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Support for Families of Youths and Adults with Intellectual Disabilities: Contributions of a Program from Families' and Specialists' Perspectives

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Abstract: A family-centered approach (FCA) is recognized as a set of values, principles, and practices aimed at strengthening families' abilities to promote the development and well-being of its members. Despite the limited information available, results show the positive relationship between the support model, based on the collaboration between families and specialists, and family empowerment. This paper seeks to analyze the opinions of families and specialists on their participation in an intervention program for families of youths and adults with disabilities. Thirteen families and eight specialists participated in the study that used qualitative techniques, such as interviews and discussion groups, and a questionnaire to gather information about the families' and specialists' viewpoints over one year. Results show that families welcomed their involvement in the program. Both families and specialists recognize that creating a space for the whole family is the main contribution of the program, as it highlights the importance of considering the family's entire system as a support unit, as well as the close relationship between the individual's and family's quality of life (FQoL).

Keywords: program; family; family-centered approach; intellectual disability; youths and adults

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1. Introduction

Current views on intellectual disability adopt an ecological perspective, giving special relevance to the context in which people develop and the support they receive. Within this framework, families have come to play a central role in promoting the quality of life of their family members while the family's quality of life (FQoL) scale has become a service goal.

In this context, the family-centered approach (FCA) has been developed since the 1990s as an intervention model oriented towards family empowerment and well-being, based on the collaboration between families and specialists [1]. On the basis of the idea that individual and family needs interact [2], the family is perceived as a support unit. From this perspective, training/empowerment is regarded as a process, while the FQoL is considered a result [3].

Today, the FCA is recognized as a key reference when providing services to people and their families in different areas such as health [4–8], mental health [9,10], social work [11], and rehabilitation [12,13]. Within the disability area, the majority of experiences and studies are aimed at childhood, particularly the early intervention (EI) services [12,14–16], although the literature includes some references to transition stages and adulthood [10,17–19].

Even though there are different approaches toward the conceptualization of family-centered practices, various authors [3,5,7,20–23] share the idea that the support unit is formed by the family rather than only the person with the disability. From this perspective, families are the ones making decisions about deciding the organization, provision of services, and support. Therefore, families play an active role in the intervention process by identifying needs, establishing priorities, defining actions, and participating in the evaluation. Thus, this approach suggests starting by identifying strengths, which requires training and empowering families in a way that allows them to identify their strengths themselves and make effective use of them in their daily lives.

It should be noted that, from the start, families and specialists have identified the FCA's positive impact compared to others in which the specialist adopts the role of expert. In this sense, various studies [6,24–28] address the FCA's positive impact, especially in EI and childhood contexts. These studies point out the relationship between the specialist's style and the family's problem-solving capacity. Accordingly, some studies [1,28,29] prove the impact on aspects such as satisfaction, self-efficacy, social support, the child's behavior, emotional well-being, and parenthood.

Up until now, increasingly more entities believe in this approach and put their efforts into different initiatives, such as the implementation of programs that support families or restructure their EI services [30], although the FCA's implementation in Spain, as in other countries, seems to be facing developmental difficulties [31]. In this vein, since its start, different studies have identified obstacles or barriers, such as lack of time or human and economic resources [12], lack of abilities to initiate family-centered practices, and the lack of support from organizations to use those practices [32]. Espe-Sherwindt also mentions the existing gap between research and practice, the lack of effective and available training [28,33], and the specialists' training from professional-centered models [33] using an expert approach [12,34]. According to Vilaseca [31] and García-Sánchez [35], the reasons for these difficulties in Spain may be due to the beginnings of EI programs in the 1970s, when training was still focused on rehabilitation and deficits. We can say that in Spain, the first step towards family-centered practices was taken with the publication of the White Book on Early Intervention [36]. In this book as in others, such as the EI Good Practices Manual [37] and the document of Technical Recommendations for the development of EI [38], as pointed out by García-Sánchez [35], the need to work with families is pointed out, but there is still no mention of collaboration between professionals and family.

