Children and Augmentative or Alternative Communication System (AACs). A perceptive vision of the role played by families and professionals

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Título: Menores y Sistema Aumentativo o Alternativo de Comunicación (SAAC). Visión comprensiva de las familias y del papel de los profesionales.
Resumen: Este estudio refleja la realidad de 8 menores, sus familias y 11 profesionales de Atención Temprana (AT) que trabajan con ellos en el proceso de aprendizaje de uso y generalización de un Sistema Aumentativo o Alternativo de Comunicación (SAAC), buscando respuestas que aporten mayor calidad de vida a sus protagonistas. Se ha realizado bajo el paradigma cualitativo y la recogida de datos a través de grupos focales en cinco sesiones de una duración de hora y media a dos horas. Los resultados obtenidos muestran las emociones y sentimientos que surgen en los entornos familiares cuando a la diversidad funcional se suma las dificultades para la comunicación en los diferentes entornos en los que se desarrollan estos menores, aportaciones que deben realizar los profesionales de los diferentes contextos buscando respuestas a las necesidades y demandas de los menores y sus familias. Los datos ponen de manifiesto la importancia de una intervención dirigida a potenciar atribuciones de competencia y capacitar a las familias para neutralizar las atribuciones generadoras de estrés, buscando soluciones de la forma más autónoma posible. Las reflexiones de los profesionales expresan la importancia de conocer las necesidades de los menores y sus familias para colaborar en la búsqueda de soluciones.
Palabras clave: Familia; profesionales; SAAC; competencia; recursos.

Abstract: The present study accounts for the experience conducted with eight children, their families and the professionals in charge of the Early Intervention Program (EI) working with them during the whole process of learning, training and generalizing of an Augmentative or Alternative Communication System (AACs) used to try and find resources that will improve the quality of life of these participants. A qualitative paradigm has been applied and the data collection has been performed using focal groups during five one-hour-and-a-halves to two-hour sessions. Results obtained show the emotions and feelings arising within the family circles when other communication problems between the different environments where these children interact are added up to the functional diversity; professional experts in many contexts need to provide resources to respond to these necessities and requests originated by these children and their families. The resulting data underline the importance of the intervention used to enhance the attribution of competencies that capacitates families and neutralizes the attributions generating stress situations to finally find the most autonomous solutions to these issues. Reflections provided by professionals show the importance of knowing better the necessities of these children and their families for them to provide an efficient collaboration during the resource-finding process.
Key words: Family; professionals; AACs; competencies; resources.

Introduction

We define the family status concept, as referred to in the works of Palacios and Rodríguez (1998), quoted by Perpiñán (2009, p.72), where they consider that it is "a union of persons sharing a lifetime project of joint existence, meant to be durable, with a strong sense of belonging established within the group and, with a personal commitment between all its members, where very close intimacy, reciprocity and dependence relationships are built." Emotional ties, feelings of reciprocity and belonging are thus significant characteristics taking shape differently in every family.

When one of the group constituents shows some kind of functional diversity, a crisis arises from within the family group affecting all its members. This situation is sometimes exacerbated by the presence of some developmental speech or communication impairment, making it essential for the Augmentative or Alternative Communication Systems (AACs) to offset its effects.

Basil, Soro and Rosell (2000), consider that these systems are a set of resources designed to ease speech comprehension and expression for people who are unable to express themselves due to some kind of impairment.

The role played by specialists supporting families, helped by different paradigms of actions, is a key factor influencing the way the latter face the new situation derived from the birth of a child affected by some kind of functional diversity. The family-centered practice paradigm is actually gaining significance as it helps its members unveil their inner strengths and compensate their difficulties from an empowerment perspective. Furthermore, it makes them feel self-efficient to handle the situation, either to provide basic care or to create situations facilitating the development of higher mental skills (attention, memorization, reasoning, speech and communication functions). This is particularly true for children affected by severe developmental speech disorders, when the double function of cognition and communication is jeopardized. Thanks to the cognitive function, children build an inner representation of the world surrounding them and, using assimilation and organization patterns, they modify their own mental structures and integrate new skills. The communicative function itself favors the emergence of social and emotional relationships and helps children realize they can understand and be understood by others.

