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**Survey for Caregivers of People with Autism Spectrum in Chile:
Access to Health and Education Services, Satisfaction, Quality of
Life And Stigma [Encuesta para Cuidadores de Personas del
Espectro Autista en Chile. Acceso a Servicios de Salud y
Educación, Satisfacción, Calidad de Vida y Estigma]**

Ricardo Garcia

Matías Irrarrázaval

Isabel Lopez

Sofia Riesle

Marci Cabezas Gonzalez

See next page for additional authors

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Authors

Ricardo Garcia, Matías Irrázaval, Isabel Lopez, Sofia Riesle, Marci Cabezas Gonzalez, Andrea Moyano, Gabriela Garrido, Daniel Valdez, Cristiane S. de Paula, and Cecilia Montiel-Nava

Survey for Caregivers of People with Autism Spectrum in Chile: Access to Health and Education Services, Satisfaction, Quality of Life And Stigma

Encuesta para Cuidadores de Personas del Espectro Autista en Chile. Acceso a Servicios de Salud y Educación, Satisfacción, Calidad de Vida y Estigma

Ricardo García^{a,b,c}, Matías Irrarrázaval^{a,b,d}, Isabel López^{a,e}, Sofía Riesle^a, Marcia Cabezas^{a,b}, Andrea Moyano^a, Gabriela Garrido^{c,f}, Daniel Valdez^{c,g,h}, Cristiane S. de Paula^{c,i}, Analía Rosoli^{c,j}, Sebastián Cukier^{c,k}, Cecilia Montiel-Nava^{c,l}, Alexia Rattazzi^{c,k}

^aPrograma Autismo, Clínica Psiquiátrica, Facultad de Medicina, Universidad de Chile. Santiago, Chile.

^bDepartamento de Psiquiatría Infantil y Adolescente, Clínica Las Condes. Santiago, Chile.

^cRed de Espectro Autista Latinoamérica (REAL).

^dMinisterio de Salud, Gobierno de Chile. Chile.

^eDepartamento de Neurología Pediátrica, Clínica Las Condes. Santiago, Chile.

^fUniversidad de la República. Montevideo, Uruguay.

^gFacultad Latinoamericana de Ciencias Sociales (FLACSO). Buenos Aires, Argentina.

^hUniversidad de Buenos Aires. Buenos Aires, Argentina.

ⁱPrograma de Pós-Graduação em Distúrbios do Desenvolvimento Universidade Presbiteriana Mackenzie (UPM). São Paulo, SP, Brazil.

^jOrganización de Estados Iberoamericanos para la Educación, Ciencia y la Cultura (OEI). Santo Domingo, República Dominicana.

^kPrograma argentino para Niños, Adolescentes y Adultos con Condición del Espectro Autista (PANAACEA). Buenos Aires, Argentina.

^lDepartment of Psychological Science, University of Texas Rio Grande Valley. Texas, United States.

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What do we know about the subject matter of this study?

The needs of caregivers of people with Autism Spectrum Disorders (ASD) is a topic under study, with few publications. Therefore, the REAL group (Red Espectro Autista Latinoamericano) conducted this study in several Latin American countries due to the little knowledge of this topic in the autistic community.

What does this study contribute to what is already known?

This survey provides relevant information about the needs, barriers, and challenges of people with ASD in Chile. It highlights the difficulties of access to health and education services and the impact on family income.

