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Normality, disability and special educational needs: Perspectives and experiences of caregivers of children in early childhood education

Normalidad, discapacidad y necesidades educativas especiales: Perspectivas y experiencias de cuidadoras de niños y niñas en la educación temprana

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Abstract

Inclusive education has been the primary route chosen for the education of students with disabilities or special educational needs in Chile. Nevertheless, accessing quality education involves navigating a lengthy journey and making decisions that become more challenging when choosing between inclusive or special education. The objective of this article was to explore the challenges and supports identified by caregivers of students with disabilities or special educational needs, as well as what adaptations they and their environments have had to incorporate for the full development of the children under their care. By employing a qualitative methodology, we conducted eleven semi-structured interviews and three ethnographic observations. The results emphasize the proactive role of caregivers in assuming administrative functions within the school community. However, the most notable aspect was their capacity for adaptation and reconceptualization regarding disability and normality, sometimes conflicting with those in their family environments and their own beliefs. This provides evidence of an innovative adaptation

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involving the reshaping of expectations and conceptualizations that impact educational trajectories.

Keywords: normalizing; persons with disabilities; special educational needs; inclusive education.

Resumen

La educación inclusiva ha sido la principal vía a seguir para la formación de estudiantes con discapacidad o necesidades educativas especiales en Chile. A pesar de ello, acceder a una educación de calidad, implica recorrer un extenso camino y tomar decisiones que se vuelven más desafiantes al deber optar entre una educación inclusiva o especial. El objetivo de este artículo fue explorar los desafíos y apoyos identificados por las cuidadoras de estudiantes con discapacidad o necesidades educativas especiales y qué adecuaciones han debido incorporar, tanto ellas como sus entornos, para el pleno desarrollo de los niños y niñas bajo su cuidado. Utilizando una metodología cualitativa, llevamos a cabo once entrevistas semi-estructuradas y tres observaciones etnográficas. Los resultados resaltan el papel proactivo de las cuidadoras al asumir incluso funciones administrativas en la comunidad escolar. Sin embargo, lo más notable fue su capacidad de adaptación y reconceptualización sobre la discapacidad y normalidad, siendo a veces contrarias a las de sus entornos familiares y a las propias. Esto evidencia una innovadora adaptación que implica la reformulación de expectativas y conceptualizaciones que inciden en las trayectorias educativas.

Palabras clave: normalización; personas con discapacidad; educación especial; educación inclusiva.

Introduction

Today, people with disabilities are recognised as individuals with physical, intellectual or sensory conditions whose interaction with their environment presents barriers that hinder their participation in society. (WHO, 2001). Under this definition, the social participation of people with disabilities depends, to a large extent, on the social context in which they live and the opportunities that society provides them with. (Kilinc, 2022).

In the field of education, inclusion has been chosen as the main way forward for the instruction of students with disabilities or special educational needs (SEN). Since the early 1990s, and especially since the Salamanca Declaration (UNESCO and the Spanish Ministry of Education and Science, 1994), inclusion has been chosen as the main way forward for the instruction of students with disabilities or SEN. (UNESCO and Spanish Ministry of Education and Science, 1994)communities have decided that the participation of students with disabilities in the regular classroom is the best way to educate them (Martínez and Rosas, 2022). (Martinez and Rosas, 2022). To this end, it becomes necessary for educational communities to implement modifications for the inclusion of students with disabilities. These modifications can range from the infrastructure of schools to incorporate students with physical disabilities, to modifications in the school culture that allow the incorporation of students, for example, within the autistic spectrum (Kurth, 2013). (Kurth, 2013).

Despite the positive evolution of the inclusive view of society, it is important to recognise that the origin of inclusion is also the source of a process of differentiation. That which is included must be included because of its difference. This categorisation has been reinforced by the medicalised view of disability, especially in the educational context, in which the diagnosis and rehabilitation of individuals is sought above other conditions of well-being (Barbosa et al., 2019). The definition of an other requires a contrast with what is considered "normal" or "expected" for society, which is the origin of a paradox whereby inclusion is also the origin of exclusion (Iturra, 2019; Wildemeersch and Koulaouzides, 2023)..

This dichotomous characteristic between the 'normal' or 'expected' versus the 'other' requires the establishment of boundaries that separate the two, which are largely determined by the social contexts in which individuals develop and determine inclusive policies (Ferdman, 2017; Nieto-Bravo et al., 2022; Skliar, 2005).

