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Children with Special Health Care Needs Section

Autism Spectrum Disorders (ASDs)
A Needs Assessment Study in Puerto Rico

Table of Contents

II. Literature Review

III. Methodology

Abstract

Autism Spectrum Disorders (ASDs) are considered as the most frequent condition among the developmental disabilities, which are defined as a diverse group of severe chronic conditions caused by mental and/or physical impairments. Persons with ASD present problems with social interaction and communication, and exhibit unusual behaviors and interests. In the ASDs are integrated the Classic Autism, Asperger syndrome, Childhood Developmental disorder, Rett disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS). The prevalence of the ASDs has increased considerably during the last years making this special population a great concern for many parents, communities and providers, as well as for many organizations and investigators.

The present study is a needs assessment of the population with ASDs living in Puerto Rico and will provide baseline data for the development and implementation of a public policy for ASDs and for the Puerto Rico Autism Registry. The target population was persons with ASDs or associated characteristics of all ages that were willing to participate in the study that was conducted from August 1st to November 30st, 2006.

A total of 529 participants completed the registry form and 464 answered the questionnaire. A male to female ratio of 4.95 to 1 was reported. Most of the study respondents (88.7%) reported that were receiving special education services through an IEP. Parents reported that an unusual development of the child was first observed by the age of 24 months, while the median age reported at the time of the initial diagnosis was 36 months. As reported by parents, 31% of the participants had a diagnosis of Attention Deficit and Hyperactivity Disorder (ADHD), whereas in Puerto Rico, among the population between 4 to 17 years of age, the prevalence of

the disorder is 8%. Among the services reported as most needed were help with communication skills, social skills and sensorial integration.

Pediatricians have the challenging role of suspecting an ASD diagnosis as early as possible and implementing timely treatment plan to achieve the best outcomes for the child and family. Also, parents have to be aware of the disorder and start identifying possible signs of atypical development in their child that may contribute to an early diagnosis.

This study provides the first data available on the needs and resources of the Autism population in Puerto Rico. It may serve as baseline data for the monitoring of ASD in Puerto Rico and for the policymakers, public and private agencies, providers and communities based organizations for the planning, development and implementation of service systems that address the identified needs.

I. Introduction

The Centers for Disease Control and Prevention (CDC) define developmental disabilities as a diverse group of severe chronic conditions caused by mental and/or physical impairments. Developmental disabilities cause problems with major life activities such as language, learning, mobility, self help and independent living. The signs may appear anytime during development up to 22 years of age and usually persist through lifetime[1].

According to the CDC, developmental disabilities include Cerebral Palsy, hearing loss, Mental Retardation, vision impairment and Autism Spectrum Disorders (ASDs)[1]. Research is emerging trying to understand the etiology of these conditions, identifying vulnerable populations, risk factors, and how to improve the quality of life of people with these disabilities.

Among the ASDs are included different categories that present a variety of symptoms at different ages during growth and development. In 1943, the psychiatrist Leo Kanner described the Autism syndrome as a disorder characterized by problems to relate with others, communication and behavior. Almost simultaneously, in 1944, the pediatrician and psychiatrist, Hans Asperger described the syndrome named by his name, characterized by autistic-like behaviors and severe deficiencies in social and communication skills. As published by Merrick J (2004), in 1980's, the term Pervasive Developmental Disorders (PDD) was used for the first time and included: the Autistic disorder, Rett disorder or syndrome, Childhood Developmental Disorder, Asperger's disorder or syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS)[2].

Magnitude and Significance of ASDs

At present ASD is considered the fastest growing developmental disability. In the United States, ASD occurs in 1 of every 150 births (CDC, 2007)[3], affecting 1 to 1.5 million Americans, based on a prevalence of 2 to 6 per 1,000 inhabitants and the population of the 2000 US Census. The increase in the prevalence of ASD has been estimated in 10 to 17% annual growth (Autism Society of America (ASA), 2007)[4]. Compared to the 1990s, the U.S. Department of Education reported that cases of ASD have increased 172%[5]. Jarbrink J (2001) estimated that the annual cost of serving this population is $90 billion, where 90% of the costs are in adult services[6]. Early diagnosis and intervention can reduce significantly the lifelong costs of the condition by 66%. The estimated annual cost by the next decade will be from $200 to $400 billions (ASA, 2003)[4].

The National Institute of Mental Health (NIMH, 2007) has reported that the ASDs can be detected as early as 3 years of age, and in some cases at 18 months[7]. In addition, Rodier PM (2005) demonstrated that the symptoms can be detected in the first 6 months of age for some of the conditions under the autism spectrum[8]. The earlier diagnosis and intervention of the disorder take place, the better functional outcomes for children are obtained.

Study Justification

As mentioned previously, during the last years, the prevalence of the ASDs has increased considerably. Many factors may explain this, such as the reduction in the stigma for the disorder due to better understanding of disability conditions, more resources are available to treat the condition, increased awareness among parents, or the implementation of a new definition that covers a wider population, among others. As a result this special population started to be noticed and became a special concern for many parents, communities and providers, as well as for many organizations and research programs.

Moreover, *Healthy People 2010* included in its objective 16-14 the reduction in the occurrence of developmental disabilities, including the Autism Spectrum Disorders (16-14c), the reduction in developmental disabilities in children, Cerebral Palsy, Mental Retardation and Epilepsy. The goal is to reduce the age of identification of Autism from 50 months in 1996 to 48 months in 2010[9].

During the past years a marked concern for ASD has been present in Puerto Rico. There is an understanding among families, providers and community based organizations that cases of ASD have increased dramatically in the population of Puerto Rico. As a result, several laws have been implemented to address the needs of the population with ASDs. Among these it is important to highlight Law No. 79, 2000 to declare April the Month of Autism; being April 10th the National Day of Autism Awareness (Día de la Concienciación Nacional de Autismo). Law No. 318, 2003 was established for the development of a public policy related to the population with ASDs and it was amended (Law No. 122, 2006) requiring the establishment of the public policy for this population by July 19th, 2007. In addition, Law No. 103, 2004 was established to adopt The Bill of Rights of Children and Adults with ASD.

As reported by the CDC, the prevalence of ASD in the United States is a continuing urgent public health concern and efforts are needed to improve early identification of ASDs. Moreover, the complex nature and unknown etiology of the ASDs, coupled with the current increase in cases and lack of genetic or biologic markers for early identification, make epidemiological research a challenge. Surveillance is the ongoing and systematic collection of data relevant to the identification of a disorder over time by an integrated health system. The States of Arizona, Georgia, Maryland, New Jersey, South Carolina, Utah, Missouri, Florida, Alabama, Illinois, Wisconsin and West Virginia have adopted surveillance systems for ASDs. Surveillance of the prevalence of ASD and other serious developmental disabilities in children is needed to understand the magnitude of these disorders and to identify subgroups of the population at higher risk. Ongoing surveillance would also provide a mechanism for addressing public concerns about possible increases in the rate of ASD in specific communities, provide data for identification and intervention strategies and for medical and educational service planning for the population with ASDs.

To address the problem of ASDs among Puerto Ricans, in 2004 the Children with Special Health Care Needs Section of the Maternal and Child Health Division of the Puerto Rico Department of Health, in collaboration with the Centers for Disease Control and Preventions (CDC) and the Council of States and Territorial Epidemiologist (CSTE) initiated a Needs Assessment Study. The present study is the first study describing ASD in the population of Puerto Rico, and will provide essential information to determine the current status and service needs of the population with ASD. Moreover, it is expected that this study will provide baseline data for the development and implementation of a public policy for ASDs and for the implementation of the Autism Registry established by Law No. 289, 2006.

II. Literature Review

A. Autism Spectrum Disorders

Autism is a severe neurodevelopmental disorder that may appear during early childhood and persists throughout life. Although clinical patterns vary depending on severity, all children with Autism demonstrate some degree of impairment with social interaction and communication and restricted, repetitive behaviors, interests and activities. It causes severe and pervasive impairment in thinking, feeling, language, and the ability to relate with others. Many people with this disorder also have unusual ways of learning, paying attention, and reacting to different sensations (Newschaffer CJ, 2007)[10].

Because of qualitative and quantitative variations in symptoms, Autism is also known as Autism Spectrum Disorders (ASDs) or Pervasive Developmental Disorders (PDDs) and include Autistic disorder, also known as “classic autism”, Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism), and Asperger syndrome (CDC, 2007)[3]. Some of the symptoms are present in all the conditions, but differ in the age when the symptoms appear, the severity and the exact nature of the symptoms. The three conditions, along with Rett syndrome and the Childhood Disintegrative Disorder, make up the broad diagnosis category of Pervasive Developmental Disorders *(see Table 2.1).*

Table 2.1 *DSM IV-TR Diagnostic Criteria for the Pervasive Developmental Disorders*[11]

	Autistic Disorder	**Asperger Syndrome**	**Pervasive Developmental Disorder Not Otherwise Specified**[¥]	
			Rett Syndrome	**Childhood Disintegrative Disorder**
Common Symptoms (DSM IV-TR)	-Qualitative impairments in the social interaction. -Qualitative impairments in communication. -Restricted repetitive and stereotyped patterns of behavior, interests, and activities. -Delays or abnormal functioning.	-Qualitative impairment in social interaction. -Restricted repetitive and stereotyped patterns of behavior, interests and activities. -The disturbance causes clinically significant impairment in social, occupational and other areas of functioning. -No clinically significant delay in language and in cognitive development or in the development of skills, adaptive behavior and curiosity.	-Apparently normal prenatal and perinatal development, psychomotor development through the first 5 months after birth, normal head circumference at birth. -Onset of ALL of the following after a period of normal development: *deceleration of head growth between 5 and 48 months of age. *loss of acquired purposeful hand skill between 5 and 30 months of age. *loss of social engagement *appearance of poorly coordinated gait or trunk movements. *severely impaired language development with severe psychomotor retardation.	-Apparently normal development for at least the first 2 years after birth. -Clinically significant loss of previously acquired skills before age 10 years. -Abnormalities of functioning in social interaction, in communication and patterns of behavior.

[¥] This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism", presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

B. Biology of Autism Spectrum Disorders

At present, the etiology of ASDs is not known. Several studies have been conducted trying to understand how the syndrome develops and how the brain functions in these individuals in comparison to healthy individuals. A number of genes have been associated to the occurrence of the syndrome, as well as different brain structures and unbalanced metabolites in plasma, among others.

In 2004, Rapin I *et al* published in their review a number of genes related to Autism. It has been shown that chromosome 15 has several abnormalities in the 15q11-q13 locus, causing either a trisomy or tetrasomy of genes. In that locus the gene γ-amino butyric acid ($GABA_A$) has been strongly associated with the pathogenesis of Autism. Also, the AS gene UBE3A in the 15q11-q13 has been implicated with Autism. In the chromosome 7, chromosomal translocations in the q22-q33 region have been implicated. Alterations of proteins such as RELN or genes such as FOXP2 in that locus have also been detected[12].

Courchesne (2002) published that in the brain, structures such as the cerebellum, cerebral cortex, limbic system, corpus callosum, basal ganglia, and brain stem have been implicated with Autism[13.] Belmonte MK (2005) reported that neurological studies have found that the social intelligence is a function of three regions: the amygdala, orbitofrontal and the medial frontal cortices; in those three regions abnormalities in people with Autism have been detected[14]. In the review of Müller RA (2007), the association of the amygdala and Autism was discussed[15]. Correlations between amygdala volume and performance on socio-emotional tests have also been described. Hardan (2006) found that adult individuals with Autism have a smaller right lateral orbitofrontal cortex as compared to healthy controls, but it has been suggested that this anatomic alteration is not the cause of the functional disturbances in that structure[16]. In 1998, Rinaldi J *et al* found that children with Autism compared with children with Down syndrome and typically developing children, performed significantly worse on both the medial temporal lobe and dorsolateral prefrontal tasks and on tasks assessing symptoms domains[17].

