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Families with a disabled member: impact and family education

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Abstract

This article debates whether the quality of life of the families is depleted or improved due to the presence of a member with a disability. A theoretical review is carried out of the impact on the family caused by the birth of a child with a disability, the detrimental effects of the disability and the positive effects of the empowerment offered by the family intervention programs.

When the family includes a member with a disability, time and effort must be dedicated to them as they normally have greater requirements for care. The repercussion of this is putting the needs of the parents and siblings to one side, creating a specific profile for these families. They show issues such as imbalance in the family system, unawareness of aspects of health and education, negative feelings, need for adaptation, etc., for which they require support programs.

With the family intervention, they are able to improve their awareness of problems, acquire efficient education strategies, initiate new friendships, improve conflict resolution, etc. In consequence, rather than focusing on the disadvantages, these families can achieve a series of highly developed skills such as communication, self-esteem, sense of humour, resilience. It is the own potential of these families that must be strengthened, not only to improve the quality of family life, but also for the benefits to extend to the community.

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1. Background: concept of disability and quality of family life

Disability has been associated with pathology, limitations and other negative concepts. Currently, the models focus on the strengths and support in order to encourage greater autonomy of the person and higher quality of life for that person and their family.

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Intellectual disability must currently be understood from the ecological and contextual model, based on the interaction of the person with the disability and the vital contexts. Based on the new concept of Intellectual Disability addressed in the 11th edition of the Manual by the American Association on Intellectual and Developmental Disabilities (AAIDD) and taking into consideration the article by Verdugo & Schalock (2010), "intellectual disability is understood not as a merely biological characteristic but is directly related to the context, leaving aside the discussion of the significance of environment and internal factors and putting everything on the same level". This definition contemplates the influence of the family as a central nucleus during the growth of any child, and constitutes a context in which it is necessary to focus efforts in order to create a climate that helps to improve the quality of life of these children (González-del-Yerro, Simón, Cagigal & Gómez, 2013).

The paradigm about disability and family evolves from a psychotherapeutical model (since the 50's), through a parent education model (70's), to a quality of life and empowerment model (from the 80's). This new period is characterised by trusting a basic idea: the families are capable of handling the disability when provided with the necessary support, i.e. they are resilient families. (Arellano & Peralta, 2012)

With the psychotherapeutical model, the professionals released the parents from their tasks of care and education and secluded the disabled people in hospitals, schools or psychiatric homes (Turnbull & Turnbull, 2002). The experts assumed control and issued opinions about the reactions, educational style and opinions of the parents. They considered the parents to be the origin of the children's limitations, obstacles for their development and irrelevant for the intervention process. The mothers and fathers were considered to be vulnerable patients in a situation of mourning, requiring a treatment complementary to that received by their children and considered, in general, less intelligent, competent and objective than the professionals (Wehmeyer, Sands, Knowlton & Kozleski, 2002).

With the appearance of the associationism movements, the stage of "professionalism" was left behind, which defended the rights of the people with disability, deinstitutionalisation, normalisation, empowerment, etc. It highlighted the role of parents in the improvement of their children's quality of life, which has been described by many as a true act of courage (Abeson & Davis, 2000). In this new stage, the families moved from being guilty of the disability to being collaborators with the professionals and recipients of specific services. It must be recognised that the mothers / fathers have been and continue to be founders and members of organisations, promoters of services, recipients of the expert decisions, teachers and therapists for their children and responsible for making decisions about the intervention (Erwin & Soodak, 2008).

The concept of quality of life is an extended concept, defined by the World Health Organisation as the perception held by individuals of their position in life in the context of culture and the system of values, and in relation to their objectives, expectations, standards and concerns. It is a multidimensional concept that reflects the conditions of life desired by a person in relation to eight needs: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights (Schalock, 1996).

It is obvious that the quality of life for people with an intellectual disability will depend on the same factors as those which are important for people without any type of disability (Gràcia & Vilaseca, 2008). However, Córdoba & Soto (2007) also believe that there are patterns that show differences throughout the family life, and indicate the importance that the study must place on the family adjustment to the people with disability throughout their life cycle.

The application of the concept of quality of life to people with a disability is subject to a series of key principals, as stated by Gómez Vela (2004):

- The quality of life of people with disabilities contemplates the same factors and dimensions which are considered relevant for people without disability.
- Quality of life is experienced when the basic needs of a person are satisfied and they avail of the same opportunities as everyone else to propose and achieve goals in the principal vital contexts, i.e., the home, school and work.
- The concept of quality of life includes objective and subjective elements, but the perception of the individual is the best reflection of the quality of life they experience.
- Although there are numerous proposals about the number and scope of the domains that compose the construct of quality of life, five dimensions are repeated frequently in the different theoretical models: emotional well-being, health, family and social relationships, material well-being and work or any other form of productive activity. Although the dimensions proposed vary from some authors to others, they must cover all aspects of life.

