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RECEIVED 15 July 2023

ACCEPTED 06 September 2023

PUBLISHED 06 October 2023

CITATION

Martinez C, Davidoff A and Briceño R (2023)
Early educational trajectories of children with
autism spectrum disorder in Chile: challenges
and facilitators.
Front. Educ. 8:1259428.
doi: 10.3389/feduc.2023.1259428

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Early educational trajectories of children with autism spectrum disorder in Chile: challenges and facilitators

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Inclusive education and special education are the means of education for people with special educational needs and specific disabilities. Inclusive education has been promoted in recent decades as the optimal method of educating in diversity. However, in Chile, access to quality education remains a major challenge for students and their families. In this article, we explore the experiences, motivations, and main factors in making early educational decisions by families and caregivers of children on the autism spectrum. In particular, using six semi-structured interviews conducted with families and caregivers of children, we study the process of initial entry into the educational system, including parents' perceptions and knowledge of the access routes to it and the facilitators and barriers present for their incorporation. The results indicate that, from the very beginning, the information available social and family attitudes, may hinder children's access to the available care and education system, with a generalized demand to strengthen social and institutional support networks. In general, and as may be expected, educational decisions, trajectories, and expectations are interdependent and evolve with the experience of caregivers and children in the educational system and their families.

KEYWORDS

special educational needs, autism spectrum disorder, early educational trajectories, parent expectancies, educational decision making

1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by difficulties in social interactions and communication and repetitive and stereotyped behaviors and interests (Morrison, 2015). These characteristics manifest early and can affect the lifelong development of autistic individuals, impacting the lives of their caregivers and their social and family environment.

1.1. Overview of special and inclusive education in the world and in Chile

Since the 1990s, particularly, since the Salamanca Statement, countries have concentrated on implementing inclusive education, which provides an education system that admits typically developing students and those with special educational needs (SEN) and disabilities (UNESCO, 1994). To achieve this, the necessary adaptations must be implemented to address the specific

needs of the students. This inclusion should promote the full participation of students in schools, considering both cognitive and social dimensions (Ballard, 1997; Van Mieghem et al., 2018).

The inclusion policies have been reinforced over time and extended to broader concepts of inclusion, including cultural, emotional, and other difficulties.

Despite the efforts made in favor of inclusive education, its results are inconclusive, compared to special education. There is evidence of a positive impact on the cognitive development of included students, but there is also evidence of adaptive and socioemotional difficulties among students with disabilities or SEN in inclusive classrooms (Lindsay, 2007; Farrell, 2010; Hehir et al., 2016; Kauffman et al., 2017; Pockock and Miyahara, 2018; Rosas et al., 2021).

The decision regarding which system to access depends heavily on families and is sometimes strongly guided by actors in the education and health system. In this context, some studies have highlighted the importance of incorporating different actors in the decision and in the development of the child's educational trajectory. Health and education professionals, family members and supporting institutions must work together in favor of the child's development and in permanent close contact, which also facilitates the transition between the different levels of education and care (Janus et al., 2008; Malone and Gallagher, 2009; Podvey et al., 2013; Stephens and Duncan, 2020).

The early stages of development, up to the age of eight, have been recognized as fundamental to the development of individuals and have been prioritized for children, as highlighted in the 2015 Sustainable Development Challenges (Thematic Group on Early Childhood Development, Education, and Transition to Work, 2015). Children face at least two transitions during this period, kindergarten entry and school entry (Echeita et al., 2021). These transitions mark pivotal developmental milestones that necessitate important decisions by families and institutions.

These critical moments in children's development can be especially difficult for students with SEN such as autism. These difficulties may result in reduced access and increased difficulties in staying in the education system (Goodall, 2018). For example, in the United Kingdom, great difficulties have been identified in the participation of autistic students in mainstream schools, resulting in a very high rate of permanent exclusion (Humphrey and Lewis, 2008; Department for Education, 2010). However, different systems have mechanisms to support these decisions and transitions. The success of this transition largely depends on the support children receive at their respective institutions. In this context, problems often arise from lacking of specialists or specialized programmes (Valeo, 2003; Janus et al., 2008).

In Chile, access to nurseries is provided free of charge for children from 85 days to approximately 5 years of age (Orrego and Sánchez, 2019). However, the coverage of Pre-school Education in the country is only 53.75% (Subsecretaría de Educación Parvularia, 2020).¹ For children with SEN or disabilities, the early education options are either

to enter the special education system or to be part of inclusive education systems in regular kindergartens."

Regarding coverage, the attention to SEN during early education in state-funded nurseries takes place in an inclusive education that also considers interculturality (Rubilar Bugueño and Guzmán Sanhueza, 2021). In this context, enrollment in state-funded nurseries in Subsecretaría de Educación Parvularia (2020) was close to 770,000 children. Of these, 144,782 children had SEN, of which 743 had autism (Subsecretaría de Educación Parvularia, 2020).

To access the school system, families must do so through the School Admission System (SAE, for its name in Spanish), which centralizes information from the country's state-funded schools (Palma Irrarrazaval, 2021). To support the development of children with SEN and disabilities, schools have the School Integration Programme (PIE, for its name in Spanish), which provides multiple specialists to attend to the student's specific needs (Sánchez Bravo and Pérez Godoy, 2021). These may include specialized teachers, psychologists, and speech therapists, among others (Ministerio de Educación, MINEDUC, 2009).

Until 2015, families of students with SEN had to look for schools with the necessary specialists to meet the specific needs of their children. This was an obstacle, as such a school could be far from the student's home. However, since the enactment of the School Inclusion Law (Ministerio de Educación, MINEDUC, 2015), the system ensures that the school chosen by the family has the necessary specialists to support them.

In Chile, it has been noted that, despite regulations, barriers do arise in the school admissions process for students on the autistic spectrum, although other SEN have not been further explored (Meza and Miranda, 2022). The conversation becomes even more blurred when incorporating potential disruptions in the preschool system, where no such clearly defined safeguards exist.

It is essential to highlight that, in Chile, the law on autism was recently enacted, which considers as a duty of the state to ensure inclusive education for people with autism, granting the necessary conditions for access, permanence, and graduation from education at all levels (Ministerio de Educación, MINEDUC, 2023a). The autism law has been received with much hope by civil society, as it aims to support the development of people within the autistic spectrum.

1.2. Diagnosis and the educational system

For parents and caregivers, receiving a diagnosis of a child's disability or SEN is a difficult time, which will determine decisions and actions to be taken that will change children's lives (Podvey et al., 2013; Fernández-Alcántara et al., 2017).

Some studies have reported high-stress levels among families and caregivers at the time of diagnosis, accompanied by feelings of sadness and frustration (Ooi et al., 2016). This emotional burden is closely tied to concerns about their child's future social and emotional experiences, as well as their potential for independent development in adulthood.

However, many parents feel relief upon receiving a diagnosis, as it aids in understanding the difficulties their children face. A study conducted by Dale et al. (2006) revealed that mothers expressed high expectations about their children's future while recognizing the difficulties associated with their autistic condition. Furthermore, the study showed that in some cases, mothers stated that the social

¹ This article refers explicitly to pre-kindergarten and kindergarten, even though they belong to the nursery education often provided by nurseries. We separate these levels because of their importance in the caregivers' accounts, as they are the current educational levels of the children in the sample.

acceptance of autism would determine their children's future. Similarly, other studies have emphasized the value families place on education to acquire the necessary skills for the future success of their sons and daughters. Consequently, parents' expectations are strongly linked to the support services that families seek for their children (Ivey, 2004; Soni et al., 2022).

Entering the education system can be a highly stressful time for children and families. Concerns vary, ranging from potential health issues to the child's adaptation and their peers, as well as the institution's capabilities. Among the difficulties described for children's transition into the education system are high costs, as perceived by parents. Additionally, the limited resources (human and material) available in schools in developing countries, and overcrowded classrooms, often make individualized attention particularly challenging (Soni et al., 2022).

On the other hand, the preparation and adaptation of schools and colleges act as critical facilitators for the transition to the educational system. In the case of children with autism, this includes the strategies employed by teachers in the classroom, such as adapting the way of teaching and giving instructions, creating quiet spaces in the classroom, and keeping sensory toys, among other possible adaptations that support the development of children with autism (Eisenhower et al., 2015).