As for youths and adults with disabilities, although to a lesser extent, the role that families play is also acknowledged. For example, during the transition to adulthood, it is considered necessary to use a person-family interdependent approach, as the family's quality of life and the future adulthood of their child with disability [19] are closely related, and the child's well-being is inseparable from his/her family's overall well-being [39]. This interdependent approach includes the need to use family-centered practices, such as including the entire family and the results of all its members, sharing the responsibility of the services with the family and other agents, and relying upon the family's strengths and priorities [19].

In Spain, despite the prominence that entities and services give to this perspective [30], in the case of youths and adults, we have not found studies [22] that analyze its implementation.

This article gathers the opinion of families and specialists on their participation in an intervention program for families of youths and adults with disabilities. The program integrates the FQoL and FCA perspectives and identifies the contributions to the program from this perspective. Previous articles showed the reference framework [40], design, and description [22] of the Family Quality of Life Support Program [41], which consists of a series of systematic and regular family meetings with the support of a specialist. The said meetings are divided into four phases taking place over one year: pre-commencement: previous contacts; first phase: agreement on the Family Improvement Plan; second phase: follow up and support; and the third phase: evaluation and closure. The number of meetings can be adjusted according to the families' needs and demands, with a minimum of five pre-established meetings in the program. The program comprises creating a meeting place for the whole family to build and put into practice a family improvement plan that includes the perspectives of all its components with the support of a specialist [22] (p. 60). To this end, family concerns and priorities are taken as a starting point.

2. Materials and Methods

The study and methodology described in this article are part of a wider participatory action research project whose main goal has been to design, implement, evaluate, and universalize an intervention program/process to improve the FQoL, seeking the future incorporation of this program in the service range of a given entity in the Basque Country, Spain. This article focuses on the opinions of families and specialists on the Family Quality of Life Support Program, which have helped us identify the program's key aspects.

Therefore, the aim of this study has been to analyze the opinion of families and specialists regarding their participation in an intervention program for families of youths and adults with disabilities. The main questions of this article include the following: "How can we identify and match the needs of each member of the family unit?" and "How can we make families feel more competent?" The answers to these questions allow for the identification of different elements that may have contributed to reaching the goals during the process while guiding us toward the practice's improvement [42].

This study used a qualitative methodology, and three techniques were implemented to gather information, conduct interviews, form discussion groups, and design satisfaction questionnaires.

2.1. Participants

The participating families were selected based on four criteria established by the specialist team:

a. Families with sons and daughters over 18 years.
b. Person with disability living in the family home.
c. Consent and wish of the family to participate in the program.
d. Consent of important family members to regularly attend the established meetings and actively work on the agreed intervention plan.

Therefore, the study participants included 13 families. A total of 28 relatives and 15 individuals with intellectual and/or developmental disabilities (IDDs) as well as 8 specialists (7 women and 1 man) with extensive experience in working with families.

Table 1 shows the demographic characteristics of the families and people with disabilities.

Table 1. Sample of families and persons with intellectual and/or developmental disabilities (IDDs).

Specialist	Families	Primary Caregivers' Average Age	PIDD Age	PIDD Gender	% Disability	PIDD's Occupation	Size (No. of Members)	No. of Persons with IDD	Socioeconomic Level *	Place of Residence	Interesting Data
P1	F1	62	22	M	65%	Occupational Training	4	1	Medium	Urban Zone	1 adopted son
P1	F2	53.5	21	F	77%	Occupational Training	4	1	Medium	Urban Zone	1 foster daughter
P2	F3	65.5	41	F	65%	No Occupation	3	1	Medium	Semi-urban Zone	
P2	F4	66	36	M	83%	No Occupation	3	1	Medium	Semi-urban Zone	
P3	F5	60	27	F	65%	Special Employment Center	3	1	Medium-low	Semi-urban Zone	
P3	F6	62.5	PIDD 1: 25 PIDD 2: 22	PIDD 1: F PIDD 2: F	PIDD 1: 65% PIDD 2: 65%	PIDD 1: Occupational Center PIDD 2: Occupational Center	5	2	Medium	Urban Zone	2 adopted daughters with ID
P4	F7	60	32	M	81%	Occupational Center	3	1	Medium-high	Urban Zone	
P5	F8	75	36	M	75.5%	Daytime Care Center	3	1	Medium	Urban Zone	
P6	F9	60	30	M	65%	Occupational Center	3	1	Medium	Urban Zone	
P6	F10	69.5	42	M	82%	No Occupation	3	1	Medium	Urban Zone	
P7	F11	69	34	F	73%	Daytime Care Center	2	1	Medium-low	Urban Zone	
P8	F12	53	PIDD 1: 57 PIDD 2: 37	PIDD 1: F PIDD 2: M	PIDD 1: 68% PIDD 2: 79%	PIDD 1: No Occupation PIDD 2: Daytime Care Center	4	2	Medium-low	Urban Zone	Mother and son with ID; aunt serving as primary caregiver.
P8	F13	72	46	F	65%	Occupational Center	3	1	Medium	Urban Zone	

