

Support, Challenges, and Opportunities for a Person with Autism Spectrum Disorder in Paraguay: Analysis from the Parents' Perspective

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Abstract: Introduction: Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with high prevalence, whose personal and family challenges begin at an early age and are for life. Objective. To examine the level of support, challenges, and opportunities of people with autism from the perspective of their parents in Paraguay, using a qualitative approach and applying hermeneutic phenomenology at an exploratory level. Methodology. Data collection was carried out through focus groups and Journey Mapping. Forty-six parents and/or guardians of people with ASD from 20 cities in the country participated in the focus groups, and five mothers from the Capital in the Journey Mapping. Results. Families who have a child with autism in Paraguay generally receive support from the microsystem such as grandparents, relatives, and friends. They perceive a change in the family dynamics and they also emphasize the urgent need for institutions and trained professionals to provide early intervention services, more inclusive educational schools, and the promotion of spaces and opportunities for caregiver care. Conclusion. These findings may serve as a basis for the development of specific programs and for the design of future public policies, with the purpose of improving the quality of life of people with autism in Paraguay.

Key words: autism spectrum disorder; Paraguay; parents

1. Introduction

Autism is a neurobiological disorder [1] with a prevalence of 1 in 36 people in the United States [2]. This condition presents as a triad of characteristics that include marked difficulties in the development of social and communication skills, difficulty coping with change, as well as fixed interests and repetitive behaviors, which in some cases also manifest as hypersensitivity to environmental stimuli [1, 2].

Global evidence estimates that 62 out of every 10,000 people have ASD [3] and that 160 of this reported number also

have comorbidity with an intellectual disability. It should be noted that the report includes developing countries [4] and that, in line with existing literature, the prevalence of autism is not related to racial or ethnic origin or socioeconomic status [5, 6].

Paraguay is a developing country. Enormous efforts have been made to improve access to education, healthcare, and other services [7]. However, barriers that hinder differences and inequalities persist. In the case of autism, these barriers are emphasized by the lack of emphasis on Neurodevelopmental Disorders. This ultimately translates into a lack of social, educational, and governmental policies and practices to address problems in the education and healthcare systems for people with autism and their families [3-7].

Research is insufficient, and efforts to explore autism in Paraguay and other developing countries are still incipient. Paraguay lacks accurate epidemiological data; however, an important step forward should be highlighted: the enactment of the autism law, which was established to promote the National Program for Comprehensive Care for People with Autism (PNAITEA), which focuses on a comprehensive and interdisciplinary approach [8].

In other systematic research carried out in contexts similar to that of Paraguay [9], the generic and individual needs of children living in poverty were assessed and highlighted the importance of designing support systems that can address the needs of children living in an environment with scarce resources and a high prevalence of poverty, which in turn would impact access to education and effective early intervention programs. Other authors reviewed interventions for children with a neurodevelopmental disorder in developing countries and reported that knowledge of developmental disorders is limited among health and other professionals in these countries, which affects access to evidence-based intervention programs for children and their families [10].

"From another perspective, studies involving close relatives of individuals with ASD reveal that parents face three major challenges: (1) initial diagnostic difficulties, (2) barriers to accessing early intervention programs, and (3) transitional challenges during adulthood due to lack of early support services [11].

Compared to other conditions, parents of children with autism experience higher levels of stress, depression, and anxiety, which can be triggered by adaptation and the impact within the family system, including siblings and possibly the extended family [11].

Given the above, this study seeks to examine the perception of support, challenges, and opportunities from the perspective of parents and/or guardians of an individual with Autism Spectrum Disorder in the context of Paraguay.

2. Methodology and Techniques

This research adopts a qualitative paradigm and an exploratory level of knowledge, using a methodology based on hermeneutic phenomenology [12]. This type of study helps explore the context of the individual, taking into account their lived experience.

The research was conducted in Paraguay during the periods of 2021 and 2022. The participants included were parents and/or guardians of a person with autism. A total of 46 people who met the inclusion criteria participated in the focus groups, and five mothers participated in the life mapping. Due to the characteristics of our population, the sampling type corresponded to probability sampling.

Table 1. Characterization of the Focus Group Sample during 2021 and 2022

Date	City	Participants
May 30	Colonel Oviedo	4
June 6	Incarnation	4

Date	City	Participants
June 20	Concepción, Belén. pitchfork	3
July 4	Saint John Nepomuceno	4
July 11	Asunción and Central	6
July 18	Guaira Falls	4
July 25	Villarrica	4
August 1	Eastern City	7
August 29	Guarambaré, Itá	5
September 5	Capiatá, San Lorenzo, Ypacaraí, San Antonio, Nemby	4

Focus groups: Ten meetings were held with 46 participants in 20 cities in Paraguay.

Life mapping sample: One meeting was held with the participation of five mothers.

The research consisted of two phases, each consisting of focus groups and a life mapping.

