

FAMILIES' PERCEPTIONS ABOUT EARLY CHILDHOOD INTERVENTION PRACTICES¹

Názory rodín na intervenčné postupy v ranom detstve

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Abstract: Presented study aims to investigate the perceptions that families supported by early childhood intervention services in the north of Portugal have regarding the quality of the support they receive. Contemporary recommended practices for Early Childhood Intervention services place the Family in a central role and as the primary decision-maker in the process. As such, these services aim not only to support the child's development but also to support and strengthen families to become autonomous in decision-making and defend their rights regarding their children with special needs throughout the life cycle. Thus, the study's primary goal is to get to know in detail and a first-hand account of the families' experiences concerning the support provided by the Local Early Intervention (LEI) teams. This study uses a qualitative research method, the case study. Here, we conducted semi-structured interviews with the participating families. The findings reveal that the families are pleased overall with the quality of the services.

Keywords: early childhood intervention in Portugal, family-centred intervention, participatory practices, recommended practices, relational practices.

Abstrakt: Cieľom prezentovanej štúdie je zistiť, ako vnímajú rodiny podporované službami predškolskej intervencie na severe Portugalska kvalitu podpory, ktorú dostávajú. Súčasne odporúčané postupy pre služby včasnej detskej intervencie stavajú rodinu do ústrednej úlohy ako hlavného rozhodovateľa v procese. Cieľom týchto služieb je nielen podporovať vývin dieťaťa, ale aj podporovať a posilňovať rodiny, aby sa stali samostatnými v rozhodovaní a obhajovali svoje práva týkajúce sa ich detí so špeciálnymi potrebami počas celého životného cyklu. Hlavným cieľom štúdie je teda podrobne spoznať a z prvej ruky opísať skúsenosti rodín týkajúce sa podpory poskytovanej miestnymi tímami včasnej intervencie (MVO). Táto štúdia využíva kvalitatívnu výskumnú metódu, prípadovú štúdiu. Tu sme uskutočnili pološtruktúrované rozhovory so zúčastnenými rodinami. Zo zistení vyplýva, že rodiny sú celkovo spokojné s kvalitou služieb.

Kľúčové slová: intervencia v ranom detstve v Portugalsku, intervencia zameraná na rodinu, participatívne postupy, odporúčané postupy, vzťahové postupy.

Introduction

Early Childhood Intervention (ECI) is aimed at children at-risk and/or with SN from 0 to 6 years of age. The current ECI paradigm shifted the focus of the services from children to children and their families (Dunst et al., 2014).

To sustain this paradigmatic shift in ECI, the *Workgroup on Principles and Practices in Natural Environments* (2008) devised seven key principles, namely: Children learn best through daily experiences and interactions in family

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contexts; All families can enhance their children's development and learning with the necessary support and resources; The primary role of the practitioner is to work with and support family members and carers present in the child's life; The ECI process, from first contact to transition, should be dynamic and individualized to reflect the family's preferences, learning styles, and cultural beliefs; The intervention plan's aim should be functional and based on the children's and families' needs and the priorities they identified; Addressing family priorities, needs, and interests is most appropriate through a facilitator who represents and is supported by a team and a community; Interventions with children and their families should be based on explicit principles, validated practices, and relevant legislation.

The evidence-based recommended practices for ECI require interacting with families by putting them at the centre of the services professionals provide (Dunst, & Trivette, 2009; Mas et al., 2022). These practices involve changes in the roles of professionals and a transdisciplinary approach to working with children and their families (Espe-Sherwindt, & Serrano, 2020). One can summarize the Recommended Practices in the following way (Dunst et al., 2014): Family and Children are at the centre of the intervention; Intervention is done in the child's natural environment; Transdisciplinary teams with the active participation of the family in all stages of the process; Individualized intervention plan, based on children's and families' needs and priorities; Aims to promote the child's development and the capacitation and empowerment of the family.

When professionals' practices in their approaches and support with families are family-centered, the support is more effective, both in terms of the family's skills and confidence and in terms of the child's development (Espe-Sherwindt, 2008; Dunst, & Espe-Sherwindt, 2016). Research, however, has identified two dimensions of family-centred recommended practices that best contribute to the effectiveness of this intervention paradigm - relational practices and participatory practices (Dalmau et al., 2017; Espe-Sherwindt, 2008; Machado et al., 2017).