* In the Autonomous Community of the Basque Country, Spain, a person with an income between 14,400 and 38,400 euros is considered middle class. Socioeconomic ranges are established based on this as follows: Medium-low (less than 14,400); Medium (14,400–24,900), and Medium-high (25,000–38,400).

Among the general characteristics, it can be highlighted that there is more than 1 person with a disability in 2 of the 13 families, 3 of the 13 families have a foster-adopted son or daughter, and 1 of them consists of a mother and a son, both with intellectual disabilities, and an aunt acting as the primary caregiver. The average age of the fathers/mothers is 63.7 years, whereas it should be pointed out that a little under half of the families (6) are above 65 years old on average. For their part, the average age of persons with disabilities is 33.9 years, ranging from 20 to 57 years, while it is worth noting that 4 out of 10 are between 20 and 30 years old. A similar proportion of men (7) and women (8) could be observed, with an average recognized disability level of 71.6%, highlighting that just over half of the sample has a level above 65%. As for the occupation of people with IDD, 5 are Occupational Center users, 4 do not attend any training or employment-related resources, 3 are Daytime Care Center users, 2 receive Occupational Training, and 1 works in a Special Employment Center.

Some characteristics of the participating sample deal with relevant aspects to be considered in support programs for families. First, families stand out for their diversity and non-traditional family models. For example, 3 of the 13 families have adopted or foster sons and daughters, whereas 2 families included more than 1 person with disability (in the case of 1 of them, the 2 daughters, while in the other one the mother and son had disabilities and the aunt served as the primary caregiver). It is also relevant that most families are experiencing a moment of change or transition for various reasons (age, life events, etc.). On the contrary, a strong gender role in relation to the care and support of people with intellectual disabilities can be identified among families. One significant fact is that, in 100% of families, the reference person and representative in the family were women and the mother in 12 out of the 13 families.

2.2. Data Collection

This study was conducted at the end of the Family Quality of Life Support Program. This process involved interviews, discussion groups, and a questionnaire for information gathering purposes.

To delve into the specialists' point of view, each specialist was interviewed, thus obtaining a total of 8 interviews. To do this, a script describing the goals and the procedure was used, which provided some guiding questions for the interviewer (Table 2). All interviews were conducted by the same interviewer at the head office of the social entity. Interviews lasting approximately 1 h and 15 min were recorded and transcribed.

Table 2. Guiding questions for interviews with specialists.

Questions
• Do you consider the program to be appropriate for the families who have participated? • Do you think that the goals proposed are suited to the program? • How do you evaluate the program's design? What about its phases? What do you think the program's strengths and weaknesses are? • Would you change, remove, or add anything? • If you had to highlight any key or essential elements or aspects of the program's performance, what would they be? They can be related to different characteristics, typical of the program, context, families, etc. • Have you encountered any obstacles that may have affected the program's performance? If so, which ones? • What skills or competencies do you think a specialist should possess to implement the program? • Do you think the program has had an impact on families? • What aspects of the family do you think it has affected the most?