Thus, while some time ago it was considered inclusive for students with disabilities to study in special schools, given the educational opportunities they were offered, nowadays, their inclusion in regular schools is sought. However, such social characteristics continue to determine the distribution of diagnosis in some populations, because the "expected" is contextual (Forstner, 2022; Kilinc, 2022).

Considering this somewhat arbitrary definition of what is "to be expected", it is not difficult to imagine that there are "borderline" spaces where definitions become difficult. For example, students who, without a diagnosis, present difficulties (Roos, 2019). Moreover, experience has shown that those students who, despite having a diagnosis, have an "expected" behaviour in the classroom, are better perceived (and received) by different actors in the school community (teachers, families and peers). (Kilinc, 2022; Kurth, 2013).. On the other hand, those students who are perceived as difficult cases, generate resistance from different actors, even before their effective participation. That is, the closer the person with a disability is to what is considered "normal", the greater the willingness to include him/her. (Kvalsund, 2023).

The reluctance of institutions to include students with disabilities can be attributed, in part, to the need to find accommodations required for their participation (Graham, 2019; Kurth, 2013).. This is in addition to parents' fear that their non-disabled children's education will be affected by the inclusion of a student with a disability, for example, by changing the demands or speed of content delivery (Kilinc, 2022). (Kilinc, 2022). Likewise, the additional demands on teachers to adapt pedagogical and curricular strategies is also a challenge that generates opposition (Bunbury, 2020). (Bunbury, 2020).. Despite this, several studies have shown that those who benefit from an inclusive classroom are often the students without disabilities (Bruin, 2019).

All of the above-mentioned elements regarding the inclusion of students with disabilities and SEN in society and the education system are undoubtedly accompanied by efforts and challenges that must be made by the immediate environment, caregivers and families for the development and participation of these children. As well as educational establishments, families must incorporate adaptations that allow their children to develop to their full potential. (Dai and Carter, 2023; Matthews et al., 2021; Maul and Singer, 2009) and it is often they who request and promote their children's participation in the educational community and society at large (Boonk et al., 2018; Dan et al., 2023).They have difficulties in transferring their adaptations to the wider environment.

Furthermore, when it comes to childcare, the literature and statistics indicate that it is mostly based on the unpaid work of women, whether they are mothers, grandmothers or others (González, 2019). In Chile, for example, the Survey for Caregivers of People with Autism Spectrum Disorders also coincides in demonstrating the feminisation of caregiving, since 86.3% of the participants were female mothers (García et al., 2021). In addition, other studies point to the shaping of the identity and roles of caregivers. For example, Sousa (2011) observes that, in the case of mothers of children with intellectual disabilities, they construct a *warrior-hero* identity by battling against social policies and regulations in search of resources for the full development of their children. Similarly, O'Hare et al. (2023) conducted a literature review in which they highlight that mothers of children on the autism spectrum acquire different roles in the interactions that develop between them and the educational system. Among these roles, we can highlight that of negotiators, monitors, collaborators and advocates against the policies and inequities of the system (Stoner and Angell, 2006).

With all of the above, in the present study, we set out to explore the challenges and supports identified by caregivers[2] of students with disabilities or SEN in the journey from suspicion and diagnosis to the early stages of their school careers. We also explored the adaptations that caregivers and their environments have had to incorporate for the full development of the children. To this end, we conducted semi-structured interviews and ethnographic observations in order to answer the following questions: How do families perceive the different diagnoses of children in the context of the relationship between normality and disability? To what extent do the adaptations made in families extend to schools, and are the adaptations incorporated in schools also implemented by families?

Methodology

Method

This study is part of a descriptive and exploratory qualitative research, part of a broader study that sought to understand the early educational trajectories of students with SEN and disabilities. An ethnographic approach was adopted (Guber, 2015) by considering the importance of language and its reflexivity in the discourses of the participants, allowing access to the practices and knowledge put in place in the decision-making process of the children's educational trajectories.

The fieldwork took place between December 2022 and August 2023 in the city of Santiago de Chile. Data were collected through observations recorded in field notebooks and interviews with primary caregivers. The information from the field notebooks and interviews was subjected to analysis through the application of grounded theory (Charmaz and Belgrave, Charmaz and Belgrave, 2006). (Charmaz and Belgrave, 2019; Glaser and Strauss, 2017).

