








# Therapeutic itineraries according to the narratives of parents of children with disabilities secondary to neurodevelopmental disorders

Celeste Puga<sup>a</sup> , Nahuel Braguinsky<sup>b</sup> , Rocío Barrios<sup>b</sup> , Andrés Pereira<sup>b</sup> ,  
Daniela Antinucci<sup>b</sup> , Ayelén Quiroga<sup>b</sup> , Adriana Dawidowski<sup>a</sup> 

## ABSTRACT

**Introduction.** Childhood neurodevelopmental disorders account for 10% of the causes of childhood disability. The search for medical care leads to therapeutic itineraries routes taken by individuals to seek health care where diagnostic and treatment opportunities arise. Our objective was to explore these itineraries in order to understand the opportunities and barriers to the implementation of therapies and child rearing patterns promoting neurodevelopment.

**Population and methods.** Qualitative study using in-depth interviews with children's parents (between June 2018 and November 2019). The analysis was based on the social model of disability and Vygotsky's approach to child development.

**Results.** A total of 16 interviews were conducted. Considering the time of diagnosis and the age when the therapeutic itinerary started, 2 groups were identified: those who started from birth to 2 years old (early initiation) and those who started from 3 years old (late childhood initiation). In the first group, the search for treatment starts at an early stage, while in the other group, decisions on the initiation and/or type of treatments are prolonged over time. Late initiation was accompanied by difficulties in school, periods of uncertainty, distress and/or family conflicts due to the complexities of parenting.

**Conclusions.** Therapeutic itineraries started early in some cases and at a later stage in others. The initiation of treatments made it possible to use tools to bridge the gap of discrepancies between the biological and cultural lines of development.

**Key words:** child development, neurodevelopmental disorders, early diagnosis, accessibility to health care services, qualitative research.

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## INTRODUCTION

Childhood neurodevelopmental disorders, which include global developmental delay, intellectual disability, and generalized developmental and learning disorders, account for 10% of the causes leading to childhood disability.<sup>1</sup> In a study conducted in a teaching hospital, the overall prevalence of disability was 3.2%; in this group, 10% had neurodevelopmental disorders.<sup>2</sup>

Some studies that look into the therapeutic and diagnostic itineraries in children with this type of disorders describe inconsistencies between the stimuli that children need according to their difficulties and the resources that institutions and the family environment offer them for an adequate upbringing and with the objective of stimulating their neurodevelopment. These inconsistencies were conceptualized by Vygotsky, who defines them as gaps among biological, social, and cultural lines of development.<sup>3,4</sup> Such mismatch can translate into parental anxiety and uncertainty regarding diagnosis, delays in starting an appropriate treatment, and stressful parenting situations.<sup>5,6</sup>

Our objective was to explore therapeutic itineraries in order to understand the opportunities and barriers to the implementation of therapies and child rearing patterns promoting neurodevelopment.

## POPULATION AND METHODS

### Design

Qualitative research using in-depth interviews (from June 2018 to

a. Department of Research.  
b. Division of Epidemiology, Quality Assurance Department.  
Hospital Italiano de Buenos Aires, Argentina.

E-mail address:  
Celeste Puga:  
celeste.puga@hospitalitaliano.org.ar

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November 2019) with the parents of children with disabilities secondary to neurodevelopmental disorders and triangulation with data collected from electronic medical records.

### Setting, population, and sampling

The target population consisted of 4- to 12-year-old children with a diagnosis of neurodevelopmental disorder who were undergoing treatment at Hospital Italiano of Buenos Aires in an interdisciplinary treatment program. Purposive sampling was used to collect data about various experiences, in relation to the different time of inclusion in the program ( $\leq 1$  year,  $> 1$  year), the type of school (regular yes/no), and the presence of a psychiatric comorbidity (yes/no).<sup>7</sup> For the selection, the total number of children in the program was categorized according to the 8 possible profiles and 1 or 2 children per profile were randomly invited to participate.

### Data collection tools

The non-directive interview model was used.<sup>8,9</sup> The research team was made up of physicians (child neurologist and medical clinician), 2 anthropologists, a nutritionist and a sociologist. They developed the interview guide collectively (*Supplementary Material I*).

