

Quality of life and family: dimensions and tools for an integrated approach

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Abstract. Quality of Life (QoL) is a central theme in studies involving individuals with intellectual disability and their families. Basic principles and a recent model developed in these research will be described. Main findings and issues from studies on QoL described by individuals experiencing disability or its consequences will be then reported. In more details the most recent framework for the analysis of Family Quality of Life (FQoL) will be described, together with useful instruments and main findings associated with these researches. Finally, components for an integrated assessment approach will be outlined. The conceptual framework, the dimensions and the instruments developed can contribute to a better understanding of quality of life experienced in complex situations, in finding new strategies and goals for professionals interested in addressing this complex theme and working for wellbeing of individuals and families experiencing diverse complex conditions.

Keywords: quality of life, individuals with disability, family, life domains, assessment instruments

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Introduction

Over the past two decades, quality of life has assumed an important role in studies involving individuals with disability. Quality of life is here defined by how an individual interprets the environment and how the relevant individuals and groups affect his/her well-being. It consists in an individual's personal interpretation, the perceptions of the individual who is reporting about family quality of life (Schalock et al., 2002).

The conceptual framework underlying the QoL framework used in studies on disabilities and on their families is based on three main dimensions of the living experience: *Being*, which refers to the psychological well-being and focuses on individual thoughts and values, self-perceptions understanding of self and acceptance of disability; *Belonging*, which refers to access to environmental resources, connections to people and places, relationships within the community; finally, the *Becoming* component refers to purposeful activities, personal development and future goals (Zekovic & Renwick, 2003).

In these studies, Life Satisfaction is the most common measure of Quality of Life and a means to assess the relative importance of individual quality of life domains. It is then considered as a subjective component of quality of life, as the cognitive component of subjective wellbeing, the cognitive judgement used by individuals to describe the quality of their own life according to a series of personally set criteria.

According to some studies QoL should be considered as a unidimensional construct in terms of individuals' perceptions of their life quality overall, and that the factors related to QOL should also be measured distinctly, not as proxies for QoL (Dijkers, 2003; Pavot & Diener, 2009). Several other studies propose QoL as a multidimensional construct defined by human values, such as happiness and health, and important aspects of human existence, such as family and work, and the relationships between them; it includes physical and material well-being, emotional well-being, community life and social affiliation (Brown, Hatton, & Emerson, 2013), self-determination, autonomy and choice (Wehmeyer, 2013), status social development, personal development and achievement, free time. Finally, quality of life has been described as a social construct based on several indices referring to different domains, both subjective and objective, such as physical and material wellbeing, emotional wellbeing, social belonging, and community living (Brown, Hatton, & Emerson, 2013). Most of these factors and issues have been assumed by Schalock and colleagues and organized in the recently developed model of quality of life.

A multidimensional model of Quality of Life

Recently, Schalock, Verdugo, Gómez and Reinders (2016) have proposed a multidimensional model attributing importance to three fundamental aspects: personal characteristics, objective conditions of life and perceptions that others have about people with disabilities. Based on results from studies conducted for more than ten years, the model takes into account, with their dynamic nature, both microsystem (the individual, his family, the school and experience), mesosystem (neighborhood, community, services), and macro-system (socio-political and socio-economic trends and factors).

As shown in Figure 1, the model includes three superordinate factors (Well-being, Independence and Social Participation) which develop in eight diverse domains.