However, to obtain results consonants with family well-being, a previous understanding of their emotions, feelings, needs or difficulties to face such diversity, is essential. This can be done using active listening techniques, providing any needed support when necessary and, enabling them to find solutions to such difficulties. Taking into account the many different dimensions linked to the family-centered care proves crucial to supply such a vision of family well-being. We hereby enclose some of the contributions made by other authors on the subject:

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a) The necessity to focus all specialized actions on family capacity-building patterns and the use of strategies encouraging optimal outcomes in the development of children and their relatives. Our approach is therefore close to that exposed by authors like Dunst and Trivette, (2009) and Dunst, Bruder, & Espe-Sphwint (2014).

b) The importance of family intervention based mainly on a family-centered practice paradigm (Perpiñán, 2009; García-Sánchez, 2014; García-Sánchez, Escorcia, Sánchez-López, Orcajada and Hernández, 2014; Giné, 2016).

c) Collaborative partnership between professionals and families as a key factor to ensure family well-being, as formulated by Blul-Banning, Summers, Nelso and Frankland (2004) and Balcell et al. (2011).

The importance of families during children learning and development processes is also underlined by Mcwilliam (2010), another major author in the field. He has shown in many studies the significance of Early start family-centered Intervention (EI). This method, based on scientific evidence, provides support to caregivers and incorporates child interventions using routine patterns. Giné (2016) states both the importance of identifying the individual and family predictive factors of quality of life to further use them as support guidelines with the families and, the importance of understanding the very nature of these supports in the promotion of well-being. Finally, the necessity to conduct further transcultural studies on major family needs that are linked to well-being.

Cerqueira, Dessen and Pérez (2012, p.867) also stress the significance of empiric studies to examine family intervention models. They state, for instance, that "though the importance of family practice for children with disabilities or at-risk is now asserted, further empiric studies are still necessary to identify and describe the resources developed with families and to account for their effectiveness as to the evolution of the child and the family compound".

Fortea, Esccandell, Castro and Martos (2015, p.34) show the relevance of including families in the AACs implementation process: "family involvement is crucial since the generalization towards other natural contexts is more effective when they know how to use the AACs, because a more positive perception of their self-efficacy reduces the stress felt and the likelihood of conduct related problems arising."

Method

We decided to use a qualitative paradigm in our inquiry since the objective was to examine and understand family functioning as far as emotions, feelings, needs and difficulties were concerned, when a child, with some kind of functional diversity, needed the help of an AACS. During the whole process, we monitored the way every family faced the situation using their own skills to try and provide better resources for professionals from and in different backgrounds

(Healthcare, Quality and Social structures, Educational and Early Intervention Centres, Pre-schools, leisure centers…).

Participants

Bearing these objectives in mind, we conducted a study in the Early Start Intervention Centre[1] of the AMAPACCE Association in Malaga (Spain), where about 170 minor children with assessed or at-risk developmental disorders are attended. Apart from these dysfunctions, participants in the present study also suffered from severe speech, language and communications impairments that needed be compensated by an AACs, featuring different stages during the acquisition process. Families facing the new situation experience various acceptance and adjustment periods while acquisition stages take place. Many of them find it difficult to use a different communication method to answer the needs of care, protection and stimulation. Initially, they go through an incredulous phase, where they doubt whether their child will ever be able to acquire new communicative competencies, until they reach a final phase where a two-fold communication shows to be effective.

Prior to research, active listening of families was first carried out. It showed the necessity of further interventions to help identify possible solutions and improvements adapted to the lives of these family compounds and that of all participant children. We equally endeavored for professionals to take actively part in the whole quality of life improvement process of these families.

