Family and disability: A theoretical perspective on the family-centered approach for promoting self-determination

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Abstract

Introduction. This study raises the need to promote family-centered intervention approaches, aimed toward improving the family's quality of life, the empowerment of all its members, and the development of self-determination skills.

Method. To this end, we review the studies on intellectual disabilities, self-determination and family-centered approaches from the last 10 years. From this basis, we proceed to describe the experiences of a small group of parents (N=4), focusing on positive aspects. In addition, we take a theoretical-applied look at the family-centered approach to intervention (FCA).

Results. Just as in the literature, the parents in this study consider that living with a disability issue has involved challenges, concerns about their children's future and something of an extra burden, but also personal and family enrichment. Notable key factors for attaining quality of life as a family included: partnership between parents and professionals, identification of family strengths, and parental development of perceived control and of self-determination skills. Some suggestions are described for helping families meet these goals.

Discussion and conclusions. Families' lack of competencies for meeting some of their children's needs calls for the implementation of family-centered intervention plans that enhance the self-determination of all family members.

*Keywords***:** Intellectual disability. Self-determination. Resilience. Family quality ol life. Family-professional relationships.

Resumen

Introducción. Este trabajo plantea la necesidad de promover enfoques de intervención centrados en la familia cuya meta sea la mejora de la calidad de vida familiar, la capacitación (*empowerment*) de todos los miembros y el desarrollo de sus habilidades de autodeterminación.

Método. Se ha revisado una amplia relación de trabajos de los últimos 10 años sobre discapacidad, autodeterminación y modelos de intervención centrados en la familia. Partiendo de esta base, se describen las experiencias de un pequeño grupo de padres (N=4), atendiendo a los aspectos positivos asociados a su vivencia de la discapacidad. Por otra parte, se analiza, desde una perspectiva teórica-aplicada, el enfoque de intervención centrado en la familia (ECF).

Resultados. En consonancia con la literatura, los padres de este estudio consideran que la vivencia de la discapacidad ha supuesto retos, preocupaciones acerca del futuro de sus hijos y cierta carga adicional, pero también un enriquecimiento personal y familiar. Se destacan como factores clave para lograr la calidad de vida familiar: las relaciones colaborativas entre profesionales y padres, la identificación de las fortalezas familiares, o el desarrollo de la percepción de control y de las habilidades de autodeterminación de los padres. Se presentan algunas propuestas acerca de cómo apoyar a las familias en la consecución de estas metas.

Discusión y conclusiones. La falta de competencias de las familias para responder a algunas necesidades de sus hijos requiere la puesta en marcha de planes de intervención centrados en la familia que contribuyan a aumentar la autodeterminación de todos sus miembros.

*Palabras clave***:** Discapacidad intelectual. Autodeterminación. Resiliencia. Calidad de vida familiar. Relaciones colaborativas.

Introduction

Social awareness of the rights of persons with disabilities[1] and of their families has evolved favorably in recent years (Keen, 2007) (positive models of disability, deinstitutiona-lization, quality as a goal, self-determination and self-advocacy movement, etc., are some of the factors responsible for this evolution). At the same time, there has been a transformation in professional practices that provide services and care for the needs of persons with disabili-ties and their families. It may be said that professional-centered intervention models have been replaced by intervention models centered on the person and their environment. In this new paradigm of services and intervention plans, the person with disability and their family occupy the central space as the main characters in the process. What differentiates these in-tervention models is not so much the service that they render (the *what*) but the way this is done (the *how*) (Dempsey & Keen, 2008; Dunst, Hamby & Brookfield, 2007; Espe-Sherdwindt, 2008). From this perspective, family quality of life becomes the main goal of professional services that, in addition, recognize the needs of *all* family members as well as how their interpersonal relationships influence the developmental and learning processes of the person with disability. This new family-centered model of planning services is especially interesting when it encourages self-determination in the person with disability, an aspect that constitutes one of the main dimensions of the individual's quality of life.

Current models of providing services adopt this systemic model and consider that per-sons with disabilities live better and are better cared for in their own homes, inevitably mak-ing family participation a priority when making decisions about the services received. The family is the only constant element in the life of the person with disability, and as such, they are the best qualified to define their support needs; moreover, to the extent that the family is able to improve its quality of life, all its members will be better able to respond to the needs of the person with disability and to contribute to his or her attainment of self-determination.