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[2] Feminine pronouns will be used in preference, as the sample consists mostly of the mothers, grandmothers or aunts of the children in question.

Participants

Ten caregivers and one caregiver of children with disabilities or SEN participated. Specifically, 7 cases of autism spectrum, 1 of visual impairment, 1 of hearing impairment and 2 of multiple disabilities were addressed, with diagnoses of hydrocephalus and microcephaly, respectively.

At an initial stage, contact with participants was established on the basis of a sub-sample derived from the study "Mil Primeros Días" (Narea et al., 2020), conducted by researchers from the same Centre to which the authors belong. The selection of participants was based on specific criteria, including confirmation of a diagnosis reported by the caregiver, previous attendance of the child at a school or care facility, and enrolment or acceptance in pre-kindergarten to first grade at the time of the fieldwork.

Given the difficulty in finding participants from the aforementioned study, and in order to achieve greater diversity, we proceeded with an open search through dissemination in social networks and schools using the snowball technique (Reales et al., 2020). (Reales et al., 2020).. This made it possible to contact two educational institutions (one inclusive and one special), which facilitated contact with four family members who agreed to participate in the study. The sample was formed as shown in Table 1.

Table 1

Socio-demographic characteristics of the sample

Name	Age	Educational level	Social Priority Index (SPI) [1]	Relation	Age child	SEN / Disability	Technique
Alba	65	Secondary school completed	High PS	Grandma	4	DV[2]	Interview
Nora	35	Secondary school completed	Low PS	Mother	4	DA[3]	Interview
Eva	26	Senior technician complete	Low PS	Mother	4	TEA[4]	Interview
Mia	30	Secondary school completed	Low PS	Mother	4	TEA	Interview and observation
Lia	33	Senior technician (c)	Medium-high PS	Mother	4	TEA	Interview
Celia	22	Senior technician complete	High PS	Mother	5	TEA	Interview and observation
Inés	35	Secondary school completed	Low PS	Mother	6	TEA	Interview
Olga	34	Full university education	Low PS	Mother	5 y 5 [5]	TEA	Interview

Ivan	37	Full university education	Without PS	Father	5	TEA	Interview and observation
Gala	40	Secondary school completed	Low PS	Mother	6	Hydrocephalus	Interview
Ana	42	Full university education	Medium-low PS	Aunt	6	Microcephaly	Interview

Note: [1]SEREMI Ministry of Social Development and Family (2022). [2]Visual Disability. [3]Hearing Disability. [4]Autistic Spectrum Disorder. [5]Corresponds to twin brothers.

Strategies

Two techniques were used: interview and participant observation. In the case of the interviews, a semi-structured script (Adeoye-Olatunde and Olenik, 2021) was designed based on a literature review in the areas of disability, SEN and early childhood education. For the search, we filtered by year, between 2015 and 2022, and used English terms such as: transit, preschool, school, special education, caregivers, hearing impairment, visual impairment, intellectual disability, and autism. In addition, terms such as: secondary education, adult life, college, employment, graduate, degrees, and vocation were excluded from the search. This review was carried out in the following databases: WoS, Scielo - WoS, Scopus, *Education Database*, *Education* (JStore) and ERIC (USDE), yielding a total of 298 results, reduced to 202 after eliminating duplicates.

This bibliographic review allowed for the construction of a theoretical framework that served as the basis for the design of the script, which was organised into 7 thematic axes: Characterisation of the family nucleus, pregnancy and early years of life, support networks, educational trajectory, application and knowledge of the School Admission System (SAE), future expectations, and educational institution: support and adaptations.

The duration of the interviews ranged from 40 to 90 minutes, in some cases requiring a second interview, specifically during the application and enrolment period (December-January), when caregivers were immersed in the decision-making process and had not yet moved on to or experienced a new school level.

Each interview was audio-recorded and recorded in a field notebook, allowing for verbatim transcription and the creation of ethnographic accounts. These accounts were complemented by participant observation records, documented in the same way, and carried out with 3 of the 11 participants, who were accompanied during the journey from home to school or vice versa. The limitation in this participation was due to the fact that, on the one hand, some caregivers choose schools very close to their homes, without having to make long journeys. On the other hand, some participants did not give their consent to be accompanied during the journey, generally on the grounds of time constraints. The observations were carried out respecting individual routines, minimising interruptions on each journey. However, we recognise the inevitable alteration of the space being observed, which is why we consider it to be an observation with active involvement, where the aim is to alter the routine as little as possible, but still participate in it. (Guber, 2015). These observations were not video- or voice-recorded;

instead, field notes were recorded to allow their systematisation in a predefined observation guideline that considered six dimensions: actors, contexts/situations, interactions/relations and dynamics, space/physical environment, difficulties, and observed facilities.

