RESEARCH

Why Privilege a Single Form of Communication if there are Many?

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In a time full of discourses of diversity and inclusion, our daily lives are shaped by social demands linked to standards of bodily integrity, competence, and independence. In this article, we analyze the emergent categories related to speech, language, and communication from critical perspectives to question the oppression of children with difference/disability. Analysis of parents' narratives show how oppression is carried out by an ableist system that imposes regulatory standards for verbal language (VL) that must be met with the application of rehabilitation technologies, although they are not accessible to the children. Challenging this reality involves presenting families and professionals with narratives about different ways of being-in-the-world and communicating using the diverse semiotic repertoires that are part of life. This requires a practice based on ontological reflections to rethink our ideas about the meaning of being human, the relationships we build, and the worlds we can weave when we experience difference/disability.

Introduction

We live in a time full of discourses advocating diversity, inclusion, and free choice, yet our daily lives are largely shaped by social demands linked to discourses and practices of ableism marked by standards of bodily integrity, competence, independence as conditions for a satisfying and productive life. Consequently, we end up erasing differences, because any way of being, existing, communicating, and interacting, either individually or collectively, is being judged from predetermined categories that define whether we achieve the expected ideal as human beings (Davies 2014).

Young people in Latin American countries do not escape this reality. In Colombia, where 31% of the population is under 18 years of age, the government has been increasingly developing policies aimed at this group over the past decades. This includes child care policies based on quality assurance discourses and practices that implicitly or explicitly carry ideal developmental standards imposed by international organizations (Dahlberg, Moss & Pence 2013; Davies 2014; Pava-Ripoll & Granada-Echeverry 2016). The ideals of what it means to be a successful and desirable human being also circulate in open spaces like television and marketing. These types of scenarios generate constant tensions between realities and the proposed ideals and are intensified in vulnerable populations, especially in countries with marked social, cultural, and ethnical diversity, such as Colombia.

This entails an unfruitful state of affairs in which families and child care professionals are trapped in debates and contradictory practices that are rarely taken into consideration in academia, social environments, education, and health care services. In this context, children with limited or no access to verbal-language-based communication, which we will refer to as verbal language[1] (VL), are expected to achieve, at some level, those ideals. As a result, their families undertake a relentless search for specialized techniques that will bring their children to produce VL. Because the emphasis of the search is on the production of VL, the significance and validity of other semiotic repertoires that are accessible to and used by children is not fully considered. As a consequence, families and professionals undervalue children's different and unique ways of being and communicating.

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[1] We understand verbal language as a structured system of linguistic signs that functions according to fixed rules. Verbal language is expressed through the different languages in their spoken, signed (sign language), and written modalities.

In this article we analyze the emergent categories related to speech, language, and communication from critical perspectives to question forms of oppression of children with difference/disability[2] and their families. In particular, we question the dominant ableist assumptions that lead one to think of VL as an essential feature of being fully human, as the ideal communication system and means of self-realization, even in children labeled as having severe disabilities. The analysis is part of a research study that addressed the question how to transform, in a collaborative work with families, the communicative interactions between parents and their children with communication-related disabilities. The application of the concept of internalized ableism made it possible to see through the analysis of the parents' narratives the oppressive experience of these children, as they have been subjected for years to the application of rehabilitation technologies with the assumption that they would overcome the impairment and finally enable 'normal' VL.

During the research, and most strongly in the analysis stage, the researchers' positioning made more sense from the intersection of the poststructuralist positions of childhood developed by Dahlberg, Moss, and Pence (2013); Davies (2014); and Moss (2014, 2019) on the one hand and the critical disability theory approach of Campbell (2001, 2009) and McRuer (2006) on the other. The analysis reveals the interconnections that exist between cultural narratives of childhood and disability and their intertwining with an ableist ontology and epistemology. The first authors made it possible to question the narratives that see childhood as a preparation period shaping generic individuals who may later become integrated into the dominant socioeconomic system. In this scenario, when children do not achieve the expectations of VL set by society, the ideal of becoming a competent human being is put in tension because any deviation is an undesirable condition. Instead, these authors propose viewing children as heterogeneous, as unique, and as beings that permanently transform themselves in their relationships with others.

On the other hand, critical theory developments, in particular those related to ableism, allowed for a deeper analysis of the oppressive experience of children for whom VL is not accessible. Ableism, understood as a network of beliefs, processes, and practices through which the corporeal standard is produced (Campbell 2001), led us to question, in the narratives of the children's parents, the privileged place given to VL, which is considered an essential feature and a necessary condition for the children's self-realization, and its absence, due to their difference/disability, is considered inherently negative. The concepts of internalized ableism (Campbell 2009) and able/bodiedness (McRuer 2006) helped us understand that bodies and minds that do not respond to the parameters considered typical of the species, due to disability, are oppressed. People with disabilities experience oppression because society constantly marginalizes and devalues those who are different. Therefore, disabled bodies that fail to meet standards of independence and control are further stigmatized and devalued (Fritsch 2015). The parents' narratives show how the oppression of the children in the study is carried out by an ableist system that imposes regulatory standards for VL that must be met with the application of rehabilitation technologies, even if they are not accessible to the children. Therefore, we have an ethical obligation to ask ourselves about the effects of ableism on children with disabilities and to think of alternative ways of listening and understanding their difference/disability using other ontological and epistemological positions.