Abstract

People on the Autism Spectrum (AS) face multiple health, education, social, and economic problems. There is limited available information in Chile. **Objective:** To describe the access and satisfaction with health and education services, family and economic impact, stigma, and quality of life of people with AS and their families in Chile. **Subjects and Method:** Parents/caregivers of AS persons completed the Caregiver Needs Survey, developed by Autism Speaks, which includes demographic information, characteristics of AS persons (previously published), use of health and education services, parents/caregivers' perceptions of satisfaction, impact, stigma, and quality of life. **Results:** 291 caregivers (86% mothers) of 291 AS persons participated, 89% were male, aged 1-40 years ($X:10.4$ $SD:6.1$). Limited and unspecific access to health services is reported. 77% are regularly attending a standard or special school system. Families pay for over 60% of therapies/medical care and over 40% of specific educational support, and 25% report difficulties in accessing services. The family income is affected by resignation (35%) or reduced working hours (46%). Stigma is associated with possible discrimination and feelings of helplessness. The main priorities mentioned for a better quality of life are support for inclusive schooling, better adjustment at home, and improved socialization. **Conclusions:** This survey provides relevant information about the needs, barriers, and challenges of AS people in Chile and highlights the difficulties in accessing health services and the severe impact on family income. Feelings of stigma, discrimination, and helplessness are reported. Collaborative strategies are needed to improve the quality and access to services and to reduce the economic and mental health burden on the family.

Keywords:

Autism Spectrum Disorders;
Caregivers;
Quality of Life;
Access to Services;
Stigma;
Economic Burden

Introduction

Autism Spectrum Disorders (ASD) are neurodevelopmental conditions, detected mainly during childhood, and affect the individual throughout life. They are defined by deficits in two main domains, namely, Communication and Social Interaction and Repetitive and Restricted Behavior¹. Throughout their life cycle, people with ASD have vast and multiple health, educational, and community needs related to the main deficit, as well as a high frequency of comorbidities that require greater use of health services².

In education, children and adolescents with ASD require and receive a wider variety of services than children with other disabilities³. These needs extend to families, parents/caregivers, and siblings who require emotional support, self-care, and psychoeducation. The accompaniment and emotional support of the family at the time of diagnosis are very important since during this period they understand, process, and accept their child with ASD. These needs for support and guidance reappear throughout life^{4,5}.

Previous studies show that individuals with ASD and their families, especially those from specific minorities, have more difficulties and less satisfaction in obtaining school placement and access to health and community services than children with other special healthcare needs (CSHCN)⁶⁻¹⁰. These difficulties increase with age, especially impacting some minorities, such as Hispanic families residing in the United States,

who face more difficulties in accessing diagnosis and health care for their ASD children than the "Caucasian" population^{11,12}.

The burden, stigma, and impact on quality of life that having an ASD child means for a family seem to be greater than in other disabilities, with high levels of stress generated by less social support, severity of the child's autistic symptomatology, economic difficulties, anxiety and worries about the future, with severe consequences for mental health^{9,13-15}. It has been estimated the high health, educational, and social costs that an ASD person requires throughout life and the significant economic detriment that this means for her/his family¹⁶.

For Chile, as well as for other Latin American countries, properly meeting the needs of ASD persons and their families is a major challenge, even more so considering the scarce information available. This information is essential for decision-making and the consequent development of effective public policies aimed at this group¹⁷.

This work is part of the Latin American Autism Spectrum Network (REAL) composed of professionals from universities and institutions in six Latin American countries. Its objective is to understand the situation of people with ASD and their families in Chile, through the perception of caregivers in relation to access to health and education services, satisfaction, family and economic impact, stigma, and quality of life.

Subjects and Method

Survey Development

The Caregiver Needs Survey, developed by Autism Speaks in collaboration with the Global Autism Public Health Initiative¹⁸, aims at parents or caregivers of individuals with a diagnosis of ASD. It can be answered by face-to-face interview, telephone, or online and takes around 30 minutes to complete. It is composed of four sections; the first one includes general and demographic information, the second one includes specific questions related to the general, clinical, and diagnostic characteristics of the ASD person, the third one addresses the use of health and education services in the local area by asking the caregivers to identify which services they have ever used and which they currently use, and the fourth one asks them to evaluate satisfaction with access to services and unmet needs, the impact of having an ASD person for the family and caregiver, the perception of stigma or self-stigma, and finally, questions about quality of life. It was translated into Spanish, adapted, and validated¹⁹.