- Together with the domains mentioned, there is a series of indicators that become particularly relevant in the case of people with disability and that must be contemplated in the conceptualisation of their quality of life: the level of participation in making decisions about issues that affect them, the level of integration and acceptance in their community and the equality of opportunities.
- The information about the quality of life for people with disabilities can be validated by different people: the individual with the disability and their family, the providers of services and the professionals that work with them.
- The data on quality of life must develop an important role in the provision of support and resources for the people with disability and their families and in the evaluation of programs.

In short, we could indicate how the quality of life represents an agent of change based on four basic elements for the entire population, including people with disabilities, as confirmed by Schalock & Verdugo (2007):

- The support is a vehicle for promoting quality of life.
- The community is the context for developing a quality of life.
- The organisations must see themselves as bridges towards the community.
- The practices for the provision of services must include the planning centred on the person.

Currently, there is a scarce amount of work on the perception of quality of the families with children of school age and to a lesser extent on minors and special education needs. Therefore, we suggest the completion of a theoretical inquiry about the repercussions of having a child with an intellectual disability in the family, highlighting the advantages that this type of family can offer.

2. Subject of study

In this document of theoretical debate, the aim is to address whether the quality of life of the families with disabled children is damaged or enriched by having a member with those characteristics. Also, which aspects of family life are altered, i.e., to what extent it increases or decreases and which intra-family and extra-family resources are activated in order to maintain the balance. What is the need to obtain family support resources in these cases and what advantages are offered by the training programs for families as an extra-family resource.

3. Sources of evidence

This review method can summarise past empirical and theoretical literature on the topic of interest: advantages and disadvantages for the family with a disabled member. The theoretical review is based on an exhaustive search for information based on key words and using specialised databases such as PubPsych, ERIC, ProQuest and Plinio, a discovery (new generation search engine) in the university library. Later, the articles on the topic were selected that appear in the references section. The information shown was extracted, analysed and commented on.

3.1. Possible detrimental aspects of the disability in the family

The birth of a child with a disability has, throughout history, been considered to be a tragic, threatening and distressing event and a very painful occurrence for the parents (Lizasoáin & Peralta, 2004). The majority of the scientific literature during the 40's and for almost two more decades about family and disability has been focused on describing the negative effects that the presence of a child with disability produced in the family dynamic, such as: depression, anxiety, frustration, guilt, economic burden, isolation, etc.

The event of having a child, in itself, is a process that requires an adaptation that begins from the moment that it is decided or desired to be a mother/father, continuing through the pregnancy until the birth arrives, when individual changes occur linked to the new functions as mothers/fathers, assumption of new roles, changes in habit, changes in the couple's relationship, etc. These changes are greater for parents that have a child with a disability, and other changes specific to this situation also take place. When, during the evolutionary development, various symptoms are shown

that are atypical in normal development, emotions and feelings such as loss, pain, doubt, threat, shock and helplessness arise.

According to the authors above, the stages through which a family tends to pass in the process of accepting a child with a disability are known. In the first instance of shock or initial impact when receiving the diagnosis, there is a stage of reaction followed by another of adaptation and guidance. The course will depend on each family, the coping strategies, the members that form part of the family, the resources availed of and the support received. Generally, the sense of loss or pain will progress and will be resolved without the need for any specific support. The parents will progressively manage to adapt to the new situation and recreate their life project, and the pain will reduce until disappearing. Furthermore, there is a stage of removal from the news or diagnosis that is experienced with unreality and various negative affective-emotional states such as shame, humiliation, rejection, denial, helplessness, guilt and resent and even social withdrawal and isolation.

Faced with the situation of children with certain functional limitations, or situations of high dependency, family stress is produced as apart for the doubt surrounding the diagnosis, there are changes in the family organisations and routines and even changes on an employment level. This stage is characterised by the demonstration of anxious symptoms: irritability, confusion, fear in relation to the doubt, emotional instability, reactions of avoidance and fleeing.

The quality of life factors where the families showed greatest dissatisfaction, according to a study carried out in Colombia and Spain, by Córdoba, Mora, Bedoya & Verdugo (2007), were the support of the person with a disability, support from the Governments and support from local entities.

Due to the risk of these negative effects appearing, there should be consideration of an intervention with the family, from the first instance, and accompaniment throughout the entire life.

3.2. Possible beneficial aspects of the disability in the family

There are study cases that focus on researching the possible advantages of having a child with a disability. There has been an evolution from a paradigm focused on pathological aspects, to another that highlights families that are "resilient" and extract positive lessons. The majority of the studies gather isolated stories, informal anecdotes from parents that had overcome the pathological view of their family and transmitted positive ideas with regards to their situation (Blacher & Baker, 2007; Hastings, Allen, McDermott & Still, 2002; Summers, Behr & Turnbull, 1988, quoted in Arellano & Peralta, 2012).