Considering the high load the parents face when approaching the educational trajectories of their children with SEN, in this study, we aim to explore the early educational experiences faced by parents and caregivers of autistic children. During the last decade, Chile has implemented different support strategies for children with SEN, however, the impact of those strategies, and how they change educational decisions in caregivers, is still to be explored, especially in the context of the COVID-19 crisis, that may have impacted these children and their families in a particular manner. Thus, we seek to understand what experiences and reasons motivate the decisions made for the educational development of their children, as well as their future expectations in the context of special educational needs and their diversity.

2. Materials and methods

2.1. Regarding the researchers and their perspectives

Savin-Baden and Major (2013) emphasize the significance of recognizing three types of positionality in qualitative research. Firstly, it's essential to consider the academic and institutional context. The current study is affiliated with the Center for Educational Justice, targeting inequalities in Chile's education system, which influences its initial design and approach (Moyano Dávila, 2020). Notably, no prior research in Chile has targeted these particular subjects, posing a challenge when trying to implement reflexivity through literature reviews (McGhee et al., 2007).

Concerning the researchers' positionality, none had experienced the disabilities under study, nor cared for a child with SEN, although one team member had ample experience researching the subject. This "outsider" viewpoint presents both challenges and benefits, necessitating a detailed understanding of disability research complexities (Kitchin, 2000; Dwyer and Buckle, 2009). As such, fieldwork findings, like variations in the children's functional dependence, prompted researchers to reassess their initial preconceptions of the topic (Goethals

et al., 2015). The interdisciplinary research team, which included a psychologist biologist specialized in cognitive sciences, an anthropologist, and a sociologist, facilitated reflexivity by broadening the theoretical and interpretative frameworks, but also anchored them in the social sciences (Romm, 1998). Consequently, the study embraced a constructivist stance, viewing qualitative research as a collaborative interaction rather than a detached observation (Subramani, 2019).

Regarding conditions and the positionality of the researchers in relation to the participants, the affiliation with the well-known Pontifical Catholic University of Chile might influence participants' responses. Furthermore, while interviews upheld ethical norms, conducting them in personal spaces like homes could influence participants' narratives. As such, research outcomes are invariably influenced by the social milieu and the researchers, and ought to be understood as such both by the researchers and by readers of this article (Darwin Holmes, 2020).

2.2. Interviews

To address the objectives of the study, qualitative research was carried out through in-depth interviews. A semi-structured interview was conducted for each participant, seeking to understand the multiple dimensions of their experience in the educational context and the educational trajectories and decisions made for their children. Thus, an interview script (Valles Martínez, 2007) was applied, which addressed the following thematic areas: family background, support networks, early educational trajectory, the school application process, transition between educational levels, future aspirations, and support from educational and public institutions. In Table 1 you can find an example of the topics and question addressed during the interviews. A full list of questions used in the interviews is provided as supplementary material (Appendix 1).

The interviews lasted approximately 90 min and were conducted between December 2022 and March 2023. They were audio-recorded and subsequently transcribed to facilitate their analysis.

In addition, at the beginning of each interview, the research, its objectives, and scope were explained to each participant, and they could give their voluntary and informed consent to participate by signing an informed consent document.

TABLE 1 Example of topics and questions addressed during the interviews.

Axis	Subtopic	Question
Educational Trajectories in School Stage (Kindergarten or First Grade)	First Days of Entering the School System	How was the experience of the first day of class for your child?
		How was the experience for you on the first day of class? Were there any unexpected difficulties or unexpected ease?
		How do you feel the school establishment initially received you?
		(If there's prior schooling) Has this new school period been different from the previous one?

2.3. Participants

The sample was constructed without following probabilistic criteria, as it is not expected to achieve representativeness but rather to capture the diversity of experiences regarding the educational trajectories of children on the autistic spectrum.

Initially, the participants were selected following the criterion of having previously participated in the study “A thousand first days” (Narea et al., 2020). Thus, the inclusion criteria established at the beginning responded to previous participation in this study, to the autism spectrum diagnosis reported by the same study and to the age of the children (between 4 and 6 years old), considering that they would be in the age corresponding to the transition from pre-kindergarten to kindergarten or from kindergarten to first grade.

In the second stage, due to specific methodological difficulties, an open call to participate in the sample was extended through social networks. Snowball sampling was also utilized, leading to contact with a school in the commune of Huechuraba. The school agreed to participate by facilitating contact with parents whose children met the inclusion criteria. In this sense, the inclusion criteria were maintained, except for their previous participation in the “A Thousand First Days” study. Thus, the sample consisted of 6 participants, as shown in Table 2.

2.4. Analysis

Data analysis was conducted using grounded theory (Glaser and Strauss, 2017), allowing for the generation of knowledge from the participant’s experiences. Thus, emerging categories were identified from the collected narratives and were subsequently classified using the ATLAS.Ti (2023) Windows software (Version 23.2.1.26990) for analysis.

The following categories of analysis were established using this software: characteristics of the family unit, pregnancy period, diagnosis, treatment and condition, home education, application to establishments, kindergarten education, school experience, pandemic, support networks, and future expectations. In Table 3, you can find an

example of the core categories, subcategories and codes used for the analyses. A complete list of categories, subcategories and codes used is provided in the supplementary materials (Appendix 2).

3. Results

To explore early educational decisions and experiences, we interviewed caregivers of seven children with autism spectrum disorder (ASD) who are in the process of entering the school system.

The discussion of results will be organized according to 3 research areas: educational decisions resulting from the diagnosis, educational trajectories resulting from the decisions, and future expectations for the children.

3.1. The decision to look for a school

All participants in this study decided to enroll their children in kindergarten early. The earliest case corresponds to enrollment at 8 months in kindergarten, while the latest were two cases of enrollment in pre-kindergarten at approximately 4 years of age. In one of these, the mother acknowledges that her child’s condition was a factor in her apprehension about enrolling her child in kindergarten:

“It’s like, I don’t know, since he didn’t speak, I was afraid of sending him to the nursery and him not doing anything.” (Marta)

There are various reasons to explain the early search for an educational institution. On the one hand, the participants felt a need for support in the upbringing and education of their child, mainly due to the lack of support networks in their daily tasks. The interviewees bear a heavy burden of domestic and care work and, in some cases, also participate in paid work (formal and informal). This added workload further motivates parents to seek an educational establishment quickly:

TABLE 2 Sample description.

Alias*	Age (caregiver)	Educational level	Employment status	Age (child)	Grade	Current school funding	Municipality’s Social Priority Index (SPI)***
Adriana	26	Completed Technical Education	On-site dependent employment	4	Pre-kindergarten	Subsidized	Low SP
Valentina	33	Completed higher education	Informal work (home-based)	4	Pre-kindergarten	Subsidized (foundation)	Medium-high SP
Isabel	22	Completed high school education	Unemployed	5	Pre-kindergarten	Municipal	High SP
Marta	35	Completed high school education	Unemployed	6	Kindergarten	Municipal	Low SP
Carolina	34	Completed higher education	Home-based dependent employment	5 and 5**	Kindergarten	Municipal	Low SP
Eduardo	37	Completed higher education	On-site dependent employment	5	Kindergarten	Municipal	Medium-high SP

*Aliases replaced the original names of the interviewees to protect their identity. **Carolina has twins with ASD. ***Área de Estudios e Inversiones Seremi de Desarrollo Social y Familia Región Metropolitana (2022).

TABLE 3 Example of categories used for the analyses.

Category	Subcategories	Coding examples
School experience	Peers	Peers learn to interact with child
		Caregiver knows the case of a well integrated older classmate with special needs
	Difficulties	Use of diapers
		Feels grateful towards all members of the school community
	Teachers and staff	The teacher agrees more with the mother than with school authorities
		“In language schools, they will not accept any child with a diagnosis”
	Language school	Familiarity with special needs education due to another sibling/cousin
	Experience of caregiver’s other children	Child likes therapy
		Knowledge about IEP
	IEP	After enrollment, specialists are contacted
		Child starts entering the school building by themselves
	First days of adaptation	School trains teachers
		Child is allowed to sleep during class
	Non-IEP adaptations	“No, there have been no issues with the school so far”
		Believes that they are treated as equals (to their peers) in the school
	Good experiences and schools	Child has a meltdown because teacher and classmates were talking a lot
		Must pick the child up due to rare meltdowns
	Crises and situations that require intervention	Differences between schooling therapies and other treatments

“Because it makes it difficult for me to work. And if I was working, who was going to look after him? Because that, too, was difficult.” (Adriana)

Alternatively, there was evidence suggesting a search for diagnostic guidance. Thus, in some cases, the early start of the school stage is accompanied by an early start of complementary therapies in specialized centres, seeking support in various areas: language (speech therapist), motor skills (kinesiologist), and sensory (occupational therapist), among others.