Participation in the study was offered in an informative letter sent to the families detailing the objectives of the research, rights and obligations of all participants, length of the study and including the communication of the final results to all participants.

Contacts with the families were initiated in 2012, after a first observation and reflection round of interviews, which helped determine family needs, fears and hopes and assess on whether they really would and could participate.

Finally, 8 families and their minor children decided to be involved, assisted by 8 Early Intervention Centre specialists and 3 assistants working occasionally at the centre. We hereby enclose a detailed description of each focus group:

Minor children participating in the study were aged between one and six, had various developmental disorders, caused by some kind of physical diversity, with affectation like infantile cerebral palsy (CP), autistic spectrum disorders (ASDs) or chromosomal abnormalities. All of them showed severe communication and speech development impairments.

No account was taken of characteristics like the age, social group, previous participation in studies or number of family members since our intention was to account for the various phases experienced by the minors and their relatives during the primary use and generalization learning processes

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[1] CAIT in Spanish, for "Centros de Atención Infantil Temprana".

of AACs. The first group included 3 families going through the initial phase of diversity acceptance feeling somehow incredulous as to possible communication with their child in the absence of speech. A second group included 2 families with children performing the first communicative exchanges, having thus overcome these feelings of uncertainty and disbelief. The third group included three families with children using quite normally an AACs to communicate. Our intention was to get some feedback from the families using mutual support schemes and to encourage them feel more and more competent.

The participating professionals provided support when the children and their families requested it, making use of intervention programs designed for all areas of development. Our research model is an interdisciplinary and transdisciplinary one: The team is formed by 2 physiotherapists, 2 speech therapists, 1 psychologist, 2 educational psychologists and 1 social worker. 1 teacher trained in special education needs, 1 educational psychologists and 1 psychologist also participated as partners in our study. All these professionals have either passed or are actually studying a Master in Early Attention.

Data collection instruments

Data was collected between February and May 2015, during five recorded sessions lasting one hour and a half to two hours. A discussion guideline collecting: the duration and dates of the sessions, the subject covered, a description of the activities to be performed, the responsibilities of each participant, the material used... helped monitor these group sessions. The guideline presented the key words or questions meant to help the participating group generate a debate or reach a consensus. All participant contributions were recorded and subsequently transcribed to be analyzed.

During every session, a record file also registered all non-audio aspects (the so crucial and useful non-verbal communication behaviors considered in qualitative analysis).

As previously agreed with the participants, anonymity was ensured by a codification system identifying each of them so that no personal data could be reflected.

Data analysis

All participant contributions were analyzed after every focus group session using five different levels of data measurement. The first level established the descriptive code (expressions used by the interviewees) and the nominal code (the transcription we made of the interviewees' contributions rather than the exact translation of the latter). The second level allowed dividing data in categories and subcategories to help answer the questions raised in the study. A

third designed level permitted to select and differentiate all data and establish causal relationships between the families and the expression patterns of emotions, feelings, difficulties and requested support. The fourth level was subdivided into two different phases: a first phase gathered the contributions made by families and a second phase gathered those made by professionals. Then, a further comparative evaluation between family needs and professional contributions was carried out. The last level helped confront the requests made by families to professionals and the family needs perceived by professionals. Furthermore, we compared the contributions professionals considered crucial to answer family needs with the needs expressed by families.

Results

Results obtained show the contributions provided by all participants and help identify the extent of their suitability regarding the questions raised in the present study to further materialize all corresponding improvements. We decided to use the model presented by Colas (1998, p. 293) as a reference in our study since, as he states, "the background and the participants are equally important. The interpretation and differentiation of transferable data, the interpretation of reality after a theoretical approach, the study of all possible general aspects, and the contrasting comparison of data with that obtained by other studies: all of this responds to an evaluative kind of process, apart from being interpretative and comprehensive as well". We used contributions from Pérez, Galán and Quintanal (2012) as a framework to organize the data reduction process:

1° Data reduction techniques: transcription, categorization, selection and differentiation of data. Data pooling, data comparison and data layout (initial approximation of findings).
2° Data layout: Conversion into symbolic representation like charts to ease readers' understanding.
3° Reliability and validity: Intended validation and conclusion.