Peralta & Arellano (2010) performed an initial theoretical study and revised the literature from the last 10 years based on the focus centred on the family and gathered qualitative information from 4 families. Said families consider that the experience of disability implies challenges, concerns about the future of their children and a certain additional burden, personal and family enrichment, according to the parents. They indicate that the key factors for achieving family quality of life are: collaborative relationships between professionals and parents, identifying the family strengths, or developing the perception of control and self-determination of skills of the parents.

Later, these two authors carried out a qualitative study with 41 families with a child with a disability and analysed the perceptions of the parents with regards to the positive impacts created by having a child with these characteristics. They state that they have learned to value the qualities of the disabled child above their difficulties. Also, entering into the world of the disability, they have learned interesting aspects about a new way of life where they have constant challenges and develop the capacity to overcome them. The families feel greater self-worth, as they see themselves as useful and necessary. Coexistence with the disability produces personal learning such as the urge to excel, strength, positivity, greater self-knowledge, awareness towards the needs of others, enjoyment of small achievements, learning not to judge or criticise others, humbleness, patience, generosity, optimism, improved family cohesion and control of character (Arellano & Peralta, 2012).

Gràcia & Vilaseca (2008) presented the results of naturalist interventions focused on the children with intellectual disabilities and their families in order to improve their communication patterns. They defend that in order to achieve a greater quality of life, the children with intellectual disabilities and their families should opt for a new methodology with the objective of coordinated and shared work among the family and all professionals and institutions involved in the process.

3.3. Family intervention: school for parents and education for parents.

What does collaboration between families and professionals mean? Following Summers and other authors, a collaborative relationship is understood to be "interaction of mutual support, which focuses on satisfying the needs of the person with a disability and their family, and is characterised by a sense of competence, commitment, equality, communication and trust" (Summers et al., 2005, p. 49). A second question would be, are the parents satisfied with the collaboration of the professionals? According to studies such as that by Bailey et al. (2012), the response is positive, and this is also obtained from other studies, with 68% of parents having a good or very good general experience (Arellano & Peralta, 2015).

Currently, the model addressed by the efforts for change in the work with the families is the "family-focused" model, for quality of life and empowerment, which means providing the family with various tools in order to cope with the disability. To be a mother/father involves assuming a new role or various functions marked by responsibilities and obligations towards a third person, in aspects such as: food, safety and hygiene, health, personal dedication that changes depending on the evolutionary moment of the child. This is a changing process which requires adaptation to the specific needs of the development. Various studies have highlighted that early intervention, directed towards the parents, is a decisive factor in the modification of behaviour that adapt to the needs of the child (Dadds, Maujean & Fraser, 2003; Díaz-García & Díaz-Sibaja, 2005).

The education of mothers/fathers aims to promote the development of parenting skills in order to educate their child. One of the most complete definitions with regards to education for parents states: "it is a set of voluntary learning activities by the parents with the objective of providing adequate models for educational practice in the family context and/or modifying and improving existing practices with the objective of promoting behaviour with the children that is positively judged and eradicating that which is negative" (Vila, 1997a).

The education for parents has followed various stages, described by Tavoillot in 1982:

- The stage that considered the child as a problem: in this period, the educator was the expert that provided the necessary information to the parents in order to solve the problems of their children through discussions or conferences.
- The mothers/fathers as a problem: during this period the education role also fell to the expert, who helped with the solution of the parents' problems, whose behaviour influenced the behaviour of their children. The work method is through personal interviews and meetings in small groups.
- The educator as a problem: there is a symmetry between the educator and the parents, where the educator is not a director but trusts the parents and their capacities, therefore the objective is to improve the parental role and favour self-confidence and parenting self-competence. This is also addressed through personal interviews and meetings in small groups.
- Society as a problem: in this last stage, the child's environment (society, family and school) is taken into account, as contexts that influence their behaviour and development. The educator acts as a facilitator for the family - school - society mediation, organising education programs for parents integrated in the school and community.

The stage that the author suggests, society-problem, is that which is closes to the inclusive model. This is the latest trend marked by the Inter-American Children's Institute of the Organisation of American States (OAS, 2001), which published in its study "The Inclusion of Children with Disability" in relation to the concept of disability which culminates in the inclusive model of human rights, which consider the environment factors as influential on the child's development, as well as the active role of the family in the treatment. Some authors compare the education of parents with other modalities of family intervention (Farrington & Welsh, 2003) and psychosocial intervention (Brestan & Eyberg, 1998), as well as different treatments such as the case of behavioural problems that arise in childhood and as a therapy modality together with pharmacological treatment in the intervention of ADHD (Chronis et al., 2004).