Methodology

Our personal life stories as a mother of a child with a disability (Nora Aneth) and a person with visual impairment (Nora Lucia), combined with our professional training (speech therapists), challenged us to think about research methods that would allow us to learn about the experiences of parents whose children do not have access to VL. As university professors, we were interested in opening a path for academic work from critical disability studies in our field. For this reason, we proposed qualitative research with a narrative perspective (Bolivar & Domingo 2006) to explore parents' experiences, how they live their lives, and how they resolve communication issues with their children. The aim was to carry out collaborative work in which the exchange of knowledge and experiences would also contribute to transform the communicative interactions according to the parents' priorities and the singularities of the children. Our intention was to illuminate innovative ways of professional practice that promote respect and foster different ways of being and becoming for children with a difference/disability and their families.

Participants

The research participants were three mothers and two fathers of two girls and a boy categorized as different/disabled who attended a neurorehabilitation center in the city of Cali, Colombia. Names have been changed due to ethical considerations. The narrative approach allowed us to learn about the forms of interaction and communication the parents had with their children (Nati, Sofi, and Pedro).

Camila and Mauricio, 37 and 47 years old, respectively, are both professionals and the parents of Nati, a 3-year-old girl. Camila decided to run a small home-based business so she could devote her time to caring for Nati, who requires constant assistance to meet her basic needs. Mauricio, being an employee of a company in the city, works away from home and returns at night. In the family's daily life, Camila shares the day with her mother and another older daughter,

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[2] A linguistic device that acknowledges difference as a primary feature of all human beings but maintains the category of disability for political reasons in order to defend the rights of persons with disabilities (De Schauwer et al. 2018).

who sometimes helps with Nati's care. Camila has a sister with a 4-year-old daughter who lives near her home. During the investigation, they became important support for Nati.

Raquel and Juan, 30 and 33 years old, respectively, are the parents of Sofi, a 4-year-old girl, who is their only child. Raquel has postponed her plans to finish her university studies to devote herself to Sofi's care. Juan is a shopkeeper; his job forces him to be away from home for long working days. They have no support network for Sofi's care, because Raquel has decided to distance herself from her family as she does not share her family's views about Sofi's disability. Juan's family lives in another city and has very little contact with them. While the study was taking place, Sofi entered an educational institution. This was a priority interest for Juan, not only with the intention of opening other spaces of socialization and learning for Sofi, but also so that Raquel would have more time for herself and could even resume her project of finishing university studies.

Cielo, 39, is the mother of Pedro, an 8-year-old boy. He has been in school since he was three and a half years old. Although Cielo is married, her husband decided not to participate in the research. In fact, Cielo said that they spend very little time with her husband, because he works outside the home, leaving early in the morning and returning late at night. After work, he spends time at his mother's house, which is very close to their own. On weekends he plays sports, so he spends very little time with Pedro, despite Cielo's constant insistence that he do so. Indeed, Cielo's accounts indicate her husband provides little support for Pedro's therapeutic, educational, and parenting decisions. It is Cielo's father who appears to be her greatest supporter and whom she often visits with the child.

Procedures

The collaborative work encounters with the participants, in which the narratives were collected, were held individually or in pairs, according to the availability of each family, with a duration of 45–60 minutes. These meetings created an atmosphere of trust and cordiality that allowed parents to share their private family world in relation to routines and forms of communicative interaction with their children. The meetings were organized in two main phases:

In the first phase, we learned about the family's concerns, needs, expectations, and resources related to their child's communication. Based on this recognition, we established agreements for collaborative work and discussed possible alternatives that the parents considered could be implemented in daily activities. During this initial phase we held two meetings with Camila and Mauricio, two with Raquel and Juan, and two with Cielo, for a total of six meetings.

In the second phase, accompaniment was provided for the transformation of communicative interactions through periodic meetings guided by an agenda in which a joint analysis of the experiences was carried out and natural supports were considered for each particular case. We held 3 meetings with Cielo, 3 with Camila, and 4 with Raquel, for a total of 10 meetings.

The purpose of the last meeting was for the parents to analyze what the collaborative work had meant for them and their children, as well as to gather their suggestions. For this purpose, a collective meeting was held, attended only by the three mothers, where they shared their experiences. The strategy used was a conversational narrative (Estupiñán Mojica & González Gutiérrez 2015; Norrick 2000; Pava-Ripoll 2015), which made it possible to evoke routine events in a conversation in which mothers shared situations about the difference/disability of their daughters and son. The intention was that this conversation would allow a mutual listening that would contribute to reconstructing and adding meaning to the lived experience.