Taking these considerations as our starting point, the objectives of the present study are: (1) To analyze parents' perception of their children's disability, paying special attention to any positive experiences that contribute to successful family adjustment. This analysis is

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[1] Although the content of this article can be extended to any type of disability, we refer mainly to intellectual disability.

illustrated by comments from a small group of parents (N = 4) of persons with disabilities[2]. (2) To consider the need to adopt family-centered intervention approaches that identify family strengths and qualities as a starting point, and consider family empowerment to be the primary goal and procedure in good practices. Toward this end we review some of the fundamentals of the Family-Centered Approach (hereafter, FCA) as a paradigm for these considerations. (3) To suggest some guidelines or strategies that prepare parents to support and stimulate self-determination skills in their children with disabilities. These guidelines are based on FCA principles as well as on proposals from authors like Dunst, Trivette and Deal (1988), Dunst and Trivette (2009), Davis and Wehmeyer (1991) and Abery *et al* (1994).

Parents' perceptions about the impact of the disability on the family

> *Having a daughter with a disability was not part of my plans, it just happened to me, that's all – we always used to say, what did we do? Because it is a bitter pill to swallow, such a shock ... He [her husband] was the first one to know, he took it so badly that he didn't have the courage to tell me, he spent the whole day throwing up. I found out that my daughter had a disability the next day, I had not suspected anything, and I couldn't believe it, it's like disbelief ...* (M. P., mother of a 17-year-old with Down syndrome).

> *How awful that this has happened to us! For a long time my husband blamed it on the childbirth, it was a horrible ordeal. It's been very hard, it's a very hard road, I look back and say, never in my right mind would I choose to go through this* (V., mother of a 14-year-old with intellectual disability).

> *When my daughter was born I felt like – what do I do? A huge emptiness! This was our lot, that's what happened and that's all there is to it. Only God knows* (M. J., mother of a 18-year-old with intellectual disability).

These are some of the reflections expressed by a group of parents of children with intellectual disability, when asked about their perception of their children's disability. Testimo-

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[2] All the comments included in this article were obtained from a series of parental interviews, focussed on the following topics: perception of the disability, family quality of life and self-determination of the persons with disability. These interviews were part of a pilot study carried out in the wider context of a research study on the Family-Centered Approach (FCA).

nies like these had led us to believe for decades that the birth of a disabled child creates in parents a series of unrelenting, negative attitudes such as guilt, denial, anger, displacement and pain, as well as multiple dysfunctional effects including social isolation, lack of marital cohesion and/or role disruption.

Undoubtedly, what the disability means to parents, and how they react to it, has to do with the historical reality and social context in which they live. Thus, between 1820 and 1910, during the gradual specialization of the medical and educational professions, moral guilt about the disability was the lot of parents. Later (1920-1980) an intrinsic connection was made between the birth of a child with disability and family pathology (siblings were also considered maladjusted or maladapted); that is, the disability in itself inevitably hurt the family, labeling it as a pathological family (Dykens, 2006). Elsewhere, Ferguson (2002) points out that the traditional responses of professionals have been characterized by assuming that tragic consequences are inherent to the disability, to the point that negative effects have entirely eclipsed any positive consideration that might be made. These are tremendously negative interpretations that accept *a priori* that the birth of a child with disability is always a tragic event, and requires that parents go through a stage of mourning the loss of the ideal child (Harry, 2002); the "tragic crisis" of this birth could only be overcome with the help of a suitable psychotherapist.

Fortunately, at this time family reactions to the birth of a child with disability have evolved toward more positive interpretations. Contributions toward this trend include the new conceptualization of disability, the appearance of positive psychology, inclusion policies, the new philosophy of services and the movement toward personal self-determination.

In any case, even with the gradual abandonment of such negative views, there seems to be an almost universal consensus that families perceive the disability of their child to be stressful, at the least. This objective burden of stress is a consequence of the multiple demands and challenges associated with disability, varying as a function of life stages and increasing during periods of transition (moment of birth, beginning school, transition to adult life, etc.) (Wehmeyer & Field, 2007). Let us look at a few examples.