In the body, several metabolites that regulate a cascade of reactions in the metabolism have been found to be related to neurological disorders. James SJ (2004) published that an abnormal folate metabolism and low glutathione (Glu-Cys-Gly) concentrations have been related to neurological conditions such as Alzheimer, Parkinson and Schizophrenia. These conditions cause oxidative stress in the body and impaired methylation capacity, which has been hypothesized to contribute to the development and clinical manifestation of regressive Autism[18].

Finally, Mills JL (2007) found that boys with ASDs in comparison with boys without ASDs have higher levels of the growth-related hormones: insulin growth factor-1 and 2 (IGF-1 and 2), insulin growth factor binding protein-3 (IGFBP-3) and growth hormone binding protein (GHBP) (all P‹ or = 0.0001). That finding could explain the fact of a higher head circumference and Body Mass Index (BMI) in the population with ASDs, although its relationship with the pathophysiology of Autism has not been determined yet[19].

C. Epidemiology

Several studies have shown an increase in the prevalence of autism during the last few decades. It has not been determined if that increase is due to an actual increase in cases or due to changes in the diagnostic criteria. The most recent data available (2003-2004) published by the Centers for Disease Control and Prevention (CDC) in the Morbidity and Mortality Weekly Report (MMWR) showed a prevalence of autism reported by parents of 5.7 per 1,000 children in the National Health Interview Survey (NHIS) and 5.5 per 1,000 children in the National Survey of Children's Health (NSCH)[20]. In addition, in February 2007, the Surveillance Summaries of the MMWR published 2002 data for the 14 sites of the Autism and Developmental Disabilities Monitoring (ADDM) Network. A prevalence of 1 child in every 150, representing 6.7 per 1,000 of children aged 8 years was reported. ASDs occur from 3 to 4 times more often in males than females. Little is known about race as a risk factor, although Croen *et al* (2002) and Hillman *et al* (2000) reported that higher prevalence has been seen among Black children[21,22]. However, Yeargin-Allsopp M (2003) found no variation in prevalence by race[23].

Twin and family epidemiological studies have suggested a genetic link to ASD (Korvatska, 2002)[24]. Müller (2007) has found that for monozygotic twins, a 70% of concordance exists, while for dizygotic twins the concordance is below 10%[15]. Walden TA (2007) published that the recurrence risk for ASD in younger siblings has been found to be in a range from 6% to 9%[25].

Several conditions have been related to ASD, one of them is epilepsy. Although at present no evidence is available supporting the fact that the epileptic disorder is the cause of Autism, Deonna T (2006) has suggested that a direct relationship between Epilepsy and some features of Autism may occur[26].

Medical conditions found among the ASD population are sensorial problems and mental retardation. Seizures occur in one of four children with ASD. The NIMH (2007) reported that the Fragile X-Syndrome affects 2 to 5% of people with ASD, while Tuberous Sclerosis, which is a genetic disorder that causes benign tumors to grow, affects 1 to 4% of the population with Autism[7]. Ming X *et al* (2007) calculated the prevalence of several motor impairments in a population with ASD, and the most common was hypotonia (51.0%), followed by motor apraxia (34.0%), intermittent toe-walking (19.0%) and gross motor delay (9.0%)[27].

Exposition to viral infections has been also associated with the occurrence of Autism. Infections with Congenital Rubella, Influenza virus, Borna disease virus and members of the Herpes virus family have been studied. The review of Libbey AE *et al* (2005) reported that studies have found a link between congenital Rubella virus with defects in the newborn, and it has been shown that the children who had the virus had higher incidence of Autism[28]. The role of Measles and Measles-Mumps-Rubella (MMR) vaccination in Autism has also been studied. Epidemiological studies to date do not support that hypothesis, but it still remains controversial. Thimerosal, a mercury-based preservative used in the MMR vaccine, has been thought to be a possible cause of Autism. Today, as reported by the CDC, with the exception of some Influenza vaccines, none of the vaccines used in the United States, including Puerto Rico to protect preschool children against 12 infectious diseases contain thimerosal as a preservative, although no causal relationship with Autism has been found yet.

People with Autism frequently present gastrointestinal symptomatology. Horvath K and Perman JA (2002) published in their review the results of three surveys, where the percentage of children with Autism Disorder that presented chronic diarrhea was close to 20%[29]. In an age-matched case control with siblings of children with Autism Disorder, it was found that 76% of the autistic patients presented at least one gastrointestinal symptom compared to 30% of their siblings. Moreover, 64% of the children with Autism presented two or more symptoms. In the review of White (2003), results from a case control study of children with gastrointestinal symptoms that had Autism, compared with children with a normal development and with similar gastrointestinal symptoms, revealed that 93% of children with Autism had ileal lymphoid nodular hyperplasia (LNH) compared with 14.3% of control children, suggesting that maybe an impaired gastrointestinal function might influence brain function[30].

Finally, as mentioned in the literature, another possible risk factor for Autism is the age of the parents at the moment of conception. It has been suggested that an increase in the age of mothers and in some studies of fathers increases the risk of having a child with the condition. Grether JK (2007) showed a statistically significant Risk Ratio of 1.31 and 1.28 for each 10-year increase in maternal and paternal age, respectively[31]. Hallmayer (2004) suggested that factors such as advanced maternal age, firstborn child, threatened abortions, epidural causal anesthesia, and labor induction could cause autism[32].

D. Diagnosis and Early Intervention

The increase in the number of cases of ASD in the population and the interest of organizations and research teams in the condition has imposed pressure on policymakers and service systems to improve and expand diagnostic and treatment services. This represents a challenge for the public health sector, which is urged to develop better practices for identification, assessment and diagnosis, so that appropriate interventions start as early as possible. Overall, Shattuck PT (2007) published that it is very important to create and improve services for all people with disabilities, including people without a specific current diagnosis[33].

III. Methodology

A. Objectives

The principal objective of this study was to obtain baseline data, useful for the future implementation of a Surveillance System for the Autism Spectrum Disorder in Puerto Rico. The specific objectives of the study were:

- To target the current population in Puerto Rico with a diagnosis of Autism Spectrum Disorders or that exhibit associated characteristics.
- To obtain an epidemiological profile of this population.
- To describe the met and unmet needs.
- To describe aspects related with the diagnosis of this disorder in Puerto Rico, such as the education of parents, household income, age of onset of the disorder, mental disorders or ASD diagnoses in the immediate family and treatments received, among many others.
- To obtain an inventory of resources for developmental screening, diagnosis and services.
- To present the results generated by this assessment in formats useful for program planning, and other planning and decision-making activities.

B. Study Design

The present study is a needs assessment of the population of Puerto Rico with ASD or associated characteristics. In order to implement a registry or a surveillance system of the autistic population, a needs assessment is necessary to identify the health status, community health needs and resources, epidemiologic and other health problems related to the disorder, which would help the Department of Health to identify the services most needed by this population. Since this is the first epidemiological study of the ASD realized in the population of Puerto Rico, a descriptive design needs to be performed in order to understand basic factors essential for future analytical studies. This study design is used when the behavior of the disorder is not well understood in the population such as the occurrence, natural history and the determinants of the disease. It is also useful to estimate the distribution and tendencies of a disease, essential to generate future hypotheses for analytical studies.

C. Population

Residents of Puerto Rico of all ages, that present signs related to ASD or have been diagnosed with ASD and that at the moment of the data collection (August 1, 2006 to October 31, 2006), attended one of the centers where the survey was available or accessed the questionnaire through the internet and completed it.

D. Inclusion Criteria

Any person that has been diagnosed with any of the Autism Spectrum Disorders: the Autistic disorder, Rett disorder or syndrome, Childhood Developmental Disorder, Asperger's disorder or syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS); or presents symptoms related to the condition under study.

E. Data Collection Method

A review group was convened, in order to prepare the protocol and to develop a methodology for collecting and analyzing the data for the Needs Assessment Study. This review group was mostly composed of parents, directors of community-based Autism organizations and investigators from the Institute of Developmental Disabilities, Graduate School of Public Health, University of Puerto Rico at the Medical Sciences Campus.

A registry form was created with the purpose of start counting the cases of ASD in Puerto Rico. The registry form included questions about the person that completed the questionnaire and of the participant, such as the name, address, gender and date of birth.

Next to the registry form, the survey titled "Cuestionario de Evaluación de Necesidades de la Población con Autismo en Puerto Rico" was created using as reference the "*UTAH Registry of Autism and Developmental Disabilities Survey*" and "*The National Survey of Early Childhood Health*". The questions were also based on reports of the American Academy of Neurology, Child Neurology Society, American Academy of Pediatrics and the West Virginia Autism Spectrum Disorders Registry.

The purpose of the survey was to collect data regarding socio-demographic characteristics, diagnosis of ASD, other diagnosed medical conditions and unmet needs. The survey consisted of six (6) sections and the questions were in the formats of multiple choice and open questions. The survey was self administered by the person in charge of the participant with ASD or characteristics associated with the disorder. Along with the registry form and the questionnaire of the study, an authorization form was included and it was mandatory to be completed by the person who participated in the survey.

In collaboration with the *Colegio Médico de Puerto Rico* and community-based autism organizations, the participants for the needs assessment were recruited through a media tour (radio, television, and the press). As part of the recruitment process, flyers were prepared and distributed through medical offices, schools, WIC clinics, churches, Head Start/Early Head Start Programs islandwide and the Department of Education.

The pilot and the main study (protocol ID A 1820106) were submitted to the Institutional Review Board (IRB) and approved on July 14, 2005 and to the Heath Insurance Portability and Accountability Act (HIPAA) Committee, approved on October 19, 2005.

A pilot study was conducted in February 2006 in collaboration with the Puerto Rico Autism Foundation and Related Disorders. During the months of March and April, 2006 the centers and the personnel to administer the survey islandwide were identified. The survey was administered in the Pediatric Centers of the Puerto Rico Department of Health, Head Start/Early Head Start Programs, Community Health Centers 330, and Regional Offices of the Epidemiology and Immunization Program. The participants had the option of completing the questionnaire at any of the available centers or through the internet in the webpage www.cuestionarios.com, where it was available to the public from October 15 to November 30, 2006. Five-thousand (5,000) questionnaires were distributed and 95% of the municipalities of Puerto Rico were represented. The survey was conducted during the months of August to October 2006.

F. Data Processing

Once the registry forms and the questionnaires were completed with information of the participants, they were separated and distributed to the seven Pediatric Centers around the island for data entry purposes. Data entry personnel at the Pediatric Centers was trained to enter the data to the website created for that purpose (www.cuestionarios.net). The website consisted of one table for the registry form and 13 tables for the questionnaire.

G. Statistical Analysis

The statistical analysis was a description of the needs and resources of the population of the study. Once the data entry was completed, it was transferred to the Microsoft Office Access 2003 software. All the frequencies and measures of central tendencies of the questions were calculated using the statistical program SPSS 11.5 for Windows.

IV. Results

4.1 Socio-demographic characteristics of the participants with ASD or associated characteristics

As explained in the methodology section, two (2) instruments (the registry form and the questionnaire) were used to collect the data for the study. The number of people who completed the registry form was different from the number of people who completed the questionnaire. Out of a total of 529 registry forms that were completed, 116 (21.9%) were completed online; and out of 464 questionnaires that were completed, 86 (18.5%) were completed online.

The relationship of the person who completed the questionnaire with the participant of the study was asked in the registry form. Out of 502 who answered the question, 449 (89.4%) were the biological mothers, 46 (9.2%) were the biological fathers, 4 (0.8%) were the persons in charge and 3 (0.6%) were the adoptive mothers.