Information was collected during the last session of the program through the Family Program Impact Perception Questionnaire to gather the opinion of families. The objective of the said questionnaire is to understand the families' views on the program, comprising four statements and one open-ended question (Table 3). The questionnaire was delivered by specialists who accompanied each family throughout the program, in the form of an interview. The questionnaire's information was collected on site and in writing A total of 13 responses were collected, 1 per family.

Table 3. Family Impact Perception Questionnaire.

Statements	Questions to Deepen Each Statement
As a family, after taking part in this program, we feel we are: - Just like before - A little better - Quite better - Much better	• What has improved? • How have things changed for the better? • If nothing has changed, what do you think was the reason?
After participating in the program, we feel we are a family more capable of dealing with concerns: - Just like before - A little more capable - Quite more capable - Much more capable	• What do you feel most capable of doing? • What caused this change/changes? • If nothing has changed what do you think was the reason?
Of the goals we have set out in the program, we believe we have achieved: - None - Few - Quite a few - Many	• Why do you think so?
Overall, we are glad to have participated in this program: - A lot - Quite a lot - A little - Not at all	• Please explain the reasons in detail.
In short, the most helpful thing we have done on the program is . . .	• Please list them in detail.

Finally, the discussion group technique was implemented with the families, as it was appropriate to gather their opinion and assessment regarding the program. To do this, a script describing the goals and the procedure, besides some guiding questions (Table 4) for the facilitator, was used. The 13 families were asked to participate. Finally, 5 family members participated on behalf of the 13 families participating in the program. The session lasted 1 h and 6 min, and it was recorded and transcribed verbatim for further analysis.

Table 4. Questions used to guide the family discussion group.

Questions
• How would you describe to other people what you have been doing? If you had to tell it to other families, how would you do so? • Would you change anything on the program? Do you think something was missing? Please elaborate. • What do you think is different from the other times you have worked with a social worker or another specialist? • Did you feel that considerable attention has been given to you? • Did you feel that what was done was really in line with what you wanted or needed? • If we group what works, what we like, and what has helped us into one column and what did not work, what did not help us, and what we did not like into another column, what would you include in both? • Do you think it has helped you? In what sense have you improved as a family? • Has your Quality of Life improved? If so, in what sense?

2.3. Information Analysis

A systematic review of the information was carried out using an inductive approach for the data analysis, using the complete sample. The analysis is based on Brantlinger's [43] approach to qualitative research in the field of special education and disability studies. First, recordings of the interviews and the focus group were transcribed verbatim. Second, the specialists collected the questionnaire's information on site and in writing, whereas the descriptive content was independently assessed by two researchers who extracted the main ideas from the text to subsequently classify the topics into general categories. Third, specific categories were established within the general categories. Fourth, the topics were defined and the most representative ones were selected in the text. To ensure the topics' credibility and consistency, the categories were contrasted along with other researchers on the team. Finally, the categories were discussed to reach an agreement. The result can be seen in Table 5.

Table 5. Analysis categories.

General Categories	Specific Categories
Program design	Program's approach: Philosophy and principles Program structure, duration, and tools
Professional practice	Family-specialist relationship Professional support practices
Impact and satisfaction with the program	Family aspects that have improved Satisfaction levels of the families

3. Results

The results below reflect the evaluations that specialists and families have made during interviews, the discussion group, and in the satisfaction questionnaire. Next, the results are examined based on the categories presented in Table 5.

3.1. Program Design

3.1.1. Program's Approach: Philosophy and Principles

This category includes the assessments that families and specialists made on the characteristics that define the FCA, such as considering the family as a support unit. Families and specialists believe that the participation of the whole family, including the person with a disability, is one of the main values of the program. Specialists emphasize that bringing all family members together, including the person with a disability, contributes, on the contrary, to improve the understanding of family functioning by demonstrating the family's ways of relating, raising issues, and making decisions. In the words of specialists, "bringing them together helps us observe aspects that have not emerged so far" and "latent situations and needs surface."

> "I believe that the success relies in the fact that it involved the nuclear family; we are just three, but we have all been exposed, both us before our son, and our son before us."
>
> "I think that one of its key points is the inclusion of the whole family."
>
> "(...) in addition, the philosophy of the program itself, the program's foundation is, in my opinion, another strength. I consider bringing the whole family together, or focusing on the whole family group, to be its strong points."

