

# Chapter 272

## Early intervention in childhood, being and being between children and adults: The point of view of families

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### ABSTRACT

To broaden the reflection on the role of the early intervention professional in childhood, we present part of the results of two investigations, developed within the scope of a postgraduate degree in special education and a doctorate in educational sciences. Both studies are part of a paradigm of qualitative and exploratory nature, considering the "voices" of families, obtained from semi-structured individual and collective interviews (*focus group*). The results show that the families consider that these professionals develop complex and multiple interventions, requiring a high degree of involvement and a wide field of action and responsibilities with children, families, and teams (pedagogical, therapeutic, and medical). They highly

value their personal and relational qualities, based on an *ethic of care* that includes listening, attention, comfort, understanding, respect, availability, authenticity, flexibility, and responsiveness. They refer to technical qualities, namely the specific knowledge of their disciplinary areas, and pay special attention to the knowledge of the ecology of families, training, professional experience, articulation, collaboration, and networking. The centrality of its action should be to cross *boundaries* between children, families, and professionals, adopting an inclusive perspective, to ensure that everyone, and each one, feel valued, welcomed, and respected. Despite recognizing the importance of the practices of these professionals, the families affirm that the services provided are insufficient because of the complexity of the intervention, identifying a set of constraints and listing some recommendations.

**Keywords:** Early Childhood Intervention Professionals, Children, Families.

### 1 INTRODUCTION

This text aims to know the point of view of families regarding the performance of the Early Childhood Intervention (IPI) professional. The results presented are based on the results of two investigations carried out in the context of a postgraduate degree in special education and a doctorate in educational sciences, in a coincident dimension.

Both studies are the result of concerns placed in the professional practice of the researchers, in a theoretical, conceptual, and methodological aspect, focused on intervention with families and seeking to improve the services provided, in a reflective logic.

In the current concept of IPI, the family has a fundamental role concerning decision-making, which directly or indirectly, influences your child and support, deciding what is best for you and your child (Pereira & Serrano, 2014).

Knowing that the role of the family is increasingly active, we consider it crucial to understand how families of children supported by IPI analyze and evaluate the response that is given by this service, taking into account their needs.

To this end, we have given the floor to the families, so that, through their testimonies, they can explain their feelings and expectations regarding the quality of the intervention provided by these professionals.

We understand that, by giving voice to the families, we will be contributing to broadening the reflection and knowledge about the appeal of these professionals and, in this sense, to improve the quality of the intervention provided to children from zero to six years old and their families, in care at IPI.

## **2 EARLY INTERVENTION IN CHILDHOOD: MAPPING CONCEPTS AND FUNDAMENTALS**

The IPI is a set of support measures in the social, education, and health areas, for children between the ages of zero and six and their families, made available to improve the child's learning opportunities, provide the skills to caregivers and promote the resources of families and the community (Correia & Serrano, 2000). This multidisciplinary approach, implying a set of community-based resources, projects a system of organized and coordinated services, intending to support children at risk or with developmental delay, embodied in the creation of a network of proximity services, formalized in the legislative normative (DL281/09) that created the National System of Early Childhood Intervention (SNIPI).

Over the years, the IPI domain has undergone a considerable evolution, going from an intervention directed only to the child and its deficits to an intervention in which the involvement of parents is fundamental, with the family being the intervention unit, considered a key element in the decision-making process and in the provision of care to the child (Carvalho et al, 2016; McWilliam, 2012).

Parental participation is an essential component of current IPI practices, and in this approach, supports include information, counseling, and guidance. Parental knowledge and capacities are strengthened, promoting the acquisition of new competencies to care for the child, and facilitating the child's involvement in family activities and routines (Caeiro & Correia, 2021).

Functioning as an active partner throughout the intervention process, current practices seek to meet the priorities and needs of the family, recognizing their strengths and resources, and improving their well-being and functioning, to enable them to respond to the demands of development and learning of their child (McWilliam, 2012).