Procedure

This research was carried out by a multidisciplinary team from biology, sociology and anthropology. This diversity favours a constant reflexivity and an approach to the topic from different perspectives. It is important to highlight that only one of the researchers had previous experience in the topic of study, while the others had to carry out an exhaustive bibliographical review to familiarise themselves with the subject, which provided interesting perspectives, but also challenges inherent to immersion in a new field of study.

As mentioned above, the instruments used were designed on the basis of a literature review and were tested in the first interviews, allowing them to be restructured or checked, adjusting them to delve deeper into the subject of the study. This process was carried out after a review of the first findings obtained, allowing for constant reflexivity at individual and group level. All instruments used are available on request by contacting the corresponding author.

The interviews were carried out in the premises that were most comfortable for the participants, who were free to choose the location. Thus, 10 interviews took place at home, while 2 took place in the children's educational establishments.

The formulation of the study was reviewed and approved by the Scientific Ethical Committee of Social Sciences, Arts and Humanities of the Pontificia Universidad Católica de Chile. For each technique used, the participant had to explicitly give her approval by signing an Informed Consent document sent before each encounter. Identities were protected by the use of pseudonyms.

Analysis of the information

The data analysis was carried out by forming categories and codes inductively, as they were constructed as the data were collected and analysed. (Duarte Quapper, 2022).. Following the grounded theory, categories and codes were elaborated from the concepts provided by the participants, relating those that were similar and consistent with the research objective.

Eleven categories were constructed using Atlas.ti software (vs. 23.3.4.28863): Characteristics of the family nucleus, pregnancy period, diagnosis, early years, adaptations at home, pre-school education, application to educational establishment, experience in educational establishment, support networks, idea of normality, and expectations for the future.

The analysis and elaboration of categories was first carried out by one of the researchers, and then reviewed by another, resulting in the conformation of the aforementioned categories, after being agreed upon by the research team.

Results

The diagnostic pathway

A first aspect to be explored in the educational trajectories in question concerns the moment when a diagnosis is received, which determines the decisions that caregivers make about their children's education.

Three points in time were identified at the time of diagnosis: During pregnancy - At birth - Months or years after birth.

In the first case, reactions of surprise and sadness could be observed, albeit followed by a period of acceptance and preparation, probably because of knowing in advance what to expect:

> *She was born with hydrocephalus, which was detected at 12 weeks' gestation. So, I didn't even have a "guatita" [pregnant belly] and I saw a prognosis and a very uncertain outlook, where it was obviously a very negative diagnosis*. (Gala)

> *[My gynaecologist] told me that everything was going well, but that I was going to have a sequela because of everything I was going through. And he told me that one of the consequences could be neurological or physical. And that's when I kind of said: Ah, now. You have to prepare yourself for what's coming* (Eva).

In one of the cases, the diagnosis was given at the time of delivery, but it was carried out in a cumbersome way and without being properly communicated to the mother, who asked about her child without getting answers: "They had already taken him out, but I didn't see him", so the impression caused her to be shocked: "I was left in a daze [...] I took it as if it was a few days later" (Nora).

Diagnoses given after birth also meant difficult reactions for caregivers, being compared in the discourse to death or bereavement:

> *[The doctor] told me: "he has a tumour in his eye, so we have to take it out, because if we don't take it out, it will go straight to his brain and he will die" [...] We wanted to die here [...] For us it was terrible.* (Alba)

> *I had a hard time with the father. He went through three years of mourning. Three years it took him three years to accept that his son was [sic] ASD, that he was not the same as the others.* (Eva)

Specifically in cases of children on the autistic spectrum, the diagnosis is often made after a long search to understand what is happening with the child's behaviours, who, as Eva points out, does not appear to be "just like everyone else". It is interesting to note the constant comparison made by caregivers in terms of the opposition between normal/weird. In fact, in some cases, it was possible to observe a moment prior to the diagnostic suspicion, where infants are described as "normal" until certain behaviours that are not expected become more and more evident:

> *He was a normal baby, he did what a normal baby did until he was eight months old. From then on, he became mute. From one day to the next he never spoke again* (Celia).