The development of the interview guide was based on the conceptualization of disability and the treatments associated with it according to the theoretical model called "Social Model of Disability"<sup>7</sup> and, within this, to the concept of "Therapeutic Itineraries" developed by Venturiello.<sup>10,11</sup> The study was also based on the theory of developmental trajectories proposed by Vygotsky.<sup>12</sup>

According to the social model, disability is a construct that does not originate in the health status of individuals, but in power relations. Based on this definition, people are exposed to limited social participation in the economic sphere, with little symbolic and material recognition.<sup>13,14</sup> In the cultural dimension, they also experience limitations and are stigmatized for their physical appearance, which is far from the ideal of "normality".<sup>12</sup> This is how people with particularly different physical capacities from those of the majority become disabled.

Families constitute the environment in which responses to such social limitations are constructed. The search for specialized medical care is an essential part of this construction, since

it is what provides families with the technical knowledge and material resources to care for these children. This process of seeking health care is a process that outlines therapeutic itineraries, understood as trajectories of seeking, producing, and managing health care.<sup>13,14</sup>

Neurodevelopment is a complex biological, psychological, and sociocultural process, and in order to uptake it, an understanding that encompasses each of these axes, as well as the interrelationships among them is necessary. Vygotsky uses the expression *developmental trajectory* to define the multiple processes in which the biological lines of development are coupled with those of social and cultural development. According to this understanding, as the child develops, a conjunction between these lines is generated, causing the social and cultural environment to respond with specific stimuli to each stage of psychomotor development, scaffolding and promoting neurodevelopment. According to this author, disability results in an uncoupling between these 2 lines, something he calls "the incongruence of development".<sup>12</sup> In other words, the social and cultural environment does not have the capacity to accompany each stage of neurodevelopment of children with disabilities, resulting in a lack of adequate therapeutic, educational, and parenting opportunities.

Based on this theoretical framework, the interview guide was designed to describe therapeutic itineraries and, within them, the possibilities for promoting neurodevelopment.

The interviews were conducted with 1 of the parents (except in 2 cases, where both parents attended) and were carried out by pairs of researchers (average duration: 2 hours). Interviews were recorded and then transcribed verbatim for analysis. The neurologist obtained diagnostic data, evaluations, consultations, and treatments from the medical records.

### Analysis

We followed the approach proposed by Emerson,<sup>15</sup> with a first stage of line-by-line reading in team meetings, identifying native and analytical categories. In a second stage, the material was reviewed again to select—according to the already identified categories—a more restricted set of ideas and categories.<sup>16</sup> This analysis was carried out iteratively and, in each iterative cycle, analytical descriptions of progressively higher theoretical level were drafted.<sup>17</sup>

The study was approved by the Ethics Committee of Hospital Italiano de Buenos Aires. Participants signed an informed consent form, and their identity was withheld through the use of fantasy names. Verbatim quotations from interviews are presented in quotation marks.

## RESULTS

### Profile of interviewees and children

Sixteen interviews were conducted in which most of the participants were the mothers (*Table 1*). Parents' level of education and occupation and what they said during the interviews reflect that families experience economic hardship maintaining health coverage.

Regarding the children, all of them required some kind of educational support; the most frequent being school integration in a regular school.<sup>18</sup> Also, 80% had been issued a unique certificate of disability. On average, they attended the program twice a week; the most frequent treatments were speech therapy and educational psychology (*Table 2*). In addition, 30% received home therapy, mostly cognitive-behavioral psychology.

### Marker events that initiated the therapeutic itineraries

Taking into account the age at which the interviewees identified and reported the moment when their children started therapeutic itineraries, 2 groups were identified. On the one side, those who started from birth to 2 years old (early initiation) and, on the other hand, those who started from 3 years old (early childhood initiation and late childhood initiation). This distinction refers to the time that the interviewees recognized as the first treatments to address the disability, which may not temporally coincide with the medical diagnosis of a neurodevelopmental disorder.

The early initiation group was characterized by the presence of some immediate perinatal or postnatal medical event, or a specific medical diagnosis (e.g., preterm birth or diagnosis of an epileptic syndrome) that prompted the early initiation of treatments (*Supplementary Material II*).