In family-centered practice, parents become of substantial importance throughout the process, being supported in their natural environments by strengthening the unique capacities they possess as individuals and as families. In this model we find, in addition to the learning opportunities for the child, also and

fundamentally, the support to families, in a practice supported by the philosophy that frames this model and that gives the family the central role in the process of choice, decision-making, and actions that involve their needs, priorities, and preferences in the IPI support process. (Dalmau et al., 2017; Dunst, 2000; Dunst & Trivette, 2009).

Concerning IPI professionals, they should be able, together with families, to build an IPI program that provides the necessary and appropriate support to the child and the family, taking into account their ecology, routines, beliefs, values, and priorities, which will have an impact on the quality of care provided to the child, with positive implications for their autonomy, participation, and involvement in contexts and quality of life, as well as on the resilience of the family (Correia & Caeiro, 2021; Dunst, 2017; Guralnick, 2001).

The birth of a child with developmental delay puts parents in a situation of greater fragility, given the understanding of the differences between their children and the daily difficulties encountered, which is reflected in their physical, emotional, or material well-being. The specificities and requirements can cause limitations in terms of the functioning and dynamics of the family system, implying a constant reorganization and adaptation on the part of the families, to establish new expectations, new realities, and improvements in the quality of life of all family members. This process, which begins at the moment of diagnosis and extends throughout the life cycle of the family, is a unique and singular process, which differs according to the characteristics of the child, family members, and the broader contexts where it is inserted, influencing the quality of interaction between parents and the child (Costa, Steffgen & Ferring, 2017).

Bearing in mind that each family is unique and will therefore deal with the situation in a particular way, the adaptation of parents is often a long process that requires the satisfaction of a set of needs, focused on solving problems. In this sense, IPI services must promote and value the skills of the family, so that it can support the development of its child and collaborate in the implementation and evaluation of programs, and IPI professionals should be able to anticipate the challenges that may occur in the family s and consider what the interventions that best respond to the needs of each child and each family (Bruder & Dunst, 2014; Dunst and Trivette, 2009; McWilliam, 2003; Pereira & Serrano, 2014).

The recommended practices constitute a great challenge to these professionals who should be able to promote family-centered support, functioning as a mediator, encouraging and helping families to implement appropriate strategies to cope, not only with their child but with all the changes resulting from the birth of a child with developmental delays and that affect the entire family structure and dynamics.

### **3 I SEEK A LOGICAL METHOD**

Considering the objective of both studies, we opted for a qualitative and exploratory methodology because of the possibility of developing a type of knowledge-based more on the description or interpretation than on the evaluation of the phenomena. We took into account that this paradigm enables the development of knowledge, as well as the valorization of the understanding of the researcher and the participants in the

research process. Despite the risks and difficulties it imposes, this approach always proves to be a deeply instigating and challenging undertaking, as it presents itself with the potential to reveal values and representations, allowing the capture and appreciation of subjectivities. Added to this is the fact that it studies "things in their natural settings, trying to understand, or interpret, phenomena in terms of the meanings that people confer on them" (Denzin & Lincoln, 2006, p. 17).

Ethical issues accompanied us throughout all stages of the studies, seeking to make them an integral part of the daily practice of research, always seeking not to cause any "physical, but above all, psychological and emotional damage to those" (Vasconcelos, 2006, p. 98), which we investigated.

The selection of participants was carried out either intentionally so that they could contribute to the collection of data related to the objectives of the study (Creswell, 2007; War, 2010). According to Creswell (2007), this number of participants must experience the issue that needs to be deepened, making the sample homogeneous, and ensuring that the data collected can contribute to the development of new theories.

In this sense, the criteria that were already after the selection of the participants were the following: families supported by IPI for at least six months; having children of different ages and problems; supported by different IPI professionals.