Our life revolves around her and social relationships also change very much (M.P.).

I believe we live under constant stress, it's like a ball that you place here [pointing to a part of her body]. *I am anxious not knowing how she is going to react, how she'll be feeling when she comes back from school, and when she goes out, will she want to eat breakfast, how will I give her her medication, when she gets out at 4, what will I do until 9?, how will I keep her entertained, will she be in a good mood, will she want to go home … you never know whether she's going to feel fine or if she'll put up a big fuss … Every day is a struggle* (V.).

Too much responsibility, too heavy a burden. She's going to need us her whole life. Sometimes she is tyrannical, she is awful at accepting obligations, she wants to impose her authority and always asks for more (M.J.).

Life has its ups and downs, our routines fit around our daughter, we have less freedom and less autonomy, and I worry about her future and the resources that society has for these people (I., father of an 18-year-old with intellectual disability).

In view of comments like these, we cannot deny that disability creates certain financial, physical and emotional burdens in families. These burdens mean a daily challenge that causes greater wear and tear, and frailty, to the point that these parents are socially identified as different from other parents because of the extra assistance they may need in order to fulfill their roles (Russell, 2003). Notwithstanding that disability is a potentially stressful factor, the families themselves also find positive aspects in their lives that must also be assessed and documented.

It is therefore appropriate to consider the global impact of disability on the family, assuming the coexistence of negative effects (such as sadness and perceived loss of control) and positive effects (such as values enrichment and strengthened family ties). This coexistence is appreciable in apparently contradictory comments that these same parents make.

Even though I couldn't believe it, I didn't feel awful, I didn't feel rejection at any moment. On the contrary, when my daughter was in neonatal I was wishing that I

could go in and give her her bottle – At that time my husband never said "I can't bear this", nor has he ever done so ... In any case, it has done more to bring us together than anything else. People think that disability is ... something bad ... I thought so myself, but later, the only thing we cared about was for her to be cured [from a cardiopathy], *we didn't even think about her disability, now things go quite smoothly* (M. P.).

There are moments of loneliness, of doubt – acceptance involves a long process, it isn't just one day, till we determined as a couple to accept the situation and to fight for it ... but certainly it has brought us together, I wouldn't exchange it for anything [this is the same mother that previously stated *"never in my right mind would I choose to go through this"*], *nor would I change what has happened, nor would I exchange my daughter for the best person in the world. I wouldn't wish to have a daughter with a disability, but I wouldn't exchange her for anything. Your values are different from other people's, my daughter has brought us closer to disabilities, to knowing people with disabilities, their family members, people with amazing human values ...* (V.).

These and other documented examples in research allow us to move beyond a purely pathological interpretation of families' reactions to their child's disability. Moreover, they shed new light on adaptation and coping strategies for living with this situation. In other words, families are also able to effectively and positively cope with the additional demands created by parenting a child with disability (Breitenbach, 2004; Krauss, 1993; Trute, Hiebert-Murphy & Levine, 2007). Research has established that there are similar levels of adjustment and general well being in the families of persons with disability and in families of persons without disabilities (Russell, 2003). Having a child with a disability is certainly not easy, but it can lead to a richer, more valuable and fuller life (Dykens, 2006). This coping capacity and the positive impact of disability on the family is illustrated in the following comments.

It has given me a different sensitivity. I work with children and I can detect which of them needs more help because of my own life experience (M.P.).

Her brother has certain sensitivities that are not fit for this world, I believe he has suffered, because he has a certain sensitivity that normal people do not have, and

that his sister offers him aspects that I feel are very great, one also must mature in life and must take on …. I have learned to accept things, it just changes your values in life completely. For example, my daughter yells a lot when speaking, so, silence, having a peaceful moment with my husband, I think I used to be more intolerant with him and he with me, but now, you've got a single objective and that changes everything. Undoubtedly it has made us stronger and more patient when facing other problems (V.).

It has helped all of us a great deal. It has taught us that there is another way of life that is not the usual one, it has been a point of reflection for the whole family, to think that there is a special person, and that there are many special persons … I think it has made me a better person, it makes you not be selfish. I am convinced … I see things differently (M. J.).