Table 1 shows the reduction and layout processes of data.

After reviewing data analysis levels 1 and 2, we hereafter present the most relevant results obtained in data analysis levels 3, 4 and 5.

The third data analysis level emphasizes that A group members refer to more stress generators attributions and frustration than those included in the B group. By contrast, major competence generator attributions -like self-control, progress and satisfaction competences- are expressed by the latter. These families always assist to the programmed sessions (Figure 1).

**Table 1.** Reduction and layout data of results.

1°Data transcription and polling under 51 coded contributions collected from the families on emotions, feelings, needs, perceived difficulties and their requests to professionals.

2°Categories (and sub-categories). The first category refers to competence generators versus those classified as stress generators. Some codes referring to the AACs were divided into facilitated communication tools and needs for improvement categories. Other created categories included the needs and difficulties expressed by families and the requests expressed by families to the professionals working in various backgrounds. The contributions provided by professionals were clustered under the following categories: appropriate resources management; reflection on teaching and therapeutic practices; supports provided to families; difficulties and needs perceived by professionals within families; needs for collaborative partnerships and mutual support.

3°A highly complex net emerged while trying to analyze any possible causal relation linking the findings on families. So that data was confronted until 2 family groups finally emerged, accounting for their kind of assistance -either regular or not- and for the activities designed to capacitate them. Families were selected and then differentiated into the following groups:

Group A families : Assist irregularly to Family Sessions or Workshops programmed: (F1-F2-F4-F5-F6-F8)

Group B families: Always assist to Family Sessions or Workshops programmed: (F3-F7)
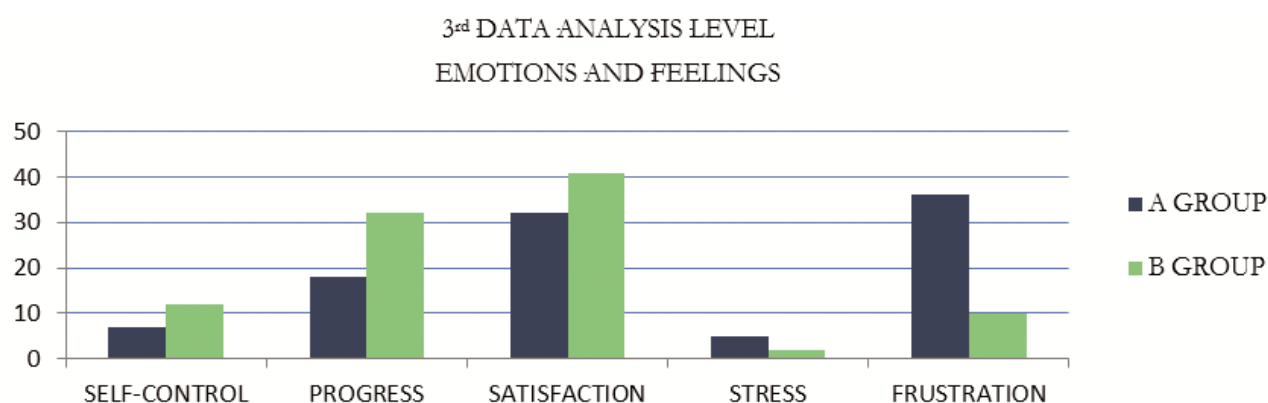
Figure 1. Third data analysis level: family emotions and feelings.

The communicative abilities acquired by B group children are higher, while in the A group, the needs to improve such communication facilitators are higher.