The "voices" of the families were heard through six semi-structured interviews (study carried out in the scope of the doctorate), and a collective interview (focus group), with the participation of a group consisting of six elements (study carried out in the scope of the Post-Graduation).

The option for the semi-structured interview technique is related to the fact that this technique allows a verbal interaction, as well as access to the representations that people have about situations, and phenomena, respecting "their frames of reference – their language and their mental categories" (Quivy & Campenhoudt, 1998, p. 194). About the reason that underpinned the use of a group interview, it was the fact that it allowed the expression of opinions in the collective, allowing a more in-depth analysis of the interactions between families, which can both establish a consensus as well as differences of opinion (Cohen, Manion + Morrison 2018).

The technique of analysis of the information collected was content analysis (Bardin, 2011), which aims to isolate, tell and interpret themes, issues, and recurring motives in the material under study, thus allowing a smaller and more easily manageable set of information.

#### **4 PRESENTATION, ANALYSIS, AND INTERPRETATION OF SOME RESULTS**

When we sought to know the point of view of families on the role of the IPI professional, several dimensions emerged that reflect complex and multiple interventions, requiring a high degree of involvement and a wide field of action and responsibility with children, families, and teams (pedagogical, therapeutic and medical).

The testimonies of the families will be cited in italics, accompanied by the codes assigned to each study (PG – Post-Graduation; TD – Ph.D. Thesis), followed by the numerical identification of the families (e.g.: PG1; TD1), as ensuring your confidentiality and anonymity.

#### 4.1 REFERENCE TO TECHNICAL QUALITIES, TRAINING, AND PROFESSIONAL EXPERIENCE: KNOW-HOW

Families report that caring for a child with developmental delay influences and changes most aspects of family dynamics, and it is essential that each family recognizes the different characteristics of their children and tries to adopt different strategies to deal with their differences and difficulties. In this sense, they recognize the need for qualified IPI professionals, realizing that there is a positive association between the quality of the support they receive and the increase in their well-being.

There is an agreement regarding the importance of the technical qualities of professionals, and families value specific training and professional experience as crucial factors for one directed to their needs.

From the point of view of the operationalization of the intervention, the families highlighted the importance of the passage of strategies, the clarification of doubts, and the work directed to the difficulties of the child, as we can verify through the testimonies of the families: we transmitted our concerns with our child and the technician gave suggestions about what could be done. And also made the bridge to the nursery (TD2); the technique that accompanied my son created a series of strategies that forced us to leave our comfort zone and evolve (TD5).

Dunst (2000) adds in the technical quality of the professional, the training, and the professional experience, where the knowledge, specialization, and skills acquired by the person are incorporated, as well as the representation of this specialization as part of the exercise of its performance.

Concerning training, they stress that professionals should have a lot of knowledge in the development of children, with disabilities, know their characteristics and then define the strategies (PG1). They refer to the need for professionals to update their knowledge, that is, not only to take their course, but then they should go on doing training (PG4); to rethink their professional role and deepen their knowledge and methodologies. It is observed that, for these professionals to have a holistic look at the child and the family, it implies that they acquire skills related to the development of the child and the ecology of the family, namely about the centrality of the family in the IPI process (Caeiro & Correia, 2021).

#### 4.2 VALUING PERSONAL AND RELATIONAL QUALITIES: ETHICS OF CARE

The participating families consider that these professionals need to have skills that go beyond their specific knowledge, namely personal and relational qualities.

The qualities selected by the families concern, in a general way, what the professionals should be when they are in contact with them, always being for the well-being of the child and the family. For these,

professionals must be available, attentive, flexible, responsible, empathetic, and have a good disposition and a sensitive listening capacity, since the priorities and needs of families are constantly changing factors.