In other cases, however, the cause of strangeness was evident from the outset:

> *When he was little, nobody could take him [...] Since he was born, I found many strange things in him, because he was a child that could not be taken, that I could not breastfeed* (Lía).

This same terminology was sometimes used to point to the child's evident developmental progress, with emphasis on his or her intelligence over other children or his or her greater-than-expected progress:

> *You see them now and it's like she has nothing, really. It was super, hyper-magical everything that was going on with her. Even though she wasn't supposed to do anything, she does everything. Obviously, in a secondary way. Because there wasn't a normal development of her brain, she has a neurological delay.* (Gala)

Meaning of diagnoses and environment

The particular realities of caregiving impact not only the trajectory of the diagnosis, but also the meanings and reactions associated with it.

Although there is initial surprise across the board, those who already recognised abnormal behaviour accept the diagnosis more readily:

> *I realised that [my son] needed attention... And [he] sometimes doesn't behave well and not everyone sees him like that, normal. So I still went prepared, I knew what I was going for* (Celia).

In some cases, there was even relief that there would be no greater divergence than expected:

> *What mattered to us was that he didn't have a physical disability, because it was going to be more difficult for him to adapt to a radical change in the house, it was more difficult*. (Eva).

It was also observed that caregivers with prior knowledge about SEN or disability were more likely to accept the diagnosis, demonstrating an ability to promptly initiate the search for appropriate therapies or institutions. It should be noted that this knowledge does not necessarily refer to technical skills, but rather to a practical understanding based on the experience of knowing other people with special needs:

> *For us, as difficult as it was, it wasn't [...] My brother has Down's Syndrome, so, for us, it's not that we are distant from this as an issue [...] We accepted it easily, because we said: There really isn't much that can be done, more than anything to understand it and try to see how to deal with everything that happens to him.* (Mía)

On the other hand, in more than one case there was even evidence of a denial of the diagnosis, when certain behaviours were not initially perceived as atypical and therefore the diagnosis was presented as an acknowledgement of a divergence from the norm.

> *What do I know about ASD? A child sitting in a corner, bent over and doing nothing. For me that was an autistic child [...] And then I came home, I was hanging clothes and I dropped one*

> *of my clothes. And one of my children came and picked it up and handed it to me. And that's when I said to myself: My son doesn't have autism.* (Olga)

> *When they told me that [my son] had to wear hearing aids, I said no, because [he] could hear me [...] And then, when it was different, when he got his hearing aid the first time [...] that's when I started crying, because I said no. I fought with the doctors. I fought with the doctors* (Nora).

The diagnosis is therefore associated with a connotation of abnormality that is accepted to the extent that it coincides with one's own conceptions of normal/abnormal. It carries a negative emotional charge because of the difficulties that are anticipated. For example, Ana states that facing the diagnosis was not "terrible", but "that the impediments are the ones that make me angry", i.e. the difficulties she will have to face as a result of the disability.

The negative reactions of the close environment are also influenced by the rejection of the diagnosis as a recognition of abnormality which, in their eyes, is not justified. This applies both to close relatives involved in the upbringing and to more distant relatives, who even mistreat or blame the caregivers.

> *For my mum it's: "They're melted [spoilt]" [...] "They're not ASD children, they're titty children" [...] Which is like: "Yeah. They're meltdowns. They're going to grow out of it"*. (Olga)

Faced with this situation, some caregivers say that they are constantly working at the family level to gain acceptance of their children. However, in some cases this has not been possible and they have opted to break off relationships.

> *They think that his crises are bad habits, that he is spoiled [...] With them it has been harder for me. And it has cost me to stop seeing them, to stop sharing, that [my son] doesn't even have contact with cousins because of the same thing [...] The moment came [when] it wasn't like not accepting him, it was like humiliating him.* (Eva)

> *But the one who has had a hard time and still doesn't understand, [is] the father [...] [He says] "No, but the child is normal", that I don't know what. That I treat her as something different, that the child is normal, that the child is normal*. (Mía)

Decision-making in educational trajectories

The choice to initiate the search for a care facility, such as a nursery, or an educational centre, such as a kindergarten or school, is influenced by factors linked to the findings described above, such as notions of normality and conceptions of disability.