Experiences like these allow us to state that families are often *resilient*. The term resilience was adopted in the context of positive psychology (Seligman & Csikszentmihalyi, 2000) and refers to people's ability to cope with stressful occurrences, coming out of them stronger (Patterson, 2002; Rolland & Walsh, 2006; Walsh, 2003, 2006). Nevertheless, why do certain families successfully cope with an experience like this, and even emerge stronger, while others, by contrast, fall into states of crisis (stress, depression, passivity or dependence)? Authors like Bayat (2007) or Knestrich and Kuchey (2009) indicate that certain variables such as the type and degree of the child's disability, socioeconomic status, level of family cohesion, existence of a firm belief system and of positive perceptions about disability, maintenance of family roles and routines, availability of a variety of resources in the community, and partnership with professionals that care for their children all seem to have an explanatory role.

On the other hand, this ability to be resilient can also be promoted in families through intervention approaches that underscore the unique qualities that characterize each family, taking these as the starting point for developing appropriate support plans. Professional intervention adopts a perspective based on family resilience when: (a) it goes beyond the individual approach, focused on the person with a disability[3], and pursues the family's well being

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[3] Especially interesting in recent years is the focus on siblings of persons with disabilities. Siblings, as a group, present a number of specific needs, and their experiences may also be crucial for understanding interaction dy-

and the well being of each member, as well as improvement in their relationships; (b) it identifies family and personal strengths and uses them as a basis; (c) it takes into account the potential value of the family's support network; (d) it establishes a partnership between professionals and families, and (e) it aims toward family empowerment, through respect for their choices and priorities, encouraging their control over desired results (Rolland & Walsh, 2006; Sheridan & Burt, 2009). These considerations are addressed by the Family Centered Approach (FCA).

The Family Centered Approach (FCA)

Founded on the same philosophy that undergirds resilience, the FCA is defined as "an approach to professional intervention that comprises a set of principles, beliefs, values and practices that give the family an essential role in planning, providing and evaluating the resources and services made available to their child with disability and, therefore, that respect their priorities and decisions". Its primary objectives are family empowerment and improving personal and family quality of life (Bruder, 2000; Dunst, 2002; Dunst, Trivette & Hamby, 2007; Espe-Sherdwindt, 2008). Two of the most characteristic aspects of the family-centered approach, then, are: (a) establishing a *partnership* between families and professionals and (b) developing opportunities for family *empowerment*.

(a) Partnership

A partnership can be understood as an "interaction of mutual support between families and professionals, focused on satisfying the needs of the person with disability and their family, and characterized by a sense of competence, commitment, equality, positive communication and trust" (Summers *et al.*, 2005). Along the same line, Turnbull, Turnbull, Erwin and Soodak (2006) list the seven principles that characterize partnerships between educational agents, professionals and families: communication, professional competence, respect, mutual advocacy, commitment, equality and trust. Establishing relationships based on these principles helps create what Ainscow (2005) calls *inclusive learning communities*. Therefore, in this type of relationship, families take on an active role from the first moment of the process and they become partners at the same level as the professionals that serve them, es-

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namics and functioning in this type of family. The reader is referred to the recently published article by Iriarte and Ibarrola (2010).

tablishing a peer-to-peer relationship. Recognition of this equality is the first step toward achieving an authentic partnership, under the slogan *Parents as partners*, and involves recognizing the complementary nature of their contributions as well as respecting their unique values and beliefs.

(b) Family empowerment

The FCA takes *empowerment* as its goal and as its main intervention procedure. To the extent that families feel empowered (perceived control) and have confidence in their ability to influence the services they receive, and ultimately their child's development, they are less vulnerable to negative results and they perceive the quality of family life positively (Bailey *et al.*, 2006; Dempsey & Dunst, 2004; Dunst & Dempsey, 2007). Research shows how potentially negative events are not as stressful when accompanied by a sense of personal control (Thompson, 2009). Thus, if families develop perceived control, they will be in a position to better manage the difficulties associated with their child's disability and to draw more positive meanings from this situation in their lives. Therefore, given the importance of this aspect to quality of life, care should be provided in such a way that *families may have control over the conditions and events in their lives* (Schalock, 2004).