Similarly, there was evidence of families attempting to “test out” how their children would cope with the school environment before it became compulsory. This was a way for them to understand “*what would happen*” when their children had to formally attend school, as expressed by Adriana. This “test” is a gradual method of adapting the child to the school environment, allowing for adjustments and modifications. For instance, there were cases where the initial approach did not work well, requiring the child to stop attending. Consequently, they had to wait another year to assess the child’s performance at school and during the journey to school.

In this way, the early search for a nursery school prepares the child, as well as their family, for the inevitable transition to primary education. This stage is viewed as a significant change for the child as they enter a more formal educational setting with increased emphasis on evaluation. One of the interviewees even likened this transition to a “war”:

“What scares me is first grade. That’s when things change. That’s why I preferred for him to have two years of adaptation, before throwing him into it [...] in first grade, he goes to war.” (Valentina)

Finally, the desire to initiate a gradual adaptation process is also related to the search for opportunities to work on the difficulties inherent to the autistic spectrum, particularly those relating to social skills. Therefore, parents aim to enable their children to interact with others, engage in play, and socialize with peers of the same age, as well as adults outside their immediate family circle:

“They needed to see other people, other children [...] And the rest of the people too.” (Carolina)

3.2. Criteria for choice and non-choice of educational institution

Possibly, the main criterion for establishment’s choice is for it to be part of regular education. All the participants in this study reported opting for regular education rather than special education for their children. In some cases, there was an initial search for language schools, which are specialized early schools for children with delayed language development. However, it was evident that access to these schools is not possible when there is a diagnosis of autism.

In this context, the choice of regular schools is influenced by various factors. One of the most frequently cited motives is the proximity of the school, as it allows the caregiver to quickly get to the establishment in case of a crisis or other problems that may arise. Nevertheless, in most cases, the establishments frequently have established effective strategies and tools to attend to the children.

The proximity criterion gains more significance when the child has sensory challenges, as ensuring a low-stimulus journey to school becomes imperative for parents. “*The bus ride took 50 min. Imagine*

taking [your child] on the bus when all the other children were leaving the school; terrible” recounts Isabel, referring to the old school her son attended. Eventually, she switched schools to another establishment just 5 min away from her home. An exception to the proximity criteria is the case of Eduardo, who selected a school far from his home because of its high support capacity. However, he acknowledges: “*I am an exception,*” as he was able to make this choice due to certain facilities such as having a car and working remotely.

Additionally, the participants indicate that their choice of educational establishment is influenced by the references they receive about the school during the application period. Thus, support networks, along with word of mouth and personal experiences, start to play a role, as there is no formal method to know how parents or guardians evaluate a particular school. Therefore, having positive opinions from friends, family, work colleagues, and even neighbors allow for a minimally informed decision to be made.

“I have a colleague [...] so she told me firsthand that a certain Special Education Integration Program was good [...] She gave me guidelines.” (Eduardo)

This aspect is also very relevant in the case of children with SEN since, when choosing a school, it must have a PIE and operate effectively to ensure a place in the program for their children. However, information about relevant aspects regarding the functioning of the PIE or the places available in the program presented in the SAE “*So, the spot in the PIE is very important. And in [the SAE], available vacants are not shown [...] But what happens in kindergarten, if a child with a higher level [more severe] of autism arrives? They will remove one of the other children.*” (Valentina).

From the above quote, it is clear that there is a concern about keeping children within the Integration Programme in the case of the enrollment of other children with SEN who may require more support resulting in the loss of the place for their children. It is evident, then, that PIE support is crucial to ensure access to education for every child, regardless of the level of support they require.

Despite its importance, accessing information about how the PIE works in the pre-application phase is difficult, rendering it a predominantly uninformed process. Thus, the lack of information leads to the parents turning to support networks that may have prior experience and knowledge about the schools. However, due to the low incidence of these networks (as reported by the participants themselves), it is often the case that they refer to their own, or their acquaintances’ experiences.

“Because I also have acquaintances who have their children in the PIE and they tell me: No, if you have another place to look, look for another school.” (Adriana)

Similarly, the importance of the PIE spot increases as children progress in their school trajectory. Many caregivers perceived that children in preschool education attended the institution mainly to play and socialize. Therefore, many of them associate their favorable experiences with the overall welcoming attitude from the teachers, even if they lacked specialized knowledge and accommodations. However, from pre-kindergarten onwards, there is evidence of concern on the part of mothers regarding access to the integration programme, which generates greater concern in kindergarten, when they begin to think about the transition to primary education:

“What I don't like is that you apply and then you don't know if there will be a vacant [...] right now it's not important, because his best therapy is spending time with other children, but what will happen when he goes to first grade?” (Valentina)

Another crucial aspect is the presence of family members within the educational institution, especially siblings and, to a lesser extent, cousins. This creates a support network for the child as they embark on their educational journey in an unfamiliar and demanding environment.

Finally, in some cases, the number of pupils enrolled in each school is also considered an essential criterion in the school choice for pre-kindergarten or kindergarten. This is because, in general, preschool education has a smaller number of children per establishment compared to primary education, which is usually taught in establishments that offer multiple levels of education. Therefore, pre-kindergarten and kindergarten are intended to allow for a gradual and smooth transition between early and more individualized education, such as that provided in kindergarten, and primary education.

“I want it [the school] to be small, comfortable, not so big that he doesn't feel so [...] uncomfortable in a school, where he is going to see more children. Because he went to a [nursery] with 90 children, and now there are almost three times as many.” (Adriana)

3.3. Barriers and facilitators in the search for and choice of educational institution

One of the main barriers caregivers face when applying for a school for their children is the scarce information the SAE provides. This system places geographic location as the main criterion of choice when looking for an educational establishment. Furthermore, it does not provide more information about the functioning of educational programmes or the PIE, which, particularly in the case of autistic children, could be of great relevance when choosing a school.

“I couldn't get information about the school, about the PIE [...] So, that was also my big barrier, that is, how the school would be rated, if it was suitable to receive him or not.” (Adriana)

An additional difficulty is the challenge of finding an educational establishment during the first years of Nursery Education, as told by one of the participants: “*you say that he/she has autism and suddenly there are no more available vacants*” (Valentina). The establishments commonly use excuses such as the lack of particular adaptations for the child's diagnosis, including insufficient infrastructure and staff training. Sometimes, the parents are burdened with the responsibility of providing these adaptations.

“They told me: No. But, in case of a crisis, how are we going to do it? I don't know how to handle a child. They wanted me to find training for the staff.” (Adriana)

In terms of facilitators, two factors are key when choosing and applying to educational establishments. Firstly, although the SAE has

been mentioned as a barrier, one of the interviewees expressed the opinion that it is a system that enables access to education without generating discrimination, as the condition or diagnosis of the child does not appear during the application process, so *“in the end, we all apply on equal terms”* (Carolina).

Furthermore, the SAE has facilitated the admission in the case of parents who were clear about which school to apply to. In one case, it is even reported that applying to a private school (that does not utilize the SAE) is more challenging due to restricted access.

Secondly, the different adaptations made in the establishment also facilitate the permanence in the institution after the initial selection. Although, as previously stated, there are no formal methods to know in practice how the establishments and the integration program work, these practices are sometimes discussed within the families' networks, which leads to caregivers applying to the schools precisely based on this information.