Relational Practices: These practices comprise a set of interpersonal behaviors of active listening, empathy, authenticity, respect for families' experiences, seeing families in a positive light, and cultivating a relationship based on mutual respect (Espe-Sherwindt, 2008). **Participatory Practices:** These practices are more action-orientated, as they give families what they need in order to be able to make decisions and deal with challenges. They also help the professionals identify the children's and families' strengths to empower and promote the families' competencies, leading to a balance in the relationship between the professionals in the ECI teams and the families they accompany (Espe-Sherwindt, 2008).

ECI in Portugal

ECI practices in Portugal have evolved in the past thirty years and built on a strong evidence-based foundation, allowing us to become closer to the Recommended Practices. This process shifted the focus of the intervention, placing families at the center of ECI (Carvalho et al., 2016).

This paradigm change began to take form in Portugal even before the development of the National System for Early Childhood Intervention (SNIPI) in 2009. Over two decades, the ECI services changed from a medical model centered on the child with developmental problems to a family-centered approach (Pinto et al., 2012; Carvalho et al., 2016). Within the medical model, the target population of ECI services were children aged 0 to 3; the intervention focused on their deficits, and the professional's word and expertise were deemed universal, leaving the families outside of this process. The teams surrounding the child worked on their specific fields, with little to no interaction or discussion about the course of treatment, with the other professionals involved in the process (Pinto et al., 2012; Carvalho et al., 2016).

The first steps towards a family-centred program happened in 1989 with Coimbra's Integrated Early Intervention Program. Despite being a program limited to the geographical area of the district, it was of great importance. This program changed the focus of the intervention for the first time, placing families in the center of the intervention, following the evidence-based recommendations of the literature, and providing professional training (Carvalho et al., 2016). These changes later translated into the first attempt at legislation, with the publication of the Joint-Dispatch 891/99, which formalized this change as well, later, the Legislation that created the National Early Childhood Intervention System (SNIPI) – Decree Law 281/2009. Then, the target population was children from 0 to 6 years of age with developmental disorders and/or at risk, as well as their families. Practitioners work in natural contexts (home, educational setting), thus valuing family knowledge and opinions. Practices were tailored to fit the family, the child, and their needs, focusing mainly on their strengths and interests. The goal is now the child's development and the family's well-being and empowerment to deal with new challenges in the future and advocate for their child's best interests. To accomplish this, the teams will ideally work in a transdisciplinary model, focusing on the family and its concerns, expectations, and priorities (Pereira, & Serrano, 2010; Pinto et al., 2012; Carvalho et al., 2016).

Reviewing the studies about actual practices in the field (Leite, 2018; Pinto, 2019), we can identify the gap between theory and practice. Despite professionals recognizing a difference between their actual and desired practices, families associate better quality practices with longer support time by professionals (Leite, & Pereira, 2013). Still, some professionals do not yet value the family's ability to participate in the intervention process (Pinto, & Serrano, 2022). However, despite these practices being far from ideal, the families still reported a high degree of satisfaction with the ECI services provided, as well as an improvement in their context and quality of life when the severity of the child's handicap is the highest (Carvalho, 2015; Dias, & Cadime, 2019).

Methodology

This is part of a more extensive study for a master's dissertation on the family perception of early childhood intervention services in Portugal. Here,

we will focus on the perceptions of the ECI team professionals in the north of Portugal, designated Local Early Intervention (LEI), about their work families and children.

Qualitative studies are usually the most appropriate when the goal is to deepen a given phenomenon by describing it in its natural context (Denzin, & Lincoln, 1994). The case study is a qualitative research method that allows us to focus on a more specific and restricted phenomenon in space and time to analyse it more in-depth (Yin, 2005).

Starting with the question, what practices do ECI teams use in their relationships with the families they work with? We will answer it by exploring the following specific points: understanding the quality of the relationship between the family and professionals from the ECI team, understanding what role the family plays in the intervention, and identifying the role of the family in the decision-making process.

This case study involved six families. Thus, the participating families eligible for this study were accompanied by ECI teams from the SNIPI North zone. Initially, an email was sent to the SNIPI North Regional Coordination Subcommittee coordinator, presenting the study and requesting authorization. After this approval, the first approach to the participating families was made through the LEI teams that were willing to collaborate with the study. All the participating families met the following criteria:

- they must be parental figures of children who have been followed up by a LEI team in the geographical area described for at least two years;
- the children had been referred for support by the team due to one of the following problems: global developmental delay, autism spectrum disorder (ASD), or developmental risk in more than one area.

The families interviewed were referred by the LEI and informed beforehand about the study's objectives, their rights, and the process for processing the information collected in the interviews—they signed an informed consent form. Identification codes were created for the participants to protect their identities and those of the LEI professionals. These codes and the families' identities are protected under the General Data Protection Regulation legislation.