As far as needs are concerned, A group family members perceive there is more lack of coordination, neglect and they also request more mutual support. On the other hand, B group members express quite opposite feelings. The interpretation of findings presented needs to be balanced because of the existing difference in numbers between both family groups participating in the study. The B group families name lack of coordination 6 times, neglect 2 times and need for mutual support once. A group families name lack of coordination up to 42 times, neglect 67 times and need for mutual support in 24 indirect occasions.

The answers referring to coordination and improvement of resources are quite similar for both groups though there are discrepancies about the need to improve training of professionals and about a more individualized attention, requested only by A group members. By contrast, the necessity to provide family training is only asked for by B group members.

Data has been divided into two different phases on 4th data analysis level. The first subcategory gathers all family contributions and the second subcategory gathers contributions made by professionals.

A further comparison of the answers given by families and the contributions made by professionals has been performed.

The emotions and feelings expressed by both family groups, after data pooling has been performed, reflect just as much stress generating and frustration indicators as competence generators (self-control, progress, satisfaction) (Figure 2).

When gathering both family groups, we become aware of the importance of further practices -using the competences acquired by their children- and of the significance of intensified actions to transform these abilities into more functional and generalized assets that will be used in any context or situation.

The information collected about family requests and needs shows, after data pooling, the importance of: collaborative partnerships improvements between all contexts, better resources availability, more individualized care and more extended training for both families and professionals.

During the second phase, we registered the needs detected by professionals in the family compounds, where they observed disinformation, more needs for collaborative partnerships between families and professionals and requests for mutual support between families. Extra time and space has therefore to be provided to multiply these collaborative moments and enhance mutual support between families.
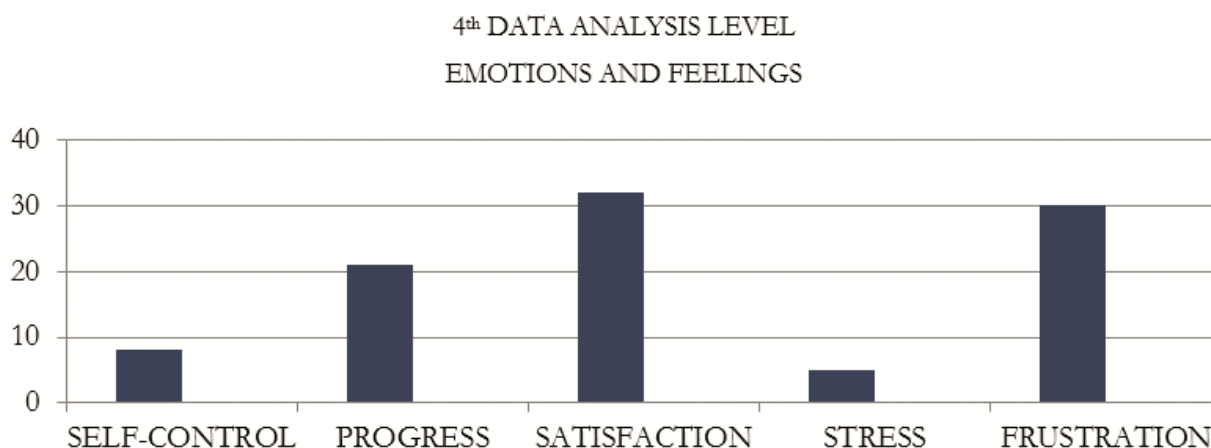
4ᵗʰ DATA ANALYSIS LEVEL
EMOTIONS AND FEELINGS

Figure 2. Fourth data analysis level: data pooling of emotions and feelings expressed by families (1st phase).