Apart from these two fundamental traits, it may be said that family-centered practice will be effective if it includes the following aspects (Dunst & Trivette, 2009):

1. Proactive and positive, conveys a true sense of understanding to families

2. Respects each family's own unique cultural values, beliefs and priorities

3. Is offered in response to an identified need

4. Reinforces the self-esteem of those who receive the assistance, thereby making access to resources and support be immediately successful

5. Encourages the use of informal support and resources as much as possible

6. Promotes the acquisition of behaviors that diminish the need for support and thus avoids creating bonds of dependency on professionals

7. Involves families in gaining access to support and resources such that their self-efficacy beliefs are reinforced.

In summary, an FCA consists of underscoring positive family qualities and aspects as well as identifying both formal and informal sources of support that are available to the family. Above all, the FCA is concerned with giving authority and empowerment to families so that they may be more competent, self-sufficient and independent, and acquire greater control over their lives, thus bringing about their own self-determination, but also their child's inclusion, autonomy, self-determination and a high quality of life, while maintaining the family's well being (Wehmeyer & Field, 2007).

Empowering parents to develop self-determination in their families

One constant concern of families is to ensure the future well being of their children with disabilities and to prepare them to cope with challenges to come; in summary, prepare them to be self-determined persons. Uncertainty about the future can trigger feelings of isolation, loss of confidence and decreased self-esteem in parents, endangering their well being, the quality of life of the whole family and their self-determination goals. Let us consider some examples.

When we talk about the topic of employment ... of whether we will have to declare her incompetent .... I'm going to give it a lot of thought, when the time comes I don't know ... I would like her to be able to do whatever she is able to (M.P.).

The future is what most worries me, unquestionably, because she's going to be dependent her whole life. My biggest worry is that her future will be assured, that her life will be on track when we are no longer here, that's why we made our parents' association. I want her to live her life, to have an independent life (V.).

And if I stop to think about what will happen to my daughter ... I don't want to think about it, I am bound to be gone before she is. What will be the best place for her? We have to confront it, to be realistic. My daughter cannot choose or decide, we have to choose what is best for her, even though we take her preferences into account (M. J.).

What will become of my daughter when we are no longer here? Her siblings have their families ... The dark shadow of tomorrow has always worried us. Since she has

limitations, her self-determination is reduced, at home we give her the chance to choose (I.).

If we understand self-determination as the set of skills that allow a person to have control over their own life and be able to direct it according to their own objectives, interests and abilities, it becomes crucial for parents to be prepared and trained for their own self-determination through family-centered training plans. Only then will they be in a position to help their children acquire the knowledge, skills and competencies that allow them more self-determination. This set of skills, moreover, constitutes one of the individual quality of life dimensions in Schalock's model (Schalock, 2004) and therefore, has large implications in the attainment of family quality of life.

For all the above reasons, we consider that supporting self-determination in all family members, including the person with disability, requires that professionals take into account and strengthen the strong points of the family as a system, and that they respond to their needs – in other words, that they adopt an FCA (Wehmeyer & Field, 2007). When professionals act according to an FCA, they maintain a respectful, cooperative, understanding and stimulating relationship with families; they start with the family's qualities; they help them identify and understand their needs; they take into account the family's own resources; they help them prioritize their goals, preferences and tasks; they encourage and support them in decision making; they assign them responsibilities; they increase the family's control over their own lives, and thus encourage their self-determination.

Having said that, both families and professionals must define what areas, tasks and actions correspond to each of the parties. This "distribution" or delimitation of responsibilities, as well as coordination of formal and informal sources of support, becomes crucial in achieving a partnership. In the same way, it is important that families, being realistic, know which areas, decisions, actions and tasks ought to come under the personal control of the child with disability, and which of these are beyond their competencies. In this respect, some studies warn that parents often leave little room for encouraging autonomy in their children with disabilities (Zulueta & Peralta, 2008). This is due in part to providing them with very structured environments, and to manifesting an excessively didactic, directive and intrusive interaction style (González-Torres, 2006; Hodapp & Fidler, 1999), which does not favor the development of self-determined behavior (Grigal, Neubert, Moon & Graham, 2003). Some families under-

estimate their children's abilities and fall to the side of overprotection. Others, by contrast, overestimate their abilities and overwhelm their children with tasks that are beyond their possibilities (Peralta, 2008). Both extremes are dysfunctional for developing self-determined behavior in the person with disability.