To gather information, first, we used a sociodemographic questionnaire to find out the age of the participants, the number of children, marital status, educational qualifications, the child's diagnosis, and the length of time the LEI had monitored them. Next, a semi-structured interview script was used to obtain the information that would allow us to understand the phenomenon under study and the specific objectives defined. The interviews lasted an average of around 50 minutes. These semi-structured interview questions were designed by the interviewer, serving as a basis for gathering the relevant information according to the study's objective and its guiding questions.

So, to better organize the presentation and analysis of the results obtained, we began by organizing the contextual information of the families participating in the study in a sociodemographic framework (Table 1).

Table 1 Sociodemographic data

Family	Age	Kinship	Household	Diagnostic
M1	27	Mother	Mom, dad and sister	Speech and Motor Skills Delay
M2	35	Mother	Mom, dad, and brother	ASD Level 1
M3	41	Mother	Mom, dad, and brother	ASD level 2
M4	40	Mother	Mom, dad, and grandmother	Speech Developmental Delay
M5	37	Mother	Mom, dad and sister	Global Developmental Delay
M6	35	Mother	Mom, dad and sister	Global Developmental Delay

(Source: own compilation)

The collected data is organized into three different themes (Table 2). The themes (and sub-themes) were built up during the data analysis process and emerged from the participants' discourse in response to the interviews. These categories have also allowed a better understanding of these families' perspectives.

Table 2 Themes and Sub-Themes

Themes	Sub-Themes
Relational Practices	Family: They feel like they are respected by the professionals and listened to.
	Children: adequate relationship with the professionals after an initial adjustment period.
Participatory Practices	Teamwork: Families are a part of the intervention process.
	Role in the intervention: Families describe themselves as a team member.
Decision-making Process	Family's priorities: The family's priorities concern the child's future and autonomy.
	Final decision: Despite families feeling they have the final say, that was not always the case.

(Source: own compilation)

Results

1) Relational Practices

The first important dimension in working with families is relational practices. These practices are based on active listening, respect for the family's point of view, empathy, and building an appropriate relationship with the child (Mas et al., 2022).

To better understand the LEI's relationship with the families and the children they support, the participants were asked to describe their relationship with the team's professionals and how they adapted to the support.

Regarding the families, all the participants said they felt listened to, that their opinion was respected and considered by the team, and that they created a professional relationship based on trust and mutual respect. A more precise description of this relationship can be found in M2's account:

"Yes, without a doubt. The IPEI [Individual Plan for Early Intervention] is done between me, the kindergarten teacher, and the therapist. We re-evaluate the points together. For example, in the part about the child's difficulties, the therapist reads it and always asks for my son's and my son's teacher's opinions. Then we readjust or don't readjust and make changes according to the evolution of the goals. For example, there was a point when the therapist and the teacher said that the child had already reached the goal, but I could not see that, so I insisted that a little more work was needed, and that is how it stayed."

In M4's case, the relationship between her and the team was one of immediate empathy:

"I liked it straight away! I liked my daughter's case coordinator. She's an incredible person, very frank and down to earth. She was there the first time, not completely, but the second time we met, it was like a team. I thought she was one of those people you look at and like immediately."

Regarding the children, establishing a relationship with the members of the teams who interacted directly with them presented some initial challenges. In some cases, their attention was quickly won by using materials that interested them – as M1 reports:

"At first, with the girl's immaturity, everything passed by her. However, it's been different, especially when we moved to this team. The girl now, truth be told, goes with everyone; all it takes is a jar of plasticine, and that's it. So, here with the teacher, after a week, she was already won over. They played with plasticine and shaving foam, and that was enough to make the connection. She was already completely enamored; that was a connection that the girl let go of straight away."

In other situations, it took longer for the child to feel more at ease, as M4 and M5 say about their children:

"Initially, the case coordinator said that the girl wasn't very 'present' and that she didn't feel her in the sessions. That she was entirely in her world. However, then she gained self-confidence and started to develop a lot. She began to discover that there were many things beyond her little world here at home."

"With the LEI team, at the beginning of last year, she had troubles with their presence and rejection, but rejection of physical contact. My child never had any problems with physical contact with us; she loves kisses and hugs, but not with strangers. The psychologist at LEI had already told us that we should not do it with strangers and that there was no point in forcing it. But now, fortunately, she's more open and interacts and knows what she's going to do, and that's it; there have been improvements, and it's easier to work with her. However, it took a while."