This study was approved by the Human Research Ethics Committee of the Faculty of Medicine of the University of Chile, following the current Declaration of Helsinki. An informed consent form describing the study was provided online, which described its content, and stated that participation was completely voluntary, anonymous, and could be withdrawn at any time. Participants were also informed that they could skip questions. There was no financial compensation for participation. Details of the development and implementation of the survey have been previously reported²⁰.

Participants

The target population was the caregivers of ASD persons in Chile. In the absence of records of the target population to select individuals or units for the study, a primary list of potential organizations was created and expanded through online searches of public information. Organizations that met the eligibility criteria were contacted by e-mail and received the primary contact list. Using a snowball sampling approach, individuals representing organizations on the list were asked to recommend other organizations not identified through the primary search which continued until saturation was reached.

The survey was sent by e-mail in all cases, completed at home (90%) and in institutions providing health or educational services or in parent organizations. Approximately one-fifth of the respondents (21.9%) needed help to answer the survey.

Results

The final sample was composed of 291 surveys answered by caregivers, 251 were mothers (86.3%), and most of them (98.2%) declared having secondary or higher education. Out of 291 ASD persons, 259 were males (89%), with a mean age of 10.4 years (SD: 6.05). Most of the families resided in urban areas, 49.8% in the Metropolitan Region, and 31.6% reported being users of the Public Health Service²⁰.

Past and Current Use of Health and Education Services

Health Services

Table 1 summarizes the findings on past and present access to health services and providers. Most participants (83.9%) accessed at least one health service in the past, 31.6% accessed between one and three, and 52.2% accessed more than four different services. 15% reported not having received any service or therapy.

The analysis of the Public versus Private Health user groups, in the latter, showed a significant difference in the number of health services ever accessed ($\chi^2: 10.1$ $p < 0.01$). 23% of the users of the Public System reported never having accessed treatment versus 11.9% of the group accessing private health care.

The most used services were speech therapy (62.2%), occupational therapy (61.5%), and pharmacological therapy (52.9%). On the other hand, psychodynamic therapy (12.4%) and relationship-based therapy (DIR-Floortime) (10.3%) were the least used. The most frequent professional services were speech therapists (72.9%), neurologists (71.1%), occupational therapists (62.2%), pediatricians (55%), psychologists (54%), and psychiatrists (47%). All professionals, except nutritionists and behavioral therapists, were mentioned by more than 45% of the sample.

Regarding services currently in use, 225 ASD persons (77.3%) receive at least one therapy, and 65 (22.3%) report no access to any treatment. Affiliation to a private or public health system did not determine a significant difference between groups in current access ($\chi^2: 3.4$ NS, $p > 0.10$).

Of those currently receiving medical treatment or therapy, more than 60% reported paying partially or totally for these services (table 1). The most frequent services were pharmacological treatment (39.9%), Occupational Therapy (36.6%), and Speech Therapy (34.7%). The most frequent current health care providers were Psychiatrists (37.1%), Occupational Therapists (37.1%), Pediatricians (36.4%), and Neuro-pediatricians (33.0%).

Education Services

Table 2 shows the access to and use of educational services. More than 2/3 of the ASD individuals belonged to a preschool (21.6%) or primary school level (43.6%). The reported school modality was mainly regular schools (49.8%) followed by special schools (23.4%). Only five persons (1.7%) of the group in the pre-school or school attendance age group reported not being enrolled in any system. As for the type of school or schooling, private and public schools accounted for 37.1% and 34.0% of the cases, respectively.

39.2% report receiving additional academic support in special classes for children with ASD, special classes for children with cognitive deficits, individual tutoring, or special teacher in and out of school. Over 40% of those who receive specific academic support are paid by family members.