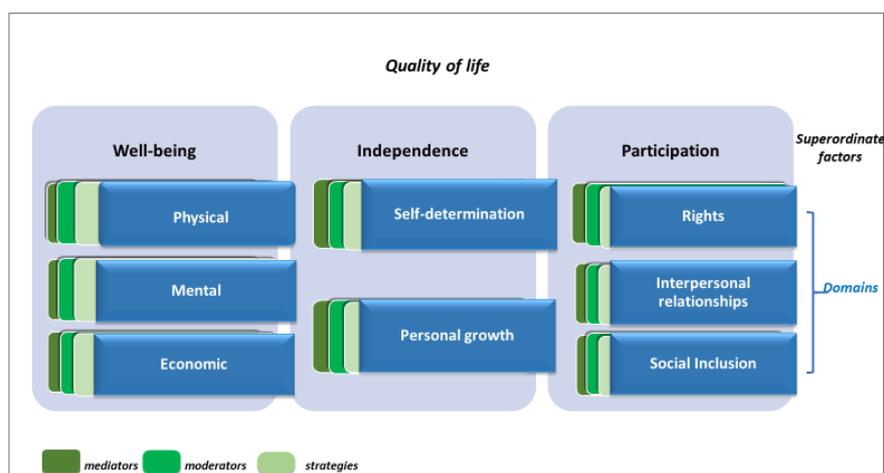


Figure 1. *Components of Schalock et al. (2016) model of Quality of Life.*

Within each of the eight domains, three components interact with each other and determining the individual perceptions: moderating variables, mediating variables and strategies to increase the quality of life. QoL can be altered by the presence of one or more moderating variables such as individual demographic variables (namely, gender, ethnicity, intellectual functioning, adaptive behavior), cultural factors or family factors (income, family size, geographical location religious preferences, family structure). Mediating factors include personal status such as the residential situation, work status, health status, self-determination and subjective well-being; the system of services such as the support system; community factors such as

expectations, attitudes, impact of the media. The third influencing element includes strategies to increase the quality of life that act as predictors and propose the development of personal strengths, maximizing personal involvement, providing individualized supports and facilitating opportunities for personal growth.

Intraindividual and contextual factors as well as interactions of the individual with the contexts of life take on a specific and significant meaning in the most recent proposals for the analysis of quality of life. All this can and should move to look at the quality of life of the individual and beyond opening the view to the context in which he/she lives and the most important interactions he experiences, that is family.

Quality of Life of individuals experiencing complexities or living a complex family life

Studies focused on single individuals significantly contributed to the understanding of relevant issues in QoL highlighting dimensions of analysis, determinants and modalities for addressing several relevant issues. A set of criteria has been also identified (Claes, Van Hove, van Loon, Vandevelde, & Schallock, 2012) for the selection of assessment tools. From a conceptual and measurement point of view they are in line with the most recent literature. Recent studies mostly follow principles as well as methodological choices proposed and adopt tools developed.

Quality of Life of individuals experiencing disability

On the individual level, the assessment of QoL has been used to provide feedback to the person regarding his/her status on domains under assessment; establish a possible change to introduce or that can occur in the multiple dimensions composing a life of quality; compare subjective and objective assessments of quality of life indicators; share information about client self-evaluation on outcomes and changes to introduce. There is a general agreement, in fact, that some key aspects can be captured only through the subjective perceptions of people themselves. But including the subjective assessment of QoL implies involving a respondent who often has limited cognitive abilities, limited attention and verbal abilities.

To address this issue, professionals often rely on informants, on proxies such as a family member or a staff member. However, several studies express caution about the validity of proxy responses in specific domains: QoL indicators, living conditions, support needs and decision making; concerns about the degree to which respondents' answers strictly reflect

the perceptions of the person concerned. To produce reliable and valid results the respondent must have known the person being rated and have had recently the opportunity to observe the person in one or more environments and for a substantial period of time (at least some weeks) in order to understand the person's current life experiences and circumstances.

Additionally, studies have shown that typically QoL scores obtained from self-reports are not the same as those obtained from a family member or staff. Best practices require then that to analyse the two sets of scores or narratives, searching for the meaning of discrepancies between the two. Different perspectives will be then taken into account in trying to understand the personal experience and provide a complete perspective on an individual's life (White-Koning, Boudet-Loubère, Bazex, Colver, & Grandjean, 2005). However, although different in some respects, generally no significant differences emerge in the self-assessments of people with or without intellectual disabilities. And correlational indices between self and indirect assessment range from moderate to good, with social health workers usually evaluating more negatively QoL of people who they care about than the self-assessed ones (Claes et al., 2012).