The age and gender were other data retrieved from the registry form. Out of the 529 participants with ASD or associated characteristics, 519 reported their gender and age in years. From those, 87 (16.7%) were female and 432 (83.3%) were male, resulting in a male to female ratio of 4.95 to 1. The highest frequencies of the range of age (years) were given by individuals between the ages from 6 to 12 years old with a frequency of 205 (39.5%), followed by individuals between 0 to 3 years old with a frequency of 135 (26.0%), followed by the range between 4 to 5 years old with 116 (22.4%) of individuals. The mean age reported was 8.2 (±6.8) years old. The age of the youngest participant was 4 months and the oldest participant was 42 years old. The distribution in ages of the 26 participants older than 22 years of age had a mean of 30.6 (±6).

Table 4.1 Relationship with the participant and the gender and age of the participants with ASD or associated characteristics.

Variable	**Frequencies X (%)**
Relationship of the person who completed the questionnaire with the participant (n=502)	
Biological mother	449 (89.4)
Biological father	46 (9.2)
Adoptive mother	3 (0.6)
Adoptive father	0 (0.0)
Person legally in charge	4 (0.8)
Stepmother/Stepfather	0 (0.0)
Person with ASD	0 (0.0)
Gender (n=519)	
Male	432 (83.3)
Female	87 (16.7)
Age (years) (n=519)	
0-3	135 (26.0)
4-5	116 (22.4)
6-12	205 (39.5)
13-17	27 (5.2)
18-21	10 (1.9)
22 and over	26 (5.0)

4.2 Information about the father and the mother of the participant with ASD or associated characteristics, as well as information about the family income and family size.

At the moment of the study, out of 438, 415 (94.7%) and out of 436, 282 (64.7%) of the participants with ASD or associated characteristics were living with the biological mother and biological father, respectively. The frequency of those participants who reported to live with both biological parents was 277 (63.2%). The number of persons living in the household, including the person with the condition was four (4)people, with a frequency of 137 (33.7%).

The main sources of the family income during the last 12 months reported was money from a job or a business with a frequency of 310 (70.8%), followed by social assistance, public assistance, general assistance and nutritional assistance program (PAN in Spanish) with a frequency of 121 (27.6%). Other sources of family income reported included food pension with 68 (15.5%); honoraries, rent incomes, commissions, interests or dividends with 4 (0.9%); social security, worker's compensation, veteran's welfare, pensions with 33 (7.5%). Scholarships, family collaboration and unemployment benefits among others, were mentioned in the category of "Other sources of income". All the sources of income reported are not mutually exclusive; that is, some families received income from more than one source.

Table 4.2 Information of the father and the mother of the participant with ASD or associated characteristics, as well as information about the family income and family composition.

Variable	Frequency X (%)
At present, does the participant with ASD or associated characteristics live with the biological mother? (n=438)	
Yes	336 (94.7)
No	85 (3.9)
Unknown	6 (1.4)
At present, does the participant with ASD or associated characteristics live with the biological father? (n=436)	
Yes	282 (64.7)
No	148 (33.9)
Unknown	6 (1.4)
Number of people that live with the participant with ASD or associated characteristics (n=407)	
1 person	32 (7.9)
2 people	32 (7.9)
3 people	105 (25.8)
4 people	137 (33.7)
5 people	77 (18.9)
6 people	14 (3.4)
7 people	6 (1.4)
8 people	2 (0.5)
9 people	2 (0.5)
The main source of family income during the last 12 months (n=438)	
Money from a job or a business	310 (70.8)
Social Assistance, public assistance, general assistance, Nutritional Assistance Program (PAN in Spanish)	121 (27.6)
Food Pension	68 (15.5)
Honoraries, rent incomes, commissions, interests or dividends	4 (0.9)
Social Security, worker's compensation, veteran's welfare, pensions	33 (7.5)
Other	10 (2.3)

Sixty-seven percent (66.6%) of participants reported to have annual family incomes in the range of less than \$10,000 and up to \$24,999 distributed as follows: less than \$10,000 with a frequency of 117 (29.4%), followed by \$15,000 to \$24,999 with a frequency of 80 (20.1%), and \$10,000 to \$14,999 with a frequency of 68 (17.1%). The highest frequency of the number of people reported that depend on that family income was 4 people, representing a 37.2% of the participants.

Other variables of interest in the study were the employment status and the educational level of the biological or adoptive parents. The employment status reported with the highest frequency among the biological mothers was housewife with 198 (46.7%), followed by a full-time or part-time job with 192 (45.3%). Only 12 of those who responded the question informed to be adoptive mothers, and among these, the categories of student and a full-time or part-time job were the most frequently reported with 8 (66.7%). Most of the biological fathers had a full-time or part-time job with a frequency of 249 (77.1%), and among the adoptive fathers, the full-time or part-time job was the most frequently reported with 14 (77.8%).

The educational level of the parents was also asked. The highest scholar degree completed by the parents was also included as one of the variables of interest. The biological mothers completed most advanced degrees in comparison with the biological fathers. The biological mothers that completed an undergraduate, master or doctorate degree were 182 (43.2%), versus 100 (29.9%) of the biological fathers. The category of course, certificate or associated degree for biological mothers was 126 (29.9%) and for biological fathers was 111 (33.1%); high school degree was 87 (20.1%) and 94 (28.1%), respectively. The frequency for the category of "never went to school or never finished school" for the biological mothers was 26 (6.2%) and for the biological fathers was 30 (9.0%). All the adoptive mothers had an undergraduate, master or doctorate degree; and the category with the highest frequency among the adoptive fathers was a course, certificate, or associated degree with 6 (33.3%).

Table 4.2 Information of the father and the mother of the participant with ASD or associated characteristics, as well as information about the family income and family composition (*continuation*).

Variable	Frequency X (%)
Annual family income (n=398)*	
Less than $10,000	117 (29.4)
$10,000 to $14,999	68 (17.1)
$15,000 to $24,999	80 (20.1)
$25,000 to $34,999	51 (12.8)
$35,000 to $49,999	42 (10.6)
$50,000 to $74,999	30 (7.5)
$75,000 to $99,999	6 (1.5)
$100,000 to $149,999	2 (0.5)
$150,000 to $199,999	0 (0.0)
$200,000 or more	2 (0.5)
Number of people that depend on that family income (n=419)	
1 person	2 (0.5)
2 people	36 (8.6)
3 people	125 (29.8)
4 people	156 (37.2)
5 people	79 (18.9)
6 people	14 (3.3)
7 people	5 (1.2)
8 people	2 (0.5)
Employment status of the biological mother (n=424)	
Student	21 (5.0)
Housewife	198 (46.7)
Full-time or part-time job	192 (45.3)
Student and a full-time or part-time job	13 (3.0)
Employment status of the adoptive mother (n=12)	
Student	0 (0.0)
Housewife	1 (8.3)
Full-time or part-time job	3 (25.0)
Student and a full-time or part-time job	8 (66.7)
Employment status of the biological father (n=323)	
Student	7 (2.2)
Unemployed	55 (17.0)
Full-time or part-time job	249 (77.1)
Student and a full-time or part-time job	12 (3.7)

*With the purpose of making comparisons with the Census, the family income which was asked as a monthly income and as an open question, was multiplied by 12, to obtain the annual income and it was arranged in the same ranges as the Census.

Table 4.2 Information of the father and the mother of the participant with ASD or associated characteristics, as well as information about the family income and family composition (*continuation*).

Variable	**Frequency X (%)**
Employment status of the adoptive father (n=18)	
Student	0 (0.0)
Unemployed	3 (16.7)
Full-time or part-time job	14 (77.8)
Student and a full-time or part-time job	1 (5.5)
Highest scholar degree completed by the biological mother (n=421)	
Never went to school	0 (0.0)
Never finished school	26 (6.2)
High School graduate	87 (20.7)
Course or certificate; or associated degree	126 (29.9)
Undergraduate degree	147 (34.9)
Master or doctorate degree	35 (8.3)
Highest scholar degree completed by the adoptive mother (n=7)	
Never went to school	0 (0.0)
Never finished school	0 (0.0)
High School graduate	0 (0.0)
Course or certificate; or associated degree	0 (0.0)
Undergraduate degree	4 (57.1)
Master or doctorate degree	3 (42.9)
Highest scholar degree completed by the biological father (n=335)	
Never went to school	3 (0.9)
Never finished school	27 (8.0)
High School graduate	94 (28.1)
Course or certificate; or associated degree	111 (33.1)
Undergraduate degree	71 (21.2)
Master or doctorate degree	29 (8.7)
Highest scholar degree completed by the adoptive father (n=18)	
Never went to school	0 (0.0)
Never finished school	3 (16.7)
High School graduate	4 (22.2)
Course or certificate; or associated degree	6 (33.3)
Undergraduate degree	2 (11.1)
Master or doctorate degree	3 (16.7)

The marital status of the person that at the moment of the study had the custody of the participant with ASD or associated characteristics was also reported. Out of 432 who answered this question, 242 (56%) were married, 63 (14.6%) were living together, 46 (10.6%) were divorced, 38 (8.8%) were separated, 6 (1.4%) were widowed and 37 (8.6%) had never been married.

The use of medications during pregnancy was also asked in the survey. Out of 411, it was reported that 245 (59.6%) mothers had taken some type of medication during pregnancy. Of those, the drug with the highest frequency was Panadol with a frequency of 99 (40.4%), followed by Tylenol with a frequency of 39 (15.9%), prenatal pills with a frequency of 34 (13.9%), folic acid with a frequency of 23 (9.4%) and Brethine with a frequency of 21 (8.6%).

Diagnosis of Autism in the biological parents of the participants with ASD was also documented. Out of 423, only 1 (0.2%) mother had Autism and out of 411, 2 (0.5%) fathers had Autism.

Table 4.2 Information of the father and the mother of the child, young or adult with ASD or associated characteristics, as well as information about the family income and family composition (*continuation*).

Variable	**Frequency X (%)**
Marital status of the person that has the custody of the participant with Autism or associated characteristics (n=432)	
Married	242 (56.0)
Live together	63 (14.6)
Divorced	46 (10.6)
Separated	38 (8.8)
Widowed	6 (1.4)
Never married	37 (8.6)
Did the mother consume any medications during pregnancy? (n=411)	
Yes	245 (59.6)
No	166 (40.4)
Reported medications with the highest frequencies (n=245)	
Panadol	99 (40.4)
Tylenol	39 (15.9)
Prenatal pills	34 (13.9)
Folic Acid	23 (9.4)
Brethine	21 (8.6)
Antibiotics	20 (8.2)
Vistaril	21 (8.6)
Iron	12 (4.9)
Biological Mother: Diagnosis of Autism (n=431)	
Yes	1 (0.2)
No	422 (97.9)
Unknown	8 (1.9)
Biological Father: Diagnosis of Autism (n=434)	
Yes	2 (0.5)
No	409 (94.2)
Unknown	23 (5.3)

4.3 Siblings of the participants with ASD or associated characteristics

The number of participants with ASD or associated characteristics who reported to have siblings was 332 (75.8%). The information asked about the siblings included gender, relationship (complete, both parents are the same; half, one parent is the same, and adoptive), diagnosis of Autism and developmental disabilities (Cerebral Palsy, hearing loss, mental retardation, vision damage and Attention Deficit and Hyperactivity Disorder). A total of 559 siblings were reported. The frequencies of those that reported the gender were 288 (52.0%) for male and 266 (48.0%) for female; 348 (62.8%) had a complete relationship with the participant, 198 (35.7%) had a half relationship with the participant and 8 (1.4%) were adopted. Twenty-five of the total siblings (4.5%) had a diagnosis of Autism and 64 (11.5%) had a developmental disability diagnosis, in which Attention Deficit and Hyperactivity Disorder (ADHD) had the highest frequency with 39 (7.0%). From the 332 participants who reported to have at least one sibling, 7.5% had one sibling with a diagnosis of Autism.

Of those 25 siblings with diagnosis of Autism, 12 (48.0%) had a complete relationship with the participant with an actual diagnosis of Autism Disorder; 5 (20.0%) had a complete relationship with the participant with an actual diagnosis of PDD; 1 (4.0%) had a complete relationship with a participant with tendencies or symptoms; 2 (8.0%) had a complete relationship with a participant with an actual unknown diagnosis. In total, it was documented that 20 (80.0%) of the 25 siblings with a diagnosis of Autism had a complete relationship with the participant of the study.