Figure 3 presents data collected in 4th data analysis level clustering the contributions considered as essential by professionals to answer family needs like: appropriate management of resources and intensified supports adapted to the needs of every particular family; improvement of collaborative partnerships in the backgrounds where both the child and family evolve; importance of a reflection on daily practice of professionals and introduction of any corresponding improvements; individualization of family interventions using models approaching those employed in family-centered practices; access to more information and training channels for families together with continuous formative schemes for professionals; provision of constant resources to set, review and implement AACs (Figure 3).
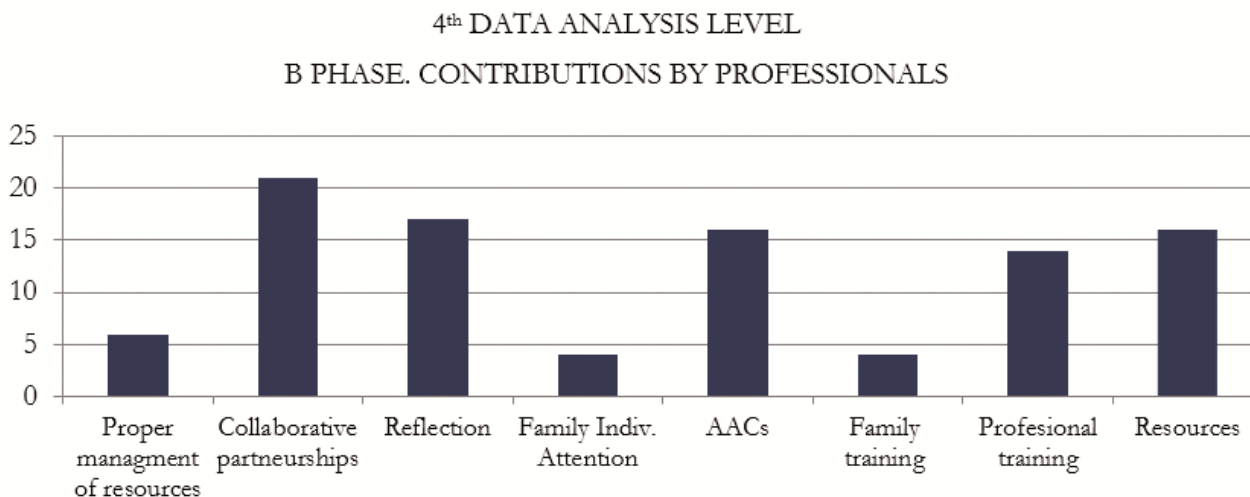
4ᵗʰ DATA ANALYSIS LEVEL
B PHASE. CONTRIBUTIONS BY PROFESSIONALS

Figure 3. Contributions made by professionals (2nd phase).

Fifth data analysis level confronts the requests provided by families on professional services and the family needs perceived by professionals. Stated family requests are: extended information and empowerment, more specific resources to implement AACs, home-based practices, more information from professionals and resources from and within any kind of background. Needs observed by professionals are: disinformation, increased collaborative partnerships with professionals and mutual support, initial and permanent training for all professionals and improvements in all backgrounds.

The confrontation of these requests made by families to the professionals with the needs observed by professionals within families shows that these contributions match the needs perceived by professionals in the families. These are basically the importance of improving: self-control strategies to face frustration and stressful situations, collaborative partnerships, communication and mutual support, together with individualized attention.

Some coincidental points can also be observed when comparing the contributions by professionals and the needs expressed by families.

The hereafter enclosed tables (2 and 3) outline the data related to emotions and feelings brought forward by families, the communication difficulties and needs in different contexts where their child evolves, together with the requests made about professional services improvements. The contributions by professionals about solutions answering family needs also have been included.

Table 2. Emotions and feelings. Difficulties and needs, requests to professionals and differences between family groups.

Emotions and feelings
- Negative or stress generating feelings: Helplessness, frustration, isolation, constraint and rejection.
- Positive or competence generator feelings: self-control, progress, empathy.