Thus, for example, some of the mentioned adaptations involve hiring specialized professionals or providing training to existing professionals, especially in cases where other therapies are less accessible:

“They helped me, they trained the staff, they hired a special educator, they adapted things so that he would be comfortable [...] they had to ask for another classroom assistant in case he had a crisis, so that they wouldn't leave his classmates aside and that he could be comfortable.” (Adriana)

Other adaptations include the provision of dedicated spaces for managing crises or particular behaviors, as well as flexibility in lunchtime and classroom activities:

“[The teacher] Leaves him his gym mattress on hand [...] because suddenly he gets stressed and goes in there by himself. So he already knows he has his space.” (Valentina)

3.4. Educational and biographical trajectories

This study has found great diversity in the experiences of children and their caregivers. Each case is unique, and various factors related to the child's condition and the contextual factors surrounding the child can significantly impact their educational experience and ability to integrate into the school environment.

Despite this, it is possible to identify similarities in how certain biographical milestones, particularly the initial diagnosis and the measures taken in response, impact the subsequent development and integration of children on the autistic spectrum. As a result, three distinct types of trajectories have been distinguished. The first type, characterized by early diagnosis and treatment, is exemplified by Adriana, a 26-year-old who works as an assistant in a foundation caring for people with ASD. Even before her child was born, professionals informed about the possibility of neurological or physical sequelae due to her high-risk pregnancy, which allowed her to be prepared for the potential need for specialized support. Consequently, when her son started experiencing seizures at 8 months old, Adriana sought the help of a neurologist, who promptly

recognized signs of autism. Although she had to wait for some time before an official diagnosis was impossible at such a young age, it was later confirmed.

This case stands out because the early identification of the condition, as well as the mother's prior expectation and preparation in case of its occurrence, led to the child receiving comprehensive treatment from his early years, which allowed the child to receive comprehensive treatment from a young age. It is important to mention that this treatment imposed a financial burden on the family; however, their prior preparation enabled them to leverage their social capital for financial support. The early stimulation of the child extended beyond the interventions provided by professionals. Adriana also sent her son to the nursery from an early age *“because it was also useful in the social area.”* Thus, Adriana's case stands out because of the prompt diagnosis and the measures and therapy regime that took place from an early stage.

“Because we did a lot of things for [his] benefit, for therapy, because [...] it's a lot, it's a lot to be able to afford treatment.” (Adriana)

Despite the advantages early diagnosis brought in terms of interventions, paradoxically, it also posed a challenge during the transition to the school environment. Due to the high probability of autism and confirmed neurological alterations, the first nursery Adriana took her son to, had a very hostile reception. She emphasizes that the initial difficulties in the school transition were not due to her child's difficulties once in the nursery but rather to the institution's reluctance to accept a child with autism. This contrasts with the challenges faced by other parents, where the shortcomings of the establishments did result in negative experiences for their children, as seen in the cases of the second identified trajectory. In Adriana's case, these initial difficulties were easily overcome when she enrolled her child in another nursery. According to Adriana, this change brought about a radical improvement as the second institution was willing to receive her child, and the professionals were trained and made adaptations according to his needs.

What is remarkable about this case, considering the previous experience, is that, once he began attending kindergarten, there were virtually no major issues with his adaptation. Although Adriana's son occasionally had crises, she reports that the educators could handle them, and they only needed to call her once. In general, Adriana perceived an excellent degree of integration on the part of her son in the nursery. While he required minor adaptations such as wearing diapers or adjusting to certain transitions, in practice, he felt comfortable and exhibited more adaptive behaviors in the nursery compared to his home, such as eating a wider variety of food.

Despite the challenges, this positive level of integration continued when her son entered pre-kindergarten. Adriana chose a school based on previous experience, and although she acknowledges that there are still some difficulties, such as occasional crises, negative interactions with peers, or toilet trips, overall, she has a positive assessment of her son's progress. She affirms that he has developed good social skills and has formed a supportive friendship. Moreover, school community members *“adore him,”* and he has had an excellent academic performance. Above all, Adriana highlights how the school recognizes the significant impact of early intervention on these outcomes and

acknowledges that the school is not solely responsible for treating her son's condition.

“What we were told is that he was an ideal ASD. Of course, he goes to therapy, he has been going for years, he has a good behavior.” (Adriana)

In contrast, another trajectory is observed in the cases of Isabel, Valentina, and Eduardo. Two of these three caregivers have a notable characteristic: Valentina already had prior knowledge of SEN issues due to her other child, who has dyslexia, and she is even studying special education because of her children's conditions. Eduardo, on the other hand, is a psychologist. Both caregivers possess specialized knowledge. However, despite their proactive efforts to seek diagnosis and treatment for their children, they share a common experience with Isabel, who does not have specialized knowledge but, due to other constraints, has undergone a similar educational trajectory. An ambiguous diagnosis, sporadic or changing treatment, and negative experiences in the nursery or school environment characterize this trajectory.

When it comes to identifying possible signs of autism, in Eduardo's case, the pregnancy was normal, and his son entered the nursery early. Although the first years were not problematic, due to his training as a psychologist, the caregiver quickly noticed that his son “*appeared somewhat behind compared to others*,” so he began speech therapy at the age of two. However, the diagnosis of autism came later.

Isabel had a teenage pregnancy with complications. When her son was about 20 months old, he stopped making communicative sounds, and she noticed his lack of eye contact. This prompted her to consider enrolling him in a language school due to his potential developmental delay. However, unlike Eduardo, her son was not admitted to early preschool education due to suspicion of autism. Lastly, Valentina did have a high-risk pregnancy, and initially, it was thought that her son's lack of responsiveness was due to deafness. However, when they realized this was not the case, there was no suggestion that it may have been due to another condition, so Valentina did not interpret potential early signs as neurodivergence.

In all cases, the pandemic exacerbated difficulties in diagnosis and the process of adaptation. Eduardo describes the pandemic years as “*terrible*” because his son had no contact with other children, making it challenging to monitor his condition, treatment, and education. To this day, Isabel has been unable to obtain an official diagnosis, and her son not only did not receive further treatment but also did not attend any school during the pandemic years.

Similarly, Valentina faced challenges accessing appointments for her son's check-ups and had to wait for a call from the clinic. She received an informal diagnosis through the telephone and a referral to a neurologist, but unfortunately, she was not contacted again for 2 years. During this period, Valentina began to notice that her son was unusually elusive, and his language was delayed, which led her to decide to finally take him to a specialist.

On the other hand, although Eduardo had observed certain behaviors in his son, he was hesitant to pursue an official diagnosis, partly due to his own experience and reluctance to get a premature diagnosis. However, when his son started struggling in preschool and could not progress to the next level, looking for an official diagnosis became necessary. Isabel, on the contrary, did not continue to pursue a diagnosis after the informal one, primarily because she lacked

expertise in the subject and had limited financial resources. Additionally, during the pre-pandemic period, her son's condition was not particularly evident to someone without specialized knowledge. Therefore, it appeared insignificant for Isabel to insist on her son's entry into the school system, especially considering the additional pressures and disruptions caused by the pandemic.

It is noteworthy, however, that both parents with expert knowledge and resources, who actively sought a diagnosis, experienced negative encounters with specialists. In Valentina's case, the psychiatrist resisted diagnosing autism, stating that “*you want all children to be autistic*” and even tore up the referral paper, diagnosing her child with epilepsy. In Eduardo's case, it is the opposite scenario, as he states that the neurologist lacked empathy and was categorical in his diagnosis, prioritizing the latter without a closer, warmer approach and proper follow-up of the case, resulting in the caregiver not returning to that neurologist.

To some extent, these initial negative experiences, combined with the parents' knowledge of the subject, led to an ambiguity in the definitive diagnosis, similar to Isabel's situation, albeit for different reasons. In Valentina's case, the first therapist claimed that her child had Asperger's syndrome instead of autism, which led Valentina to switch therapists because “*Asperger's is no longer used [as a diagnosis] and she should know that*” (Valentina). Later, based on her research on the subject, Valentina took her son to another neurologist and a second therapist. However, a pediatrician once again questioned the diagnosis, suggesting it could be a sensory disorder. It was not until the last psychologist and the child's school teacher declared that the child had ASD that Valentina finally felt that the diagnosis had been confirmed.

“And then the teacher realized it right away [...] So I said: Why am I going to keep spending money on tests, on specialists, if even the teacher noticed it on the first day, right?” (Valentina)

It is worth mentioning that, throughout this process, Valentina not only made a deliberate effort to seek a diagnosis but initiated a self-training process. She even pursued studies in Special Education to support her children's education better. However, these efforts were largely hindered by the disruptions caused by the pandemic and the lack of consensus among professionals.

