.4 (18.0 - 78.7)	0.0 (-)	35.9 (4.8 - 86.3)	28.3 (3.4 - 81.5)	0.0 (-)	52.7 (13.4 - 89.0)
Physical							
Children	6	24.4 (11.5 - 44.5)	100.0 (-)	57.5 (14.4 - 91.6)	0.0 (-)	0.0 (-)	35.1 (5.1 - 84.4)
Adult	<5	22.4 (5.4 - 59.6)	0.0 (-)	0.0 (-)	100.0 (-)	0.0 (-)	55.9 (7.3 - 95.4)
Individualized PE							
Children	9	38.5 (21.8 - 50.4)	100.0 (-)	0.0 (-)	0.0 (-)	0.0 (-)	0.0 (-)
Adult	<5	9.9 (1.3 - 47.9)	0.0 (-)	0.0 (-)	100.0 (-)	0.0 (-)	0.0 (-)

Table 3: Type of current health/educational services received by type of insurance that financed the services.

Note: †: All data is weighted depending on the type of service; PE = Physical Education.

Discussion

To our best knowledge, this study is one of the few comparing service use in children and adults with ASD from an epidemiological perspective, in a middle-low-income country. Sex proportion was almost threefold for females as compared to males [3], the age of first symptoms were observed one year before the diagnosis was confirmed, similar to other epidemiological studies [2,18]. However, the age of first symptoms and diagnosis for the adult group is more delayed. This result could nevertheless be due to retrospective report, or to the fact that for 15 ASD adult children, a relative was the informant, and might not have access or know the precise age of the child/adult when he/she was first diagnosed.

A considerable proportion of the population in Puerto Rico (approximately 45% in 2010) was living on poverty [17] with a monthly family income of less than \$1000 and only a third of this population had a full-time job. This situation differs from that of other studies of predominantly middle-high-income countries [6] and could have a detrimental impact on access to health and educational services. In the US, parents receive SSI (Supplemental Security Income) of approx. \$750 per month that is designed to help families with low-income; however, it is not available in Puerto Rico. These results provide some of the first evidence related to autism health and mental health service use in a middle-low-income country, a topic that has been identified as a priority for research by many experts in the field [6,7].

Parents and relatives of individuals with ASD reported that most of them were receiving some kind of treatment. Nevertheless, one in five families of participants were not in treatment with any health specialist. This absence of treatment increased in the adult stage group. Most people receiving services were also receiving special education schools or day care centers. This fact is relevant given the chronic nature of this disorder, and the constant support these families need to maintain an adequate quality of life. Interventions mediated by parents and other non-specialist providers have the potential to significantly increase access to care [1].

The most frequently consulted specialist was a neurologist. The reason for this first consultation might be to confirm or rule out other neurodevelopmental disorders. Similarly, pediatricians and psychiatrists were highly consulted by this group of parents with children or adults with ASD. These specialists may have initially identified the first symptoms of ASD and were later in charge of continuing treatment. As expected, educational, developmental and psychological services were the most commonly used therapies for ASD [1]. A relevant factor is that the cost of most of these therapeutic interventions are covered by the Department of Public Education, an Institution that seems to provide and/or finance most of the services needed by this special population of children and adults with ASD in the island. Given the extensive and costly types of specialty health and educational services required by children with ASD, it may be necessary in the future to examine whether the Department of Education in the island has been assigned a sufficient budget to be able to provide high quality (or evidence based) education. The Health Department may need to become more involved with the Education Department to share the costs and type of service required by children with ASD in Puerto Rico. However, in the adult group, other public programs, private insurance and Medicaid were the main funders. In the mainland, States have a multi-agency committee that decides how to share the costs associated with ASD services among agencies, but that is not the case in Puerto Rico. Besides the Department of Health, there are other agencies, as established in the current law in Puerto Rico, responsible for providing essential services to ASD families. For example, the Family Department is supposed to give parents support services and training for respite services; the Housing Department should create assisted and independent living housing for these families, the Recreation Department is responsible for providing integrated sports programs and/or camps, but these agencies have not trained personnel to ensure proper care and integration. Despite having a comprehensive policy to serve the ASD population in Puerto Rico, the implementation and development of services has not been as prompt or efficient in many of the agencies. We consider that the government should strengthen the health, educational and other support systems to detect and deliver integrated care, and implement policies and plans based on international policy frameworks with the involvement of multiple public sectors [1].

We would have expected higher use of services paid by the Health Department since Puerto Rico is one of the few jurisdictions with full health coverage for ASD [19]. However, since the data was collected in 2013-14, some law regulations have not been implemented. Second, in Puerto Rico a mandatory registry for ASD exists which allows to identify the ASD population more precisely. Third, this law establishes a special coverage system in both Medicaid and private insurance with no coverage limits for the ASD population. There are no coverage limits in the island, neither public nor private insurance in Puerto Rico is covering evidence-based therapies, such as Applied Behavior Analysis (ABA), unless it is provided by a psychiatrist as they require the provider to have a medical degree. However, there are many other non-medical professionals, who are authorized providers of ABA. It may also be possible that not every parent or relative with a minor or adult with ASD is aware of the ASD regulation, which gives families full coverage.

However, since most therapeutic services currently offered are covered by the Department of Education, the future of adults with ASD once they turn 21 years old is worrisome because they are no longer eligible for services provided by the Department of Education. Given an absence of appropriate programs and therapeutic services, the adult population with ASD is mostly limited to community exposures and more family economic barriers since the burden of caretaking relies exclusively with the parents. Further studies to explore the need for services of the adult population with ASD are needed to respond to the increasing number of those that are children now and will soon be adults with no access to services through the Department of Education. Parents need to receive respite services, economical and in-home supports. Adults with autism need daycare, behavioral training and supports, vocational/employment and assisted/independent living programs. Medical and therapeutic providers should be trained on how to serve this growing population. The main strength of this study is, that is the first in our knowledge to report the use of health services in ASD children and adults in Puerto Rico a middle-low-income country from an epidemiological and not only clinical-sample perspective. However, this study has several limitations. First, a larger sample would be desirable in order to demonstrate more consistent results. Second, measures relied on retrospective reporting by the caregiver who might not recognize, understand or recall labels such as “Asperger’s or pervasive developmental disorder”, although autism is generally well known. Furthermore, diagnosis by self-report of caretaker is not the ideal way of ascertaining a diagnosis, a comprehensive measure such as ADI-R or ADOS will be more desirable. In addition, survey questions did not tap into the costs or duration associated with delivery of health services. Finally, this study is cross-sectional and retrospective and it is not possible to discern whether services and diagnosis are primary or secondary to ASD.

Conclusion

Use of services by ASD children and adults, as reported by parents and relatives in this middle-low-income epidemiological sample, was different between these two developmental stages. As expected and driven by existing policies most of the services obtained by children in Puerto Rico are funded by the Department of Education and mostly consist of speech therapies, occupational therapist and psychological therapies to support educational progress according to their individualized education plan. In the health system, neurologists and psychiatrists are the specialists most frequently consulted for this neurodevelopmental disorder. Public programs or private insurance services were the ones funded mainly for adults with ASD. Policies and programs should focus on the development and provisions of services provided by the Health Department and other government agencies once children leave the Department of Education, where the provision of services is mainly guaranteed by the Federal Individuals with Disabilities Education Act (IDEA). Other agencies should start footing the bill for ASD services, especially of adults.

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Conflict of Interest

The authors declare no conflict of interest.

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