Besides involving proxies most productive alternatives are: constructing user-friendly instruments and developing parallel version which, with similar measuring capacities, can provide information on the same variables but from different perspectives and with items having different formats; personalizing and adapting the tools to specific characteristics of the people involved. This can increase the percentage of self-responders and, consequently, the reliability of self-evaluation answers. An example of this type is the set of instruments developed and used by researchers working for ten years for the "Centro di Ateneo Disabilità, Riabilitazione e Inclusione" (Center for Disability, Rehabilitation and Inclusion) at the University of Padova. Different formats of instruments (questionnaires or interviews) were developed that can be used under different modalities (direct and indirect), collecting information from different perspectives (parent or professionals) and adopting various personalizations (for visual or hearing disabilities, limited fine motor motility or linguistic production). The items address:

Satisfaction with the quality of relationships with family members

Satisfaction for perceived well-being

Satisfaction with the professional activity carried out

Satisfaction with the established educational relationship

Satisfaction for your free time

Satisfaction with the presence of supports and supports

Satisfaction with the possibility of self-determination.

Using these measures, we have learned that differences in the satisfaction for the opportunity to benefit from social interaction opportunities and for characteristics of the living environments are associated with age of the persons considered, global intelligence, level of cognitive difficulty but also with executive abilities and basic social skills both in young people and adults with developmental or acquired intellectual disabilities (Nota, Soresi, & Perry, 2006; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Sgaramella, Nota, & Soresi, 2014).

Besides addressing intraindividual characteristics and their role on QoL experienced and/or reported by family members caregiving or professionals familiar with the person, recent studies have pointed the attention to the relationship between intra-individual and environmental characteristics. Studies involving a large number of individuals with different diagnosis, gender and age found that personal as well as social and organizational variables both play a significant, although different, role on users' quality of life (Gomez, Peña, Arias, & Verdugo, 2016; Alves et al., 2016). This, in terms of Schalock and colleagues words, points the attention also to *meso* and *macro* systems and to the role of their characteristics on quality of life.

Parents Quality of Life

Being parents of a child with disabilities requires facing many challenges and difficulties starting from the diagnosis to the first years of the child's life, from school experiences to the transition periods of life, from the world of education to that of work, from youth to adult and old life.

Life satisfaction of parents of children with Intellectual Disability (ID) is at the core of a body of research aimed at understanding the relevance of how they perceive their life and at the same time describing their cognitive appraisal of stressors or the burden possibly associated with caring for their children. Lower levels of life satisfaction are reported among parents of children with ID compared with levels of life satisfaction experienced by the general population (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009). Having daily physical and mental assistance tasks can create high levels of stress in parents of children with disabilities.

Family caregivers who describe their quality of life in the context of their caregiving role often report they are overburdened with responsibilities, lack personal time and time for self-care, feel that their life is interrupted or lost, endorse anger and other negative emotions

(Alves et al., 2016; Lin et al., 2009). Several common themes in both qualitative and quantitative studies arise. Table 1 summarizes the most meaningful associations found.

<i>Demands of caring</i>	Functional impairment of the person with disability which is a predictor of carer burden and negatively associated with carer QoL.
<i>Carer emotional well-being</i>	Emotional well-being is negatively associated with carer burnout and carer stress; the ability to find meaning in caring and a sense of coherence is positively related to carer QoL.
<i>Support received</i>	Types and extent of support received improves QoL.
<i>Carer independence</i>	Irrespective of the activity measured (e.g., leisure activities, employment, household activities, or service to others), there is positive association is found with carer QoL.
<i>Carer self-efficacy</i>	Individual's confidence in coping effectively with different caring tasks influence self-efficacy
<i>Carer self-efficacy</i>	Individual's confidence in coping effectively with different caring tasks.
<i>Future</i>	Worrying about the future, particularly in relation to disease progression, is perceived as worsening carer QoL.

Table 1. Main determinants of caregivers quality of life

However, a change of pace has been emphasized in the last ten years in the way in which parents who experience the challenge of disability are perceived. The emphasis on resources and strengths can reduce, albeit slowly, stereotypical and negative visions towards them and highlighting that service personnel should certainly take into account their difficulties and stress levels that persist over time (Baker, Blacher, Crnic, & Edelbrock, 2002), but also to enhance the potential that accompanies the life stories of these people and their contribution to the benefit of their own children's self-determination, to change things for the benefit of all (Nota, Ferrari, Soresi, & Wehmeyer, 2007). Many parents can respond to everyday challenges with positive coping strategies and resilience; they recognize that they attribute new meanings to their life as well as attribute themselves previously unimaginable skills as well as the ability to reformulate personal goals for oneself and for the child (Hastings, Allen, McDermott, & Still, 2002).