This situation is similar to Eduardo's case, where there are tensions with professionals, partly due to the caregiver's expertise. This, however, is a unique situation in that it highlights how events and disruptions in the family environment can impact educational trajectories. In this case, the parents divorced soon after the child was born, and Eduardo found employment in another city. He is now the primary caregiver; however, initially, the child's mother had primary custody, which posed a challenge for Eduardo in monitoring his son's progress, especially during the pandemic.

These obstacles resulted in delayed and interrupted therapy and a fragmented educational experience. Due to his specialized knowledge, Eduardo had disagreements with the mother regarding treatment and educational decisions for their child, as well as the associated costs. Unlike Valentina, who could immediately implement her decisions, Eduardo had to seek an opportunity to take his son to a trusted neurologist due to the mother's hesitations: “*If she does not do it, I will*.” He focused on finding specialists utilizing the Denver Model, which created tensions with the speech therapist treating his son. Eduardo

recounts that he had to exert pressure on the mother's family to ensure that his son would receive the treatment that he, based on his expertise, believed was necessary, as he perceived that the therapies his son was receiving were not contributing from a more holistic perspective and did not prioritize the child's autonomy.

As mentioned earlier, Isabel's case stands out in that the challenges in obtaining treatment were primarily due to economic difficulties, as she could not access the necessary professionals through the public health system. Additionally, she did not need to seek an early diagnosis actively, as there were no official concerns about autism in the early stages. When her son entered school, he had a positive experience at a nursery school recommended by a friend, with support from the PIE professionals. However, due to her son's sensory difficulties, she had to withdraw him from school because of the long and challenging commute. As a result, she had to limit her son's daily activities and the support he received at the nursery school, leading to interrupted and delayed therapy. Despite these challenges, Isabel believes his time in the educational system was a beneficial experience for her son's development.

In Eduardo's case, similar to Isabel's, the experience during the first years of nursery school was mostly positive, with the only difficulties being related to learning delays. The school had an alternative approach to education, which Eduardo considered very beneficial for his son. However, it's important to note that he did not choose this preschool based on its ability to accommodate his child's needs. Instead, like Isabel, he relied on a recommendation and was unaware of its pedagogical excellence. Therefore, during this period, his primary focus was on supporting his son through therapies rather than seeking a specific diagnosis, as it was not necessary to address his son's needs.

Unlike Isabel and Eduardo, whose difficulties began in the pre-kindergarten and kindergarten stages, Valentina faced challenges even before that. Despite the uncertainty, the autism diagnosis generated resistance when she attempted to enroll her child in a nursery school and disclosed his condition. Even after gaining admission, her child encountered difficulties in terms of integration. Valentina observed that her son was being excluded from activities and soon realized that the environment was unsuitable for him, despite his initial enthusiasm. However, she allowed her son to decide to stop attending the nursery on his own:

"And he was happy for the first few days. So after the second week, he went for three days and didn't want to go anymore." (Valentina)

Thus, the school system transitions have presented different challenges for the three caregivers. In Eduardo's case, this meant a first school change driven again by family circumstances. Despite Eduardo's opinions, the mother chose a private school, regardless of its limited adaptations for children with SEN and the additional cost it imposed on parents for support. Although Eduardo mentions that the diagnosis came "a little later" during this period, so he wasn't seeking many specialized adaptations but a respectful environment for his child, the child had to withdraw from the institution due to a lack of support. Once again, due to the physical distance, there were incidents involving the school staff that Eduardo found out later. It is partly because of this experience that Eduardo, through a family mediator, gained primary custody of his son, as he argued that there were more schools capable of adapting to his son's needs in the capital, where he resides.

"I knew that the school did not have the necessary characteristics to be able to attend to [son] at school. So [he] ended up going to school very rarely [...] He always had to be picked up early. There were times when they didn't even change his diaper [...] In September, last year [he] had to leave the school. They had to take him out of school." (Eduardo)

The educational experience has significantly improved in Valentina's and Eduardo's cases, after these events. Valentina even affirms that for her son, pre-kindergarten "has been his best therapy." It is worth mentioning, however, that this has involved significant intervention on the part of the caregiver, as she has even registered as a "shadow tutor" (assistant individualized instructor) for her son. She also recounted that there were initial tensions due to the use of diapers, and she had to explain the guarantees of the autism law to the teacher: "so they have even less reasons to exclude my son from education because he needs diapers." Although in Eduardo's case, the school has not posed any obstacles, as they offer many more specialized adaptations and even change the diapers themselves, his active participation and careful monitoring of his son's development also resembles that of Valentina:

"So I came with the intention of participating, of being a member of the class board [...] So I have direct communication with the teacher. I also have communication, if needed, with the program coordinator, with the special educator, with the speech therapist." (Eduardo)

The case of Isabel is significantly different. Unlike the other two caregivers, Isabel found herself lacking the necessary resources. As a result, she made the decision to enroll her child in a school closer to their home, believing that any school participating in the PIE program would offer adequate support for her son. Unfortunately, her current experience has proven otherwise, as she feels that the school "does not want" her child. The PIE program does not align with her child's schedule, disrupting the ongoing treatment that was initiated during preschool, despite being hindered by the geographical distance.

Additionally, the informal diagnosis that did not present a problem in the previous institution has become a significant hurdle, as the school now requires an ADOS-2 assessment for PIE enrollment. Isabel lacks the financial means to obtain this certification. Moreover, she cannot afford the other expenses imposed by the school, such as a "shadow tutor," an individualized instructor. Consequently, her son's integration has suffered, leading to disruptive behavior, frequent outbursts, and attempts to flee the classroom. Instead of providing support, the school has consistently called Isabel to remove her son from class, exacerbating the difficulties in achieving integration. Moreover, they have failed to communicate openly with Isabel regarding her son's progress and treatment.

"I feel that they don't want him in the classroom, but they also don't have anyone to keep an eye on him. For example, yesterday the teacher called me, she said: No, I'm alone. The technician [assistant teacher] did not come [...] and someone will have to come and pick him up [...] So, how? If there's no technician, does it mean my son can't attend class?" (Isabel)

This last fact underscores a connection with the situations of Eduardo and Valentina, even if their children have achieved significantly better integration. In all three cases, a very active role from the parents is required. This is particularly true for Valentina, who directly attends to certain needs that the school does not meet. On the other hand, the school that Eduardo's son attends, offers adaptations and much more intensive support, but also maintains very close communication with the caregiver, who keeps constant contact with the professionals in charge and has even become part of the course's board.

An ambiguous diagnostic process and interrupted treatment, whether due to biographical reasons, professional problems, or lack of resources, seem to impact the ease of children's integration. Even in exceptionally equipped schools like the one Eduardo's son attends, this often necessitates greater parental involvement. Consequently, parental tools play a significant role in adaptation. This does not mean, however, that the schools themselves do not have an important role to play. While Isabel may need more resources and expertise from the other caregivers, the school has demonstrated no willingness to involve her in a collaborative effort, instead shifting the entire responsibility onto her.

Finally, a third trajectory can be recognized in the case of two caregivers: Marta and Carolina, the mother of twins. Both caregivers' children attend the same school, which may partly explain their similar adjustment experiences. However, the similarities in their trajectories extend beyond their experiences within the school environment.

In Carolina's case, she did not start suspecting anything until her sons turned three and displayed language development delays. However, she did not pursue an in-person diagnosis, due to the pandemic. Instead, she contacted the support center director, who reassured her that it was normal for children not to speak at that age. Only when the twins began attending kindergarten in person did their teachers notice certain indicators and reached out to specialized evaluators. This led to a diagnosis of autism, which Carolina initially found difficult to accept because she held certain preconceptions about the condition. Her children's ability to pay attention to their surroundings and interact with other children did not align with her understanding of autism. However, as she became more informed about ASD, she now recognizes that her children have a "unique condition."

Regarding her experience in kindergarten, Carolina states that the diagnosis "was not a major issue" and that the professionals did not treat her children differently due to their condition. However, it is worth mentioning that Carolina's children did not progress in language development during this stage, as they still communicate by repeating words and have yet to develop full language abilities.