3.1.2. Program Structure, Duration and Tools

This category includes the evaluation that families and specialists make with regard to the programs phased structure, its duration, and the tools used throughout the process.

Families and specialists believe that the very structure of the program, which is divided into phases and involves joint working sessions, helps make the planned action proposals or decisions more adjusted to each family situation and can be contrasted from the beginning. It provides a space for dialog to help identify the needs of each household member and make them compatible, thus increasing its chances of success.

> "A program's advantage is its structured format, meaning that the one conducting the program and monitoring the family has a clear idea of the path or road to follow."
>
> "(...) they have known each other better; there has been a greater understanding of each family member's aspirations by the others."
>
> "(...) it helps unify criteria and opinions."

Performing activities following the sequence established by the program facilitates the process and is one of the aspects that make a difference in the achievements made by families. Some of the comments collected in this regard can be found below:

> "The program helped us reach a goal. I mean, we needed to do something. Sessions were not aimed at venting and complaining. Well, in case of complaints, the program will help you enhance your family well-being, right? 'Well, come on, let's do something.' I think the power lay there, it made sense and didn't fade away, right?"

Both specialists and families positively valued the limited duration of the process, as it allowed families to work toward shared goals.

> "The family undertook the program for a year. (...) the year went well (...) let's say that throughout the plan development period, a greater union between the family was observed, so it was like squeezing the family, you know what I mean? One year seemed perfect."
>
> "The period also seemed right to me, not overwhelming at all."

As for the program tools, both specialists and families indicated their positive assessment with regard to the toolset provided. Specialists value the fact that the tools helped in tracking and sorting the process, and highlight the Ecomap as the tool that served the most during the process.

> "(...) it's the tool that helps you create and generate dynamics as well as highlight aspects that would otherwise go unnoticed."
>
> "(...) I think this is something that, in my opinion, most of the people, or at least a certain proportion of them, will agree with. Well, I think the strongest point is probably the Ecomap."

3.2. *Professional Practice*

3.2.1. Family-Specialist Relationship

This category includes the assessment of professionals and families on the collaborative relationship that is established in a program with an FCA-based design, which distinguishes this approach from others. It gathers, for example, information about the impact that the specialist's style has had on the family dynamics.

Families and specialists believe that the meeting space that takes place with a "witness," the support professional, in an orderly conversation seems to help the family feel accompanied and helps them "stimulate." Introducing themselves in person before a third party in the family group, when this has been agreed upon, facilitates starting new dialogs and speeches that refer to the content of interest and point to several new relational ways.

> "Having a sort of witness makes things easier, isn't it? This has come out a lot, it's true, and families have also mentioned it. I say it, and simultaneously, others hear it."
>
> "Speaking is already... speaking is also healing. Well, I don't know if it heals, but it does help, calm, and defuse; you have witnesses of what happens to you every day, you feel more heard... I don't know if it cures, but it relieves a lot, that's certain"

Families appreciate undergoing that process with the support of a specialist, as it helps listen to each other and make commitments.

> "(...) exposing him before a stranger to the family is not the same as talking to him en petit comité at home."
>
> "A stranger told her that, which was too much for her."

Finally, according to specialists, their years of experience working with families and meeting families or one of their members seems to have facilitated the program's implementation. The relationship of trust and the bond created over the years seems to facilitate the intervention throughout the process.

> "I already knew these families, so it has been easy and simple to connect with them and have a close relationship."
>
> "During the initial phase, the climate, the environment, and the confidence mean that this is already... well, me and all my colleagues (...) these are families we already know, therefore, that phase was already completed."

3.2.2. Professional Support Practices

In this category, the assessments of the strategies that the specialists used and that have positively impacted families are gathered.

In relation to professional support practices, both families and specialists positively valued the use that the specialists made of some strategies and skills—active listening, empathy, acceptance, adaptation, giving voice, reflecting a positive image, positioning people and dynamics, sharing information, and stimulating the use of family skills—during the intervention process. In this sense, families and specialists said the following:

> "Seeing a positive self-image is really helping them."
>
> "It helps you recognize yourself as part of the family; seeing their image reflected helps the family get better."