The technique consisted of forming a conversation group around a round table to facilitate an exchange in which they could look at each other. The mothers were invited to talk about their communicative interactions with each of their children in relation to concrete experiences of daily life and their impressions of the weaknesses and strengths of the work done. They guided the entire conversation, moderated the turns, and finalized the topics and the conversation itself.

Analysis

The analysis of the information was supported with the use of Atlas.ti 8.15.1 software. Each meeting with the parents was recorded for subsequent orthographic transcription. The analysis was carried out while we collected the narratives; this was fundamental because of the collaborative emphasis of the work with the families. During the analysis process, we used various analytical tools (Strauss & Corbin 2012). For coding we proceeded with the following steps (Creswell & Poth 2018): 1) Careful reading of all transcripts at each stage of the collaborative work. 2) Information cleaning, which was guided by the question 'Are there parts of this transcript irrelevant or not usable for the purpose of the research? This allowed us to exclude repeated or unnecessary information. 3) Information reduction, performed through immersion in the information with repeated readings of the transcripts to obtain the overall meaning. Here we performed a first preliminary coding with memos elaboration to synthesize the information to a higher level of analytical meaning in which we brought together multiple concepts that emerged in the narratives. 4) Further reduction of the information through re-readings of the memos, which allowed us to reduce, add, and refine the codes. This favored the definition of categories and the grouping of themes. The categories related to speech, language, and communication emerged during the analysis as a priority and concern of the parents. These were analyzed mainly based on critical theories of disability. In particular, the ableism approach gradually gained strength in the analysis of the parents' narratives in

relation to their children's communication. This led the theoretical body of the analysis to shift towards this topic. We present these findings in the following two sections.

Cultural and personal narratives about verbal language and their relation with ableism

Personal narratives are significant because they shape identity. Identity and personal narratives are not created in a vacuum but are embedded in cultural narratives that communicate an ideological framework, an idea of how the world should be. For this reason, our analysis starts from the assumption that narratives shape human life and communicate being to others (Gergen 2018). In this sense, it is important to examine them because they not only have the ability to highlight an individual's perspective of himself, his history, and the view he has of reality, but also because they are a lens through which social values are made manifest (Tabatabai 2020). Specifically, we are interested in analyzing the possible relationships between the narratives of parents of children without access to VL and the dominant narratives of what Campbell (2009) calls the project of ableism in neoliberal societies and the place of VL in shaping able, competent, and productive individuals. We question the assumptions that are invisibilized and that determine that some things are self-evident and 'real', such as the naturalness and universality of VL as a privileged system for the individual and collective realization of human beings, their agency, and their communication (St. Pierre 2012). Consequently, other semiotic repertoires are subject to doubt or are presented as impractical and, therefore, are undervalued, limited, or denied (Gómez-Victoria & Pava-Ripoll 2019) because, from an ableist stance, these are not considered an essential feature of the naturalized understanding of what it is to be fully human (Campbell 2001).

Two key concepts in this article are ableism and semiotic repertoires. Ableism is understood according to Campbell (2001: 44) as 'a network of beliefs, processes, and practices that produces a particular type of self and body (the corporeal standard) that is projected as perfect, species-typical, and therefore essential and fully human. Disability is then presented as a diminished state of being human'. The concept of semiotic repertoires emerges to address communicative diversity (Kusters et al. 2017) and is based on theoretical approaches framed in translanguaging studies. It is related to the analysis of how different semiotic practices, which have different histories, previously functioning independently at the moment of enaction, blend together and are experienced as a new whole (García & Li 2014). In other words, children develop a kind of multicompetence that is not linguistic but rather constituted by semiotic repertoires that have been produced by the particularity of their bodies and their stories, which are embodied, coexist in their minds and their bodies, and are experienced in encounters where there is space for difference. In other words, the semiotic repertoires make up an interconnected whole, an ecosystem of mutual interdependence. According to Blommaert and Backus (2013: 25), 'A repertoire is composed of a myriad of different communicative tools, with different degrees of functional specialization. No resource is a communicative panacea; none is useless'. Semiotic repertoires include forms of meaning making constituted by sounds, images, textures, smells, objects (material world), screens, and the body. They are in connection with different ways of being, feeling, thinking, knowing, imagining, acting, and communicating. Recognizing their ontological dimension is part of the vindication of the differences in human beings and the diversity of the worlds they interweave (Gómez-Victoria forthcoming).

We begin the analysis with the next two stories of the mothers of Pedro and Sofi that reflect cultural narratives about the compulsory nature of VL despite the fact that it is not accessible to these children given their difference/disability. That is we can explore in these narratives the features of the ontologies of ableism through the effects of the obligation to emulate ableist regulatory norms with respect to VL. Additionally, we can see the connection with independence and personal responsibility, important features in the ideology of neoliberalism (Tabatabai 2020). These narratives have helped shape standards that are incorporated into the individual narratives of the parents in the study, privileging the role of VL in achieving independence and self-realization. In light of a biopolitics perspective, the body is interpreted in terms of the requirements of certain forms of communication in order to participate productively and later to succeed in the socio-economic system (St. Pierre 2012).