Three positions were identified with regard to this decision-making: Reluctance to seek a facility out of fear - Seeking a facility to restore normality - Seeking a facility to reinforce skills.

In the reluctant cases, it was noted that caregivers' fear could originate for two reasons. On the one hand, the fear that the children would be teased because of their condition or appearance.

> *I didn't want to put him in any kindergarten. Because... There are children who are cruel, and the child was missing his little eye [...] I would come by bus, by metro - because there was no*

> *way to get around - and sometimes a child would pass by: "Oh, the little boy, look at the little boy, the monster". Then the child felt bad*. (Alba)

On the other hand, the fear that the child would not be able to fulfil the expectations for his or her stage of life due to certain characteristics - especially cognitive - of his or her condition.

> *My mum used to say to me: "You need a garden". I was like... My first child, I wanted to have him there, next to me [...] It was like I was afraid... I don't know. As he didn't speak, I was afraid to send him to the kindergarten and he wouldn't do anything*. (Inés)

The cases that sought a facility in order to restore what is, again, called "normality" were motivated by the desire to regain life before care. More specifically, the hope was to be able to return to work, as caring for these children often becomes a full-time job. Therefore, when asked about the reason for looking for a garden, Ana pointed out:

> *To see if my sister [the mother] could have a more normal life and have a job in that schedule [...] I imagine all the mothers who take care of these children, the dependents, if they don't accept them in a garden, what schedule do you have time to work?* (Ana).

Finally, in cases that sought to strengthen children's skills, specifically in the areas of social and language, many caregivers mentioned having initially considered a language school, only to find that such institutions do not accept children with a diagnosis or suspected diagnosis. According to Eva, "they don't receive any child with a diagnosis, because they are not trained for that, despite having speech therapists" and other specialists.

> *When he was 2 years old I decided to take him to see how I could help him, because he was already a bit delayed, unlike the other children [...] I wanted to put him in a language school, because he didn't speak... [But] I did my internship in a language school and I understood that there couldn't be children with a diagnosis or suspicion*. (Celia).

In other cases, caregivers received direct suggestions from the institutions that provide therapy for their children, whose recommendations pointed directly to facilities that are able to meet their needs.

> *We started with the Teleton and they also started to suggest to me that [my daughter] needed structure, that she needed to learn more, that she needed schooling. [...] From the Teleton they suggested this school to me, because my daughter is secondarily visually impaired - she is not blind, but she does have corneal leukoma - [...] And it was wonderful, because not a "but", quite the opposite*. (Gala).

This case contrasts with what happens in language schools and raises a scenario in educational decision-making that, again, is accompanied by fear, this time linked to the choice of alternative routes in education, specifically the path of special education.

> *There is a lot of fear on the part of parents to send them to school [...] they are afraid of special schools, that's why I think people look for the integration programme a lot, I don't know if it's not to not accept the condition, but rather because it scares you [...] because for some people it's like saying: "No. My child is not so fucked up [sic] as to go to a special school"*. (Gala).

Adaptation strategies

Cooperation between institutions and caregivers was observed, where caregivers are key participants in enabling schools to adapt to the needs of their children. However, this relationship does not seem to be the other way around, as school accommodations rarely influence the accommodations implemented by families.

This does not mean that schools do not have their own adaptation strategies and initiatives, both as part of Inclusion Programmes and other flexibility policies for specific needs, such as the use of nappies or dietary restrictions. In general, these adaptations are restricted to the school reality, as they are designed to enable children's participation within schools, rather than to support their holistic development.

Moreover, as parents' experiences show, this adaptive capacity is shaped by resources and culture, but also, in large part, by the level of disruption to the functioning of the setting, be it inclusive or special education.

This is where the strategies that caregivers develop to support and compensate for school deficiencies in the face of their children's specificities play a critical role. The accounts show that even in experiences that are considered positive, in many cases the school's adaptations require the active participation of the caregivers:

> *The [educators] would call me on the phone to tell me how they could do it. And until I showed them how to do it. I told them: "When the stuff you take out of the child's eye falls out, you clean it like this, you put a little cream on it".* (Alba)
>
> *If I talk about it, yes [...] Because if I don't know what to do or if I don't approach the teacher, they won't have any idea what to do. They don't know who to go to either. (Mía)*
>
> *The aunt said to me: "He doesn't seem to hear well". I said: "Yeah, I'll go and check it [the hearing aid]". And sure enough, it was the battery that had run out* (Nora).