Facilitated communication
- Acquired abilities: Capacity to communicate with their child and to use new technologies.
- The need to improve existing lack of communication and lack of progress -as some existing signals were not perceived by families-. Identification of communication boosters. Access to new technologies. Organization of daily routines and their corresponding records.

Needs and difficulties indicated by families
- Lack of coordination: between professionals operating in different contexts, for alternative or other types of communication.
- Neglect: very low empathy and responsiveness showed by healthcare professionals. The way they express a diagnosis. Families still feel neglected in further revisions because of the lack of general information provided on children development and because specialists tend to be more centered on their specialty.
- Need for mutual support: communication between families. Information shared on many existing solutions to help answer the difficulties arising in families.

Requests made by families to professional services
- Collaborative partnerships: between professionals of all backgrounds.
- Training of professionals: specific training for all healthcare professionals. Ways to convey diagnosis. Continuous training schemes for professionals working in different backgrounds.
- Family training schemes: group therapies. Information provided on both children and family needs (only evoked explicitly by one family).
- Individualized attention: they ask for more resources to get a more individualized attention, where the needs of every particular family will be taken into account.
- Resources: provided by all public and semi-public healthcare centers.

Family groups
- A group: more stress and frustrations references were observed; less competence generating attributions; major needs to improve facilitated communication and less acquired abilities; they feel more neglected, perceive more lack of coordination and lesser understanding of their child needs by healthcare professionals; they also request more information from professionals and a more individualized attention.
- B group: They face better all kinds of challenges.

Table 3. Perceived difficulties and needs. Contributions made by professionals.

Family difficulties/needs perceived by professionals	
Misinformation	Difficulties to aprehend the real needs of their child, either because they can't face the situation or because of other factors.
Improvement of collaborative partnerships	Increased implication of families to foster the functionality and the transmission of AACs.
More mutual support	Necessity to facilitate meetings between families to improve communication of these families and between them.
Contributions made by professionals to answer family needs	
Appropriate management of resources	Importance of the optimum use of all and of any kinds of resources.
AACs facilitating resources	Any resources promoting the functional use of the AACs by families.
Resources	To be provided by all implied services providers (Early Start Intervention Centers, Healthcare and Social structures, Educational centers…)
Collaborative partnerships between professionals and providers of services	Meant to erase all doubts and uncertainty feelings in families. Better information transfer from one context to the other.
Reflection on teaching and therapeutic practices	A necessary reflection on the inclusivity and quality of family life centered inclusion process. How and to what extent in professional contexts.
Personalized attention	Better understanding of family and children circumstances to provide solutions that are adapted to their needs. Approach based on empathy and responsiveness.
Training of professionals	Initial and continuous training, to help answer the many challenges emerging during professional practice, with particular coaching sessions on family centered practices.
Family training	Permanent information to families about the evolutive process their child is going through, about their specific needs. Family empowerment to offset its effects.

Discussion and Conclusions

Data analysis performed in the present study provides information on the improvements required in many backgrounds where children and their relatives evolve. We have observed the significance of a family needs analysis, carried out by professionals, to provide solutions to such necessities. Furthermore, we registered the importance of engagement in all backgrounds when the families most needed it. All concerns exposed by families and those perceived by professionals need thus to converge towards a focal point where the global development of these minor children will be fostered.

The extension and generalization of AACs towards other contexts also proves to be crucial since it facilitates fluidity in all relationships and helps increase the implementation of normalization processes.

One of the suggested improvements underlines the necessity to provide specific training to all professionals involved in family intervention practice. The majority of families actually describe the moment they were informed about the diagnosis as one of the worst days in their lives, linked forever after to negative emotions and feelings. It is not yet clear as to how this is affecting the relationship established with their child.

Quality of Family Life models are to be strengthened with quality considered as a whole and not only as one of the components, as stated by Verdugo, Rodríguez, and Sainz (2012). In their Scale of Quality of Family Life they reflect observed improvements in quality of life of participants after the implementation of family empowerment models. Active family participation has to be developed using proceedings that will make family members feel more self-efficient and help them identify their own priorities. Then they can further design their own objectives and decide on their own ways to reach them using, for example, the routine based interview method.