Phase 1: The first consisted of focus groups with semi-structured questions that took into account Bronfenbrenner's (1986) ecological model for the development of the questions. This model studies the development of individuals through the relationship between closely related systems, centered on the person with autism from the perspective and experiences of the parents [13].

Phase 2: The second phase of this study uses a dynamic called Life Mapping. According to Pane et al., this strategy enables the experiences of a family with a child with autism in Paraguay, emphasizing the stages of their respective lives, the difficulties, and the emotions of the families. Through this dynamic, the parents were introduced to a fictitious family with a child with autism. From there, questions were asked, addressing areas such as support this family receives, difficulties, and future goals for themselves and their child with autism [14].

Table 2. Table developed to guide questions in the focus groups, taking into account the Bronfenbrenner Ecological Model, 1986 [13]

Regional Diagnosis of Autism in Different Cities of Paraguay		
School (Mesosystem)	Family (Microsystem)	Society/State
Makes reasonable adjustments	Impact on my family dynamics	Macrosystem
Level of education	Level of preparation of the family environment to address difficulties of the person with ASD	There is an Autism Law, and it is enforced by its regulations.
School receives training	Family members are willing to receive training	Is there an institution (health, recreation) in which they participate?
Learn more about children and adolescents with ASD at that school	Relationship with siblings	They have the care of therapists (state, private) and are multidisciplinary.

The collected information is processed and presented in narrative fragments. With the consent of the participants, the focus groups and the dynamics of the second phase, consisting of life mapping, were recorded. The data were transcribed and analyzed using Framework Analysis [15]. This technique allows the researcher to conduct qualitative analysis through five interconnected steps:

- (1) Familiarization. This first phase helps the researcher understand the general results of the focus group discussions.
- (2) Creating a thematic framework. In this phase, the researcher prepares a way to organize the interview data. It is iterative and generally allows for the design of a framework.
- (3) Text indexing. In this phase, the transcript fragments are identified that correspond to the thematic framework created in phase 2.
- (4) Graphics. This phase consists of placing the text of each transcript in relation to the theme of each question in the focus groups.
- (5) Mapping and interpretation. In this final phase, after placing the fragments in their respective dimensions, the characteristics of the information obtained are examined, and then the data obtained are mapped and interpreted as a whole [15].

Regarding ethical aspects, the research is framed within the ethical principles of research. Each participant was informed of the purpose of their invitation to participate, and they were asked to sign the informed consent form. The identity of all participants is guaranteed [1].

3. Results

This section presents the results of this study, highlighting the emerging points from the data that were recorded, systematized, and analyzed using Framework Analysis [15].

In both data collection processes—the focus groups and the life mapping—parents indicated that:

"They perceive a state that does not provide all the services their children with autism require, citing therapies, specialized care centers, trained professionals, and a more inclusive educational system that can allow individuals with autism to develop and enhance their abilities." Summary of Participants' Reflections

3.1 Families in Paraguay receive more support from the microsystem

Participants indicated that they mostly only receive support from close family members, in some cases relatives, as there are no effective social, state, or educational policies for individuals with autism and their families in Paraguay. This can be interpreted as a lack of government-sponsored programs for comprehensive care for individuals with ASD.

"Existing support is inaccessible and not multidisciplinary due to a lack of professionals specialized in ASD in the country." Participant 3.

Access to health services and therapies is almost nonexistent and is limited to the country's main cities, leaving people with ASD living in the interior of the country, including rural areas, unable to access therapies. For these reasons, the vast majority of children with autism in Paraguay do not receive specialized therapies if they live outside of the departmental capitals. This is a significant difference discussed in the focus groups.

"Support is inaccessible and not multidisciplinary, and there are not many professionals specialized in ASD in the country." Participant 20.

Furthermore, due to a lack of early stimulation and opportunities, family members of people with ASD are concerned about adults with ASD, as programs serving this population, including inclusive education in higher education and job placement for adults with autism, are currently almost nonexistent. This means less independence for adults with ASD.

"My biggest concern is the lack of support for adults with ASD in our country, since in Paraguay there are no programs that can include them, including university education. In general, there are no programs for adults with ASD, and that is very discouraging." Participant 1.

"We need vocational schools for our children with ASD, because they finish university and don't have opportunities for technical or job training, or internships," Participant X10 said.

This lack of opportunities for young people and adults with autism in Paraguay would be relevant to evaluate in another in-depth study, examining the barriers and seeing how to eliminate them.

3.2 Having a child with autism in Paraguay means many sacrifices

Family dynamics change when having a child with autism. This includes giving up leisure activities, extra work hours, and the quality of relationships with partners and children.

"Having a child with autism means a change in family dynamics, including interactions with partners and children." Participant 13 said.

Another participant indicated that the cost of therapy is high, which is why she must work overtime and in other settings to cover the expenses for her child with ASD, leaving no time for herself.

"I have to work three jobs to cover the expenses for my son with autism." Participant X15.