These stories show that, despite the training that teachers may have, dependency on female caregivers persists, and in some cases they must always be available when the school has difficulties in taking care of their children:

> *Yesterday the [educator] called me. She told me: "No. I'm alone. The technician [sic] didn't come, she had a problem and they're going to have to come and get him" [...] so how is it? If there is no technician, doesn't my child go to class?* (Celia)

Many school policies involve caregivers, such as allowing the caregiver to join the child in the classroom or enrolling as a shadow tutor. But there are also forms of adaptation that tutors take on their own initiative to facilitate school integration:

> *I stay with [my son] playing, waiting for 08:00 to leave him in the classroom. And that helps a lot so that [he] also feels comfortable at school.* (Iván).

Conversely, there are cases where caregivers' opinions are not taken into account, even if they are good ideas that could have a positive impact on their children's school experience:

> *It is when he sees other children playing in the common playground that [her son] gets "disoriented" and so he runs around, throws himself on the ground, etc. She thinks that maybe, if they let him into class a few minutes later, without all the chaos at the entrance, it would be very different. Even at this time, when it is 13:15-13:20, there are no more children or tutors around, so it would be a good entry time.* (Ethnographic observation, 20/07/2023, Celia).

A particularly critical adaptation in this regard relates to transport. Those caregivers who do not have facilities, such as Ana, report the risk of illness for their children due to the cold in the mornings. On the other hand, in the case of Iván, although his son enjoys travelling by public transport, it is noted that "*the car, despite the changing traffic, is clearly a huge facility to be able to make a long journey*" (Ethnographic observation, 28/06/2023, Iván).

On the contrary, in Mia's case, it shows how many adaptations caregivers have to make in order to be able to travel between school and home:

> *Mía has a series of strategies to cope with transport problems: getting on at the other bus stop, using the bus that is not so full and, in case of rain, going to pick [her daughter] up earlier.* (Ethnographic observation, 28/08/2023).

Finally, some caregivers seek to influence wider school policies. This is reflected in cases such as Eva, who suggests a safe space for support, but also in parents such as Iván and Ana, who even participate actively in the community and the Parents' Centre with the aim of facilitating the school's work with their children:

> *This Parent Centre works to improve the quality of teachers. That is our focus. Because, if they are well, [...] as a consequence, our children will be well*. (Ana).

Thus, despite the varying capacities of schools to care for children, the importance of access to resources for caregivers is highlighted, who must respond to specific demands that cannot be compensated for by more general adaptations.

Discussion

Different understandings of the concepts of disability, what is expected or normal have become evident. For example, in cases where a diagnosis was not available from birth, the long and uncertain path that caregivers have to go through once they identify certain abnormal behaviours in their children was evident, going through what is expected and what is not expected. Echeita et al. (2021) call a "diagnostic pilgrimage". The results show that this pilgrimage not only leads to the rejection or confirmation of maternal or paternal doubts, but also generates a transformation in the conception of the aforementioned concepts, all of which are implicitly or explicitly questioned as behaviours that escape the norm are questioned, denied or understood by caregivers, their environment and society.

Whether they thought of their children as "a child sitting in a corner, bent over and doing nothing" (Olga) or that they thought that "they would do nothing" (Gala) because of their neurological impairment, their current accounts reveal a great satisfaction in having overcome those expectations.

These results show that concepts of normality or the expected are not immovable, but rather are shifting or "running" (Kvalsund, 2023). (Kvalsund, 2023) along different axes of understanding and analysis according to the context in which they are developed. Thus, the definition of diagnosis and its impact are determined by the social and cultural context at different levels.

In contexts where SEN are heavily medicalised, diagnosis requires medical consensus that varies over time, according to the advances in knowledge and medicine (Barbosa et al., 2019; Green et al., 2019).. This diagnosis is subsequently interpreted by society and educational institutions according to the historical context and the visibilisation of the specific conditions of each case (Ferdman, 2017; Kvalsund, 2023; Skliar, 2005).. An example of this is the implementation of educational and urban policies for inclusion (Irarrázaval, 2023; Martínez and Rosas, 2022).