> Someday she will have to do it alone, because that is the expectation, that she can learn to be a normal girl, that this condition that she has, does not affect her in her studies. [Music] will force her to learn the songs, will force her to move the functional part of her brain, will force her to have to repeat and have to pronounce, to know what to do (Raquel).
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> You have to demand more from him, precisely in language, because the rest they can do it, right? Because, if the child pronounces a word and pronounces it well, he can pronounce the others. That's it, we must continue to demand more of him than what we are demanding now and he will succeed. [...] Right now, he is in school, it's not like at home where I can understand him, that he points out to me, that he shows me, then I can understand (Cielo).

These stories affirm the preference for the regulatory norms related to VL as well as the compulsory nature of their compliance. In both cases, it is expected that the children learn to pronounce well, in Sofi's case so that she can become a normal child and study and in Pedro's case so that he can be understood at school. It is a discourse that marks the body of preference, a body that produces VL while revealing that disability is inherently negative. Neither of the children is celebrated in their difference/disability; their ways of being different remain unvalued. Both children are in the process

of educational inclusion, yet at the same time, their particular way of communicating is currently being rejected. Campbell (2009: 12) points out the double bind of ableism when it takes place within neoliberal Western societies: on the one hand, discourses of equity proclaim inclusion, on the other, ableism denies the ontological possibilities of people with disabilities:

> […] ableist discourses proclaim quite emphatically that disability is inherently negative, ontologically intolerable and in the end, a dispensable remnant. This casting results in an ontological foreclosure wherein positive signi-fication of disability becomes unspeakable.

These narratives also contain expectations that are profoundly shaped by a system that makes able-bodiedness desirable and mandatory (McRuer 2006). This is an ableist narrative, according to which the production of VL is part of that able/bodiedness and therefore must be guaranteed. Disability is seen as the opposite of that perfect body/mind imagined, and any difference/disability must be cured, ameliorated, or eliminated (Campbell 2009), in this case, the childrens' different ways of meaning-making. According to McRuer, it is as if we live in a world in which the natural state of people is not to be disabled. This 'natural state' is highly valued and desired in the capitalist world because it promises privileges and rewards. This leads us to think that privileging VL as the ideal form of communication, agency, and self-realization, while undervaluing or ignoring any other semiotic repertoires used by children, is not a question of parental prejudice but rather a reflection of a cultural narrative constructed in socio-economic systems that sustain the inequality of people with disabilities (McRuer 2006).

In other words, the norms that are established from an ableist perspective shape both the lives of people with disabilities and their perceptions of them (Ljuslinder, Ellis & Vikström 2020). Consequently, bodies and minds that do not respond to the parameters of normality are oppressed by a system of compulsory able-bodiedness (McRuer 2006). For the research participants, this has meant the incessant application of rehabilitation technologies to achieve VL production. We are talking about an oppression that is shaped by norms and stereotypes that dictate an ideal of language and communication creating a subordination of semiotic repertoires to the VL system privileged by society. This oppression is not deliberate but the result of a complex network of social constraints (Taylor 2016).

This, of course, is also linked to the ideas that parents have about how their children should experience childhood based on narratives rooted in the gradual scaling of the stages that have been naturalized as characteristic of child development—a narrative that homogenizes and imposes one model of being a child. Living up to these expectations conditions the exercise of power over children, as they are expected to achieve what is necessary to comply with the standards imposed by society in order to participate in it. In Nati's case, we wonder how Nati is understood and valued as she achieves the expectations placed on her. In the following narrative, it seems that her present being is judged by how conscious, independent, and communicative she can become and how close she is to being a capable child.

> Nati is basic, very basic. […] I hope that when Nati is more conscious she will be able to speak, I hope that when Nati is more conscious she begins to eat (Camila).

What does Nati's mother mean by 'basic'? The expectations placed on what this three-year-old will be able to do in the future lead us to wonder how these children are viewed and valued in the present, when they do not yet use VL or do not do so in a 'normal' way. So, is basic a qualifier that detracts from Nati's expression of being as she is in the present? According to Campbell (2009: 17),

> from the moment a child is born, he/she emerges into a world where he/she receives messages that to be disa-bled is to be *less than*, a world where disability may be *tolerated* but in the *final instance*, is *inherently negative*. We are all, regardless of our status, shaped and formed by the politics of ableism.