Finally, according to M2, M3, and M6, since their children were the center of attention from a very early age, they took the support provided by the LEI staff more naturally, and adapting to it was straightforward and unconstrained. This situation is well described in M3's account:

"My youngest son, I don't think he felt any difference because when he was one and a half years old, he practically started to be the center of attention. He's always had many people around him because he went to nursery when he was one year old; in other words, he started having his peers around him straight away: the teacher, that's it. However, when we started to see the differences, that's when we started doing therapies and everything. In other words, from an early age, he started having therapists there, the LEI, and the educator more present. The family here at home has always been very close to him. In other words, he doesn't know any other reality; everything has always been around him."

2) Participatory Practices

When we talk about participatory practices in ECI – as contextualized earlier - we're referring to practices where the team accompanying the child involves the family in the whole process, allowing them to become a member of the team that actively contributes to promoting the development of competences in the child being accompanied. Here, the family – and other elements within their support network, such as kindergarten teachers – is another element that puts skills-promoting activities into practice, according to their priorities, and fit into their day-to-day lives to increase the child's learning opportunities in their natural context.

When asked, all the participants said they felt they were an active part of the support and intervention team for their children. At first, they actively participate and apply the intervention suggestions and guidelines with the children daily to continue the team's work at home. Taking M3 and M4's accounts, we can see how these dynamics work and how the families embedded at home and within daily routines, suggestions that they observe and discuss with professionals as if they were another member of the team that accompanies them:

"I learn in therapy and then apply what I learn at home (...). I've taken this break in my professional life to be 100 percent with the team and help my son in the best possible way. Working 35 km from home, I couldn't give my son all this support and participate in everything."

"Otherwise, I think it always went well, and I always felt that I was part of the team because they also believe this is a job that must always be done jointly by all parties. Although my mum always resisted because the little girl didn't speak, I had to give her things, but it was always important to know how to manage both things, and it worked out well. It always went well, and what we did there was what the team and the therapist decided. Everything we had to work on there, such as dressing, brushing their teeth alone, and all those little activities, we always worked on together, and that's the only way to succeed because they (ECI services) give us the tools to succeed."

However, if we carefully analyze M5's experience, we understand that is not always the case. The family's involvement is passive, and the role of the professionals stands out in the intervention:

"It's the same system with LEI (me not being present but getting videos of what they did after the sessions), although not with the psychologist. With him, feedback is only given weekly via phone call after the session with my child."

Given these accounts, we can infer that in this dimension, the ECI teams don't always put into practice one of the most important principles of recommended family-centred practices, directly involving and supporting the primary carers of the children, and monitor how to put into practice the intervention strategies/adaptations which will increase child participation and promote the desired developmental competences.

3) Decision-making

As we saw earlier, the participants in this study feel that they are an active part of the team in the intervention process and are listened to and respected when it comes to their concerns and challenges for their children's future. However, for the work of ECI teams to be genuinely family-centred, the family makes the final decision regarding the work carried out with the children.

Families begin to define goals and priorities for their children's development. Of these, the biggest – and most important – goal is for children to have the highest possible level of autonomous functioning in the future. Autonomy is a comprehensive and general objective that cannot be worked on all at once. Therefore, smaller, more specific objectives emerge, then divided into steps or stages that meet the family's priorities. In the case of this study, the main specific objectives within autonomy are speech and motor skills, and these were the main signs that led the families taking part in this study to seek help. Once these have been overcome, the other major challenge and concern for these families is the transition to primary school and the start of the children's formal schooling.

The testimonies of these families show a great deal of concern for their children's future due to what they describe as their differences from children of the same age with typical development. These concerns are common to all the families interviewed but are best illustrated by the testimony of M3 and M1: *"That he can be independent, that he can process things around him, that he can have a more independent life. To acquire as many skills as possible before going to elementary school, we're still going to see if he goes next year."*

"Initially, we just wanted her to speak and make a few sentences. That was the first thing we asked. So, when she started to make sentences, albeit a little sloppy, that was fine with me. They work very hard and help with the preparation, so much so that my daughter comes home and starts telling the stories of her day and sometimes brings new vocabulary. She's usually the most talkative on Tuesdays, so I can tell there's already been some progress and work done. There are words that we don't use daily, and she brings them, so I notice that she's sucked in a little something and that something has got inside her head. I can see that they're working on it. The girl can already draw a line, she can paint a picture, that's it, it

can't be too long. She gets tired quickly with long work. But she can already sit in the chair for an hour working on her own, drawing lines, numbers, a few letters of her name, paintings, and collages."

Because the families' priorities were addressed in the intervention, the priorities and specific objectives of the evolution evolved as the families' concerns were addressed and considered.