At the level of families, diagnosis is a fundamental moment that defines the educational spaces that can be accessed, which in turn shapes the expectations of the environment about the child's future (SSánchez Bravo and Pérez Godoy, 2021).. In these educational spaces, family experiences are combined with regulations, as the support they will receive is defined by the educational system and the regulations in force.

Finally, in the intimate context, the reception of a diagnosis depends strongly on the socio-cultural context and previous experience with similar conditions. At this last level, the results show that, within the same family nucleus, different approaches can be faced, even between parents. Despite shared parenting, it is sometimes more difficult for the father to accept the condition of disability, resorting to the reinforcement of the characteristics of normality present in the child.

It is clear that different levels of analysis of disability refer to different representations of normality. Sometimes these definitions are clearly aligned, but at other times, experiences strongly modify perception, altering the normality/difference relationship. (Kilinc, 2022). The results presented allow us to understand that the boundaries and definitions of the other and the normal are not only given by social contexts (Ferdman, 2017; Kvalsund, 2023; Skliar, 2005)but also by local, family and relational contexts which, in addition, are mobilised and modified throughout individual biographies, changing not only what is understood by each concept, but also expectations and attitudes towards children's disability or needs.

As for Kilinc (2022)the parents' negative reactions to their children's potential 'abnormality' are primarily based on their concerns about the difficulties it would cause for their lives and especially for their education. These concerns are not unfounded since, even in positive experiences, it is found that caregivers are primarily responsible for promoting and demanding the integration of their children in the educational space (Dan et al., 2023). (Dan et al., 2023) when their specific needs are not met by available inclusion strategies.

Particularly common is the assistance of caregivers in prosthetic care or crisis management, who become experts in the field (Echeita et al., 2021). (Echeita et al., 2021).. There is, however, significant pressure to take on this role, as in many cases the facility does not have the capacity to respond without their support. In fact, in the face of eventualities, the main response of schools is to call on caregivers, which positions permanent availability as one of the many adaptations needed from the family environment (Matthews et al., 2021; Maul and Singer, 2009).

Beyond these adaptive responses, many parents are proactive in assisting the process of educational integration, for example, in actively participating in administrative roles in the school community, which allows them to influence and facilitate the adaptive work of the institution. Thus, caregivers assume and internalise a key role in compensating and facilitating schools to adapt to the specific needs of their children when general adaptations are insufficient for their degree of divergence from normality, or their departure from the 'expected' (Kurth, 2013). (Kurth, 2013).

Conclusions

From the present research it has been observed that the concepts of normality and disability in the context of special educational needs can be dynamic and are shaped by social and cultural contexts, as well as throughout the life of each individual. In this way, carers face a process that redefines their initial expectations and reconfigures their understanding of disability and normality. Therefore, future research in the area, as well as public policies that address inclusive education, need to consider flexibility and conceptual diversity in definitions of disability.

In addition, caregivers play a fundamental role in promoting, educating and demanding inclusion at the educational and family level for their children. Therefore, one of the main contributions of this study is the identification of the dynamism and variability in the acceptance and understanding of disability and normality within families. In addition, the proactive role of caregivers who stand out as experts in managing the specific needs of their children, and in some cases, their active participation in school communities as a crucial practice to achieve what is expected from educational inclusion. However, this also generates a dependency on the part of the schools towards the caregivers, a practice that has a negative impact on their daily lives and that stands out as a line of research that would be interesting to develop in the future.

Thus, it is imperative to strengthen research on the role of families - especially women - in ensuring the effective educational inclusion of children with disabilities or SEN. This is necessary both to provide them with greater support and resources to enable them to play their role effectively and sustainably, avoiding further overburdening and promoting the responsibility of institutions in making the necessary accommodations for the inclusion of children with disabilities or SEN.

This study should also be understood as a contribution to inclusive educational contexts, where non-disabled students often benefit more than disabled students. (Bruin, 2019). It is relevant to understand how the conceptualisation of disability operates and how concepts of what is normal or expected move in different spheres, as this benefits the entire educational community, challenging categories and expectations that are often considered immovable.

Furthermore, although in these educational contexts the additional demands on the teaching teams have been highlighted, the results show a concern and an active role on the part of the caregivers to achieve a teacher's well-being that will eventually positively affect their children. The question is to find a balance between the burdens and responsibilities of each actor influencing the educational trajectories of the children in question.

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