"Therapy costs are so high that I have to work long hours to be able to afford at least one therapy session, but not all the necessary ones." Participant 24.

3.3 The starting point should be more inclusive education

An important concern for participants is their children's education, given the stigma and lack of knowledge about autism in Paraguay, which significantly affects the learning of people with ASD in the educational institutions where they attend.

"Institutions must be prepared to make reasonable adjustments that truly help our children acquire, even if they are essential life skills." Participant 3.

Institutions do not make the appropriate adjustments for their specific learning needs." Participant 8.

"Teachers do not know how to make reasonable adjustments for their students with autism." Participant 22.

A mother indicated that the school her son attends does not use recommended pedagogical strategies during teaching, such as the systematic and structured teaching recommended when instructing a person with autism in the classroom.

"I only take my son to school for two hours, and reasonable adjustments are only made for preschool, even though my son is in fifth grade. I don't see any kind of stimulation for his learning." Participant 38.

3.4 It is necessary to promote spaces for caregiver care

During the life mapping process, a pleasant, but also worrying, conversation arose about the importance of self-care in terms of mental health, as well as having support networks and associations, among others. Participants unanimously considered this aspect very important for improving the quality of life of parents of a person with autism.

"I consider it important to be part of a network to learn from the experiences of other parents who have a child with autism." Participant 5.

Another participant indicated that being part of a network is an excellent way to avoid feeling alone.

"Meeting other mothers with the same difficulties and experiences has helped me not feel alone, and I have learned a lot from them, for example, how to manage disruptive behaviors." Participant 12.

Spaces for caregiver care could also improve parents' mental health by providing them with more tools to gain from these learning and support spaces.

4. Discussion

Little research has delved into autism in Paraguay and other developing countries. Therefore, this study's main objective was to examine the perception of support, challenges, and opportunities of people with autism in a group of people in Paraguay from the perspective of parents. A total of 46 people participated in the focus groups conducted virtually, reaching coverage of 20 cities in Paraguay, including participation of five mothers in the life mapping process. [3]

Regarding support, the results show that families in Paraguay receive more support from the microsystem, which, according to Bronfenbrenner (1986), [14] includes siblings, parents (grandparents), and close relatives. Although health services are available, they are not accessible to everyone as they are focused on Paraguay's main cities, leaving children with autism in the interior of the country without comprehensive care, according to the participants. In this regard, Lyngnegard (2013), in response to this social problem, points to the importance of designing support systems that can address the needs of children with neurodevelopmental disorders living in poverty. Consequently, this will affect the accessibility of quality education and effective early-stage multidisciplinary intervention programs [9-16].

Furthermore, they stated that, even if services exist, they are not provided by a multidisciplinary team due to the lack of access to therapies and professionals specialized in ASD. This is consistent with research analyzing interventions for children with neurodevelopmental disorders in developing country contexts, stating that there is little knowledge about autism among health professionals, thus affecting access to intervention programs designed and informed by evidence-based practices and with a comprehensive and multidisciplinary approach [10-17].

Regarding challenges in the field of education, parents are concerned about the inclusive education their children with autism receive. Despite the existence of the Inclusive Education Law of the Ministry of Education (MEC) (LAW No. 5, 136), practices that promote learning and do not enhance the skills of students with ASD are still lacking. This process also involves the same concerns as children with autism, who, as can be seen in a study by Waldman (2023), have different concerns and motivations than neurotypical children [18].

A significant finding regarding opportunities has been highlighted through life mapping techniques. Mothers have emphasized the importance of establishing dedicated spaces for caregiver support, mental health services, and educational programs to develop deeper insights into autism, while also learning from other parents' experiences. In Paraguay, parents of children with autism are constantly compromising their daily activities after receiving the diagnosis, due to the high costs of multidisciplinary therapies which require consultations with at least two to three autism-specialized professionals. This reality is compounded by the long overtime hours they must work to earn additional income for professional fees. These compromises undoubtedly influence family dynamics, relationships with partners, and care for children without autism. This suggests that parents of individuals with autism face challenges from the moment of diagnosis and are more likely to suffer from stress, anxiety, or depression [11-19].

As with all studies, this research was not without limitations. First, its cross-sectional design made it difficult to understand how parents' perspectives change over time and how their children's lives change during the different stages of the transition from childhood to adulthood. Furthermore, the majority of participants were mothers. Future similar research could focus on parents of children with autism, also considering other members of the microsystem, such as siblings.

This study is important because, in light of the increasing number of children diagnosed with autism in Paraguay, the meanings that parents assign to their experiences could be used to inform future policies and the development of programs that begin to address individuals with autism from the macrosystem (government) and the mesosystem (school and community) from a more holistic, comprehensive, and multidisciplinary perspective.

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Conflicts of Interest

Fabián Franco is a collaborator of the Association of Parents with Children with Autism Spectrum Disorder and has a diagnosis of ASD. The author declares no conflicts of interest regarding the publication of this paper.

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Author Contributions

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