The participants were, therefore, asked about their role in making the final decisions regarding their children's early intervention process, namely on the topics of most significant concern or priority. As with the previous questions, all the interviewees gave the impression that the final decision was in their hands and that this was never questioned. M3 described clearly and concisely how decision-making in this process has worked with families:

"Yes, yes! Nothing changes without me being present and giving my opinion, not just with the LEI but also in consultations. Ultimately, the decision is always mine, and they respect that. It's done so that I have an active role in the intervention and support for the child."

However, in M1's testimony, we find a description of an experience in which the LEI has a different view on the need for her daughter to move straight into primary school as soon as she finishes the last year of preschool she was attending at the time of the interview, which is contrary to that the family wants, who believes their child should stay on for another year. When asked how she intended to resolve the issue, M1 said that the formal support figure whose opinion most influences her is the development paediatrician doctor, but at the same time, she doesn't want to disappoint the LEI if her opinion is contrary to theirs:

"No, at LEI, they don't think it's beneficial for her to stay another year at the kindergarten. I'm candid. It will be up to the development doctor. Whatever she thinks will be done. So far, that doctor has been excellent. She's always ready. I just ask her anything, and she clarifies everything. So, let's just say that whatever she tells me afterward, that's the order. If she thinks the child should stay on for another year during the assessment, she'll stay; if not, we'll move on to Year 1. I'll go by what she says. I don't know. Maybe if the girl stays in preschool for another year, they [the team] will be slightly disappointed. Alternatively, because they think she has more abilities than the doctor says, I don't know... they expect her to go on, to continue the same path as other children her age. They might be disappointed because I'm devaluing the team's work and that they have just had a year, but that's not the case. Nevertheless, I don't know. I think it would be better to stay."

Finally, we can see that the LEI has addressed and considered families' concerns throughout the ECI process and evolved with the work carried out. We must also bear in mind that, although there is an evolution, families' concerns will not end with the end of support and the transition to primary school but will change throughout children's lives as new challenges arise at different stages of development.

Considering these recorded testimonies, it is safe to infer that the teams accompanying these families mostly respect and listen to their opinions, basing their intervention plan on their priorities and always respecting their decisions. Despite that, one of the participants felt that her opinion about one topic was not fully respected, and she didn't feel secure in her decision because it might upset the dynamic of the ECI team. We can also recognize that overall, the LEI teams made a sustained effort to include the families in all the different stages of the intervention process by empowering them so that they, themselves, can provide support for their children and fit the appropriate strategies for promoting their development into their routines and natural environments, per the priorities and concerns they report.

Discussion

The main goal of this study was to identify the practices of the ECI team and their relationship with the family. Three main categories emerged: relational practices, participatory practices, and decision-making. All six participants in the study said they felt like part of the team and had an active voice in most of the decision-making and planning intervention objectives. They also felt respected and that their concerns were listened to, having developed a relationship of trust and mutual respect with the LEI professionals who accompany them and their children.

Effective support practices in the current family-centered paradigm include participatory and relational dimensions. In the participatory dimension, the LEI team is expected to treat the family as an active element in promoting their child's competencies, and the family should be the main driving force behind the child's development, creating more learning opportunities daily as they learn to manage existing community resources better and defend their interests, concerns, and priorities for the future. On the other hand, the relational dimension includes practices such as active listening, respect for decisions, empathy, understanding of the surrounding family context, and information sharing. Relational practices can exist without participatory practices, but the opposite is invalid, i.e., participatory practices must coexist with relational practices if our goal is family empowerment (Machado et al., 2017). The role of the family as the final decision-maker is one of the key points of the current paradigm of recommended practices on ECI (Rouse, 2012).

On the other hand, the results suggest that overall, the participants are satisfied with the ECI services and see them as an asset. However, it seems they do not yet fully fit into a paradigm of family-centered practices. As we can see, although the teams acted in a way that complied with relational practices, which can be seen in the quality of the relationship they established with the participants, professionals didn't always promote participatory practices in their work with families, as they didn't always have followed and respected the families' priorities.

As such, bearing in mind that the primary goal of today's recommended practices for ECI places the family in the centre of the intervention and that

the professionals must aim to enable and empower families, these outcomes are better achieved when professionals have the adequate training and more opportunities to develop their professional skills in evidence-based programs that promote reflective practice and supervision (Dunst et al., 2019). Professionals must find a balance and navigate the relationship with the family in a way that provides them with security and peace of mind while at the same time preparing them for a future without their presence (Hughes-Scholes, & Gavidia-Payne, 2019; McCarthy, & Guerin, 2022). This makes the work in ECI complex, requiring continuous professional development to ensure quality practices and expected outcomes for families and children.

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