In these cases, the families had a diagnosis or medical condition (craniosynostosis, extreme prematurity), which they considered to be related to disability, even though the diagnosis

TABLE 1. *Profile of interviewees*

	Interviewee	Age	Level of education	Occupational status
p1-Eliseo	Mother	47	Complete tertiary education	Works at home
	Father	55	Complete university education	Employee
p2-Juan	Mother	39	Incomplete secondary education	Works at home
p3-Mariana	Mother	46	Incomplete university education	Self-employed
p4-Clarisa	Mother	42	Complete secondary education	Self-employed. She is looking for a job
p5-Yamila	Mother	60	Complete university education	Self-employed
p6-Jimena	Mother	33	Incomplete university education	Self-employed
p7-José	Mother	50	Complete tertiary education	Employee
p8-Santino	Mother	39	Complete university education	Employee
	Father	39	Incomplete university education	Owner/employer
p9-Patricia	Mother	39	Complete tertiary education	Employee
p10-Marina	Mother	41	Complete secondary education	Self-employed
p11-Dante	Mother	36	Complete university education	Employee
p12-Benicio	Mother	38	Complete secondary education	Self-employed
p13-Denise	Mother	46	Complete secondary education	Unpaid work
p14-Vanina	Father	52	Complete secondary education	Owner
p15-Valentina	Mother	40	Complete tertiary education	Employee
p16-Tobías	Mother	52	Incomplete tertiary education	Does not work

TABLE 2. Profile of children

	Age at interview (years)	Sex	Age at diagnosis*	Current medical diagnosis	Current treatment	Education**	Coexistence group
p1-Eliseo	12	M	5	Developmental disorder	OT PSY	Regular school with integration	Mother, father, brother
p2-Juan	9	M	5	Language and learning disorders	ST PSY EDPSY	Regular school with integration	Mother, father, brother
p3-Mariana	7	F	3	Language and learning disorders	OT EDPSY	Regular school with integration	Mother, mother's husband, sister
p4-Clarisa	9	F	3	Behavioral disorder	ST PSY EDPSY	Regular school with integration	Mother, father, brother, sisters (2)
p5-Yamila	13	F	4	Intellectual disability	ST EDPSY	Catch-up school	Mother, father
p6-Jimena	6	F	3	Intellectual disability	ST OT PSY EDPSY	Special school	Mother, grandmother
p7-José	13	M	6	Learning problems	PSY EDPSY	School with integration	Mother, father, sister
p8-Santino	5	M	3	Developmental disorder	ST OT PSY	Pre-school with integration	Mother, father, brother
p9-Patricia	9	F	1	Intellectual disability	ST OT	Special	Mother, father, brother
p10-Marina	11	F	3	Intellectual disability	ST EDPSY	Regular school with integration	Mother, father, brother
p11-Dante	6	M	2	Intellectual disability	OT EDPSY	Regular school with integration	Mother, father, sister
p12-Benicio	11	M	5	Intellectual disability	ST OT PSY EDPSY	Regular school with integration	Mother, sisters (2)
p13-Denise	9	F	7	Intellectual disability	ST EDPSY	Regular school with integration	
p14-Vanina	9	F	4	Intellectual disability	ST EDPSY	Special	Mother, father
p15-Valentina	6	F	2	Global developmental delay	ST OT EDPSY	Regular school with integration	Mother, mother
p16-Tobías	9	M	4	Intellectual disability. Language disorder	ST OT PSY	Regular school with integration	Mother, father, grandmother

\*Medical diagnosis: age at the time of diagnosis of neurodevelopmental disorder.

\*\*Regular school: a school that meets the objective of ensuring that the schooled population acquires the knowledge, skills, abilities, attitudes, and values required by the structure of the education system within the time frame and at the theoretically established ages.<sup>17</sup>

ST: speech therapy, OT: occupational therapy, PSY: psychology, EDPSY: educational psychology.

of neurodevelopmental disorder was made years later. This made them quickly assume that their children should start some kind of therapy. One example is told by Valentina's mother:

*She was born with 560 grams, she was in the Neonatology Unit for 5 months and since then she has not stopped having consultations with doctors (...) today, she has to see the speech therapist, she goes to one check-up or another control, that is how it is, you see a doctor and they tell you that she should see an educational psychologist and then, every year, when we make a balance of her condition, other doctors appear or she stops seeing some.*

In the second group (early childhood and late childhood initiation), most of the children started with speech therapy ( $n = 11$ ) as a result of a referral from the pediatrician or a suggestion from the kindergarten. It was the delay in language or communication skills that set off the alarms. In several cases, the diagnosis of neurodevelopmental disorder occurred years later, mostly at the beginning of primary school. In others, although early medical record notes were compatible with disability, it was not mentioned during the interviews.

In this group, the identification stage of a possible problem was longer. In most of children, it included several types of evaluations and involved the opinions of different actors (mainly father, mother, pediatrician, teachers, speech therapists, and family members) who interpreted the signs and symptoms presented by the children in different ways (*Supplementary Material II*).

