

Family participation in early intervention programs

A participação familiar em programas de intervenção precoce

Participación de familiares en programas de intervención temprana

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Cross-sectional, descriptive and exploratory study, with a mixed approach, carried out in 2016 in the state of São Paulo, Brazil. It aimed to identify, from the perspective of professionals, how family participation in Early Intervention services for children between zero and five years of age takes place. Data were collected through a questionnaire and audio-recorded semi-structured interviews. 32 professionals from nine Early Intervention services, located in the area covered by the *Programa São Paulo pela Primeiríssima Infância*, participated. Data analysis was performed using descriptive statistics techniques and content analysis methodology. In the steps of the intervention process: Assessment, Planning, Development of interventions, Reassessment and Discharge Planning, families have low participation. Four thematic cores were built: *Challenges from perception to action*; *Professional-family partnership*; *Impact of pre-concepts*; and *Real perspective of participation*. There was a reduced participation of families in services, especially in control, decision and active contribution, showing barriers to be overcome in the search for the implementation of practices recognized as more effective.

Descriptors: Child health; Family; Health personnel; Professional practice.

Estudo transversal, descritivo e exploratório, com abordagem mista, realizado em 2016 no estado de São Paulo, com o objetivo de identificar, sob a ótica dos profissionais, como se dá a participação familiar em serviços de Intervenção Precoce destinados a crianças entre zero e cinco anos. Os dados foram coletados através de um questionário e de entrevistas semiestruturadas audiogravadas. Participaram 32 profissionais de nove serviços de Intervenção Precoce, localizados na área de abrangência do Programa São Paulo pela Primeiríssima Infância. A análise dos dados foi feita segundo técnicas de estatística descritiva e da metodologia de análise de conteúdo. As famílias têm baixa participação nas etapas do processo de intervenção, a saber: Avaliação, Planejamento, Desenvolvimento das intervenções, Reavaliação e Planejamento da alta. Construiu-se quatro núcleos temáticos: *Desafios da percepção à ação*; *Parceria profissional-família*; *Impacto dos pré-conceitos*; e *Perspectiva real de participação*. Verificou-se reduzida participação das famílias nos serviços, especialmente no controle, decisão e contribuição ativa, mostrando-se barreiras a serem superadas na busca pela implementação de práticas reconhecidas como mais eficazes.

Descritores: Saúde da criança; Família; Pessoal de saúde; Prática profissional.

Estudio transversal, descriptivo y exploratorio, con enfoque mixto, realizado en 2016 en el estado de São Paulo, Brasil, con el objetivo de identificar, desde la perspectiva de los profesionales, cómo se produce la participación de los familiares en los servicios de Intervención Temprana para niños entre cero y cinco años. Los datos se recogieron mediante un cuestionario y entrevistas semiestruturadas grabadas en audio. Participaron 32 profesionales de nueve servicios de Intervención Temprana, ubicados en el área de cobertura del Programa *São Paulo pela Primeiríssima Infância*. El análisis de los datos se realizó según las técnicas de estadística descriptiva y la metodología de análisis de contenido. Las familias tienen una baja participación en las etapas del proceso de intervención, a saber: Evaluación, Planificación, Desarrollo de intervenciones, Reevaluación y planificación del alta. Se construyeron cuatro núcleos temáticos: *Desafios de la percepción a la acción*; *Colaboración profesional-familia*; *Impacto de las preconcepciones*; y *Perspectiva real de la participación*. Se verificó una reducida participación de las familias en los servicios, especialmente en el control, la decisión y la contribución activa, mostrando barreras a superar en la búsqueda de la implementación de prácticas reconocidas como más eficaces.

Descritores: Salud del niño; Familia; Personal de salud; Práctica profesional.

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INTRODUCTION

Early Intervention (EI) has been consolidated in numerous countries as a fundamental resource for the development of children exposed to risk factors of the most different natures, throughout early childhood. The effectiveness of EI services is directly related to the planning of individualized interventions, preferably developed in natural environments, within a family-centered perspective¹⁻⁴.