With regards to the evidence that appears, we can mention Martínez and Pérez (2004), who analysed educational evaluation and intervention programs in the family scope and found positive effects of the programs for parents. Among these, they highlight the increased self-esteem of the mothers and fathers and reduced feeling of guilt: they learn to use efficient behavioural and thought strategies used by other families, they feel listened to and understood,

they learn to bring the content into practice, they develop a sense of humour, affective bonds are created with other families, they accept the idea of the imperfect parent and they learn from the professionals.

Robles & Romero (2011) analyse the efficiency of the training programs for parents based on the results extracted from the meta-analysis and revision articles over the last 20 years (1989-2009). The results: they reflect the robustness of the training for parents in the promotion of positive changes in the child's behaviour, in the improvement of daily interactions between parents and children and in the parental behaviour and attitudes. The training for parents showed its efficiency in other factors of the family dynamic: communication, resolution of problems and reduced parental stress.

Therefore, through the parent training programs the objective sought is to coordinate the different education actions between the families, school and society (close environment) in order to jointly contribute, in an efficient manner, to the development and education of the children. Following these premises, when a school for parents is suggested, the needs and characteristics of the participants must be taken into account, as well as the context in which they develop and the objectives to be achieved. The majority of the programs seek two objectives: to support and assist the parents and to efficiently stimulate the development of their children. According to Cataldo, 1991, other objectives can be set, such as:

- Provide the parents with information, guide them and advise them in relation to the development, learning and socialisation of their children.
- Favour active participation by the parents in the learning and school experiences of the child.
- Provide specific techniques adapted to the child's evolutionary development and to behavioural control.
- Learn to detect the problems that may affect the family dynamic or development of the child with the objective of preventing problems in the development and in the family relationships.
- Offer advice and rehabilitation for families that present problems in the development of their children or in the family dynamic.
- Inform and guide the parents with children that require special education.
- Provide the community with social support.
- Motivate and support the initiatives promoted by the parents.

It is fair to wonder, is the school for parents efficient? The majority of authors that have presented data on the evaluation of efficiency of these programs highlight positive aspects in different aspects (Cataldo, 1991):

- Improved development of the children.
- Improved family relationships.
- Increased feeling of satisfaction and self-competence of the parents in relation to their tasks and responsibilities as mothers and fathers.
- There is an improvement in the family - school - society relationship.

With regards to the advantages offered by educating parents, Martínez & Pérez (2004) completed an educational evaluation and intervention in the family scope and identified the following positive aspects: increased self-esteem of the mothers and fathers and reduced feeling of guilt in general, and specifically:

- They learn to use efficient strategies for behaviour and thought used by other participants.
- They are aware that what they have learned can be brought into practice.
- They feel listened to and/or understood.
- They learn from the coordinators.
- Friendship bonds are created between the participating members.
- They develop a sense of humour.
- They accept the idea of "imperfection" as mothers/fathers.

More recently, Robles & Romero (2011) carried out a study on the efficiency of the intervention type of the parent training, and verified positive changes in the child's behaviour, improved daily interactions between parents and children and in the parental behaviours and attitudes. Also, the training for parents showed its efficiency in other aspects of the family dynamic: communication, resolution of conflicts and reduced parental stress.

Given that this article has been a theoretical debate, in future research it would be interesting to obtain empirical evidence both for the negative impact and for the positive aspects of the family empowerment. Comparative studies among parents of children with and without disability, as well as research on the verification of the efficiency of specific intervention methods for this type of family, comparing control and experimental groups, and with standardised tests on quality of life. There must also be inclusion of measures on the repercussion of the family intervention programs in the quality of life for people with disability.

4. Conclusions

The presence of a child with a disability alters the quality of family life, as it requires greater adaptation to the needs of all of the members. Said needs, marked by the illness and an atypical development, have a more exclusive character for these families as they are based on a lack of knowledge that must be resolved. They must seek information about each of the differential characteristics of their child and the risks involved. This "extra" and "unknown" work generates a weariness that may alter the quality of family life, as it requires greater dedication of time to the child with problems, and may lead to lack of care for other members. This logical consequence can be remedied if support and education is offered to these families.

With regards to the advantages, considered as the highlights of this paper, it must be recognised that these families generate superior skills of detecting needs and risks, seeking resources, adaptability and flexibility, attention to diversity, empathy and patience. In summary, it is an improvement in the quality of attention for the disabled child, that may be extended to other children or family members and society. Therefore it would be true that there is "strengthening" or "empowerment", as alluded to by the new trends in family intervention. It is the own potential of this type of family that must be strengthened, not only to improve the quality of family life, but also for benefits for the entire collective.

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