Let's see, some testimonies of the families that attest to the appreciation of these qualities: *It is very important that they know the families, and perceive how they live, because we are all different*, (PG4); *When I realized what my son had, I felt terrible, it was terrible. It was as if someone had died, in this case, my son, which is even worse. The technique helped me overcome this and have another perspective on my son* (TD2); *She has been a very important person in our family for her availability, she is always ready to help. It's very human, it cares about knowing about our state. He talks, and he listens to us, but everything in a quiet way, it seems that there are no other children, that he is not in a hurry, and he often seems to put himself in our place* (PG5); *We talk a lot, she's a good listener, she's a great supporter, she listens to me, she helps me think. I feel treated with dignity and respect* (TD3)

In this regard, Bernheimer and Keogh (1995, cited in McWilliam, 2012) allude that to structure an intervention plan according to the child's disorders, professionals will have to understand the ecology of the family, its perceptions, values, beliefs, supports and daily experiences that contextualize the child's developmental path. Bronfenbrenner's (19, 8, 9) biopsychosocial conceptual model reminds us precisely of the importance of contexts in human development and how they influence it, directly or indirectly. Each child has a life path, with different experiences, so it is very important that professionals truly know the family, intending to outline an intervention that suits their dynamics. This respect for the uniqueness of each family demonstrates that these professionals base their practices on an ethics of care that includes listening, comfort, understanding, respect, availability, authenticity, flexibility, and responsiveness.

#### 4.3 ACTING IN DIFFERENT DIMENSIONS: A SHARED RESPONSIBILITY

Families recognize the complexity of the role of professionals, given that they work in different contexts of intervention, simultaneously, with the child and with the different significant adults in the child's life. The testimony of the TD5 family: *The great difference that I felt, is that I work with ourselves as a family, with the therapists, and with the daycare*, it reveals the awareness of the scope of functions of the professional, contemplating a wide field of action and responsibilities.

The intervention practices of these professionals are based on collaborative consulting processes, based on equitable and reciprocal relationships between IPI professionals, families, and pedagogical teams, which allow the design of interventions that legitimize the various experiences of children, in their various contexts, valuing the different knowledge and experiences of the different interveners in the process (Boavida et al., 2018). Although different, these skills are complementary, and all contributions are fundamental to implementing a quality intervention directed to the needs of each child and those around them.

The following testimony illustrates the importance of the looks of the different adults surrounding the child and the need to take advantage of the significant opportunities for learning and development that



arise naturally in the child's routines in different life contexts: *I know my son well because I am a father and I do things with him. The educator knows it differently. The intervention technique still knows him differently, and he does different things with each of us, which is cute. And when we sit down, we put everything in common and find out what he already knows how to do and where he has difficulties* (PG3).

Likewise, they allude to the importance of welcoming and valuing the singularities of each child and making them opportunities for learning and development for all involved, thus adopting an inclusive perspective. This fact is visible in the words of the following families: *often, the other children with curiosity, also came and did the activity that was being directed to my son, and this was also a very positive aspect because it was good for everyone* (TD6); *with the help of IPI, the educator did a wonderful thing, she understood that inclusion starts from within. And she's doing it very well. She is including my son in everything and is creating that sense of community in everything* (TD2).

#### 4.4 BORDER CROSSING: NETWORKING

Teamwork skills are also considered by families as fundamental skills to develop their role with quality, so they say that these professionals *should know all the elements that work with the child and create a link, all speak the same language*(PG1 ). We would say that we are in the presence of professionals who must intervene across borders, with spaces and times of sharing, articulation, cooperation, and reciprocal learning (Vasconcelos, 2009).

The networking with the medical teams is also identified by the families as an important technical quality, since it may consist *of an added value for all because if the work is articulated with the medical teams, the consultations could be more spaced and there could be a greater sharing among all* (PG3). Reference was also made to the work carried out with the therapeutic and pedagogical teams, the *technician went home, to the school and spoke to the therapist. And, the two together, helped to pass information to the educator and us about how we were going to deal with our child* (TD1).

Bruder and Dunst (2015) affirm that an articulated intervention between professionals and services translates into an improvement of the relations between professionals and families and in the improvement of the development of the child and the quality of life of the families.