In EI, family-centered practices emerge in the United States within the framework of partnership models between parents and professionals, being a characteristic of programs known as “third generation”. Its emergence stems from the evolution in the possibilities of control that the family exerts over the care provided to their children and from the growing understanding of its decisive importance on the results of the intervention⁴⁻¹².

The principles of this model are based, therefore, on the concept of the perpetuity of the family in the child's life, to the detriment of the transitory nature of intervention services; in facilitating care by establishing partnerships between parents and professionals; respecting ethnic, religious, cultural and socioeconomic diversity; implementing policies and programs that support the needs of families; respecting individualities, capacities and ways of coping; in encouraging and facilitating activation of support networks; in ensuring care services that meet the needs of all its members; and in the design of flexible, culturally competent and responsive systems to the capabilities of families⁴.

Based on these principles, “parents should be provided with information that supports their ability to care for their children and facilitate learning without threatening self-confidence and cultural, religious or family traditions”^{13:109}. In this way, interventions shift from a paradigm centered on the professional and on the individual and unique needs of children, to one that respects and treats the family with dignity, “ensuring the active involvement of all its members in the mobilization of resources and support necessary to care for and raise their children in order to have great benefits for children, parents and family”^{14:341}.

However, despite the recognized effectiveness of this model, a study has shown that, in Brazil, practices based on the needs of children and that prioritize “neurological fundamentals and preventive principles” still seem to predominate, with little evidence on family participation in services¹⁵. Thus, this study aims to identify, from the perspective of professionals, how family participation in Early Intervention services for children aged between zero and five takes place.

METHODS

This is a cross-sectional, descriptive and exploratory study, with a mixed approach, carried out in two stages: characterization of services (according to institutional data, composition of teams and family participation) and analysis of EI practices. Data were collected through a questionnaire and semi-structured interviews, applied from June to August 2016, with professional coordinators and technicians working in EI services for children aged zero to five years, located in municipalities in the interior and coast of the state from Sao Paulo.

The selection of services was carried out based on the identification of those located in the coverage area of the *Programa São Paulo pela Primeiríssima Infância* (PSPPI), which was done by indication of the municipal health secretaries (after formal request), as well as by a survey through of the *Cadastro Nacional de Estabelecimentos de Saúde* (CNESNet).

No EI services were identified in one of the regions that make up the PSPPI. After identification, 09 services agreed to participate in the study, marking this option in the Informed Consent Form. The coordinators of these services were sent a link to the virtual platform, in which the questionnaires on the characterization of the services and on the participation of families in EI were made available (an instrument reviewed by a committee of

experts), the latter being composed of four closed questions that encompassed different aspects of family participation in the intervention stages.

After completing the questionnaires, descriptive statistical analysis of the data was carried out and the selection of a service in each region to carry out the interviews, through the evaluation of the following criteria: a) presence of indicators of family-centered practices (recognition of families as participants of care and its insertion in different stages of the intervention); b) time of existence of the EI team, prioritizing the oldest ones; c) composition of the team, prioritizing those with the greatest diversity of professionals; d) length of work of professionals in the team, prioritizing those in which professionals have been working for the longest time.

Data collection for the second stage was carried out through a semi-structured interview (form reviewed by a committee of experts), which contained 27 questions about the different stages of intervention, such as: reference, first contacts, evaluation, development of the intervention plan, implementation and monitoring, evaluation of results and transition.

The interviews were conducted in person, recorded and later transcribed in full. Data analysis was carried out from the perspective of Content Analysis, in the thematic modality. For this purpose, the documents were encoded, followed by exhaustive reading through which the nuclei of meaning were delimited and later grouped into thematic categories¹⁶.

This study was submitted for consideration by the Ethics Committee for Research with Human Beings of the Universidade Federal de São Carlos, and was approved under Opinion No. 1,539,965.