Parent/Caregiver Perceptions

Satisfaction with Access to Services, Unmet Needs

In relation to the degree of satisfaction with ac-

cess to health and education services, 26% of those surveyed reported being always or generally frustrated in their efforts to access services. Among the obstacles to accessing services in the last 12 months are costs (36.1%), waiting lists (34.7%), lack of availability (26.1%), or not qualifying for assistance (23.4%).

Family and economic impact of having an ASD person in the family

Caregivers perceive a negative impact on siblings or family members of having an ASD person in the following aspects: “stop doing regular activities with their other children such as going out, attending school meetings” (27.2%), “their other children spend less time than expected for their age in social activities, sports, or recreational activities” (15.5%), “their other children have expressed concern about their friends knowing that they have an ASD sibling” (15.1%), and “their other children have dropped out of school or fallen behind in their studies to take care of their ASD brother or sister” (3.1%). Over 70% of the caregivers

Table 1. Access/Use of Health Services and Providers in 291 people with Autism Spectrum Disorder

Health Services	Occasionally N (%)	Current N (%)	Current Paid N (%)
• Behavioral Therapy	80 (27.5)	47 (16.2)	33 (70.2)
• Biomedic Therapy (diets, supplements)	79 (27.2)	37 (12.7)	37 (100)
• Cognitive Therapy	68 (23.4)	35 (12.0)	25 (71.4)
• Medicines	154 (52.9)	116 (39.9)	84 (72.4)
• Occupational Therapy	171 (61.5)	106 (36.4)	70 (66.0)
• Physical Therapy	88 (30.2)	50 (17.2)	32 (64.0)
• Psychodynamic Therapy	36 (12.4)	19 (6.5)	12 (63.2)
• Relational Therapy (DIR-Floortime)	30 (10.3)	10 (3.4)	10 (100)
• Sensory-Integration Therapy	106 (36.4)	40 (13.8)	25 (62.5)
• Social Skill Training	110 (37.8)	65 (22.3)	41 (63.1)
• Language Therapy	181 (62.2)	101 (34.7)	69 (68.3)
Health Provider	Occasionally N (%)	Current N (%)	
• Speech Therapist	212 (72.9)	63 (21.7)	
• Behavioral Therapist	55 (18.9)	57 (19.6)	
• Neurologist	207 (71.1)	96 (33.0)	
• Nutritionist	47 (16.2)	88 (30.2)	
• Occupational Therapist	181 (62.2)	108 (37.1)	
• Pediatrician	160 (55.0)	106 (36.4)	
• Psychiatrist	131 (45.0)	108 (37.1)	
• Psychologist	157 (54.0)	84 (28.9)	
• Differential Educator	135 (46.4)	15 (5.2)	

surveyed reported not perceiving a negative impact on the aspects mentioned.

Figure 1 shows the impact on family income or workload of having an ASD person. More than half of the respondents (53.6%) perceived economic difficulties derived from their ASD child. In 35.1%, a family member resigned, and in 46.1% a member had to reduce work hours.

Stigma Perception

Respondents agreed or strongly agreed with the following statements: “having a child with autism imposes a negative impact on me” (16.5%), “other people would discriminate against me because I have a child with autism” (31.6%), “I worry about other people knowing that I have a child with autism” (9.6%), and “I feel powerless because I have a child with autism” (28.1%). Most participants expressed disagreement with these statements (Figure 2).

Quality of life: relevance and satisfaction

Most respondents felt that it was “important” or “very important” for their family’s quality of life that their ASD children had support to succeed in school (81.4%), to develop at home (81.8%), to make friends (80.8%), as well as to have a good relationship with professionals (81.8%). Satisfaction in achieving these objectives was evaluated as “very satisfied” in more than 50%, except for “support to make friends” (39.5%). The highest percentages of dissatisfaction were in having support to make friends (26.1%) and support to succeed in school (22%) (Figure 3).

Challenges

The most relevant challenges identified were that their children receive an adequate education (74.6%), that their children’s basic rights are protected (62.9%), and that they receive good health services (60.1%). Only 16.5% consider that “ensuring adequate rest for themselves and their family” is also an important challenge.