The siblings of the participants with a diagnosis of Depression, Bipolar Disorder or Emotional Disorder were reported to be twenty-one (21), representing a 5.5% of the 379 participants who answered the question.

Table 4.3 Information of the siblings of the participant with ASD or associated characteristics.

Variable	Frequency X (%)
Does the participant with Autism or associated characteristics have siblings? (n=438)	
Yes	332 (75.8)
No	106 (24.2)
Sibling number 1 (N=317)	
Gender (n=315)	
Male	159 (50.5)
Female	156 (49.5)
Relationship (n=314)	
Complete (Both parents are the same)	226 (72.0)
Half (One parent is the same)	88 (28.0)
Adoptive	0 (0.0)
Autism Diagnosis (n=314)	
Yes	16 (5.1)
No	291 (92.7)
Unknown	7 (2.2)
Developmental Disability Diagnosis (n=317)	
Cerebral Palsy	2 (0.6)
Hearing loss	3 (0.9)
Mental Retardation	4 (1.3)
Vision damage	3 (0.9)
ADHD	28 (8.8)
Other	25 (7.9)
Sibling number 2 (N=160)	
Gender (n=157)	
Male	89 (56.7)
Female	68 (43.3)
Relationship (n=158)	
Complete (Both parents are the same)	86 (54.4)
Half (One parent is the same)	69 (43.7)
Adoptive	3 (1.9)
Autism Diagnosis (n=156)	
Yes	8 (5.1)
No	145 (93.0)
Unknown	3 (1.9)
Developmental Disability Diagnosis (n=160)	
Cerebral Palsy	1 (0.6)
Hearing loss	2 (1.3)
Mental Retardation	3 (1.9)
Vision damage	3 (1.9)
ADHD	7 (4.4)
Other	10 (6.3)

Table 4.3 Information of the siblings of the participant with ASD or associated characteristics (*continuation*).

Variable		Frequency X (%)
Sibling number 3 (N=54)		
Gender (n=54)		
	Male	28 (51.9)
	Female	26 (48.1)
Relationship (n=54)		
	Complete (Both parents are the same)	21 (38.9)
	Half (One parent is the same)	30 (55.6)
	Adoptive	3 (5.5)
Autism Diagnosis (n=52)		
	Yes	1 (1.9)
	No	48 (92.3)
	Unknown	3 (5.8)
Developmental Disability Diagnosis (n=54)		
	Cerebral Palsy	0 (0.0)
	Hearing loss	0 (0.0)
	Mental Retardation	3 (5.6)
	Vision damage	0 (0.0)
	ADHD	3 (5.6)
	Other	0 (0.0)
Sibling number 4 (N=21)		
Gender (n=21)		
	Male	11 (52.4)
	Female	10 (47.6)
Relationship (n=21)		
	Complete (Both parents are the same)	10 (47.6)
	Half (One parent is the same)	9 (42.9)
	Adoptive	2 (9.5)
Autism Diagnosis (n=21)		
	Yes	0 (0.0)
	No	20 (95.2)
	Unknown	2 (4.8)
Developmental Disability Diagnosis (n=21)		
	Cerebral Palsy	0 (0.0)
	Hearing loss	0 (0.0)
	Mental Retardation	0 (0.0)
	Vision damage	0 (0.0)
	ADHD	1 (4.8)
	Other	1 (4.8)

Table 4.3 Information of the siblings of the participant with ASD or associated characteristics (*continuation*).

Variable		Frequency X (%)
Sibling number 5 (N=6)		
Gender (n=6)		
	Male	1 (16.7)
	Female	5 (83.3)
Relationship (n=6)		
	Complete (Both parents are the same)	4 (66.7)
	Half (One parent is the same)	2 (33.3)
	Adoptive	0 (0.0)
Autism Diagnosis (n=6)		
	Yes	0 (0.0)
	No	5 (83.3)
	Unknown	1 (16.7)
Developmental Disability Diagnosis (n=6)		
	Cerebral Palsy	0 (0.0)
	Hearing loss	0 (0.0)
	Mental Retardation	0 (0.0)
	Vision damage	1 (16.7)
	ADHD	0 (0.0)
	Other	0 (0.0)
Sibling number 6 (N=1)		
Gender (n=1)		
	Male	0 (0.0)
	Female	1 (100.0)
Relationship (n=1)		
	Complete (Both parents are the same)	1 (100.0)
	Half (One parent is the same)	0 (0.0)
	Adoptive	0 (0.0)
Autism Diagnosis (n=1)		
	Yes	0 (0.0)
	No	1 (100.0)
	Unknown	0 (0.0)
Developmental Disability Diagnosis (n=1)		
	Cerebral Palsy	0 (0.0)
	Hearing loss	0 (0.0)
	Mental Retardation	0 (0.0)
	Vision damage	0 (0.0)
	ADHD	0 (0.0)
	Other	0 (0.0)
Sibling’s diagnosis of depression, bipolar disorder or emotional disorder (n=379)		
	Yes	21 (5.5)
	No	327 (86.3)
	Unknown	31 (8.2)

4.4 Other information about the family of the participants with ASD or associated characteristics

Before receiving the news of diagnosis of the child, it was reported that 56 (12.3%) parents had diagnosis of Depression, Bipolar Disorder or Emotional Disorder. After receiving the news, there were 62 (13.7%) parents with the diagnosis.

Finally, it was asked if the aunts, uncles or cousins of the participant with ASD or associated characteristics were also diagnosed with Autism, reporting 65 (14.4%) diagnosed.

Table 4.4 Other information about the family of the participant with ASD or associated characteristics.

Variable	Frequency X (%)
Parents' diagnosis of Depression, Bipolar Disorder or Emotional Disorder before knowing that the child had a diagnosis of Autism (n=455)	
Yes	56 (12.3)
No	376 (82.6)
Unknown	23 (5.1)
Parents' diagnosis of Depression, Bipolar Disorder or Emotional Disorder after knowing that the child had a diagnosis of Autism (n=453)	
Yes	62 (13.7)
No	372 (82.1)
Unknown	19 (4.2)
Diagnosis of Autism: aunts, uncles or cousins of the participant with Autism or associated characteristics (n=452)	
Yes	65 (14.4)
No	336 (74.3)
Unknown	51 (11.3)

4.5 Information about the diagnosis of ASD

Information about diagnosis, age at time of diagnosis, initial concerns, and other medical conditions was collected. Pediatricians are the physicians most frequently visited by the participants with ASD (71.4%), followed by language therapists (67.5%), physical or occupational therapists (56.3%), psychologists (36.6%) and neurologists (26.0%).

Questions about the initial and current diagnosis of ASDs were asked. The frequencies for the initial diagnosis of ASD in descending order were 176 (42.4%) for Autism or Autism Disorder, 117 (28.2%) for PDD or PDD-NOS, 55 (13.3%) for symptoms or tendencies, 45 (10.8%) were unknown, 19 (4.6%) for Asperger's Syndrome, 2 (0.5%) for Childhood Disintegrative Disorder and 1 (0.2%) for Rett's Syndrome. The frequencies of the current diagnosis of ASD were 165 (39.4%) for Autism or Autism Disorder, 104 (24.8%) for PDD or PDD-NOS, 65 (15.5%) for symptoms or tendencies, 58 (13.8%) were unknown, 24 (5.7%) for Asperger's Syndrome, 2 (0.5%) for Childhood Disintegrative Disorder and 1 (0.2%) for Rett's Syndrome.

The professionals who did the initial and the current diagnosis of Autism were documented. Psychologists were the professionals who most frequently made a diagnosis with a frequency of 95 (30.1%), followed by neurologists with a frequency of 51 (17.2%), pediatric neurologists with a frequency of 33 (11.1%), speech-language therapists with a frequency of 25 (8.4%) and psychiatrists with a frequency of 21 (7.1%). For the current diagnosis, the professionals with the highest frequencies were psychologists with a frequency of 83 (35.3%) and neurologists with a frequency of 44 (18.7%), followed by pediatric neurologists with a frequency of 25 (10.6%), psychiatrists with a frequency of 22 (9.4%) and speech-language therapists with a frequency of 10 (4.3%).

The median age at time of the initial diagnosis of ASD reported was 36 months. In total, 85.7% of the participants were diagnosed before 5 years old. The median age of the participants by the time that parents first observed an unusual development of the child compared to the other children was 24 months of age.

The major initial concerns reported in order of frequency include: delay in language development in 405 (90.4%) of the participants, limited visual contact in 304 (67.9%) of the participants, difficulty to relate with others in 280 (62.5%) of the participants, repetitive behaviors in 265 (59.2%) of the participants, no response when called by name in 246 (54.9%) of the participants, “in his or her own world” in 238 (53.1%) of the participants, anger or grieve in 233 (52.0%) of the participants. In the “others” category were mentioned self aggression, motor delay, obsession with objects, isolation and no notion of danger.

Table 4.5 Information of the diagnosis of the participant with Autism or associated characteristics.

Variable	**Frequency X (%)**
Type of professionals or doctors that mainly assist the participant (n=462)	
General Pediatrician	330 (71.4)
Developmental Pediatrician	61 (13.2)
Family Doctor	39 (8.4)
Neonatologist	9 (1.9)
General Doctor	24 (5.2)
Language Therapist	312 (67.5)
Audiologist	47 (10.2)
Physical or occupational therapist	260 (56.3)
Psychiatrist	75 (16.2)
Psychologist	169 (36.6)
Social Worker	34 (7.4)
Nutritionist	51 (11.0)
Other	197 (42.6)
Geneticist	54 (11.7)
Neurologist	121 (26.0)
Diagnosis with Autism (n=451)	
Yes	359 (79.6)
No	77 (17.1)
Unknown	15 (3.3)
Initial Diagnosis of Autism Spectrum Disorder (n=415)	
Autism or Autism Disorder	176 (42.4)
PDD or PDD-NOS	117 (28.2)
Childhood Disintegrative Disorder	2 (0.5)
Asperger’s Syndrome	19 (4.6)
Rett’s Syndrome	1 (0.2)
Symptoms or tendencies	55 (13.3)
Unknown	45 (10.8)

Table 4.5 Information of the diagnosis of the participant with Autism or associated characteristics (*continuation).*

Variable	**Frequency X (%)**
Age of diagnosis in years (n=380)	
Less than 1 year	2 (0.5)
From 1 to 2 years	25 (6.6)
From 2 to 3 years	133 (35.0)
From 3 to 4 years	92 (24.2)
From 4 to 5 years	74 (19.5)
From 5 to 6 years	20 (5.3)
From 6 to 7 years	11 (2.9)
From 7 to 8 years	11 (2.9)
From 8 years and over	12 (3.1)
Age of first time suspicion of Autism (n=389)	
Less than 1 year	15 (3.9)
From 1 to 2 years	171 (44.0)
From 2 to 3 years	146 (37.5)
From 3 to 4 years	35 (9.0)
From 4 to 5 years	11 (2.8)
From 5 years and over	11 (2.8)
Initial concerns (n=448)	
Language delay	405 (90.4)
Difficulty to relate to others	280 (62.5)
Intense interest in one or a few persons	160 (35.7)
Repetitive behaviors	265 (59.2)
Did not respond when called by name	246 (54.9)
“In his/her own world”	238 (53.1)
Limited visual contact	304 (67.9)
Suspect of hearing loss	196 (43.8)
Did not enjoy being touched, cuddled or hugged	141 (31.5)
Loss of language skills	209 (46.7)
Anger or grieve	233 (52.0)
Others	83 (18.5)
Current diagnosis of Autism Spectrum Disorder (n=419)	
Autism or Autism Disorder	165 (39.4)
PDD or PDD-NOS	104 (24.8)
Childhood Disintegrative Disorder	2 (0.5)
Asperger’s Syndrome	24 (5.7)
Rett’s Syndrome	1 (0.2)
Symptoms or tendencies	65 (15.5)
Unknown	58 (13.8)

It was reported that one of the most common characteristic that the individual presents is being more or less active compared with children of the same age with a frequency of 234 (52.2%), followed by frequent problems of constipation or diarrhea with a frequency of 111 (24.8%). Other characteristics were inability to sleep consistently during the night with a frequency of 94 (21.0%), and self aggression with a frequency of 72 (16.1%).