RESULTS

32 professionals participated, including coordinators and technicians working in EI services for children aged zero to five years old.

All services signaled the existence of family involvement in EI care, in which only one of the nine did not consider the family as a target for assessment and intervention, as well as the child (Chart 1).

Chart 1. Involvement of families in EI care, in each service. São Paulo, 2016.

Service	Are the families involved in EI care?	Is the family, like the child, the target of assessment and intervention?
S1	Yes	Yes
S2	Yes	Yes
S3	Yes	Yes
S4	Yes	Yes
S5	Yes	Yes
S6	Yes	Yes
S7	Yes	Yes
S8	Yes	No
S9	Yes	Yes

Five axes that constitute steps in the intervention process were investigated: Assessment, Planning, Development of interventions, Reassessment and Discharge Planning.

The evaluation axis, as shown in Table 2, was subdivided into three items that contemplated the presence of the family at the time of the evaluation, in the choice of instruments that would be used and in the discussion of results. Family participation is expected by all services at the time of feedback in relation to the assessments carried out. However, in none of the services the family is invited to participate in the selection of instruments used, despite being able to be present at the time the assessment is carried out.

Chart 2. Participation of families in the actions of the evaluation axis. São Paulo, 2016.

Services	Families accompany the children during the assessment	Families are informed of the results of the assessments	Families discuss and choose the best instruments for assessment with the team
S1	Yes	Yes	No
S2	Yes	Yes	No
S3	Yes	Yes	No
S4	Yes	Yes	No
S5	Yes	Yes	No
S6	No	Yes	No
S7	Yes	Yes	No
S8	Yes	Yes	No
S9	Yes	Yes	No

As for the planning of interventions (Table 3), there is unanimity in relation to being informed about proposals that will be worked on with the children, but only one service scored participation of families in the preparation of the plan as well. Despite this, in the development of interventions, all families can accompany the child in the intervention and receive guidance/training on how to stimulate their child at home.

Chart 3. Participation of families in planning actions and development of interventions. São Paulo, 2016.

Service	Planning of interventions		Development of interventions	
	Assist the team in preparing the intervention plan	Informed of the objectives of the intervention plan	Accompany the child during the intervention	Guidance or training
S1	Yes	Yes	Yes	Yes
S2	No	Yes	Yes	Yes
S3	No	Yes	Yes	Yes
S4	No	Yes	Yes	Yes
S5	No	Yes	Yes	Yes
S6	No	Yes	Yes	Yes
S7	No	Yes	Yes	Yes
S8	Yes	Yes	Yes	Yes
S9	No	Yes	Yes	Yes

Seven services reported family participation in child reassessment actions, and in all of them this participation is restricted to being informed about the reassessment and the results obtained. No service indicated involvement of families in deciding the best time to carry out the reassessment, as shown in Table 04.

Chart 4. Participation of families in reevaluation actions. São Paulo, 2016.

Actions/Services	S1	S2	S3	S4	S5	S6	S7	S8	S9
Reports on reevaluation and results	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes
They decide the best time for reassessment with the team	No	No	No	No	No	No	No	No	No

With regard to discharge planning (Table 05), in eight services, families are informed about discharge, in three they decide this moment with the teams, and in all services there is guidance on other services that can be sought for continuity of care.

Chart 5. Participation of families in discharge planning actions. São Paulo, 2016.

Actions/Services	S1	S2	S3	S4	S5	S6	S7	S8	S9
Discharge reports	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
They decide the time of discharge with the team	Yes	No	No	No	No	Yes	No	No	Yes
Guidance on services available for continuity of care	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Four services were selected for the interviews, with a view to understanding the participation of families in different stages of the intervention process, from the perspective of professionals working in EI services. Four thematic cores were built: *Challenges from perception to action*; *Professional-family partnership*; *Impact of pre-concepts*; and *Real perspective of participation*.