Discussion

Surveys directed to parents have proven to be very useful in the collection of relevant information about the child and youth population since they and their children are the final recipients of actions and interventions in health and education and the main decision-makers. The information collected provides valuable insight into the situation of people with ASD and their families in terms of access and satisfaction with priority services, as well as family and economic impact, quality of life, perception of stigma, and priorities.

Table 2. Access/Use of Educational Services and providers in 291 people with Autism Spectrum Disorder

Current educational level	N (%)	
Pre-Escolar	63	(21.6)
Primary School	127	(43.6)
Secondary School (High School)	26	(8.9)
Tertiary School (College)	7	(2.4)
Labor Workshop/Technical School	3	(1.0)
Other	32	(11.0)
Does not apply	15	(5.2)
Do not respond	18	(6.2)
School type	N (%)	
Regular School	145	(49.8)
Recovery School	5	(1.7)
Special School	68	(23.4)
At home School	3	(1.0)
Other	31	(10.7)
Does not attend	5	(1.7)
Does not apply	17	(5.8)
Does not respond	17	(5.8)
Public/Private School	N (%)	
Public	99	(34.0)
Private	108	(37.1)
Other	42	(14.4)
Does not attend	5	(1.7)
Does not apply	17	(5.8)
Does not respond	19	(6.5)
Additional Academic support	N (%)	
No	167	(57.4)
Yes	114	(39.2)
Does not know	9	(3.1)
Does not respond	1	(0.3)
Specific academic support	N (%)	Paid N (%)
Autism Spectrum Special Class	42 (14.4)	17 (40.5)
Intellectual Deficit Special Class	28 (9.6)	7 (25.0)
Tutor	42 (14.4)	18 (42.9)
Differential Teacher in classroom	64 (22.0)	26 (40.6)
Differential Teacher out of classroom	29 (10.0)	27 (93.1)

TEA: Trastorno del Espectro Autista.

As we have previously reported²⁰, this convenience sample has a bias toward an above-average socioeconomic group related to higher educational level, a higher proportion of urban versus rural families, and a higher percentage of people enrolled in the private health system compared with the general Chilean population, reflecting an advantageous situation with respect to the general population for many of the aspects addressed in this survey.

Regarding access to health services and previous and current providers, the information collected reveals that a significant proportion of people have not previously (15%) or currently (22.3%) accessed any

health service, a percentage that increases in the public health user group. If we consider that around 80% of the Chilean population belongs to the Public Health System, it is possible to assume that the proportion of people with ASD who do not have access to specific health services is probably higher than what was found in this survey. This lack of treatment is a serious situation since this implies for these people a significant vulnerability in terms of their functional prognosis and the future burden that this means for their families and society. In addition, the fact that more than 60% of the families that currently have access to therapies state that they pay partially or fully for these treatments at