It was reported that 242 (55.6%) of the participants with ASD or associated characteristics had a diagnosis of another medical condition, hereditary defects, developmental delays or impairments. Among these, allergies were documented as the most frequent with 89 (36.8%), followed by gastrointestinal problems with a frequency of 73 (30.2%), otitis media with a frequency of 44 (18.2%), chronic nasal congestion with a frequency of 40 (16.5%), epilepsy or seizures with a frequency of 33 (13.6%), nutritional deficiencies with a frequency of 30 (12.4%), hypotonia with a frequency of 28 (11.6%) and frequent viral infections with a frequency of 25 (10.3%). In the "others" category, asthma was the condition with the highest frequency (14.9%). The diagnosis of cases with epilepsy was mostly made by neurologists with a frequency of 18 (60.0%) and pediatric neurologists with a frequency of 7 (23.3%).

A diagnosis of other developmental disabilities was also reported. Attention-Deficit and Hyperactivity Disorder (ADHD) had a frequency of 76 representing a 31.4%, followed by mental retardation with a frequency of 28 (6.3%), vision impairment with a frequency of 14 (3.1%), hearing loss with a frequency of 13 (2.9%) and Cerebral Palsy with a frequency of 2, representing 0.2% of the population of the study.

The age of the participant with ASD or associated characteristics when the last intelligence test (IQ) was administered was reported. Out of 357; 145 (40.6%) reported the age, 49 (13.7%) did not know the age and 163 (45.7%) have never been tested. In total, only 54.3% of the population of the study had a psychometric test administered. The median age reported for the last IQ test administered reported was 5.5 years old.

Table 4.5 Information of the diagnosis of the participant with ASD or associated characteristics (*continuation)*.

Variable	**Frequency X (%)**
At present, participant presents the following characteristics (n=448)	
On purpose, do things that harm himself/herself	72 (16.1)
Inability to sleep consistently during the night	94 (21.0)
Frequent problems with constipation and/or diarrhea	111 (24.8)
Compared with other children of the same age, he/she is more or less active	234 (52.2)
None of above	96 (21.4)
Diagnosis of another medical condition, hereditary defects, developmental delays or impairments (n=435)	
Yes	242 (55.6)
No	177 (40.7)
Unknown	16 (3.7)

Table 4.5 Information of the diagnosis of the participant with ASD or associated characteristics (*continuation*).

Variable	**Frequency X (%)**
Diagnosis of other medical conditions (n=242)	
Tuberous sclerosis	2 (0.8)
Congenital rubella syndrome	0 (0.0)
Phenylketonuria (PKU)	2 (0.8)
X-fragile syndrome	3 (1.2)
Frequent viral infections	25 (10.3)
Epilepsy or seizures	33 (13.6)
Otitis media	44 (18.2)
Oral or gum diseases	21 (8.7)
Nutritional deficiencies	30 (12.4)
Gastrointestinal Problems	73 (30.2)
Allergies	89 (36.8)
Chronic nasal congestion	40 (16.5)
Auto-immune problems	2 (0.8)
Hypotonia	28 (11.6)
Others	85 (35.1)
Diagnosis of Developmental Disabilities (n=242)	
Cerebral Palsy	2 (0.8)
Hearing loss	13 (5.4)
Mental Retardation	28 (11.6)
Vision impairment	14 (5.8)
Attention Deficit and Hyperactivity Disorder	76 (31.4)
Others	29 (12.0)
Age of the last intelligence test administered (I.Q.) (n=145)	
Less than 2 years	2 (1.4)
From 2 to 3 years	12 (8.3)
From 3 to 4 years	21 (14.5)
From 4 to 5 years	23 (15.9)
From 5 to 6 years	17 (11.7)
From 6 to 7 years	11 (7.6)
From 7 to 8 years	9 (6.2)
From 8 to 9 years	11 (7.6)
From 9 to 10 years	13 (9.0)
From 10 to 11 years	10 (6.9)
From 11 to 12 years	2 (1.4)
From 12 to 13 years	5 (3.4)
From 13 years and over	9 (6.2)

F. Access to services

Treatments or services that the population of the study had received during the last 12 months and their usefulness were reported. The treatments or services asked were behavior modification; psychotherapy or guidance; diet intervention; treatment with medications; exercise therapy; facilitated communication; music therapy; relaxation therapy; craniosacral therapy; sensorial integration techniques; sign language; social learning; visual image; vitamins, enzymes and hormones; hearing therapy; visual therapy; speech or language therapy; physical or occupational therapy; equestrian therapy; and aquatic therapy.

The services or treatments with highest frequencies of use were speech or language therapy with a frequency of 307 (76.0%) and physical or occupational therapy with a frequency of 284 (72.8%), followed by behavior modification with a frequency of 154 (43.1%), sensorial integration techniques with a frequency of 141 (40.5%), medications with a frequency of 132 (36.6%) and psychotherapy or guidance with a frequency of 100 (28.4%). Among services or treatments with the lowest frequencies of use were music therapy with a frequency of 60 (17.1%), visual therapy with a frequency of 58 (17.0%), hearing therapy with a frequency of 45 (13.1%), relaxation therapy with a frequency of 38 (11.1%), facilitated communication with a frequency of 32 (9.4%), aquatic therapy with a frequency of 28 (8.4%), equestrian therapy with a frequency of 25 (7.4%), sign language with a frequency of 25 (7.3%) and craniosacral therapy with a frequency of 11 (3.2%).

Among those services that have been used and reported as very useful in descending order were: facilitated communication with a frequency of 27 (84.4%), speech or language therapy with a frequency of 257 (83.7%), physical or occupational therapy with a frequency of 230 (81.0%), aquatic therapy with a frequency of 22 (78.6%), exercise therapy with a frequency of

69 (78.4%), music therapy with a frequency of 44 (73.3%) and psychotherapy guidance with a frequency of 71 (71.0%).

During the last 12 months, the sources of payment for the services received were: Government Insurance Plan with a frequency of 173 (39.0%), private health insurance with a frequency of 165 (37.2%), had a health insurance but paid with out of pocket money with a frequency of 100 (22.5%), other ways of payments with a frequency of 58 (13.1%) and did not have a health insurance, therefore paid with money with a frequency of 13 (2.9%). In the "others" category, the most frequent was Department of Education with a frequency of 35 (7.9%).

Out of 444 respondents, the services or supports reported as needed by the participants in order of frequency were: help with communication skills with 330 (74.3%), help with social skills with 265 (59.7%), help with sensorial integration with 207 (46.6%), additional education with 179 (40.3%), skills to handle the anxiety and stress with 143 (32.2%), help with gastrointestinal and diet problems with 142 (32%), and coordination of medical services with 104 (23.4%). The services with the lowest frequencies were: legal services with 55 (12.4%), training for employment or vocational training with 41 (9.2%), sexual counseling with 39 (8.8%), finance counseling with 36 (8.1%), medications monitoring with 34 (7.7%) and evaluation of functional skills with 25 (5.6%). Only 7 (1.6%) reported that no service was needed.

Out of 416 respondents, 196 (47.1%) reported that during the last 12 months, a service related to autism was needed but not received; and out of 402 respondents, 190 (47.3%) reported that during the last 12 months, a service related to autism was needed but it was received later than expected.

Some of the reasons provided as explanations for why the service was not received or received later than expected were: that the health insurance did not cover the services with a frequency of 79 (17.8%); could not pay or did not have a health insurance with a frequency of 51 (11.5%); problems with transportation with a frequency of 44 (9.9%); did not have a professional to go with, with a frequency of 42 (9.5%); and the doctors or professionals did not consider it a problem with a frequency of 33 (7.4%). The category of "other reason" had a frequency of 143 (32.2%) and included delays of the Department of Education, delays in services, lack of information, lack of professionals or was not selected to receive any service.

Problems of access to specialized medical services during the last 12 months that were reported included finding specialized doctors with the skills and experiences to treat the person with a frequency of 134 (30.2%), obtaining the medical referrals for services with a frequency of 89 (20.0%), had health insurance, but the service was not covered with a frequency of 64 (14.4%), obtaining appointments with specialized doctors with a frequency of 60 (13.5%), coordinating services with specialized doctors and other providers with a frequency of 48 (10.8%), and obtaining the needed number of appointments with a frequency of 33 (7.4%). Nineteen (19, 4.3%) reported that have not obtained medical services, and 97 (21.8%) have not had any kind of problems.

Table 4.6 Access to services of the participant with ASD or associated characteristics.

Variable	**Frequency X (%)**
Access to services during the last 12 months	
Behavior modification (n=357)	
Have not use it	203 (56.9)
Have use it, not useful	15 (4.2)
Have use it, slightly useful	44 (12.3)
Have use it, very useful	95 (26.6)
Psychotherapy / guidance (n=352)	
Have not use it	252 (71.6)
Have use it, not useful	7 (2.0)
Have use it, slightly useful	22 (6.3)
Have use it, very useful	71 (20.1)
Diet intervention (n=358)	
Have not use it	238 (6.5)
Have use it, not useful	22 (6.1)
Have use it, slightly useful	39 (10.9)
Have use it, very useful	59 (16.5)
Treatment with medications (n=361)	
Have not use it	229 (63.4)
Have use it, not useful	15 (4.1)
Have use it, slightly useful	28 (7.8)
Have use it, very useful	89 (24.7)
Exercise therapy (n=351)	
Have not use it	263 (74.9)
Have use it, not useful	6 (1.7)
Have use it, slightly useful	13 (3.7)
Have use it, very useful	69 (19.7)
Facilitated communication (n=341)	
Have not use it	298 (87.4)
Have use it, not useful	4 (1.2)
Have use it, slightly useful	12 (3.5)
Have use it, very useful	27 (7.9)

Table 4.6 Access to services of the participant with ASD or associated characteristics (*continuation*).

Variable	Frequency X (%)
Access to services during the last 12 months	
Music therapy (n=350)	
Have not use it	290 (82.9)
Have use it, not useful	4 (1.1)
Have use it, slightly useful	12 (3.4)
Have use it, very useful	44 (12.6)
Relaxation therapy (n=341)	
Have not use it	303 (88.9)
Have use it, not useful	4 (1.2)
Have use it, slightly useful	9 (2.6)
Have use it, very useful	25 (7.3)
Craniosacral therapy (n=339)	
Have not use it	328 (96.8)
Have use it, not useful	3 (0.9)
Have use it, slightly useful	1 (0.3)
Have use it, very useful	7 (2.1)
Sensorial integration techniques (n=348)	
Have not use it	207 (59.5)
Have use it, not useful	15 (4.3)
Have use it, slightly useful	29 (8.3)
Have use it, very useful	97 (27.9)
Sign language (n=342)	
Have not use it	317 (92.7)
Have use it, not useful	8 (2.3)
Have use it, slightly useful	5 (1.5)
Have use it, very useful	12 (3.5)
Social learning (n=334)	
Have not use it	255 (76.3)
Have use it, not useful	17 (5.1)
Have use it, slightly useful	18 (5.4)
Have use it, very useful	44 (13.2)

Table 4.6 Access to services of the participant with ASD or associated characteristics (*continuation*).