Marta's son also had a late diagnosis, and once again arose from his delay in language, although in this case it was identified from the controls in the consulting room: "The nurse suspected that he was fair behind [his peers] when it came to talking, and he did not look at you in the eye when you spoke to him" (Marta). In spite of perceiving certain unusual behaviors, Marta did not suspect the possibility of autism prior to this diagnosis either. Unlike Carolina's children, her son did not attend kindergarten, since she wanted to have him by her side as her only child.

Therefore, in both cases, the diagnosis and initiation of treatment were delayed, but there is some consistency in the treatments. In

Carolina's case, after her children were diagnosed, they started attending occupational therapy, speech therapy and received neurological care at a therapy center. As for Marta's son, he only received psychiatric and neurological treatment at the hospital where he was diagnosed, partly due to the pandemic.

Regarding school entry, in Marta's case, initially through virtual classes, her son started attending school 1 year after his diagnosis. This posed a unique challenge for Marta, as her son is very restless and struggled to adapt to this learning modality. On the other hand, Carolina decided to enroll her children in regular school despite the recommendations from the therapy center, which suggested special education. Over time, the therapy center acknowledged Carolina's decision's the positive aspects.

"They also saw the progress [...] Then they also saw that it was not ... That it had not been as difficult [for the children] to enter the school as they had expected." (Carolina)

Despite the differences in both cases, there has been progressive adaptation. Marta shares that, initially her son struggled to be alone at school and "did not pay attention," but now he is comfortable attending classes independently and quickly says goodbye to her. Carolina mentions that while one of her children had a more challenging time adjusting, they now cooperate and enjoy going to school. Therefore, both caregivers have a positive evaluation of the support and integration provided by the school. The PIE, specifically, has been a valuable source of support and, in Marta's case, the primary avenue for treatment:

"Here, he [son] is receiving speech therapy and seeing a psychologist. He has all of that at school." (Marta)

However, in terms of inclusion, although they have been well received by the school community, the level of integration and the formation of bonds with peers is not as comprehensive as in the case of those who received early therapy. In Marta's case, she even must stay at school as her son has a shortened school day. It is challenging to determine whether this is due to the treatment or the specific characteristics of their special educational needs (SEN) conditions.

3.5. Personal and general expectations for the future

An initial crucial aspect in examining parents' expectations for the future is that most of their responses primarily focused on the immediate future of their children, with only a few exceptional cases considering a more distant timeframe. Concerning the transition to the school environment, a common short-term worry revolves around their child's social integration and the potential for peer bullying or mistreatment, rather than solely academic progress. However, overall, positive previous experiences tend to alleviate these initial concerns:

"Because when he first started, I saw him as such a little chick. I said, is he going to go to school? Is he going to adapt to the school? And now that he has adapted to the school, he likes to go to school. And now, my son is going to go to college." (Marta)

Beyond immediate transitions, in the long term some caregivers have a degree of uncertainty about their children. This uncertainty is not necessarily damaging, as some caregivers emphasize the significance of embracing each stage and avoiding expectations that may be restrictive or put undue pressure on the child, as Eduardo expresses: “*It is enough for me that he progresses according to his stage of development*” However, other parents do express specific concerns about the future:

“I’ve never thought about what to expect for the future, it’s always like, it’s the now [...] I would like him to, I don’t know, to feel comfortable.” (Adriana)

In this regard, the current experience within the school system can influence these expectations. Although Marta does not have a precise vision of her son’s future milestones, she is determined that he attends university and mentions that the family is making substantial efforts to make this financially viable. However, she admits that she had only considered this possibility once she witnessed her son’s adaptability within the school environment. Even Valentina, who had previously contemplated taking direct responsibility for her children’s education due to concerns about inadequate adaptation, acknowledges that her perspective has shifted as she recognizes the significance of socialization.

The focus on the present educational development of their children is also reflected in the caregivers’ rather general responses regarding their children’s future as adults. The responses are more general in nature except for Marta, who has had conversations with her son about his aspirations when he grows up. They primarily revolve around the possibility of their children being able to adapt to adult life without their condition significantly impacting them. Carolina, in particular, recognizes that many individuals on the autism spectrum have successfully integrated into society, stating, “*so why would not my children be able to do the same? They are not different.*”

The impact of personal experiences, however, can also have a significantly negative effect. Isabel, in particular, has had such a negative experience in her current situation that she was deeply affected by the question regarding her son’s education and overall future. As a result, she chose not to continue with the interview and only expressed her greatest wish as a mother: to hear her son say “*three or four words*” at some point in his life. Therefore, it is essential to acknowledge that this section of the article does not include her experience, which could provide profound insights as it differs from the positive experiences of other caregivers. This is an important limitation to consider.

Despite the protective stance of certain parents, promoting autonomy in their children is a shared objective among many of them. This entails a dual process. Firstly, it involves the children learning to self-regulate and effectively manage their condition, thereby attaining a level of “normalcy.” Secondly, parents acknowledge that this also necessitates a cultural shift in which the environment, currently marked by challenges and hostility, becomes capable of accommodating the needs of their children.

“I don’t know, I would like for him to be very autonomous [...] At the end of the day, people understand. Children are super intelligent, so you can tell them ‘no’ when it comes to [son]. ‘No,

look, he likes to play but he doesn’t like to be touched.’ ‘Ah, ok’” (Valentina)

It is important to note that caregivers find relevant references from other individuals with the same condition when envisioning their children’s future. Carolina, for instance, shares how her personal experience with a peer with autism during her school years influences her perception of her child’s educational integration. Eduardo and other parents also refer to their experiences with other family members with ASD, which can even aid other family members, like Adriana’s son’s sibling, to better adapt to the child’s situation. Expectations can also be influenced negatively by people in the environment. Valentina recounts how negative accounts from other parents with children with the condition heightened her initial concerns about schooling. Even references from popular culture can provide a visualization of how children might be integrated in the future.

“Look, how many people with autism are there in society? Many. The other day I was telling the teacher, I mean, [famous football player] ... Now I understand [famous football player]’s attitude.” (Carolina)

After finding institutions capable of accommodating their children, caregivers do not typically expect to encounter significant problems in these schools, although there may be some concerns and suggestions. Some of these suggestions are formal, such as proposing changes to the vacancies system. Some parents also recognize the importance of integration between different institutions involved in treating children with SEN, given potential discontinuities that may arise between support networks such as hospitals or therapy centers and the PIE program. However, most of their expectations focus on maintaining the positive experience and the warm reception provided by the educational establishment.

The school system, as a whole, presents a distinct scenario where many parents, partly due to negative experiences, recognize the necessity for substantial transformation. Adriana, for instance, mentions that numerous teachers, even those specializing in the field, lack adequate knowledge in dealing with dyslexia. Eduardo shares this opinion, emphasizing the need for more professional training and a system that relies excessively on individual schools instead of offering a comprehensive support framework. Adriana also highlights the limited availability of information and suggests implementing a recommendation system for the PIE program. Thus, caregivers’ expectations and proposals for the future tend to be directed toward the system as a whole rather than focusing solely on individual schools.

“From the Ministry itself, it should come from them, they should not ask for the school to take these measures [...] Because in the end all of them [the teachers] are going to continue working in public, subsidized, private schools.” (Adriana)

Their expectations for external support beyond the school system also reflect this broader perspective. Almost all parents feel insufficiently supported by their environment, especially by local municipalities, and rely primarily on their families as a support network. On a legislative level, the obstacles and needs vary significantly. However, all the participants acknowledge the current

system's limited provision of formal and widespread support regarding their children's special needs and parental accommodations. In this regard, the expectations aim for an institutional transformation that facilitates the experience of children and individuals with autism, a system with policies "that effectively respond to [child]'s needs" (Eduardo).

Some of these adaptations focus on the assistance that can be offered to caregivers, including providing support for their personal development and learning about the condition, as right now they must independently seek information on the topic, particularly when they do not have previous specialized knowledge. Marta considers it important to have contact with other parents of children with ASD, which reveals that this expectation is not solely focused on education but also, as expressed by other caregivers, encompasses emotional support.