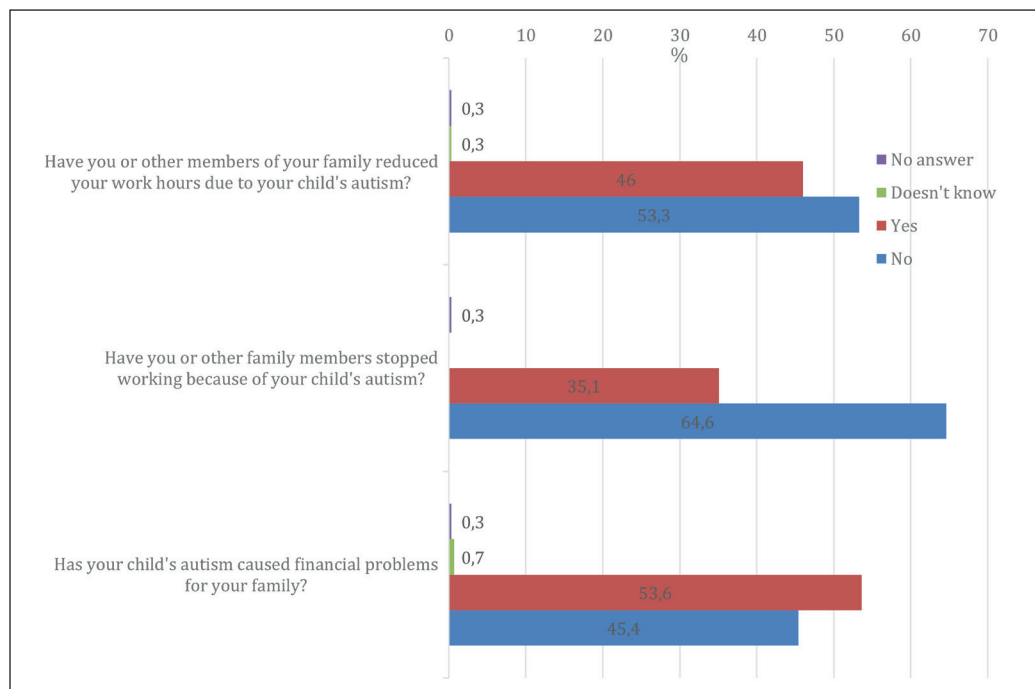


Figure 1. Impact on family income and workload in 291 people with Autism Spectrum Disorder.

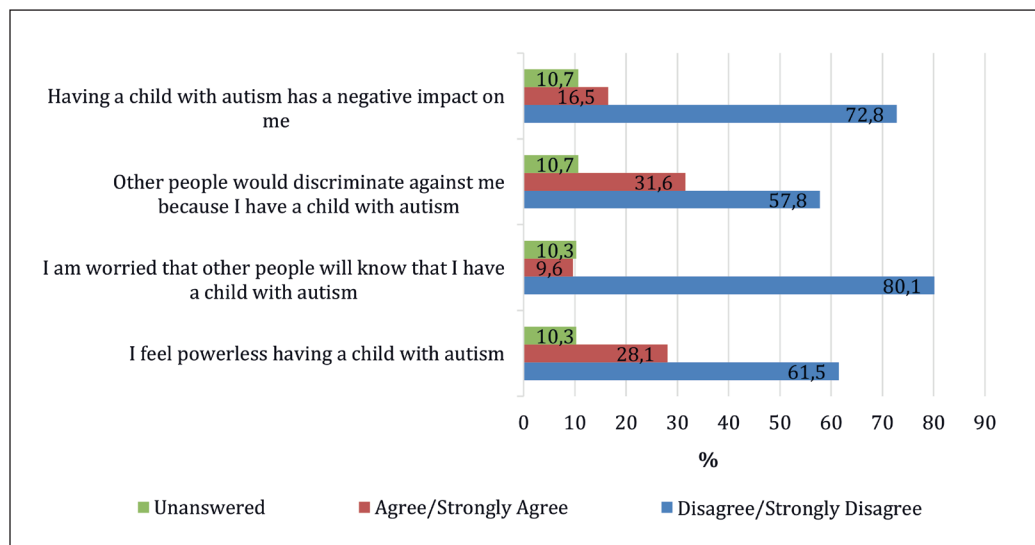


Figure 2. Perception of Stigma reported by caregivers of 291 people with Autism Spectrum Disorder.