Variable	**Frequency X (%)**
Access to services during the last 12 months	
Visual image (n=344)	
Have not use it	257 (74.7)
Have use it, not useful	12 (3.5)
Have use it, slightly useful	16 (4.7)
Have use it, very useful	59 (17.1)
Vitamins, enzymes, hormones (n=348)	
Have not use it	264 (75.9)
Have use it, not useful	12 (3.4)
Have use it, slightly useful	18 (5.2)
Have use it, very useful	54 (15.5)
Hearing therapy (n=343)	
Have not use it	298 (86.9)
Have use it, not useful	8 (2.3)
Have use it, slightly useful	5 (1.5)
Have use it, very useful	32 (9.3)
Visual Therapy (n=342)	
Have not use it	284 (83.0)
Have use it, not useful	9 (2.6)
Have use it, slightly useful	11 (3.2)
Have use it, very useful	38 (11.1)
Speech/ language therapy (n=404)	
Have not use it	97 (24.0)
Have use it, not useful	16 (4.0)
Have use it, slightly useful	34 (8.4)
Have use it, very useful	257 (63.6)
Physical/Occupational therapy (n=390)	
Have not use it	106 (27.2)
Have use it, not useful	18 (4.6)
Have use it, slightly useful	36 (9.2)
Have use it, very useful	230 (59.0)
Equestrian therapy (n=337)	
Have not use it	312 (92.6)
Have use it, not useful	7 (2.1)
Have use it, slightly useful	3 (0.9)
Have use it, very useful	15 (4.5)
Aquatic therapy (n=335)	
Have not use it	307 (91.6)
Have use it, not useful	2 (0.6)
Have use it, slightly useful	4 (1.2)
Have use it, very useful	22 (6.6)

Table 4.6 Access to services of the participant with ASD or associated characteristics (*continuation*).

Variable	**Frequency X (%)**
During the last 12 months, the form of payment for the services received was: (n=444)	
Health Reform Insurance	173 (39.0)
Private Health Insurance	165 (37.2)
Don't have an insurance, paid with money, or credit cards	13 (2.9)
Have an insurance, but paid with money or credit cards	100 (22.5)
Others	58 (13.1)
The kind of services or supports needed by the participant with ASD or associated characteristics reported by parents were: (n=444)	
Evaluation of functional skills	25 (5.6)
Help with communication skills	330 (74.3)
Help with social skills	265 (59.7)
Additional education	179 (40.3)
Training of employment/ vocational training	41 (9.2)
Skills to handle with anxiety and stress	143 (32.2)
Help with gastrointestinal and diet problems	142 (32.0)
Help with sensorial integration	207 (46.6)
Sexual counseling	39 (8.8)
Medicaments monitoring	34 (7.7)
Legal services	55 (12.4)
Recreational activities	201 (45.3)
Finance counseling	36 (8.1)
Coordination of medical services	104 (23.4)
Other	44 (9.9)
No service was needed	7 (1.6)
During the last 12 months, a service related to Autism was needed but not received it (n=416)	
Yes, it was received	160 (38.5)
No, it was not received	196 (47.1)
Unknown	60 (14.4)
During the last 12 months, a service related to Autism was needed but received it later (n=402)	
Yes, it was received later	190 (47.3)
No, it was not received later	139 (34.6)
Unknown	73 (18.2)

Table 4.6 Access to services of the participant with ASD or associated characteristics (*continuation*).

Variable	**Frequency X (%)**
Reason for not receiving the service or why it was received later than expected (n=444)	
Could not pay or did not have a health insurance	51 (11.5)
Had health insurance, but the service was not covered	79 (17.8)
Did not have any kind of professional to go with	42 (9.5)
The medical personal did not consider it was a problem	33 (7.4)
Has problems with transportation, care of child (children) or problems related to the job	44 (9.9)
Other reason	143 (32.2)
Did not have any kind of problem	67 (15.1)
Problems of access to specialized medical services during the last 12 months (n=444)	
Obtaining medical referrals for services	89 (20.0)
Services not included in health insurance benefit package	64 (14.4)
Obtaining the needed number of appointments	33 (7.4)
Obtaining appointments with specialized doctors	60 (13.5)
Finding specialized doctors with the skills and experiences to treat the person	134 (30.2)
Coordinating services with specialized doctor and other providers	48 (10.8)
Others	44 (9.9)
The person have not obtained specialized medical services	19 (4.3)
Have not presented any kind of problem	97 (21.8)
Unknown	36 (8.1)

G. Screening, evaluation and early intervention of children between 0 to 5 years of age.

As mentioned previously, 48.4% of the participants were children between ages from 0 to 5 years old. The questionnaire included a section to be answered only by parents of children from 0 to 5 years of age. Data collected is of particular importance for policy makers, parents and providers since early identification of developmental disabilities and intervention are related to better outcomes and lower expenditures in future costs of special education services. It was reported that out of 235, 158 (67.2%) of the participants have received an evaluation of the development of the child by doctors or other health professionals. Out of 239, 190 (79.5%) reported that doctors or other health professionals made the child handle small objects, organize blocks or place cubes one on top of the other, throw a ball or recognize different colors. Psychologists were the professionals that most frequently made an evaluation of the development of the child with a frequency of 27 (21.4%), followed by occupational therapists with a frequency of 21 (16.7%), developmental pediatricians with a frequency of 18 (14.3%), pediatricians with a frequency of 15 (11.9%), neurologists with a frequency of 9 (7.1%), speech and language pathologists with a frequency of 7 (5.6%) and psychiatrists with a frequency of 2 (1.6%), among others. Parents of 232 (93.2%) participants considered as very important the administration of tests to evaluate child development.

Several questions were made trying to get some information about the communication between the parents of the child with ASD or associated characteristics and doctors or other professionals. Out of 246, 53 (21.5%) reported that the doctors or other professionals have not asked about how the child communicates or manifests the needs; and 46 out of 53 (92.0%) said that an orientation about how the child communicates or manifests the needs would have been helpful. Out of 246, 54 (22.0%) reported that the doctors or other professionals have not asked about the words and phrases the child uses or comprehends, and 50 out of 54 (96.2%) said that an orientation about the words and phrases the child uses and comprehends would have been helpful. Finally, out of 245, 47 (19.2%) said that the doctors or other professionals never asked about how the child related with other children, and 43 out of 47 (93.5%) informed that an orientation about it would have been helpful.

It was also asked if the doctors or professionals have referred the child to a specialist or to a child development program; and out of 246, 146 (59.3%) did refer the child. From those who were referred to a specialist, the kind of specialist was reported. From the 146, 111 (76.0%) were referred to a speech or language specialist, 97 (66.4%) to a physical or occupational therapist, 87 (59.6%) to a hearing specialist, 77 (52.7%) to a psychiatrist or psychologist, and 23 (15.8%) to a social worker.

Out of 242 participants; 158 (65.3%) reported that physicians have always considered that the person in charge of the child is the one that knows the child best; 33 (13.6%) usually; 15 (6.2%) sometimes; 10 (4.1%) rarely, 13 (5.4%) never considered it. Out of 246 participants, 54 (22%) answered that the doctors or other professionals asked if someone was available to provide emotional support; and out of 244, 204 (83.6%) said that the doctors or professionals should discuss if someone is available as an emotional support.

When the parents expressed their concerns about how the child was developing to the doctors or other professionals by the first time, 89 (25.4%) said to wait to see if progress occurs, 81 (23.1%) referred the child to a specialist, 42 (12.0%) made an evaluation of the development of the child, 38 (10.9%) said not to worry about it and 11 (3.1%) never paid attention.

Early intervention services are crucial in preventing a cascade of problems that may affect later functioning. Out of 229, 178 (77.7%) reported to have received or was receiving early intervention services.

Individual Family Service Plan (IFSP) is a roadmap through the early intervention program; it documents and guides the early intervention process for infants and toddlers with disabilities and their families. According to IDEA Part C regulations, an IFSP should be in place 45 days after the child is referred to the early intervention system of services, if determined as eligible to the program. Out of 230, 140 (60.9%) have an IFSP.

Table 4.7 Information of screening, evaluation and early intervention of children between 0 to 5 years of age with ASD or associated characteristics.

Variable	**Frequency X (%)**
Have the doctors or another professional made an evaluation of the development of the child? (n=235)	
Yes	158 (67.2)
No	55 (23.4)
Unknown	22 (9.4)
Have ever the doctors or another professional made the child handle small objects or organize blocks or cubes one on top of the other, throw a ball or recognize different colors? (n=239)	
Yes	190 (79.5)
No	36 (15.1)
Unknown	13 (5.4)
How important or not important the person thinks are the medical tests to evaluate the development of the child (n=249)	
Very important	232 (93.2)
Important	4 (1.6)
Some important	2 (0.8)
Little important	0 (0.0)
Not important	0 (0.0)
Unknown	11 (4.4)
Since the birth of the child, the doctors or other professionals have asked about how the child communicates or manifests the needs? (n=246)	
Yes	177 (72.0)
No	53 (21.5)
Unknown	16 (6.5)
Would it help you an orientation about how the child communicates the needs? (n=50)	
Yes	46 (92.0)
No	2 (4.0)
Unknown	2 (4.0)

Table 4.7 Information of screening, evaluation and early intervention of children between 0 to 5 years of age with ASD or associated characteristics (*continuation*).

Variable	Frequency X (%)
Since the birth of the child, the doctors or other professionals have asked about the words and phrases the child uses and comprehends? (n=246)	
Yes	180 (73.2)
No	54 (22.0)
Unknown	12 (4.9)
Would it help you an orientation about the words and phrases the child uses and comprehends? (n=52)	
Yes	50 (96.2)
No	1 (1.9)
Unknown	1 (1.9)
At some moment, have the doctors or other professionals asked you about how the child is learning to relate with other children? (n=245)	
Yes	188 (76.7)
No	47 (19.2)
Unknown	10 (4.1)
Would it help you an orientation about how the child is learning to relate with other children? (n=46)	
Yes	43 (93.5)
No	1 (2.2)
Unknown	2 (4.3)
Since the birth of the child, have the doctors or other professionals referred the child to a specialist or a program of development? (n=246)	
Yes	146 (59.3)
No	87 (35.4)
Unknown	13 (5.3)
Kind of specialist the child was referred to (n=146)	
Specialist of speech/language	111 (76.0)
Hearing specialist	87 (59.6)
Physical/Occupational therapist	97 (66.4)
Psychiatrist or psychologist of children	77 (52.7)
Social Worker	23 (15.8)
Other	39 (26.7)
Unknown	1 (0.7)

Table 4.7 Information of screening, evaluation and early intervention of children between 0 to 5 years of age with ASD or associated characteristics (*continuation*).

Variable	**Frequency X (%)**
Since the birth or the child, how often the doctors or other professionals have considered that you are the person that better knows the child? (n=242)	
Always	158 (65.3)
Usually	33 (13.6)
Sometimes	15 (6.2)
Rarely	10 (4.1)
Never	13 (5.4)
Unknown	13 (5.4)
Have the doctors or other professionals asked you if you have someone to go as an emotional support? (n=246)	
Yes	54 (22.0)
No	177 (72.0)
Unknown	15 (6.1)
Should the doctors or other professionals discuss with one of the parents if they have someone to go for an emotional support? (n=244)	
Yes	204 (83.6)
No	19 (7.8)
Unknown	21 (8.6)
What the doctors or other professionals did when concerns about how the child was developing were expressed the first time? (n=350)	
Never expressed your concerns	17 (4.9)
Never paid attention	11 (3.1)
Said to not worry about it	38 (10.9)
Said to wait, to see if a progress occurs	89 (25.4)
Made an evaluation of development	42 (12.0)
Referred to an specialist	81 (23.1)
Don’t remember	9 (2.6)
Other	7 (2.0)

Table 4.7 Information of screening, evaluation and early intervention of children between 0 to 5 years of age with ASD or associated characteristics (*continuation*).