When we asked the specialists about their methods and if they could identify any strategy, skill, or dynamics, the answer, in all cases, referred to strategies and relational practices, such as listening, empathizing, accepting, reformulating, and reflecting a positive image or showing affection. Some of them are highlighted below:

> "I think I am a good listener; I easily adapt to what they say and can mediate between two opposing parties. I also translate, certify, and expand information

> and literally repeat and reformulate things. I summarize, provide opportunities, and I give a voice to people who may be felt left behind at a given time. I position people; I'm a witness and I contrast."

> "I try to develop a very close relationship with them, showing affection, and I think families like that too. I also rely on precision a lot, although sometimes I delve into the abstract concept, and then I like to visualize the concrete issues."

They also point out that sharing information and developing courses of action and dynamics to stimulate the use of new skills promotes the program's successful performance.

> "(...) doing an activity, talking, trying to describe to people their family members again, but using positive language."

On the contrary, the rigorous tool use and the performance of activities in the sequence established by the program also facilitated the process and made a difference in the achievements of the families.

3.3. Program Impact and Satisfaction

3.3.1. Family Aspects That Improved

This category includes aspects that, from a family and professional point of view, improved among families after their participation in the program. Both families and specialists agree that the program mainly impacted their family interactions, enhancing communication and family relationships. In other words, it has allowed them to speak, listen, and become aware of several family issues. Accordingly, specialists emphasize that the program helped different family members listen to each other, consider different points of view, and raise awareness.

> "The program has helped them listen to each other regarding certain things and play another role (...) they have become aware of what doesn't work."

> "They have got to know each other better; I think that there has been a greater understanding of each family member's aspirations on the part of others."

In particular, families appreciated the opportunity provided by the program to address matters that have raised concerns for them as a family, as they reported not having found the perfect timing to do so. They also emphasize their opportunity to talk, listen, stop, and reflect on day-to-day issues.

> "Talking and listening to each other have been the things that helped us improve the most."

> "It has given us a chance to stop."

> "Reflecting a little bit on how you're doing it, what your day-to-day life is like."

> "Speaking openly."

According to specialists, taking part in the program helped families identify their formal and informal supports, become aware of their importance, and use them in perhaps a more strategic way so that they could obtain a greater benefit from them. The program helped make these supports visible and order them.

> "(...) the network on which they rest is broad and consolidated... they are now fully aware of the supports they have, how they can rely on them, and use them strategically."

Families also mentioned that their involvement in the program has helped them feel more competent as a family; 83.4% of families claim to have improved, most of them at moderate levels.

> "It entailed regaining 'control'."

> "It strengthened our coexistence."

> "It brought security to us."
>
> "It made us feel stronger, relieved, and calm."
>
> "It made us alert, more prepared for when things happen (...) it provided us with some unforgettable tools, right?"

3.3.2. Family Satisfaction

In this category, data are gathered regarding the satisfaction of families after their participation in the program through the collection of the answers families have given in relation to the satisfaction questionnaire's various items.

All families are pleased to have participated in the program; 58.3% are satisfied, while 41.6% claim to be very satisfied and say they would recommend this program to other families.

> "It's been a very positive experience (...) I would recommend it to other families (...) I would tell them that it is a very positive thing to do, especially as a family. Its family-block methodology is an essential characteristic of this; it should never be conducted as an individual project because nothing would be taken out of it."

Regarding the achievements made, 66.6% of families believe that they have achieved quite many or many of their goals, while 33.3% think they have only achieved some.

> "(...) it has been a very positive experience, because it was the first time our son has decided, by himself, to collaborate on something. That was already a big step forward, because he has always refused to participate in self-advocacies or collaborate on outings... so it's been really beneficial. First, because he wanted to collaborate and, second, since we achieved goals that seemed to be out of reach."

Finally, as for the question of whether they are better off as a family after having participated in the program, the results show a trend toward moderate improvement as 74.9% claim to have improved, the answers predominantly indicating a slight improvement (50%) or a significant improvement (16.6%).