An example of this is the case of Yamila. Her mother perceived that her development was not equal to that of other girls, but interpreted this as being due to her being an only child and the lack of contact with peers. Her kindergarten teachers talked to the family because she was not integrating with her peers. Subsequently, her aunts mentioned to her mother that they noticed a delay in the acquisition of maturity patterns. After a consultation with her pediatrician, she was referred to a speech therapist and, at the age of 5, after different evaluations, she was diagnosed with global developmental delay.

Up to that moment, her mother thought the problem was not defined in terms of medical diagnosis, even though the girl showed different conditions that worried her. Since the recognition of the diagnosis, the need for "something" to treat was confirmed, so they mentioned it as a distressing moment:

*Yes, it was disturbing. I felt it was more distressing*

*because it was like there was an issue to be solved, you know, having to work and be present.*

In this group, we observed that treatment initiation enabled the introduction of tools into the children's lives that allowed them to shorten the incongruence gap between the biological and cultural lines of development.

In some cases, a trustworthy figure of reference intervened in the process. For example, in Denise's case, her mother described the positive role that her doctor played in the beginning of her treatments:

*It is a very long process that I went through (...). From the first time they told us that Denise had a problem, we could not accept it, (...) so we had a very hard time (...) it was a long process, I went to different places and I did not accept it, I thought it was a mistake, I thought they made a mistake, my husband felt the same. When we found this place, I was very anguished (...) the doctor told me: "We are going to help you." That was the word that kind of took the weight off my shoulders, it gave me confidence (...). We started to do all the paperwork, I did everything I was told to do. (...) I imagined that, hopefully, everything they told me was wrong, that it was wrong, but I was already confident (...). I am accepting it little by little.*

In the interviews, children's experiences with school and difficulties in socializing with their peers were also reported, as well as long periods of uncertainty, distress and/or family conflicts due to parenting difficulties (*Supplementary Material II*). In all the cases of late onset, treatment initiation brought about a change of school to other facilities that provided conditions in accordance with the children's possibilities. In this new context, they were able to integrate into a peer group and, in most cases, became literate.

## DISCUSSION

In this study, it was possible to observe that, after diagnosis or treatment initiation, families began to internalize the idea that their child would need frequent medical visits and treatment and that they would be forced to organize themselves in a different way.

In the early initiation group, it was observed that families were quick to accept and initiate the therapeutic itineraries and to carry out all the rearrangements in daily life that this implied. Such arrangements constitute the incorporation of what Goffman calls the *habitus* of disability, which is the internalization of views and rules that society applies to disability, and the power relations that these rules imply.<sup>18,19</sup> In contrast,



in the second group, the incorporation of this *habitus* was progressive and the diagnosis was subsequent to treatment initiation.

This division, made according to therapeutic itineraries, does not refer to substantially different groups in terms of types of treatment, but rather constitutes a distinction that was useful for analyzing the place of medical diagnosis in both these itineraries and child rearing. We observed that, in the early initiation group, the possibility of formulating other parenting proposals or exploring different therapeutic approach options was enabled early on. On the other hand, in the second group, decisions on the initiation and type of therapies were temporarily extended, and situations of suffering appeared due to the invisibility of the difficulties that arose.

As to the possibility of generalizing these profiles to other groups, it is important to bear in mind that the study was carried out in children with access to private health coverage, so it would be advisable to study each group in its own setting.

In their studies on disability, Conrad and Potter point out that agreement between physicians and the family is necessary to achieve a diagnosis that allows redefining the “problem child” as a child with a legitimate condition to be cared for.<sup>20</sup> The time elapsed since the moment families detect some difficulties until the diagnosis is finally reached and the consequences that follow have also been described by other authors. In autism spectrum disorders, a significant number of patients are not diagnosed until they start school, although diagnosis is possible from 16 to 24 months of age.<sup>20</sup> Delayed recognition of the problem represents missed opportunities to provide answers, however tentative, aimed at stimulating neurodevelopmental patterns. It also prevents families from acquiring strategies and tools to deal with the situation and, as we observed in this study, it exposes both children and their families to stressful experiences.<sup>3,21</sup>

## CONCLUSIONS

Therapeutic itineraries started early in some cases and at a later stage in others. The initiation of treatments made it possible to use tools to bridge the gap of incongruence between the biological and cultural lines of development. ■

**Supplementary material** available at: [https://www.sap.org.ar/docs/publicaciones/archivosarg/2022/2444\\_AO\\_Pugal\\_Anexo.pdf](https://www.sap.org.ar/docs/publicaciones/archivosarg/2022/2444_AO_Pugal_Anexo.pdf)

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