Variable	Frequency X (%)
Received or receiving early intervention services (n=229)	
Yes	178 (77.7)
No	51 (22.3)
Unknown	0 (0.0)
Have an Individual Family Service Plan (ISPF) (n=230)	
Yes	140 (60.9)
No	45 (19.6)
Unknown	45 (19.6)

H. Information about school (0-22 years old)

A total of 26 participants (5%) were 22 years old and over. The kind of school that participants with ASD or associated characteristics were attending was asked. Out of 371; 216 (58.2%) were attending public school, 68 (18.3%) were attending a Head Start center, 43 (11.6%) were attending private school, 15 (4.0) were attending a home care, 2 (0.5%) have home schooling. For reasons of age 27 (7.2%) were not attending school. The specific kind of schools was also asked, and out of 320; 78 (24.4%) were attending a school with autism program, 66 (20.6%) were attending school with services of special education, 55 (17.2%) were attending a school with services of resource room, 41 (12.8%) were attending pre-school/ Head Start with regular education, 30 (9.4%) were attending pre-school/Head Start with Autism, 14 (4.4%) were attending pre-school/Head Start with special education and 8 (2.5%) were attending a school with no resources.

An Individual Education Plan (IEP) is a detailed description of the educational program of the child with disabilities eligible for the program. Eligible children in the range from 3 to 21 years of age receive special education services according to an IEP. Out of 355; 315 (88.7%) reported to have an IEP. The reasons reported for receiving IEP were: autism with a frequency of 224 (71.1%), communication disorder with a frequency of 74 (23.5%), developmental delay with a frequency of 37 (11.7%), specific impairments of learning with a frequency of 31 (9.8%), emotional problems with a frequency of 10 (3.2%), intellectual impairment with a frequency of 10 (3.2%), multiple impairments with a frequency of 8 (2.5%), visual impairment with a frequency of 6 (1.9%), orthopedic problems with a frequency of 3 (1.0%), brain damage with a frequency of 3 (1.0%), hearing impairments/deafness with a frequency of 2 (0.6%), deaf or blind with a frequency of 1 (0.3%), and other reasons with a frequency of 11 (3.5%).

The degree of satisfaction with the special educational services received was asked, ranging from unsatisfied (1) to very satisfied (5). Out of 296; 46 (15.5%) were unsatisfied, 65 (22.0%) were between satisfied and unsatisfied, 78 (26.4%) were satisfied, 57 (19.3%) were between satisfied and very satisfied and 50 (16.9%) were very satisfied. The reasons of why the services received did not satisfy were asked, and a valid answer was taken from those who answered (1) or (2) in the degree of satisfaction (n=111). The highest frequency was for inadequate training of teachers with a frequency of 40 (44.1%); followed by a low degree of integration with a frequency of 39 (35.1%), lack or some security at school with a frequency of 16 (14.4%) and no acceptance of the child by the teacher with a frequency of 15 (13.5%).

Table 4.8 Information of the school of the participant with ASD or associated characteristics between 0-22 years of age.

Variable	Frequency X (%)
Kind of school (n=371)	
Public School	216 (58.2)
Private School	43 (11.6)
Care Home	15 (4.0)
Care Center- Head Start	68 (18.3)
Home Schooling	2 (0.5)
Too young to go to school	22 (5.9)
Too old to go to school	5 (1.3)
Specific kind of school (n=320)	
Pre-School / Head Start with Autism	30 (9.4)
Pre-School / Head Start with Special Education	14 (4.4)
Pre-School / Head Start with regular education	41 (12.8)
School with services of Special Education	66 (20.6)
School with services of resource room	55 (17.2)
School without resources	8 (2.5)
School with Autism program	78 (24.4)
Other	36 (11.3)
Individual Education Plan (IEP) (n=355)	
Yes	315 (88.7)
No	31 (8.7)
Unknown	9 (2.5)
Reasons for receiving IEP (n=315)	
Autism	224 (71.1)
Communication disorder	74 (23.5)
Deaf/Blind	1 (0.3)
Developmental delay	37 (11.7)
Emotional problems	10 (3.2)
Hearing impairment/Deafness	2 (0.6)
Intellectual impairment	10 (3.2)
Multiple impairments	8 (2.5)
Orthopedic problems	3 (1.0)
Specific impairments of learning	31 (9.8)
Cerebral damage	3 (1.0)
Visual impairment	6 (1.9)
Other impairment	11 (3.5)
Unknown	31 (9.8)

Table 4.8 Information of the school of the participant with ASD or associated characteristics between 0-22 years of age (*continuation*).

Variable	**Frequency X (%)**
Degree of satisfaction with the special education services that receives (n=296)	
1 (Unsatisfied)	46 (15.5)
2	65 (22.0)
3 (Satisfied)	78 (26.4)
4	57 (19.3)
5 (Very satisfied)	50 (16.9)
Reasons of why the services received did not satisfy (n=111)	
Inadequate preparation of teachers	40 (44.1)
No acceptance of the child by the teacher	15 (13.5)
Lack or some security at school	16 (14.4)
Low degree of integration	39 (35.1)
Other	35 (31.5)

I. Occupation and Income (18 years old and over)

Employment status of the adult with ASD or associated characteristics was reported. A frequency of 13 (out of 29) participants were not employed (44.8%); three (10.3%) had a part-time job with no economic assistance; two (6.9%) were in transition services from public schools; one (3.4%) had a full-time job with no economic assistance; one (3.4%) had a full-time job, with economic assistance; one (3.4%) had a part-time job with economic assistance, one (3.4%) was attending a college or university or an institute of higher education; one (3.4%) had a volunteer job or training and one (3.4%) was receiving occupational therapy.

It was reported that out of 29, one (3.6%) adult with ASD or associated characteristics was living independently with no assistance; three (10.7%) were living independently with some assistance; and 20 (71.4%) were living with their parents, family or person with the custody. None of them was living in a group home or home care institution.

Finally, out of 28, 9 (32.1%) participants were receiving pension for disability and nobody reported that were receiving special help in a hospice home.

Table 4.9 Information of occupation and income adult with ASD or associated characteristics.

Variable	Frequency X (%)
Occupation of adult with Autism or associated characteristics (n=29)	
Not employed	13 (44.8)
Full time job, with no economic assistance	1 (3.5)
Full time job with economic assistance	1 (3.5)
Part time job, with no economic assistance	3 (10.3)
Part time job, with economic assistance	1 (3.5)
College / University or higher education	1 (3.5)
Transition services from public school	2 (6.9)
Volunteer job or training	1 (3.4)
Occupational therapy	1 (3.4)
Other	5 (17.2)
At present, the adult with Autism or associated characteristics lives… (n=29)	
Independent without assistance	1 (3.6)
Independent, with some assistance	3 (10.7)
In a group home	0 (0.0)
With parents, family or person with the custody	20 (71.4)
In an institution (care home)	0 (0.0)
Hostel of higher education	0 (0.0)
Other	0 (0.0)
Unknown	4 (12.3)
Receive pension for disability (n=28)	
Yes	9 (32.1)
No	16 (57.1)
Unknown	3 (10.7)
Receive special help in hospice home (n=28)	
Yes	0 (0.0)
No	25 (89.3)
Unknown	3 (10.7)

V. Discussion

Autism Spectrum Disorders (ASDs) are lifelong neurodevelopmental disabilities with early onset in life, of unknown etiology and considered as the fastest-growing developmental disability with an estimated 10 to 17% annual growth, as reported by the Autism Society of America[4]. A surveillance of ASDs is needed to understand their magnitude in the population and to identify the subgroups in the population at higher risk. The purpose of the study was to obtain baseline data for the Autism Registry, actually in the implementation phase at the Puerto Rico Department of Health, and for the implementation of an Autism Surveillance System in the future. This needs assessment study provides the first epidemiological data of the population with ASD in Puerto Rico.

In order to accomplish the study purpose and objectives of this study, a self-administered questionnaire and a registry form were created and completed with information of the target population. Data about the person who completed the survey and the age and gender of the participants were retrieved from the registry forms; the rest of the data including socio-demographic characteristics, medical history and access to services were obtained from the questionnaire. A total of 529 registry forms and 464 questionnaires were completed. Once completed with the participants' information, the questionnaires and the registry forms were distributed separately to the seven (7) Pediatric Centers for data entry purposes. A difference of 65 between the registry forms and questionnaires was observed. It is not known if that difference was due to the fact that the long self-administered questionnaire may have caused people to only complete the registry form or if it was due to missing completed questionnaires.

As reported in the literature, boys are affected with ASDs more often than girls. In this study a male to female ratio of 4.95 to 1 was reported, similar to those reported by others. Fombonne

E (2005) reported a male to female ratio of 4.3 to 1[34]. Although many studies have found that the prevalence of Autism is higher in males than females, the cause of the difference is not known as yet. Schendel D (2007) suggested that maybe the difference in prevalence is not etiologic and could be due to a bias in the diagnostic criteria that recognizes autistic behaviors more successfully in males than females[35].

Regarding the family income, Mortensen *et al* (2005) showed that low parental income was associated with an increased risk for Autism[36]. The annual family income reported had a trend similar to the one reported in the *U.S Census Bureau 2000* and adjusted for 2005 in Puerto Rico. In this study, 66.6% of the participants reported to have annual family incomes in the range of less than $10,000 and up to $24,999. In the census, 58.6% were in the same range. The calculated median family income was $16,644, while the median family income in Puerto Rico reported in the Census was $20,107. The main sources of income reported were a job or a business followed by social assistance, public assistance, general assistance and the nutritional assistance program (PAN). All the sources of income reported are not mutually exclusive; that is, some families received income from more than one source.

In addition to the family income, other variables such as the level of education of both parents have been analyzed by previous studies. Klug MG (2003) found that mother's education level of less than high school was associated statistically with ASD, while no association was found with father's education level[38]. In this needs assessment, most of the biological mothers completed a college degree, while a certificate or associate degree was the category with the highest frequency among the biological fathers. Women resulted with higher education levels as compared with fathers. On the other side, most of the biological fathers had a part-time or full-time job (77.1%), while the employment status of the biological mothers was divided in the categories of housewife (46.7%) and a part-time or full-time job (45.3%).

The use of medications during pregnancy was investigated in this study considering it as a possible exogenous factor that may enhance the risk of having a child with ASD, since some drugs are known to have teratogenic effects. In this study, 89.4% of the surveys were completed by the biological mothers; while the rest of surveys were completed by the biological fathers (9.2%), persons legally in charge (0.8%) and adoptive mothers (0.6%). The fact that 89.4% of the surveys were completed by the biological mother is an advantage since history of medications intake during pregnancy was easily obtained. Out of 411, it was reported that 245 (59.6%) mothers consumed medications during pregnancy. Of those, the medication with highest frequency was some type of acetaminophen with a frequency of 138 (56.3%), followed by prenatal pills with a frequency of 34 (13.9%), folic acid with a frequency of 23 (9.4%) and Brethine with a frequency of 21 (8.6%). No evidence was found in the literature associating ASD with most of the drugs reported, except for brethine. As documented in *Medline Plus*, Brethine, also known as terbutaline sulfate, is used to prevent and treat wheezing, shortness of breath, and troubled breathing caused by asthma, chronic bronchitis, emphysema, and other lung diseases[39]. It is also used as a tocolytic to delay premature labor, although this use has not been approved by the U.S. Food and Drug Administration (FDA). Slotkin *et al* (2004) suggested that terbutaline is a developmental neurotoxic and may cause brain damage to the infant[40]. Connors SL *et al* (2005) suggested that terbutaline can lead to Autism by over stimulation of the beta2-adrenergic receptor, which is part of the catecholamines system[41]. The American College of Obstetricians and Gynecologists (ACOG), in its last Practice Bulletin about management of preterm labor (2003), mentioned terbutaline sulfate as a Beta-mimetic tocolytic agent. The fetal and neonatal side effects reported were tachycardia, hyperinsulinemia, hyperglycemia, myocardial and septal hypertrophy and myocardial ischemia[42]. No long term side effects were reported.