Additionally, in a study involving parents of people with different disabilities (visual impairment, hearing disability, Down syndrome or autism) and a group of parents of children without disabilities searching for differences in the quality of life, surprisingly parents of children with impairments did not systematically and significantly differ from parents of

people without disability, thus showing once again that parents are not a homogeneous category but present with high variability and specific differences (Soresi, Nota, & Ferrari, 2007).

Global Life Satisfaction of parents of children with ID is also at the core of a body of research aimed at understanding the relevance of their perception and at the same time describing their cognitive appraisal of stressors or the burden possibly associated with caring for their children. Lower levels of life satisfaction are frequently reported among parents of children with ID compared with levels of life satisfaction experienced by the general population (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009). Levels of life satisfaction seem, however, predicted by potentially protective factors in parents of children with ID (Ginevra et al., 2018). Suggestions can be derived from these last findings for actions that practitioners who work with these parents should undertake.

Siblings Quality of Life

The relationship between brothers has peculiar characteristics that make it different from the other types of relationships that an individual can undertake. It is the generally one of the longest relationships a person can experience in his/her life and therefore has a strong impact on the individual. When there is a person with disability within the fraternal relationship, this might significantly affect the "typical" relationship between brothers.

Studies investigating the relationship between siblings with disabilities and siblings without disabilities examined their contacts, closeness, degree of involvement and support provided. Siblings generally report a good relationship with their brother having a disability, and the type of relationship varies along a continuum ranging from a strong involvement to no contact (Hodapp & Urbano, 2007).

Several elements may influence the impact of disability within the fraternal relationship, such as the type of disability, severity of impairment, gender and age of the siblings involved in the relationship. The siblings of subjects with Down syndrome report having a closer and warmer relationship than the siblings of autistic subjects, claiming to have even more contact with the siblings (Hodapp & Urbano, 2007) while brothers of people with autism report fewer contacts and positive feelings about the fraternal relationship (Orsmond & Seltzer, 2007). From these analyses emerges also that elements with more impact are the level of severity, the load of care and assistance required of the siblings and the behavioral problems that the brother with disability presents.

However, a recent study has also shown that siblings of children with a chronic illness often report a better QoL compared to their peers, indicating that chronic illness of a child does not automatically predispose siblings to report a lower QoL (Houtzager, Möller, Maurice-Stam, Last, & Grootenhuis, 2015). Parents are often worried about the effect of an illness on siblings' well-being. Living next to a person with disabilities does not necessarily imply negative consequences on the life of the brother without disability. The siblings of people with disabilities often show greater empathy, tolerance, patience and sensitivity compared to their peers (Benderix & Sivberg, 2007; McGraw & Walker, 2007; O'Brien, Duffy, & Nicholl, 2009). Generally, adult siblings are particularly concerned at the time when parents will no longer be able to provide adequate support for their brother with disabilities (Benderix & Sivberg, 2007; Orsmond & Seltzer, 2007). When parents can no longer guarantee their child the care they need, the siblings are naturally considered as future caregivers.

Family Quality of Life

Moving from individual to family oriented QoL, the inquiry becomes focused on quality of life within the family unit as a whole, as opposed to the separate QoL of each individual that comprises the family unit.

The basic assumption made is that families form a structure that is of primary importance to the functioning and ongoing stability of all human societies. Many scholars recognize the definition of family as the nucleus of people who are strictly involved in the management of the place where they reside, who support each other on a regular basis, linked by relationship of consanguinity, marriage or close personal relationship (Rillotta, Kirby, Shearer, & Nettelbeck, 2012). FQoL is defined as a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members (Zuna et al., 2009). It is collective because it is concerned with how the family members feel about their family's quality of life, as a group; it is also dynamic because it can change in response to significant events such as moving home, losing a family member, or having a child with disability (Bhopti, Brown, & Lentin, 2016). Families that function well support societies, and families with effective QoL are considered as a social resource.