"Because it would also be good for us, that is, to know more. One enters this as a game, so to speak, without knowing what it is all about. And one goes along the way seeing how things are. And you end up learning with them [the children]." (Carolina)

However, there are also multiple structural expectations beyond the caregivers' training. Although Adriana, in particular, proposes several policies for children with SEN, such as stimulus sets and general registries. Other factors affecting families, not necessarily related to the specific condition, have an equally or even more significant impact, such as economic inequality in Marta's case or the challenges mothers face in pursuing entrepreneurship and employment. Within this context, Eduardo's case stands out as the only male primary caregiver, who acquired primary custody after multiple obstacles within the judicial system, which hindered his ability to be present and make decisions regarding his son's education during the divorce. Despite these differences, all of these demands share a central objective: to provide resources for the children and the families, given the specificities of each case. Above all, these proposals aim to provide facilities enabling parents to access and utilize these resources to support and accompany their children according to their individual needs.

"Today, I must say that remote work is the best tool that can exist so that I can be here, close to [my son] and accompany him in a real way [...] Please, so that people who take care of little ones, who have some particular need, can integrate family, school and work. Because that needs to exist." (Eduardo)

Finally, it is essential to highlight that the recently enacted Autism Law has generated positive caregivers expectations. For instance, Valentina shares that when she encountered challenges at school, she utilized her knowledge of this law to assert her right to retain her son's diapers. On the other hand, Carolina anticipates that the legislation may also facilitate improved access to therapies and provide financial support.

4. Discussion

In the present study, we explored, through semi-structured interviews, the experiences of parents and caregivers during the early

childhood of their children with autism. In particular, we examine the extent to which the diagnosis of autism shapes their educational decisions and prospects.

4.1. General findings

When accessing the field, multiple adversities were present that significantly impacted not only the research procedure but also the final composition of the study participants. We consider that some of these obstacles, beyond their influence on the research, offer valuable information by revealing certain phenomena that today surround families with preschool children diagnosed with disabilities or special needs.

Among the main obstacles, the revocation or uncertainty in the diagnosis of several children stands out. This specific situation partly arises from the fact that the study in which the disability status was initially recorded was conducted in 2019 and was then severely affected by the COVID-19, mainly because of the restrictions to attend medical services. Thus, over time, some diagnoses and conditions had changed.

Finally, regarding practical considerations, contacting the participants and coordinating the interviews presented a significant challenge. This is somewhat foreseeable, as the participants, in addition to their daily responsibilities, are parents who must undertake particularly demanding care work due to their children's condition. It raises the question of which unique characteristics might be present in children whose families did not respond to the research team's attempts to contact them.

4.2. Educational decisions

The diagnosis of autism significantly influences the educational decisions made by caregivers, although it may not always be the sole determining factor. The choice to enroll a child in an educational institution often stems from the need for caregiving support or to provide appropriate early-age stimulation to mitigate the impact of the autistic condition, particularly regarding socialization.

In terms of the specific institution for enrollment, a notable preference for inclusive schools emerges. Among the cases examined, all caregivers opted to enroll their children in inclusive schools rather than specialized schools. This aligns with the policy established since the 1990s to promote inclusive education instead of special education. Furthermore, international experiences have demonstrated the positive effects of inclusive education for students with special educational needs (SEN; [Hehir et al., 2016](#); [Pocock and Miyahara, 2018](#)). Another crucial factor is the institution's ability to meet the child's specific needs, such as accommodating diaper changes. Prior knowledge of an institution from acquaintances who can provide references about the institution is also an important consideration.

However, the challenges involved in enrolling children with autism in the educational system are significant. Some nursery schools outright rejected these children from the outset, while in other cases, parents had to seek out a second institution after a negative initial experience. Remarkably, in certain instances, parents made these decisions despite the resistance of their social circles and even the professionals responsible for their children's treatment, resulting in

positive outcomes. Similarly, it is crucial to observe the sense of insecurity that the PIE program can engender in parents, as they perceive the possibility of losing its support if a student with greater needs is present or in the case of future educational transitions.

Parents face various barriers when enrolling their children in educational institutions, including a lack of public information regarding the enrollment process and the support services available at each establishment, as well as the quality of these services.

On the other hand, among the factors that facilitate the experience for parents, establishments that prioritize training their staff to provide appropriate support for the specific condition are noteworthy. Additionally, physical adaptations of the school environment that enhance the inclusion process for students with autism are also beneficial.

4.3. Educational trajectories

Regarding decision-making, educational paths are significantly influenced by the diagnosis of autism. The timing of the definitive diagnosis is also crucial in this regard. Once the definitive diagnosis was received, students received additional support and adaptations within the educational institutions. In some instances, this led to a change in the educational establishment to meet their needs better. As other studies have shown, the moment of the diagnosis is a very stressful period, but it is also a time of relief that gives the opportunity of making decisions regarding their children's future (Fernández-Alcántara et al., 2017).

Hence, receiving a diagnosis at a young age entails earlier involvement with specialists for targeted support of specific needs. While some parents may not recognize potential autism signs, others' suspicion promoted the search for a definitive diagnosis and its consequent treatment. This may be due, to a large extent, to the specific characteristics and previous knowledge of the caregivers. In this sense, an early and precise diagnosis proves to be an ease for caregivers to react and seek adaptations for their children, even if it may hinder the institution's reception. The ambiguous diagnosis seems to be the most detrimental to development, implying an interrupted and uncertain process for parents. Moreover, it is worth mentioning that an early diagnosis has proven to improve social behavior in children with ASD (Gabbay-Dizdar et al., 2022), reinforcing the importance of the quest for an early diagnosis.

Due to the significant impact of early diagnosis on trajectories, it is crucial to highlight that, for an extended period and in some cases exacerbated by the consequences of the COVID-19 pandemic, parents have reported either a lack of diagnosis or diagnoses based solely on a physician's observations of certain behaviors or general questions rather than standardized tests. Furthermore, two parents disclosed that they still did not possess official documentation confirming their child's diagnosis, and they had to undergo assessments to enter the PIE system. The COVID-19 crisis, strongly affected the health access of children, reducing their access to health institutions, heavily relying on telehealth (Jeste et al., 2020; Aishworiya and Kang, 2021), which, as shown in this article, may not be the best answer for children with ASD.

The cases of Valentina and Eduardo are particularly noteworthy, as they are caregivers who possess exceptional competencies and actively engage in their children's development, much like Adriana.

However, various factors, including family and geographical circumstances, as well as disagreements among professionals, resulted in a delayed definitive diagnosis, fragmented therapy histories, and negative initial experiences in school and preschool environments. In both cases, their higher knowledge contributed to this fragmented history, as they become aware of potential shortcomings in the professional support they receive.

4.4. Future expectations

Regarding caregivers' expectations for their children's future, the responses often focus on the short-term and addressing immediate needs. There are concerns about upcoming transitions to primary education and integration into larger educational settings.

Based on a study conducted by Graungaard and Skov (2007), it has been observed that female caregivers tend to have more immediate expectations related to caregiving, while male caregivers tend to have more future-oriented expectations. Our sample composition does not allow us to directly compare our results to those reported by these researchers. Nevertheless, our findings may align with the tendency of female caregivers to show greater concern regarding the child's present needs, given that a significant portion of our sample comprises female caregivers. Moreover, this immediate focus is also reflected in the responses provided by the only interviewed father, however, it is noteworthy that, like the mothers, he serves as the child's primary caregiver.

While existing literature emphasizes the significance of parents' characteristics in projecting their children's future, the findings of this study highlight the predominant impact of their personal biographies and present experiences (Papageorgiou and Kalyva, 2010). These experiences encompass the specific conditions of their children and the success they have achieved in the inclusion process, which influence their caregivers' outlook beyond any preconceived notions. This aspect has also been identified as relevant by authors such as Hebert and Kouloughlioti (2010) and Hodges et al. (2020). Consequently, when children have undergone a successful process marked by developmental milestones and positive social performance, future expectations become clearer, often including aspirations for higher education. Moreover, the experiences and support networks they acquire throughout the process can also shape their perceptions of their children's future and encourage their active involvement (Lense et al., 2022). In this regard, parents' outlooks involve a complex construction influenced by their characteristics, demands, interactions, and environment feedback. Conversely, in cases like Isabel's, the negative experience at her son's current school, characterized by limited support and demands that Isabel has been unable to meet due to her circumstances, has profoundly impacted her perception of the future.