Although some environmental exposures are considered to be risk factors for ASD, endogenous factors have also been implicated with the disorder. Therefore, a diagnosis of Autism of biological parents and siblings of the participants with Autism was also documented. Out of 423, 1 (0.2%) mother had Autism and out of 411, 2 (0.5%) fathers had Autism. From the 332 participants who reported to have at least one sibling, 7.5% had one sibling with a diagnosis of Autism. In 2007, Walden *et al* reported that studies have estimated the recurrence risk for ASD in younger siblings of children also diagnosed with ASD to have a range from 6% to 9%, although rates of 29% and 37% have been also reported[25]. The *American Academy of Pediatrics* in a technical report (2001) recommended genetic counseling to the parents, to aware them about the risk of ASD in subsequent children[43]. Furthermore, another condition with high frequency in siblings of children with Autism was a diagnosis of ADHD. In the study 7% of the siblings had ADHD, while Canino G (2004) reported that in children aged 4 to 17 years the prevalence of ADHD is 8%[44].

As reported by Schieve *et al* (2007), in comparison with parents of children with other developmental disorders, special health care needs or without special health care needs, parents of children with Autism have higher stresses and it is aggravated if the child recently needed special health care services[45]. Moreover, Mortensen *et al* in 2005, showed a statistically significant association between parental history of any psychiatric disease and increased risk of Autism[36]. Because the news of having a child with Autism can cause several stresses and concerns, a diagnosis of Bipolar Disorder, Depression or Emotional Disorder on parents before and after receiving the news was asked obtaining 12.3% and 13.7%, respectively.

A diagnosis of ASD was determined using two questions of the initial and current diagnosis of any of the ASDs (Autism Disorder, Rett Syndrome, Asperger Syndrome, Childhood Disintegrative Disorders or PDD), or characteristics associated to the syndrome (in case that a defined diagnosis had not been made yet). The most common diagnosis reported was Autism Disorder, which has the highest prevalence of ASDs reported in the literature, followed by the PDD or PDD-NOS. It is important to draw attention to the fact that 15.5% of the participants reported symptoms or tendencies of the condition, but no current diagnosis of ASDs has been established. This finding points to the need of educating primary physicians for the early recognition of presenting signs of Autism. Fombonne in 2005 reported a prevalence of Autism disorder as 13 per 10,000; Asperger's disorder as 3 per 10,000; childhood disintegrative disorder as 0.2 per 10,000. The NIMH (2007) reported that the prevalence of Rett Syndrome is 1 per 10 to 15,000[7].

The NIMH (2007) reported that the ASDs can be detected as early as 3 years of age, and in some cases at 18 months. In the same report, the NIMH published that an early diagnosis of Autism can dramatically reduce the symptoms and increases the child's ability to develop, however only 50% of children are diagnosed before 5 years of age[7]. In addition, Rodier PM (2005) demonstrated that symptoms of Autism can often be detectable in the first six months of age[8]. In 1998, De Giacomo and Fombonne reported that 90% of the parents recognized some abnormality in the development of their child by 24 months of age[46]. In this needs assessment the median age of the initial diagnosis of ASD among the participants was 36 months, while the median age by the time that parents first observed an unusual development of the child was 24 months; 12 months before the diagnosis. In total, 85.7% of the participants were diagnosed before 5 years old. These findings support present efforts to identify children between 1 to 2 years of age and the recognition of early signs by primary physicians and referral to early intervention programs.

The major initial concerns reported were delay in language development (90.4%), limited visual contact (67.9%), difficulty to relate with others (62.5%), repetitive behaviors (59.2%), did not respond when called by name (54.9%), "in his or her own world" (53.1%) and anger or grieve (52.0%), among others. The major initial concerns reported by Surveillance Summaries were language skills followed by social concerns[20].

Parents reported that participants with ASD had behavioral problems such as hyperactivity with 52.2% and self aggression with 16.1%. Another problem was inability to sleep during night with 21%. As mentioned by many investigators, people with Autism frequently present a variety of gastrointestinal problems. In Puerto Rico, 24.8% of the participants had frequent problems of constipation or diarrhea. Other medical conditions, hereditary defects and developmental impairments were also documented, having those 55.6% of the participants with ASD. Allergies were reported as the most frequent with 36.8%. Only 1.2% and 0.8% reported a diagnosis of Fragile X-Syndrome and Tuberous Sclerosis, while the NIMH (2007) reported a prevalence of 2 to 5% for Fragile X-Syndrome and 1 to 4% for Tuberous Sclerosis[7].

Attention-deficit and hyperactivity disorder (ADHD) is the most common neurodevelopmental disorder of childhood. As reported by Rowland AS (2002), estimates of the prevalence of ADHD are in the range of 2% to 18%[47]. In this needs assessment, ADHD was the developmental disability reported with the highest frequency (31.4%), while in the general population of Puerto Rico, Canino G (2004) reported a prevalence of ADHD of 8.0% among children between 4 to 17 years of age[44].

The *MMWR Surveillance Summaries* (2007) reported that in three states in United States with Autism Surveillance Systems more than 85% of children had psychometric test results: Georgia with 94%, Arizona with 90%, and South Carolina with 89%. In the present study, it was asked how old the participant with Autism or associated characteristics was when the last intelligence test (IQ) was administered. Out of 357; 145 (40.6%) reported the age, 49 (13.7%) did not know the age and 163 (45.7%) have never been tested. In total, only 54.3% of the population of the study had the psychometric test administered. The median age for the last IQ test administered reported was 68 months. It is important to highlight that 48% of the study population were between ages of 0 to 5 years old, while in the MMWR Surveillance Summaries the study population is 8 years old and the intelligence test is recommended for children older than 6 years old.

Services received that were reported by families as very useful to the population with ASD or associated characteristics were speech or language therapy (83.7%), physical or occupational therapy (81%), aquatic therapy (78.6%), exercise therapy (78.4%), and among others psychotherapy guidance (71%). In order to plan for services that address the needs of the Autism population, it is necessary to monitor the disorder, identify their needs, develop and implement programs and evaluate functional results of the child and family satisfaction. The Puerto Rico Department of Health actually has the responsibility to develop and implement a public policy for the population with ASD in the island. Early identification of presenting signs and appropriate intervention are crucial to obtain better outcomes. The Autism Registry in the other hand will allow data collection for the future investigations.

Among the services reported as most needed were help with communication skills, social skills and sensorial integration. Also, availability of recreational activities seems to be very important to the parents. According to parents, developing social skills of the children with ASD since very young is apparently the main concern regarding services. One important aspect that the public policy needs to address is the high percentage of the population with ASD that reported that when a service is needed, it is not received (47.1%) or is received later than expected (47.3%). It is important once more to stress on the need to educate doctors and health professionals regarding early identification and referral of children with developmental delay. In addition it is also important to identify the services available for the autism population of all ages and services not available and those difficult to access. Another area in need of improvement is the preparation of personnel to appropriately manage this population.

One of the major problems reported was finding specialized doctors or health professionals with the skills and experiences to manage this population (30.2%). As a strategy to overcome this problem, a guide with a list of physicians and other professionals that are available islandwide and willing to serve this population must be provided to the families.

Only 67.2% of families with children between 0 to 5 years of age reported that the doctors made an evaluation of the development of the child. The professionals that most frequently made the evaluation of the child were, in descending order, psychologists, occupational therapists, developmental pediatricians and pediatricians. It is worrisome that pediatricians rank so low, considering that this professional is the one most visited by families during the early childhood years. Most of the parents reported that they consider as very important an evaluation of the development of the child (93.2%); and among the participants, 21.5% responded that the doctors never asked about how the child communicates, what phrases uses to communicate

(22%), or how he (she) learns (19.2%); they also reported that doctors should ask them about child development(92%). Eighty-four percent (83.6%) of respondents said that doctors or other health professionals should discuss if someone was available as an emotional support, but only 22% reported that doctors or other health professionals asked them about this need. It is important to underline the need to develop and implement an array of coordinated, multidisciplinary services for this population, as well as for their families. Families are constant in the lives of children and for many adults with disabilities, so is necessary to plan in collaboration with ASSMCA and ASES in order to make emotional support services available for families. The promotion of one-stop orientation and service centers islandwide is a strategy to overcome this barrier. Only 59.3% of the children were referred to a specialist or a developmental program, and they were mostly referred to a specialist of speech/language specialist (76%). It was reported that most of the time the doctors recognize that the parents are the ones who know the child best (65.3%).

One important aspect in the early diagnosis of ASD in children is the pediatricians' role in recognizing the clinical manifestation of the disorders. The first time that parents expressed their concerns about their child development to the doctors, 25.4% of doctors said to wait, to see if a progress in the development of the child occurs. The committee on Children with Disabilities, in a technical report of the AAP (2001) reported that pediatricians need to be aware about the challenging task of suspecting an ASD diagnosis as early as possible, and make referrals in order to implement a timely treatment plan to achieve the best outcome for the child and family[43]. In addition to the pediatrician's role in early intervention, the parents' role is also important in the recognition of the early signs of the disorder in their child. Public awareness campaigns as part of the public policy need to involve parents as well.

At the moment of the survey, most of the participants were attending public schools (58.2%). It was asked if they had an Individualized Education Program in place (IEP) and 88.7% answered positively. According to Shattuck PT (2007), not all children with ASD who receive special education services are classified and counted in the Autism category[33]. In this needs assessment seventy one percent (71.1%) reported that the reason of having an IEP was Autism. The degree of satisfaction with the special education services received was reported in the average category (from unsatisfied to very satisfied) (26.4%). The main reason for "unsatisfied" was inadequate preparation of teachers (44.1%). Since children spend most of the time at school, it is also necessary to educate and train teachers regarding not only the achievement of the educational outcomes in the IEP, but also functional outcomes related to socio- emotional development and integration to daily routines at home and at school.

Finally, information about the adult population with ASD was documented. Although this is a lifelong disorder, people tend to associate ASD with children and not with adults and the elderly population. Little is known about the adult population with ASD or associated characteristics. Moreover, some parents have claimed that no services are available in the public or private sector once they reach the age over 21 years. In this study, in the registry form only 36 persons were 21 years old or older. Although the study was announced through different media sources, the small sample of the adult population could be due to the fact that the survey was available in places that are most commonly attended by the school age population, such as Pediatric Centers and Head Start/Early Head Start, among others. Another reason may be that many persons called because their immediate need was to obtain services for adults with Autism and decided not to participate. In the questionnaire, of the 29 that answered the section, 44.8% did not have a job and 71.4% were living with their parents, family or person with legal custody.

Strengths and Limitations

The present study is a source of valuable data that describes the population with ASD or associated characteristics living in Puerto Rico. Although the sample design was not representative of the population of Puerto Rico with the disorders, it represents a good start for describing and monitoring the ASD, as well as a source of information for policy makers and service systems.

Information bias could have occurred in the study due to the fact of the long self administered questionnaire. Moreover, a diagnosis of ASD, as well as other conditions was reported by the parents of the participants in the survey. No more data sources were identified to support the data documented in the survey; therefore this study only presents information reported by parents.

One limitation of this study was that in spite of the Department of Health efforts, the Department was not able to obtain the collaboration of the Department of Education for the identification of the cases from school sources. It has been reported by the CDC Surveillance Summaries that the percentage of cases with ASD from school sources reported in the network ranged from 0% in sites with no school collaboration to 85% in the states with access to special education records. Moreover, studies have demonstrated that data sets from one single source underestimate prevalence calculations, as cited in the Surveillance Summaries[20]. Therefore, for studies interested in calculating the prevalence of ASDs in Puerto Rico, more data sources from Health and Education Departments, as well as other sources have to be available and a representative sample of our population has to be target, in order to estimate an accurate rate. Estimates of the prevalence of ASDs in Puerto Rico are necessary for public policy decisions and early intervention strategies. Furthermore, surveillance of the disorder will provide essential information for the formulation of new hypotheses that could lead to the understanding of the ASD in Puerto Rico.

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