> "We're better off (...) it strengthened coexistence among the family members, and it also made us feel more confident . . . For what? Well, for example, to cope with any potential problem in the future. This program really helps you build your self-confidence."

Finally, Table 6 summarizes the results of the study.

Table 6. Summary of results.

General Categories	Specific Categories	Results
Program design	Program approach: philosophy and principles	The main value is the participation of the whole family: • Improved understanding of family functioning • Evidence of intra-family relationships • New situations and needs emerge
	Program structure, duration and tools	The structure of the program helps to: • To make adjusted and contrasted proposals • Making decisions The dialogue space that is created helps to: Identify individual and family needs Making needs compatible Following the program sequence facilitates the process The limited duration of 1 year allows families to become active around shared objectives. Tools: • Order the process • Facilitate follow-up

Table 6. *Cont.*

General Categories	Specific Categories	Results
Professional Practice	Family-professional relationship	The meeting space and the orderly dialogue that is generated with a professional witness helps the family: • Feeling accompanied • Go to • Staging new dialogues and discourses • Edit new content • Establish new ways of relating • Listen to • Assuming commitments
	Professional support internships	• Relational practices: For example, active listening, empathy, giving back a positive image, etc., are the most highly valued. • Participatory practices: Developing courses of action and dynamics stimulates the use of new skills and the smooth running of the program. • Using the tools rigorously and doing activities in the established sequence facilitates the process and facilitates achievement.
Impact and satisfaction with the program	Aspects of the family that have improved	• Family interactions • Communication • Family relationships • Making different points of view compatible • Addressing concerns • Identify formal and informal supports, give them importance, order them and make strategic use of them. • Feeling more competent
	Family satisfaction	Participation in the program: • 58.3% satisfied • 41.6% very satisfied Achievement of objectives: • 66.6% quite a few or many • 33.3% some We feel better as a family: • 50% a little better • 16.6% much better

4. Discussion and Conclusions

The Family Quality of Life Support Program consists of a structured intervention that adopts the FCA and aims to improve the well-being of families of youths and adults with disabilities.

The analysis of the families' and specialists' assessments of their participation in the program helps identify their contributions concerning its design, professional practices, and the achieved results.

With regard to its design, both families and specialists identified the creation of a meeting space for the entire family as the main contribution of the program. This fact, in line with the FCA, reaffirms the importance of considering the family system as a support unit as a whole and the close relationship between the individual quality of life and the FQoL.

Other FCA's elements, such as identifying the support the family is given as well as family activation around an action plan, are also aspects that families mentioned as contributions to the family's empowerment and prominence. According to Trivette & Dunst [44], family-centered practices provide or mediate the provision of resources and supports that families need to provide their children with learning opportunities and experiences that promote their development. These resources and supports are family-centered and result in family strengthening and competence.

Accordingly, the Family Quality of Life Support Program is based on the fundamental principles and elements of the FCA and the components of family-centered practices. The program orders intervention under a reference framework arising from the relationships established between the FCA and the FQoL approach. In summary, this frame of reference is based on the relationships between the key beliefs and values that guide professional action with a view of the family as a whole, placing family strengths and resources in the foreground and emphasizing the relevance of social networks (both formal and informal) of support. All of this exists within the framework of a collaborative relationship, with equality and respect for the uniqueness and perspective of the family itself [22].

As mentioned in the introduction, several studies have demonstrated the positive relationship between the support model based on family–specialist collaboration and empowerment. According to Rappaport [45], empowerment is achieved by creating opportunities for family members to acquire knowledge and skills to manage daily life events so that this positively affects sense of control and family well-being. From the empowerment perspective, families, including the person with a disability, actively participate throughout the intervention process, identifying and developing strengths, competencies, and decision-making capabilities so that they can decide by themselves over which priorities they can develop improvement actions. All this is done with the assistance of a specialist who uses family-centered practices whose relational and participatory components will make it easier for families to gain control over their lives and develop actions to achieve what they want and need [24,25].