Furthermore, Van Goidsenhoven and De Schauwer (2020) argue that we frequently fail to see children in their difference/disability due to the fact that they are trapped in stereotypes, diagnostic categories, official labels, and the expectations we have about them; therefore, we lose sight of who they really are, their unique ways of being, communicating, and interacting. This is related to the fact that these children are really different from what we know. This difficulty can be interpreted as a result of the division generated by the practices of ableism. According to Campbell (2009: 10), 'The significance of the enforcement of a constitutional divide, for the practices of ableism, is that [it creates] orderings [that] are not just repressive but they are ultimately productive; they tell us stories, they contain narratives as to "whom" we are and how we "should be"'. In this study, they tell us who Nati, Sofi, and Pedro are and how they should be as children. Cielo, Pedro's mother, narrates:

> […] he does something like a conversation, but in his language, which is not understandable, he makes guttural sounds, like those of a baby, right? He is still in it, and he speaks to me and I [think], what is he saying? And I start to ask him, are you looking for a comb? Are you looking for such a thing? And he says no (Cielo).

From a narrative that is rooted in naturalized ideas about the staggered development of language, Pedro's communication is described in terms of guttural baby-like sounds, yet this nine-year-old boy uses other semiotic repertoires to engage in complex interactions with his mother and grandfather, as we see in other accounts made by his mother. Is Pedro's present being judged by an ability to speak that he has not yet achieved and perhaps never will? According to McRuer (2006), the answer would be yes.

Due to neoliberal narratives, the success of people with disabilities is based on how closely they can approximate an able body, under the assumption that able-bodied identities are preferable. These capable, competent, and self-sufficient bodies correspond to the ontological and ethical orientations demanded of people in societies shaped by neoliberal policies (Castillo 2016). This can be seen in the following narrative from Sofi's father:

> [...] We are looking for a nurse who will take care of her, even if it is in the morning, so that she becomes self-sufficient first, and secondly that she learns, learns and that the learning she is going to have, develops her further. [...]. I do not care what they are going to charge at school, but what matters to me is that she no longer has a limitation, so that she can learn everything, do everything, that is what I want (Juan).

We can observe that Sofi's father expects his daughter to become more self-sufficient and to learn to do everything, as this is an important part of achieving their parenting goals of independence. To achieve these goals, the father is willing to offer whatever support is necessary, no matter the cost, without this requirement being part of a collective or community project. According to Tabatabai (2020), this would be another feature of the neoliberal political framework, in which parents make sense of their practices within this sociopolitical framework by supporting the development of independent children with little state support. From these narratives, people are expected to take care of themselves, rather than requiring the assistance of others (Tabatabai 2020).

Internalized ableism and the obligation of a normalized communication

Dominant cultural narratives about VL assert that it is the most natural, basic, and universal form of communication and a fundamental trait in the configuration of subjects with the competencies necessary to participate in society, such as rationality, agency, and human identity (St. Pierre 2012). To challenge these narratives, in this section we elaborate on two issues: first, the naturalization of VL and its preference from an ableist standpoint even in children for whom it is not accessible; second, the idea that the application of appropriate rehabilitation technologies always leads to the production of VL. In particular, we apply the concept of internalized ableism to explore the oppression that children suffer due to the belief that the impairment they experience, which entails the lack of VL, is intrinsically negative and, therefore, must be cured (Campbell 2009) through the application of rehabilitation technologies.

Because ableism, refers to 'a convergence of networks of association that produce exclusionary categories and ontologies (i.e. ways of being human)' (Campbell 2009: 19–20), and because difference/disability is a category that is not recognized and embraced as an intrinsic part of being, the processes of ableism induce an internalization that devalues disability making it ontologically unfeasible and non-valid (Campbell 2009).

First, we analyze three accounts from Pedro's mother in which she shows the expectations of the father, the teacher, and herself related to production of VL:

> Yes, because I strongly believe that he has to speak. And also, my husband who says to me, 'Why doesn't he speak?' and 'Why doesn't Pedro speak?'(Cielo).
>   What do I get out by desiring he has to speak, that I have to hear his voice, it's almost like I would have to enter his brain in order to see how I can help him (Cielo).
>   The teacher told me: 'One day a boy called me: teacher'. And I thought to myself: 'Oh, I haven't heard that little voice'. When she noticed, 'Oh, it's Pedro who spoke to me!' And she was moved because she hadn't heard his voice before (Cielo).

These three stories show that VL is a highly valued trait that Pedro does not have but must come to have despite the significant limitations it represents for his interactions. The fact that this expectation is shared by three natural interlocutors who know the uniqueness of his communication, mediated by other semiotic repertoires, leads us to investigate the reasons for such a collective expectation. We can see here the functioning of the network of beliefs that, according to Campbell, sustain ableism and produce the corporeal standard, which in this case includes the production of VL as a species-typical trait, so it is essential that Pedro speaks and his voice is heard. Because ableism establishes a binary dynamic that is not simply comparative but is constitutive of correlation, the correlate of this belief is that his difference/disability is not seen as an intrinsic part of his way of being but as a diminished state of being (Campbell 2001). These arguments may explain why the limitations that the VL system actually imposes on the children in the study are overlooked.