Thus, a family environment that brings about self-determination should be characterized by the establishment of clear rules and limits, and at the same time, by certain flexibility in adapting to changes. On the other hand, parents, by their own actions, act as models and vital support for their children: there is no more significant relationship than that established between parents and children (Martínez, Inglés, Piqueras & Ramos, 2010). Consequently, an FCA assigns great importance to developing the self-determination skills of all family members, especially in parents, who are the main figures of reference for the person with disability.

Nonetheless, despite the importance parents give to their children being "independent, autonomous, self-sufficient, etc.", and even having verified that self-determination is very much involved in achieving family quality of life, it is noteworthy that little work is aimed at promoting this goal in the family setting. For this reason the following proposals are of particular interest. These proposals make it possible to work explicitly on self-determination skills in all family members, and they assign the professional a role of facilitation and collaboration, in line with FCA principles, where families have a central place in intervention processes.

A) To increase parents' skills and knowledge

Davis and Wehmeyer (1991) suggest a series of guidelines or strategies that underscore strengths and positive qualities, in line with FCA fundamentals. These guidelines can be useful when structuring an intervention in the family environment that supports self-determination in children with disabilities:

1. Keep a *balance* between necessary independence and sufficient protection. Children ought to have the chance to explore their own world. As long as there are obvious, explicit boundaries, parents should "let live", and this is never easy. For this reason, it is fundamental that parents allow their children with disabilities to do what they are able to do by

themselves, to take risks, make mistakes, to fail and to learn from their failures. In summary, they should let them experience the "dignity of risk" and give them the chance to live this (calculated) risk (Geenen, Powers, Hogansen & Pittman, 2007; Peralta, 2008; Wehmeyer, 2006). When persons are denied participation in significant experiences, with the reasonable risks that these involve, they are hindered from living a full life.

2. Make children understand that *what they say or do is important*, and that it may be important to others. Parents can encourage their children to ask questions and to express opinions. Participation in family discussions and decisions is a good opportunity to practice this (for example, when planning vacations).

3. Make the children understand that they are important and are worth spending time with. It is essential that children participate in family activities and decisions so that they feel valuable and more *self-confident*. Shared history between parents and children helps to promote positive relationships that are key to self-determination (Wehmeyer & Field, 2007).

4. *Address the children's questions* about their disability. The important thing is for parents to stress that each one is a unique person with his or her individual profile and strengths, also with limitations, which the individual can modify and can learn to accept.

5. *Value the children's goals and objectives* and do not focus only on results and performance. To do so, parents can encourage development of self-control through positive guidelines; in other words, they can model behaviors that involve organization and goal setting. For example, the family can make a chart with each member's daily activities and place it in a visible spot (if necessary, visual cues, drawings or photos can be included, to make explicit how a task is to be carried out). It is good for parents to reinforce each step and each effort that their children make towards reaching the final goal.

6. Encourage *social interaction* with other children and in different contexts. In this way opportunities are created to develop skills in communication, interaction, negotiation and self-advocacy.

7. *Rely on the children's strong points* and have realistic expectations that are also ambitious. Parents can facilitate their children's learning by taking a more active role: provid-

ing support and affection, accompanying and comforting them with their fears and mistakes, and avoiding activities that only lead to frustration.

8. *Provide opportunities* for their children to assume responsibility for their own actions, successes and failures. As educators, parents should place clear boundaries and give reasons why. When requests are accompanied by reasons, this leads children to internalize these suggestions and activities.

9. Plan opportunities for *making choices*. Any occasion is good for children to express their preferences, make choices (clothing, food, free time) and have these be respected by others. For example, grocery shopping can be used for talking with the child about what they like and don't like (this will improve their self-awareness).

10. Give honest, positive *feedback*, making the children see that everyone, including parents themselves, make mistakes, but that these can be corrected. It is important to make them understand that no one does everything well or everything badly, and it is always possible to look for alternative tasks, objectives or goals that are within one's possibilities (reality principle) (Szymanski, 2000). Negative results on certain tasks or activities should not be converted into personal failures ("This activity turned out poorly" is not the same as "You are a disaster" or "You do badly on everything").