On the other hand, a general concern is the capacity for independence and the adaptations of the environment for appropriate inclusion. These expectations for social adaptations are general demands, not aimed at specific institutions, but at society.

4.5. Combined effects

Decisions, trajectories, and expectations are closely interconnected. For instance, educational decisions play a significant

role in shaping children's trajectories within the educational system. As a result, the historical and biological characteristics of children have a direct influence on parents' trajectories, decisions, and expectations.

In particular, the diagnosis of autism plays a crucial role in determining the search for specialized support and the educational setting in which children will be enrolled. Furthermore, the specific characteristics of each child, including early exposure to specialist support, shape the necessary adaptations in their environment. As a result, the more comprehensive the adaptations required, whether due to their condition or their progress in therapy, the less resistance they are likely to encounter in educational settings.

It is important to highlight that half of the interviewees reported a negative experience in the initial educational establishments where they enrolled their children. This negative experience, stemming from the autism diagnosis and the establishments' reluctance or difficulty in accommodating their children, should be less present in primary education establishments. This is because the SAE does not consider SEN as a factor in school assignments (Palma Irarrázaval, 2021), but rather expects all schools to accept students with SEN. However, such issues may be persistent within the preschool system, as applications are made directly to the establishments, making it more challenging to centrally control discrimination in access.

Paradoxically, parents have expressed concerns about the potential presence of students with more significant adaptive difficulties, as they fear it may result in competition for specialized support and potentially hinder their children's successful adaptation process. This apprehension may be rooted in an increase in the enrollment of autistic children in recent years, coupled with legislation that imposes limitations on the capacity for individualized care. Decree 170 establishes a maximum of two students with permanent SEN per inclusive classroom (Ministerio de Educación, MINEDUC, 2009).

Additionally, discrepancies have been identified between the official registration of students with SEN in the Program for Inclusive Education (PIE) and the actual number of students with SEN attending educational establishments with PIE. According to data from the Ministry of Education, there has been a significant increase (>1,000%) in the number of children registered in the program (Ministerio de Educación, MINEDUC, 2023b). Additionally, the Survey on Disability and Dependency conducted in 2022 reported 587,709 children and adolescents with disabilities in Chile (MDSF (Ministerio de Desarrollo Social y Familia), 2023). This is in stark contrast with the 183,272 students with special needs registered in 2018 (Holz, 2018), a total number that includes not only children with disabilities but also those with conditions such as attention deficit or language disorders.

Based on their experiences with institutions that have not adequately met their children's needs despite having this resource, parents also express concerns about the quality of the support offered. It is worth highlighting the recently enacted law on autism, which aims to promote access, participation, and successful transition of individuals with autism within the education system while ensuring quality. As a result, it is expected that the difficulties faced by parents in finding appropriate support will be reduced.

Despite the necessary adaptations, there are external factors unrelated to the condition of autism that strongly influence decisions and trajectories. The proximity of the educational establishment and the presence of siblings or relatives play important roles in the

selection process. A significant challenge for parents is the lack of personal and institutional support networks, including municipalities, government programs, health centers, and more. And, even when sources of support are available, many parents recognize the need for integration and communication among these networks. Previous studies have highlighted the importance of support networks for reducing stress and alleviating the emotional and practical burdens associated with caregiving, in parents of children with ASD (Luther et al., 2005; Lu et al., 2015). Notably, parents are seeking institutional responses that go beyond direct support for their children, but also provide tools and resources for them to accompany their children's development.

Finally, the aspect of expectations are influenced by the specific characteristics of the children and the families' experiences with individuals on the autism spectrum. These experiences can be personal or influenced by public figures, such as football players. This finding highlights the importance of role models, which help shape a clearer vision of the future and the potential for various developments, such as pursuing different career paths instead of becoming a police officer. According to Dasgupta (2011), for marginalized groups, the decision to strive for further development can be hindered by a lack of representation, making it difficult to identify with peers outside these marginalized groups. Additionally, previous studies, such as the one conducted by Holmes et al. (2018), indicate that parents' future expectations for adolescents with autism are strongly influenced by their perceived IQ. Furthermore, these expectations shape the actions taken by parents to support their children.

4.6. Conclusion

Overall, one common thread that significantly influences various aspects of early education for children with ASD is the caregivers' biographical and immediate personal experiences. The influence of other autistic individuals, whether they are family members, peers of the child, or even public figures, often appears to shape future expectations and educational decisions more than considerations of the child's specific condition or diagnosis.

Moreover, factors such as convenience and proximity of schools become a priority not only because of the parents' material constraints, but also because, once again, there are no guidelines indicating what criteria should be considered during the selection of a school specifically for a child with ASD. Consequently, and in addition to the lack of resources such as transport, they are often guided by criteria very similar to those of parents of neurotypical children. However, biographical milestones such as ease and age of diagnosis, external events - such as the experience of divorce or the pandemic - and the very difficulties they face in the school system will also influence these criteria, restricting or expanding parental possibilities and, in turn, facilitating or hindering children's adjustment. Although all but one caregiver in the sample consider that their children are well adapted to the current institution they attend, it is important to note that the standards of what constitutes a good adaptation are also determined by previous experiences and require different levels of involvement from the caregiver. Thus, some parents consider it a good level of adaptation if the child can attend the establishment without feeling uncomfortable, while others are concerned about the child interacting with peers or their academic achievement.

In practice, the reliance on personal experience and the contingency of decisions is not surprising, considering that all parents, regardless of their resources and knowledge, need more support networks, particularly institutional ones. The absence of a unified and integrated system to guide caregivers of children with SEN and facilitate their therapeutic and educational journey makes pre-planning parenting decisions impossible. Without predictability and institutional tools to address specific issues and considering the high demands of raising a child with ASD, families are left with no choice but to rely on their own experience and find improvised solutions as challenges arise. Caregivers themselves recognize this deficiency, leading to their expectations for the emergence of a more systemic and centralized support, such as the Autism Act.

4.7. Regarding data credibility

In adherence to quality, trustworthiness and credibility standards (Brantlinger et al., 2005), and despite limitations in the field access, the sample of caregivers selected adequately reflected the conditions under study. The interview guidelines, developed by the interdisciplinary team, were clear and versatile, as evidenced by the participants' understanding and the variety of their responses, which showed no apparent biases. These were recorded using specialized equipment and transcribed verbatim under a confidentiality agreement.

Due to the exploratory nature of the study, emergent coding was utilized (Blair, 2015), aiming to deconstruct meanings with fidelity to the participants' voices (Drisko, 1997). As a first step, semantic coding was employed, annotating the precise description of each proposition (Braun and Clarke, 2006). These codes underwent a collective review and adjustment, enhancing trustworthiness through triangulation between the investigators. Any disagreements were easily resolved through open discussion, thanks to the explicitness of the codes (Chinh et al., 2019).

Subsequently, codes were grouped into broader thematic categories, following an indexing logic (Deterding and Waters, 2021). For instance, "child likes trucks" was classified under "child's personality," which was later included in the "child's characteristics" folder. These code folders were later structured according to the study's objectives and themes in order to ensure validity (Skjott Linneberg and Korsgaard, 2019). The team reviewed each of these steps, emphasizing reflexivity and collaboration.

In the final stage of results and conclusion formulation, various practices were implemented to ensure credibility, based on Brantlinger et al. (2005) criteria. Emphasis was placed on disconfirming evidence, leading to a detailed particularization and dense description of results, emphasizing both similarities and differences in each study area. From this detailed approach, the team collectively reflected on connections between themes, identifying recurrent patterns which led to analytical conclusions, such as the potential link between trajectories and referents.

Data availability statement

The datasets presented in this article are not readily available due to protecting the participants' anonymity. Requests to access the datasets should be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Comité Ético Científico de Ciencias Sociales, Artes y Humanidades from the Pontifical Catholic University of Chile. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

CM: Conceptualization, Investigation, Writing – original draft, Writing – review & editing. AD: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Writing – original draft, Writing – review & editing. RB: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare financial support was received for the research, authorship, and/or publication of this article. This research was funded by ANID PIE CIE160007.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/feduc.2023.1259428/full#supplementary-material>

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