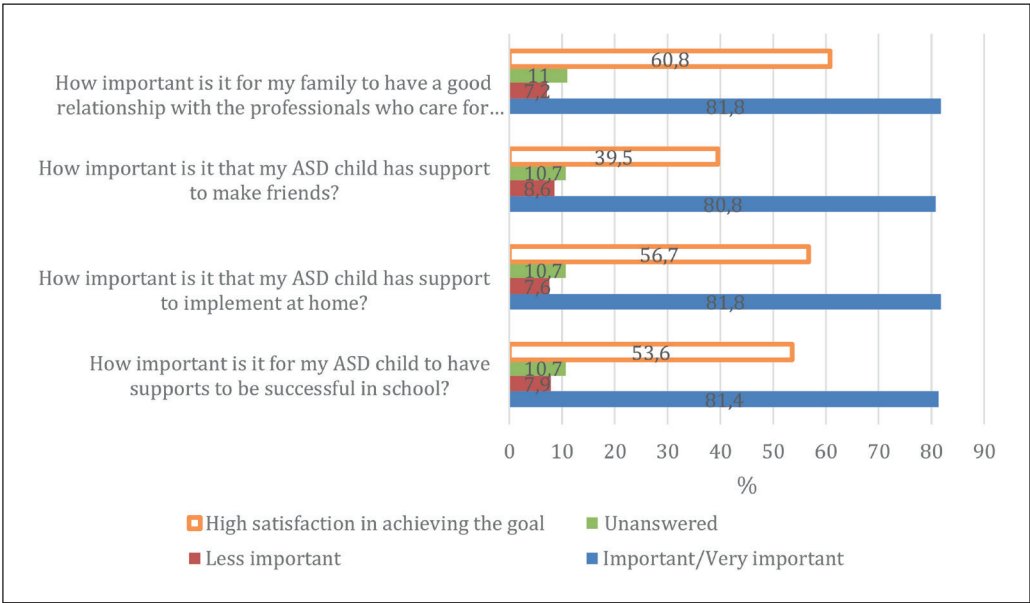


Figure 3. Priorities and satisfaction with what was obtained in each of them, reported by caregivers of 291 people with Autism Spectrum Disorder. ASD: Autism Spectrum Disorder.

their own expense, which again highlights the shortcomings of the health programs aimed at people with disabilities and the high family burden of having a child with ASD.

Therapies received are mentioned generically (Speech and Occupational Therapy), while specific therapeutic practices or models with established evidence of effectiveness were reported in the minority^{21, 22}.

In our country, there are many limitations to adequately implementing interventions in ASD persons due to the limited resources of professionals, equipment, and services. Only in recent years has there been greater dissemination and professional training in specific therapeutic interventions. It is also necessary to incorporate and build capacities in parents and families, in a cultural and social context, that allows to carry out an intervention at home²³.

The high use of medication in this sample, both in the past (52.9%) and at present (39.9%), is higher than that observed in other Latin American countries, except for Uruguay²⁴. Figures similar to those in Chile have been observed in the USA, United Kingdom, Australia, New Zealand (52%), and Southeastern Europe (36% and 26%)^{9, 25}. The introduction of pharmacological treatments has an upward age trend, from middle childhood through adolescence²⁵. Among the possible causes of the frequent use of drugs are high psychiatric comorbidity, a “compensatory” intervention for insufficient or inadequate access to therapeutic interventions, a predominance of the medical model of care, or possible pressures from the educational system.

In terms of access to educational services, a high percentage (92%) of ASD persons attend some type

of educational system and a significant proportion of them receive additional subsidized support. This contrasts with survey data from Southeast Europe where 19% of children aged five years and older are not enrolled in schools⁹.

In Chile, there is little specific information about the school placement of children and adolescents with Permanent Special Educational Needs (SEN) and, especially, ASD persons. Undoubtedly, in recent years the Ministry of Education (MINEDUC) has made great efforts to move towards an Inclusive School System, which is reflected in the progressive increase in access to the School Integration Project, particularly in primary education^{26, 27}.

Chilean parents of ASD persons face many barriers in accessing services. One-quarter of the caregivers surveyed declared themselves very frustrated in their efforts to obtain them, revealing dissatisfaction of basic demands in a significant percentage. Beyond the issue of availability, parents of ASD children experience 3.4 times more difficulties with school enrollment and access to community health services, and 2.7 times more likely to be dissatisfied compared with children with special care needs²⁸. These families may be more affected because their children have multiple co-occurring disorders, requiring a wide range of services, with increased stress, additional financial burden, and mental health problems for them^{28, 29}.