With regard to professional practices according to the studies cited at the beginning of the article, professional style and the use of relational and participatory practices are indicated as key aspects for family empowerment. During their interventions, specialists mainly identify the use of relational strategies, such as active listening, empathy, and affection, and although to a lesser extent, they also observe the adoption of some participatory strategies, such as the use of specific dynamics that help implement new skills or share information.

The FCA identifies two important components related to the professional support style that contribute to family empowerment [26]. Both practices are necessary, although various studies [28,46] point out the use of participatory practices as the key to family-centered intervention because of their greater impact on satisfaction, self-efficacy, trust, competence, well-being, and parenthood enjoyment.

In this regard, Dunst [6] reports that specialists make better and greater use of relational practices, which is in line with the answer given by the specialists participating in this study when they were asked about this. In most cases, use of relational practices could be identified, indicating regular use. As for the participatory ones, after the specialists' accounts, we can identify their use, although not in a conscious way. In this connection, we consider that the program itself promotes this type of practice, explicitly proposing concrete dynamics that seek family activation, promoting decision-making and the acquisition of new skills through the families' active participation.

Finally, the sample description reports two aspects that could be crucial if we think about the families targeted by these programs.

Consistent with its approach, the program is intended for diverse families. In this regard, proposals for family self-definition [47] may be particularly suitable for responding to non-traditional families.

Given the average age of people with disability who have participated in the program (most of them between 20 and 35 years old), we could say that the program has especially aimed at working with families who are dealing with transition processes to adulthood with disabled members. More generally, families that were selected also share the characteristic of undergoing times of change or adaptation to a given event (age and stressful situations, among others). The literature [48] highlights the need to consider family perspective during transition to adulthood. Therefore, a one-year program that helps the family clarify its priorities and establish an action plan with concrete goals within the framework of a process that gathers data on the perspective of all members would be particularly relevant. During these transition periods, families cope with new arising needs and, in this sense, as some authors [49] point out, access to information and services/specialists brings certainty to families.

A noticeable gender role was also identified across families with regard to the care and support of people with disability. On the one hand, the situations of the different families indicate that women, particularly the mother figures, play the role of the primary caregiver in all families. According to various authors [50,51], this could induce higher stress levels due to task overloading and restricted development of individual projects associated with their social life and integration into the community [52–56], which may entail a decrease in their FQoL. On the other hand, the role of the mother in some of these families seemed somewhat undervalued. On this basis, one of the main needs for FQoL improvement involves paying special attention to the female caregiver's situation.

In summary, bringing the whole family together creates a space for dialog that helps identify and make compatible the different needs of each member of the family unit. Furthermore, it improves understanding of family functioning and helps understand their interactions and ways of relating to raise issues and make adjusted and consensual decisions. Being able to talk about concerns and establish courses of action based on the family strengths make families feel more competent. In this sense, person–family interdependent approaches should be considered for their implementation in support services for youths and adults with disabilities.

This study provides positive evidence of the implementation of an intervention program focused on families of young and adult people with disabilities, which is all the more novel since in the case of young people and adults this perspective is less common and it is not easy to find studies that analyze its implementation. In addition, the program is available to any entity or team of professionals who wish to implement it, and it is part of the portfolio of services of the social entity participating in the study.

With respect to the limitations of the study, we consider that the sample represents the greatest weakness. On the one hand, the size of the sample, and on the other, the composition of the sample. The participating families are families accustomed to participating and with a strong link to the association, which could have influenced the positive impact of the program on the QoLF. We wonder if the impact would be the same in families with other characteristics and other problems of a greater nature. The second limitation is related to the lack of follow-up of the families after their participation in the program with the aim of verifying whether the improvements reported by the families are maintained over time.

With a view to the future development and implementation of the approach, this limitation could be a line of research. We also believe it is necessary to investigate relational and participatory practices, especially the latter, about which little is known, and thus contribute to their conceptualization and exemplification, providing information and training to professionals, thus eliminating some of the barriers that limit the development of the approach. Finally, it is worth noting the need to adopt a gender perspective during the intervention. The role of the female caregiver requires special attention from services and programs, as the burden of family care falls on women, usually on the mother figure.

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