#### 4.5 CONSTRAINTS AND RECOMMENDATIONS IDENTIFIED BY FAMILIES: CLUES TO INCREASE THE QUALITY OF INTERVENTION

Despite recognizing the importance of the practices of professionals, families feel that they are limited in their performance, due to a set of constraints that are related to the complexity of the field of daily action – being and being between children and adults.

Knowing the need that these children have to carry out persistent and predictable work, the families refer to several aspects that reduce the quality of the intervention, namely: insufficiency in the response provided - *I feel that there are few supports, the time is too little to work with the children, there is a lack*

of resources for the needs that exist, and so it is impossible to be able to properly support all children (PG2); the reduced time that is made available for the intervention - *It is insufficient! It is not enough to give 50 minutes to a child in a week. It's almost like they don't give anything away!* (PG5); the high number of children that are assigned to each professional - *Because logistically you have your schedules, you have your timings, you have your numbers of kids and you don't stretch. The kids stretch and you are less and less* (TD2); the mobility of professionals - *There is no continuity, people are always different. Because there is a person who comes, then comes another who already has other ideas, then comes another who already has others, and this is lost everything in the middle* (TD3) and the lack of training, of some of the professionals, *This is a matter of luck. Because there are technicians, who I realized, are even more lost than we are, and there are others who know exactly what it is that they are doing.* Fuertes (2021), when referring to the professionalism of these professionals, considers that "it is not at all easy to exercise professional in early intervention, if, on the one hand, the technician must be guided by scientific evidence, on the other hand, no technical training prepares the professional for human diversity" (p. 8).

To help increase the quality of the service provided, the families suggested some recommendations. Namely:

- Investment in the training and qualification of professionals, so that they can, in a more consistent and qualified way, use the practices recommended in IPI in the specificity of children and families - *There is more training for professionals, without a doubt. I think constant training is fundamental* (PG2)

- The strength of ELI's human resources contributing to increasing the number of hours available to children and families - *"There had to be more staff working. With this amount of children increasing, you have to increase as well"* (TD2)

- The change in the process of placing the professionals, with a view to greater stability in the composition of the teams - *The technicians did not have to keep changing. The continuity of the teams is fundamental"* (TD3)

- Greater care in the assignment of the professional responsible for the case, should be the one who, from the theoretical and practical point of view, gathers greater knowledge and more experience - *They should be more careful with the people who send because they do not always realize the problems that we have and that our child has* (PG3).

## 5 FINAL CONSIDERATIONS

The families involved in these two research projects, when referring to the professionals who carry out the intervention, did so with great sympathy. In their perception, IPI professionals present as the greatest competencies of their profile the ability to intervene with the child and the family, while demonstrating the ability to adapt to emerging needs.

Regarding the relationship they maintain with the professionals, the families highlight, as the main facilitating factors, their posture and interpersonal characteristics, in particular, the way they engage with



the family and consider it as an integral and effective part of the team, allowing it to collaborate and make decisions about the provision of care to their child. In addition to these characteristics, they consider it essential that these professionals have theoretical and practical knowledge directed to the problems of development, feeling that this reality does not always happen.

Regarding practices, families value the informative support, as well as all the help, received to increase their skills to understand the development and needs of their child, to deal with specific behaviors, and to make choices and implement the intervention, making them more participative and confident in the whole process. They emphasize the need for professionals to consider them as a team member, adapting the answers to their concerns, priorities, and resources. Nevertheless, the complexity of the organization and structuring of the service often does not allow this to happen.

It is perceived through their testimonies that they recognize that the centrality of the action of these professionals is to cross borders between children and adults (families and professionals) and that they adopt an inclusive perspective, to ensure that everyone, and each one, feel valued, welcomed and respected, and the "main tool at its disposal is becoming itself, for its own humanization and professional construction" (Fuentes, 2021, p.8).

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