Challenges from perception to action

Based on the professionals' perception, it is observed that the family is recognized in its importance, and its participation is referred as a decisive condition for ensuring the best results of the intervention, as shown in the excerpts below:

I think the family, we have to be... we always talk, right? That we can't work without family help. (P14)

It's... very important. First because, I think, if they are seeing the evolution, they also have the notion how much the child is improving, how important the rehabilitation is, right? It's a motivation too. [...] so I... I think that, when the family participates in interventions here or at home, the support is much better and so is the evolution. (P20)

However, despite the recognition, the family remains limited to the secondary role of receiver of the guidelines offered by professionals, kept away from the protagonism in relation to decision-making about care:

Most of the time they are spectators of the... of the process. Mothers are rarely involved, fathers even less, [...] So, some have grandmothers, they are cared for by a cousin, a relative, they spend the whole day at daycare, in short, it's very limiting. Most of the time they are spectators. (P1)

[...] and the family only helps with what the teacher asks, that's all. (P21)

But it is always at the end of assessment, then I give feedback, along with the guidelines: what I can do, what I cannot be doing. (P8)

Professional-family partnership

Partnerships established between families and professionals follow a hierarchical model, in which the cooperation of parents is often limited to providing data on health history, observation of care and/or learning techniques for reproduction at home, a function similar to of a co-therapist:

So, the issue of orientation, right? Of stimulation at home, right? Which is very important, that we always emphasize this. We have little time here, there are many patients, right? And that at home is fundamental, right? So... it's... beyond that question, guidance, it's... I think it's more like that. The question at first is usually more of guiding the mother, right? How to proceed with some exercises, we teach the exercises, right? How to stimulate this child at home. (P3)

We have families that come in, learn how to do it, learn some movements, stimulation, to do this at home. They, they participate. (P13)

I call the mother, "Mother, oh, I guided you. You did? You're doing it?" (P19)

Impact of pre-concepts

It was shown that the socioeconomic and cultural levels of families influence the participation and interference in actions, as well as a judgment of professionals regarding the ability of families to care for their children, which affects the ability to identify and work with potential:

Sometimes the economic situation is difficult, the culture and they don't understand what we explain, they think... neglect... they think they don't need to [...]. (P5)

Look, I don't know if the families, if most of the families here would be able to help planning it. It's because, like, it's so difficult when you have the parents, like, that they are so resistant, that, like that, the more who end up having a greater economic power, they have the issue of denial, right? Not liking... seeing their child here, right? We have a family that did not want the child to go on the tour "how come my child is going on a disabled people's tour?" So I... I think that hasn't been considered. (P5)

Yeah... I understand that here at the cultural level. [...] It's a very poor population, well... you know? Usually the mother has many children, and then I think that the public we serve here is complicated. (P7)

The family, it... it has this primary role of responsibility, right? Also responsibility for the stimulation, ok? We try to make them understand that they are the main actors in stimulation. What is right, when it works, when we are happy, is when the mother understands that she came here to learn, the movements, stimulations, treatment... and she reproduces it at home. That's the main point, okay. Then it is a family that takes responsibility, it is a family that is not lack, it is a family that creates conditions, thinks about activities, and so on. There are families with more ease, families with more difficulties. (P12)

Real perspective of participation

Ambiguities were found between what is done and what is believed to be done, which are shown by the attribution of a decisive role to the family, while it is expected that it simply complies with all guidelines to the letter; or the perception of the knowledge that the family has about the child, but with little possibility of giving an opinion about interventions, which reflects difficulties inherent to the transition from the care model:

They can. But we don't have these cases, it's... the mother's opinion, because what she thinks is better, or not, is very rare. They give their opinion when we're going to say "Look, he's ready to feed himself by mouth. Shall we take this probe out?". Then they are... very anxious, right now. They say "Oh, but will I be able to?", "Will he manage to be fed without the probe?", right? But then we talk, guide the mother, it's not overnight. When she's ready, I do it with her, right there with her. (P8)

