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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.

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