According to Campbell (2009: 22), internalized ableism uses a twofold strategy: 'the distancing of disabled people from each other (dispersal) and the adoption by disabled people of ableist norms (emulation)'. Our analysis explores these two strategies in the parents' narratives.

> I think that [being at school] has been a fundamental part of Sofi's communication, because she must say to herself, 'If they [the speaking peers] don't understand me, I have to pronounce well'. And sometimes Sofi makes me laugh because she gets mad that you don't understand her (Raquel).
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> [...] that [Sofi] can *express* herself perfectly, if the day comes that I am not there for her or if I were to be no more, to have the means to be able to be understood (Raquel).

In the above narratives, we observe how internalized ableism works through the desire to emulate the norm of VL, of the Other who is considered the standard. Likewise, when Raquel explains the role that the school has played in improving Sofi's communication, we can see the strategy of dispersal. The fact that Sofi is in the process of inclusion is interpreted as a positive condition, because it brings her together with abled peers who use the VL system. As a result, she is forced to comply with its regulatory norms and to express herself perfectly. In Campbell's (2009) view, the acquisition of new skills to perform the parts of a disembodied individual is evidence of successful inclusion. The mother's account also speaks of the emotional cost to Sofi of complying with this demand, manifested in anger. An emotional cost that seems not to be taken to heart by the mother and that can be recognized as a sign of internalized ableism: 'The emerging counter-story of the disability survivor prevents us from exploring the personal costs of disability subordination and normalization'(Campbell 2009: 25).

Under this scenario, the value that society places on VL leads families to a relentless search for methods that will enable children to achieve the VL standards. In this context, technologies, as knowledge assemblies, instruments, people, systems of judgments and constructions (Rose 1998) play an important role because they were invented to govern the ways in which we experience ourselves as human beings. In the field of childhood education and intervention, technologies are part of a perspective in the current geopolitical scenario that responds to a dominant cultural narrative in which the discourse of quality prevails. It argues that if the appropriate human technologies are applied in childhood, great economic returns will be obtained and social problems will be solved (Moss 2014). These technologies are associated with evident conceptual references in the research narratives, such as the notions of child development goals, prescriptive learning, and observation techniques, that together make up a powerful control technology. The following narratives illustrate the role given to technologies by the parents in the study:

> I don't know if there is any other method, there has to be something, let's say, apart from the images and the kinemes, what else can you do? Because there are words that no matter how much she repeats them to me I don't understand. So how to find another method, so she can clearly pronounce them. At least she already pronounces the /d/, /l/, /m/ and /p/' (Raquel).
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> I told the therapists what we are teaching him. He has already learnt the numbers 1 and 3; in the vowels, we go to the vowel i. That's why I told them to help me to repeat them to him, because he keeps forgetting them (Cielo).
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> They [the therapists] told me, 'You have to do the same exercises at home'. Then I wondered, if Sofi does this here (in the neurorehabilitation centre), she also does these exercises at school, why am I going to exhaust her by doing them at home as well? (Raquel).

According to St Pierre (2012), these technologies are applied with the help of different professions, which play an important role in creating standardized speech production expectations. This author, who addresses the topic of stuttering, argues that although speech therapy can do good from an altruistic perspective, given their position of authority, professionals such as speech and language therapists not only reflect how things are in the 'real world', but also participate in creating the world of expectations of normalized speech where 'The bodies that are not capable of responding to the expectations of time and productivity are disqualified for full participation, not only in the economic sector but in social situations' (St. Pierre 2012: 5).

> One specific thing about Nati is that she is not interested in anything. According to the speech therapist as long as Nati is not interested in things, there will be no communication (Camila).
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> Well, that he learns to name the object he wants, for example if he wants to watch television. Because if he does this [points the finger], hugs grandpa, or pass him the TV remote control, they will guess what he wants. Then, he doesn't need to speak [...], so if they [the therapists] could collaborate with that, make him speak, that he tries to speak (Cielo).

In the first narrative, we see that the mother refers to the knowledge received from the speech language therapist based on the stages and prerequisites of developmental theories. Within the context of a power relationship, this knowledge shapes the mother's expectations and limits her possibilities to explore and construct her own knowledge from daily experiences and interactions. It is a professional narrative that places the child's intentionality as a prerequisite for communication and not as something closely linked to the interaction itself. We could argue that, many times, professionals that work with children are not aware of the ethical and political implications of intervention programs derived from developmental psychology, theories with standards rooted in ableism that dictate the expected

achievements for children. It seems that the consequences are that these children are put in a provisional ontological state, as their bodies are put on hold until the technologies provide the expected results. In Pedro's case we see how the mother is hoping that the therapists will help the child to speak, while his particular way of being mediated by other semiotic repertoires is diminished.