We exchange information, right? Yeah... try to understand how it's happening at home, right? It's not exclusion, right? We have this conversation, we have this look, got it? But not in a structured way "Look, come here so we'll plan the activity, what do you suggest, such", that's not. (P4)

But what I notice is happening: they're there doing an activity, then the family says "Oh, she does it like that". Then the educator adapts the activity, sometimes. Yes, they listen to what the mother is saying, "Ah, he prefers it this way", "Ah, I would do it this way". It's... this... this characteristic, it's more informal than sitting down with the family and actually planning something. Because the family maybe participates every day. (P12)

DISCUSSION

Despite the evidence of family participation in some intervention contexts and the undeniable interest that professionals have for this to happen, the inclusion of the family in EI services remains limited in terms of control, decision and active participation, demonstrating that there are still barriers to be overcome in the search for the implementation of practices recognized as more effective.

The findings corroborate other work that pointed out a gap between EI practices developed in the Brazilian reality and family-centered practices, especially focused on intervention, above all, on the prevention or minimization of factors that impact the development of children with disabilities¹⁷.

The few possibilities of participation demonstrated are not enough to characterize a family-centered approach, as a model in which "the needs and concerns expressed by a family are not enough to be valued, 'prescribing' to it strategies and actions that the family does not want, does not understand, does not agree with and that they will in no way reassure or respond to the needs expressed by it"^{4:80}. This reality is in line with studies that point to the incorporation of comprehensive practices in the context of EI in Brazil as one of the main challenges, highlighting the need to rethink the way services have been structured^{11,15,18,19}.

Successful experiences have shown that breaking with the "paternalistic model" (in which the family is seen only as a passive and receptive agent), strengthened the family role as a source of resources to solve their own problems²⁰, and culminated in effective results for the development of family members, as well as reducing the need to access many services to solve their demands. Brazilian EI services should be planned based on empirical data, on systemic development references and on family-centered practices, considering the determining factors for the success of the intended transformation²¹.

The transition from the traditional to the family-centered operating model has not been identified as easy in the countries where it has occurred, as it implies changes in the relationship between families and professionals and in the roles they play throughout the intervention process, requiring a transition paradigm in the way services are developed^{11,22}.

Thus, "the ability of a professional to become family-centered requires a change in valued models and beliefs about families, beyond their own role as a service provider"^{4:78}, as well as "the full participation of parents in team requires that these and professionals build a relationship of trust, based on respect for different perspectives and skills"^{23:44}.

Such statements highlight the challenge that must be overcome by professionals working in EI in Brazil, to leave the perception of adequacy of families strictly linked to compliance with guidelines, giving little value to their skills and abilities.

The possibilities for families to follow the guidelines are permeated by a series of factors such as: number of roles performed, daily routines, child behavior, among other factors that are not necessarily related to their understanding or availability.

Overcoming the traditionally developed care model also requires investment in professional training, so that they can "promote and build knowledge, acquire skills, adapt attitudes and qualify performance, to improve the quality of services and support provided to families in EI"^{24:115}.

CONCLUSION

Despite the interest and effort to bring families closer to professionals and create spaces for their participation in EI services, there are still barriers and difficulties to be overcome in the direction of implementing more comprehensive practices.

It is necessary to invest in professional qualification, in the updating of references, in the restructuring and organization of services, as well as pioneering experiences in practice and research, well structured and that produce consistent evidence, which can constitute a starting point for the implementation of programs in large scale.

It is noteworthy that the results of this study refer to a small sample of programs located in a single state in the country, which may present a limitation in relation to the portrayal of different models employed by these services. Thus, it is not intended that these data be considered absolute to illustrate the EI scenario at national level, but rather that they encourage reflection and contribute to the development of new investigations that deepen knowledge on the subject.

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CONTRIBUTIONS

Bruna Pereira Ricci Marini participated in the design, collection and analysis of data, writing and reviewing. **Patrícia Carla de Souza Della Barba** contributed to the conception, writing and reviewing.

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