Regarding the perceived impact on the siblings of the ASD member, a significant percentage of respondents report fewer regular activities with their other children and the restriction of their time in age-appropriate social and recreational activities. Having an ASD

sibling has been considered a primary stressor with potential effects on mental health. Its impact is modulated in relation to some factors such as family size, sex, and age of the sibling, among others³⁰.

A relevant finding in this study is the negative economic impact of having a child with autism. In a high percentage of cases, family members must stop working or shorten their working hours, and there are also direct outlays in therapies or access to special educational systems. In other countries with greater benefits and state support, it has been reported that this economic burden accounts for 14% of losses in family income, an annual family expense equivalent to double what the State invests, and an additional annual expense of US\$17,000 to meet the health, social, and educational needs of the person with ASD^{28,31,32}. It is urgent to make these estimates in our country and to promote, from the decision-making levels, care programs and direct subsidies that contribute to reducing this inequity.

Of note is the relatively low proportion of caregivers who perceive a negative impact of having an ASD child and who express concern about others knowing about it. One-third of them agree that they feel powerless and perceive other people would discriminate against them. In the literature on autism, the concept of stigma has been used to analyze the experiences of shame and social exclusion of parents of children and adolescents with ASD³³. Parents of children and adolescents with ASD would experience considerable stigmatization due to their children's socially inappropriate behavior, with violations of norms in social situations that can lead to exclusion from normal social activities³⁴. Parents would resist stigma by deploying the ambiguous medical discourse and performing a strategic reconstruction of normality. This creative process would explain in part why in this and other samples, the perception of stigma has a lower impact than expected³⁵. Regarding reducing stigma and improving the social inclusion of people with ASD, the dual approach means a contribution since, on the one hand, it recognizes the disability and, on the other hand, autism as a difference, a human variation, with a neurodivergent profile of strengths, and weaknesses³⁶.

Finally, most respondents assign high relevance to their quality of life to support their child's educational, personal, and social development. However, only 50% of respondents reported adequate satisfaction with these achievements. Their main challenges and priorities are that their children have access to good health and education services and that their basic rights are protected.

The limitations of the information reported in this study derive from convenience sampling, with a bias towards a higher socioeconomic group than the general Chilean population, and therefore reflecting the "better situation" of ASD people in Chile. Second,

we have a wide time window, with an age range of respondents' children from 1 to 40 years, possibly averaging downward the positive changes that have occurred in the last two decades, particularly in the increased availability of health and education professionals with formal and specific training in the area. Finally, this study did not include people on the autism spectrum who responded to the survey due to regulations in force at the time of this study on people with disabilities

Conclusions

This first descriptive study of ASD caregivers in Chile brings us closer to their experiences, providing valuable information for the development of health, education, and psychosocial strategies and policies. Even though the sample is biased towards a higher educational and socioeconomic level than the average Chilean population, it highlights the insufficient access to non-specific therapeutic interventions in health and education, with less effectiveness and less future functional impact. This situation is likely to be more precarious at lower socioeconomic levels.

The economic and quality of life deterioration is evident in the families of people with autism, who make great efforts to obtain satisfaction of their main needs, being health and education their main priorities to ensure that their children are people with rights and worthy of respect.

There is an urgent need for studies that broaden the view on these and other priority aspects of people with ASD, in order to maximize their potential through access to evidence-based therapeutic guidelines, duly adapted to the cultural context and age period, with qualified professional resources, and minimizing social, environmental, and personal barriers that affect their development and adaptation. In addition, it is necessary to estimate the economic burden of an ASD child and to develop the necessary initiatives to reduce the inequities that this condition generates.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

Financial Disclosure

Authors state that no economic support has been associated with the present study.

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