It is worth noting that Sofi and Pedro, from their position of agency, reject behavior control technologies. The narratives below show Sofi's annoyance with the permanent application of techniques, as well as Pedro's disinterest in the unnatural use of images to achieve the production of phonemes and words. The analysis also reveals that in this eagerness to apply the appropriate technologies, communication itself takes second place in favor of the 'correct', 'normal' production of VL. Meanwhile, interlocutors and society in general do not have to make a significant effort to transform their own ways of being, and in consequence, their forms of communication, to build a diverse world. Their contribution to the communicative interaction is left unchallenged, and all responsibility is placed on children.

> She can pronounce /pa/ and /po/ well. However, it is difficult for her to pronounce /pe/ and /pi/. So, you make so many demands and therapy, exhaust her and there comes a moment when she becomes annoyed (Raquel).
>
> Difficult, difficult isn't it? As for making him understand, right? It is difficult for me that he does not want to study with me, that he sometimes does it for a while and […]. He goes and hugs me, looks me in the eye and kisses me, but as for me to leave him, that he wants to continue playing with his cars, with his things and that he does not want to stay at the desk with me (Cielo).

In contrast to this practice of control, it may be more fruitful and fair to view children not as monolithic subjects, capable of full awareness, but as beings built on the contingencies of life, involved in processes of continuous meaning construction (Lather 1991) and being. That is to reconceptualize the idea we have of children, to think of them as beings who are always transforming in relationships with others, beings who become in each encounter, as opposed to an individualized and fixed understanding of them (Davies 2014). Children are individuals who are permanently mobile, who are affected in each encounter with others (Taguchi 2011). In this sense, we rather recognize children and value their unique way of being in their difference/disability in each encounter. As Campbell (2009: 9) argues, we must let go of the need to represent disability in fixed terms and refuse to keep people with disabilities in a provisional ontological state, as she states '[…] an essentialized disabled body is subject to constant deferral—standing in reserve, awaiting and escaping able(edness) through morphing technologies and as such exists in an ontologically *tentative* or *provisional* state'. Perhaps, she says, it is in this release where we can find possibilities for other imaginaries in the ambiguity of difference/disability and some kind of resistance to ableism in marginality.

People are heterogeneous, unique, and fluid; they never achieve full self-awareness, and therefore, there can be no ideal individuals (Dahlberg, Moss & Pence 2013). Based on these assumptions, we can question the logic that imposes VL as the ideal language for self-realization, agency, and communication and ask what can be learned if we resist the urge to 'fix' language. What does the experience of children who use other semiotic repertoires reveal about them and about language and communication? In this line of thought, we may wonder why these children cannot be recognized in their different nuances of being. The mothers' narratives tell us how their children are configured with semiotic repertoires that are accessible to them and that are assembled in singular communication activities.

In the following narrative, we see how Nati's mother reflects on this issue and becomes aware of the importance of daily life activities as play:

> At first, I thought that my responsibility was to bring her to therapy, and do at home the same thing that therapists do, and that was the biggest mistake I was making. I have learned as a fruit of the research, that I can be a good partner for Nati, by playing, by following her initiative, and I think she has changed a lot in communication as a result (Camila).

In order to imagine disability differently, Fritsch (2015) argues we need to understand that the contemporary neoliberal hegemonic imagination works with policies and practices that individualize able bodies and disabled bodies through an ableist mindset and through the economization of social relations and of life itself. Such an imagination expands as a process of signs, discourses, material relations, and feelings that are concurrently constructed by and are constitutive of a subjectivity, aiming both to stabilize and unify the neoliberal subject. It is therefore an imagination on which people's understanding of themselves and others is shaped and impacts their expectations and norms of relation, including their ability to think about what lives are worth living. Thus, a context is created whereby disability continues to be an undesirable way of life.

Alternative Paths

Faced with this hegemonic imaginary, two alternative paths may be proposed: the first related to rethinking what a worthwhile life means from the point of view of a new normal and the second based on what disability teaches us to build other ways of being, of making meaning, and ultimately of designing other worlds with diverse semiotic repertoires. For the first, to maintain the advantages of norms to avoid destructive behaviors, Kittay (2019) proposes the

creation of a new normal, with new values that create their own source of desirability. This involves establishing norms that are of greater capacity based on the recognition that normalcy may not have fixed parameters. In Kittay's (2019: 59) words, 'those who are anomalous in certain regards work to redefine and reclaim the normal, to create their own sense of normalcy, and to locate those from whom they can find validation and support'. In the case of the children in our study, the new normal would include not only VL but also semiotic repertoires that are accessible to them, making their unique way of communication intelligible to others. In Pedro's case, it validates the assemblages he builds with his semiotic repertoire of gestures and gazes, his touch, kisses and hugs, as well as objects like the TV remote control in particular assemblages to engage in social activities with his mother and grandfather. Following Kittay, perhaps in this way the desire for normalcy will be a desire based on the recognition, appreciation, and love of these children in their uniqueness, in their difference.