Elsewhere, Abery et al. (1994) use a more formal structure, and have prepared a family curriculum containing 15 modules (*Self-determination for Youth with Disabilities: A Family Education Curriculum*). The modules seek to train all family members in acquiring greater control over their lives, and offer knowledge and skills needed to support the person with disability in exercising their own self-determination skills (Abery *et al.*, 1994). This curriculum has been evaluated in families of persons with intellectual and physical disabilities and results indicate that participates exercised a significantly greater degree of personal control after participating in the program (Stancliffe & Abery, 2003).

B) To improve the professional's services

The four-component model by Dunst, Trivette and Deal (1988; Dunst & Trivette, 2009) allows professionals to take FCA principles into their practice and to promote the families' own self-determination. These components, identified below, can be worked on simultaneously:[4]

1) Identify the needs of the family. In a climate of trust, where families may express their preferences and say all that concerns them without feeling judged, professionals adopt an attitude of active listening and empathy, and help them to identify the relevant factors that define their quality of life. This is how they will be able to *translate the family's concerns into needs*. To do so, this type of worksheet can be used:

FAMILY:		
Date	Concern expressed	Need identified
	A father says he feels depressed because he is worried about his child's future	Information about resources and options for independent living
	Some parents comment that whenever they leave home, their child shows defiant behaviors that draw attention, so they seldom go out	Training on behavior management and consultation with a specialist

Figure 1. Worksheet for translating concerns into needs

2) Identify the family's resources and strengths. The first step is to identify the positive aspects of family functioning in order to understand the family reality and to verify how it manages and monitors its own needs. To do so, professionals must pay special attention to positive behaviors and make an effort to translate negative aspects into positive aspects. A simple worksheet like the following serves as an example:

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[4] For broader information on this model, see Leal's book (1999), *A family-centered approach to people with mental retardation*, as a manual of good practices.

FAMILY:		
Date	Family behavior	Strength identified
	The mother attends horseback riding classes with her daughter every week where she must ride with her	Highlight the activity as a new hobby, the physical exercise involved, the time shared with her daughter in a relaxed, stress-free atmosphere

Figure 2. Working on identification of family strengths

3) Identify sources of help. This means trying to discover what formal or informal support (services or social networks) the family has available to them, and how they meet their needs (for more information on social support networks, see the chapter by Álvarez and García, 2007). Certain questions can facilitate identification of this support, so that, if necessary, other types of help can be provided, for example: *Who helps you take care of your children?, Whose shoulder do you cry on when you feel bad?, Who do you talk to about your problems?, Who do you meet with when you want to have some fun?, Who spends time doing things with your child?, Who helps you with household chores?*

4) Give authority and empowerment to families. The key lies in creating opportunities for each and every family member to be more competent, independent and self-sufficient. Families can learn what they do not know and develop strategies and skills that will help them with their tasks, with future problems and with their needs. Instead of families being dependent on the professional, the aim is to promote their self-determination, their feelings of control and their authority over their own lives and actions.

A view that focuses on resilience and on the positive impact of disability in the family, as mentioned above, favors and supports models like these and allows us to move beyond past approaches that are merely pathological and overly focused on the professional.

By way of conclusion

Although it is true that disability can be considered an objective, potential source of stress for families, positive psychology in recent decades has put forward a view that focuses on resilience and on the possible benefits that may be produced in those affected (benefits that are also identified by the families themselves, as we have seen here). This more comprehensive view leads to family-centered approaches to intervention whose goal is to improve the family quality of life, through empowerment of all family members. Respect for family values and decisions, establishing true partnerships and developing proposals like those suggested by Davis and Wehmeyer or Abery et al. will allow families to obtain greater control over their lives. Only in this way will they be able to promote the same skills in their children with disabilities, without needing to turn to external agents or create overly dependent bonds with professionals. When parents have a perception of control, reflect on their beliefs about disability and perceive self-determination as an attainable, desirable educational goal, they will be prepared to accompany their children, without taking their place, through the challenge that is involved in living life on your own.

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