This is how, making use of methodological strategies, this kind of planning can provide real and effective solutions on quality of life dimensions, both at individual and family levels. Active participation can foster facilitated communication and stimulate family resources, helped by, both formal and informal supports.

A significant milestone for professionals is to create appropriate contexts where families interact in optimum conditions. Then families perceive they can make improvements that will influence their own quality of life. Nothing will however be achieved without actively listening to families first. In the present study, we noticed that participant families had passed onto us their emotional burden, their concerns, their needs… and requested solutions to improve all contexts.

As regards how professionals can help improve the functional use of AACs, the significance a more intensive empowerment program provided to families has, once more, proved to be crucial. Families need guidelines, they need

coaches. Apart from finding solutions to the challenges they face –with specific care, nutrition and, in essence, breeding-they are also confronted to the difficulties deriving from the use of a different communication method.

We believe that this issue needs to be examined more in depth and that a sense of continuity could be provided from the very moment data collection starts -with the support of activity boosters, photographs…- The main objective of a created bank of resources would be to create facilitated communication tools and, at the same time, to provide a focal point where all families could meet and provide mutual support to each other. They need to feel capacitated to answer the communication needs expressed by their child and also need to get ready and accept the attention offered by other family members -like brothers, sisters or friends…-with the support provided by professionals. It is crucial for them to experience sympathy, security, self-confidence and continuity to apprehend this new form of communication as well as being aware that, although they want immediate results, these are not always reachable.

Access to new technologies has to be granted to families and its use has to be functional and entertaining. This can be helpful when creating an AACs: a collaborative partnership with families, service providers and the children will enable the creation of an active learning framework during the whole evaluation, design and implementation process of the AACs. Because of the complexity of these resources, accessibility to them has to be facilitated with the performance of a previous selection of systems and supports, that will take into account their costs and functionality.

We have also registered the need of improvements in all Early Start Intervention Centers. It seems equally important to build a school programmed to attend diversity, where all children will learn together. The lack of resources (staff, space and materials) never should motive their exclusion from the system because children need to experience the values brought by diversity since early ages.

Contributions made by professionals in various backgrounds show, as reflected in the present study, the significance of collaborative partnership and competences transfer, together with that of acquired learning in these contexts. Perceived lack of coordination conveys insecurity and hesitation feelings and can even lead to a refusal to use AACs.

All resources provided have to be adapted -in number and intensity- and have to be managed and supervised correctly. Such resources are scarce, though their non-utilization for the intended purpose is sometimes observed. Here are a few examples: unjustified absence during therapy sessions, use of allocated financial aids for other activities than those previously assigned… When Governmental Administrations are responsible for financial assignment they also have to monitor responsibly its further optimized usage.

Supplying personalized attention requires knowing all family members, their concerns, expectations and their previous knowledge on diversity and child needs. These professionals need be extensively acquainted with: the particular

capacities and difficulties affecting every minor, how these can be compensated, the informative supports available to help the family and the existing resources; specific training at both technical and emotional levels proves crucial in these cases.

A specific training in family intervention, new technologies and AACs is thus necessary for all professionals. Ultimately, the design of university programs has to include improvements in all intervention fields and criteria to ensure that continuous training is adapted to the necessities of both the personal and working lives of professionals.

By favoring innovation, investigation and reflection on professional practice, and thanks to such developments, pro-fessionals will get more implied in quality improvement of family life.

Future research lines comprise:

- Inclusion of role played by brothers, sisters and alike to verify the extent of their help in facilitated communication and socialization processes.
- Extension of the study to other contexts (Educational, Healthcare, Social entities) to provide coordinated improvements on Quality of Family Life.
- Extension of the research to new families that could benefit from its findings.

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