The second alternative also implies decentering the gaze from VL and embracing semiotic repertoires that children use given their difference/disability, to face the challenge posed by Fritsch. It is about seriously imagining what it would be like if we perceive and conceive the world using our senses in different ways than we are used to. Letting ourselves be seduced by the imaginaries of disability to think, feel, and speak landscapes that not only imply a different way of being in the world, but also of 'conducting perceptions, mobilities and temporalities' (Campbell 2009: 15). These imaginaries are being thought and put into practice from post-humanist and neo-materialist positions whose analysis exceeds the scope of this article. Suffice it to say that we can invert our senses to imagine the world in terms of olfactory, tactile, or acoustic images, as we are taught not only by people with disabilities but also by artists and animals. Fritsch (2015) exemplifies what a neo-materialist approach would be with the experience of Michalko, a blind man and his guide dog. A heterotopic imagination is used to understand the intracorporeal emergence of a Michalko together with his dog, as a mark of different sensory and perceptual capacities that alter what the two bodies can do together. With this imaginary, the man and the dog intra-act, composing a movement that is within each one but belongs to neither. All these ideas are inspiring for thinking about how both children's semiotic repertoires, which include the material world, and their interlocutors configure assemblages where their communicative activities take place. We are talking about an idea of language and communicative competence that is distributed, meaning coming from many places (Canagarajah 2018) as described by the parents in the study.

Conclusion

We argue that the maintenance of ableist narratives with the imperative of VL as the privileged form of communication, self-realization, and agency restricts the configuration and expression of different ways of being, living, and interacting of different/disabled children without access to VL. Such narratives result from internalized ableism, which causes an oppression that stems from within people and prevents us from really asking about the meaning of difference/disability and what it says about other ways of being human, because it is assumed as something intrinsically negative, something to be improved or cured. For the children in the study, this means living lives of ontological vulnerability, always in a tentative state, waiting for what they will become if they reach the regulatory norms of verbal language, that is, if they achieve the typical corporeal standard. Maintaining these narratives can make VL a hegemonic system and a source of oppression for both children without access to VL and their families. Such hegemony can be exercised as unintended coercion in power/knowledge relationships that are established with professionals working with children. This hegemony is also exercised by consent, given that the expectations of families in which VL is privileged, despite not being accessible to their children, are part of an ableist framework of knowledge and way of being. This frame upholds the ideals of competent, independent, and productive individuals for whom able/bodiedness is mandatory. Therefore, we believe that there is an ethical obligation to question the impact of ableist practices that impose VL on children and their families and that it is necessary to talk about the harm that can be caused by insisting on a system when it is not accessible.

We propose that in order to challenge the implicit hegemony of VL and to facilitate encounters with the difference/ disability of children and their families, alternative narratives about different ways of being and communicating must be presented to families and professionals as part of the human experience and as a valid form of expression. Once we value difference over normalization, we can begin to change the narratives that govern the language and communication of children without access to VL. The task will not be easy because it involves making an ontological transition that implies questioning the privileged place of VL in the configuration of the corporeal standard and denaturing its use when it becomes hegemonic. This will challenge professionals and parents to examine critically what the consequences of ableism are and, in particular, of internalized ableism in the way they imagine, think, and experience life, as well as in their relational practices.

Given that in encounters with children with a difference/disability it is not convenient to make prescriptions in terms of patterns, norms, or fixed expectations in their social practices or construction of meaning and communication, assuming a monolithic notion of language linked to VL and its use is insufficient to understand what really happens in their communicative interactions. Consequently, it is proposed to apply the notion of semiotic repertoires from theoretical approaches framed in the study of translanguaging. In the context of children with a difference/disability, we could say these are practices that are not linguistic but are constituted by semiotic repertoires that have been produced by the particularity of their bodies and their histories, which are embodied, coexist in their minds and their

bodies, and are experienced in encounters where there is space for difference (Gómez-Victoria forthcoming). That is, the parents' narratives evidenced that children have a type of multicompetence that is related to different semiotic repertoires: they have invented ways of using the resources that are accessible to them and that they have in the environment to communicate. From an ontological position, recognizing the value of their semiotic repertoires is a way of opening up spaces for the flourishing of different ways of being, feeling, thinking, knowing, imagining, and acting using images, sounds, and other materials to make and create meaning with senses and movements.

Although Colombia is a country with policies and guidelines for working with families, the provision of these services is not always implemented in real contexts. Based on the results of this research, we confirm the need to listen to families when working with children with a difference/disability, acknowledging their value through collaborative working relationships. However, we would emphasize that such work should involve undertaking changes in professional practice based on ontological reflections that lead to rethinking the ideas we hold regarding the meaning of being human, the relationships we build, and the worlds we create using different semiotic repertoires.

Ethics and Consent
Informed consent has been obtained from all the participants in this research.

Competing Interests
The authors have no competing interests to declare.

Author Contributions
Both authors contributed equally to this article.

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