The main purpose of developing a FQoL framework was to understand the impact of individuals with intellectual disabilities on the life quality of members of their families, factors involved and to explain why some families flourish in the presence of disability while others do not. Studies attempted to explore how various domains of life are impacted when there

is a child with a disability, that is facing long lasting, often unpredictable increased needs, and what are the perceptions of family members about family life in general. Such studies often explore the influence of each individual family member on the family as a whole, as well as the effects of services and community. FQoL can then provide a comprehensive indicator of program outcome that encompasses the broad impacts of services and offers opportunities to compare program effects across different service models (Summers et al., 2005).

A basic assumption strongly made is that the same major principles of quality of life may also be relevant to family quality of life, and these have been employed in the development of the survey instruments (Poston et al., 2003; Summers et al., 2005; Isaacs et al., 2007).

Two instruments currently are available for those who are interested in working on quality of life of families dealing everyday with disability of different origins and future perspectives.

The Beach Center Family Quality of Life Scale (Park, Hoffman, Marquis, Turnbull et al., 2003) is organized in three sections dedicated to demographic aspects of the family, the importance given and the perceived satisfaction in five different domains: family interactions, parenting, emotional well-being, physical well-being, material well-being and disability support. The psychometric characteristics, the test-retest reliability and the convergent and construct validity are satisfactory (Wang et al., 2004). A five-factor solution resulted in a 25-item scale, encompassing five domains of family quality of life. Respondents are asked to describe what the specific dimension means for them and how satisfied are in the related domains (Table 2).

<i>Family interaction</i>	Spending time together; supporting each other to accomplish goals.
<i>Parenting</i>	Helping the children with schoolwork and activities; teaching them to make good decisions.
<i>Emotional well-being</i>	Receiving support needed to relieve stress; time to pursue personal interests.
<i>Physical/material well-being</i>	Getting medical care, having transportation when needed.
<i>Disability-related support</i>	Support to progress at school or workplace; good relationships with service providers.

Table 2. *Domains of quality of life assessment in the Beach Center Family Quality of Life*

The Beach Center Family Quality of Life Scale and other family outcome measures have shown multiple potential users in policy makers, administrators, and practitioners in agencies providing supports and services to families of children with disabilities (Brown & Schippers, 2018).

The FQOL Survey-2006 measures the quality of families' lives (Brown, Brown, Baum, Isaacs, ... & Neikrug, 2006). In the underpinning idea, FQoL is multidimensional and influenced by many factors. Both subjective and objective elements are addressed using multiple methodologies (qualitative and quantitative). The purpose is understanding and improving life for individuals with ID and their families (Verdugo, Schalock, Keith, & Stancliffe, 2005). The questionnaire provides a qualitative and quantitative measurement along four concepts:

- *Opportunities*, refers to options available to families that are relevant to their needs;
- *Initiative*, refers to families taking advantage of available opportunities;
- *Attainment*, refers to getting or accomplishing those things that the family wants and needs;
- *Satisfaction*, refers to the overall perception of family members.

Attainment and Satisfaction are considered as outcome measures; these concepts represent, in fact, what families have been able to achieve in a specified life area and how they feel about their achievements. Opportunity and Initiative are descriptive dimensions. They refer to external conditions necessary for achieving a good FQoL, dependent on a wide range of interacting and changing factors and circumstances.

Each of these four concepts is measured in each of nine key areas of family quality of life, chosen on the basis of the literature on families with children who have intellectual disability: *health, financial well-being, family relationships, support from other people, support from services, careers and preparing for careers, spiritual and cultural life, leisure, and community and civic involvement*. At the end of the questionnaire respondents are required to report their satisfaction for their overall quality of life. The most promising use made of the survey is in supporting individual families to identify their own needs and sources of life quality.

The authors in a research study involving families of a person with disabilities highlighted that Family Relationships, Cultural and Spiritual Values and Career and, despite the difficulties encountered, Experienced Satisfaction mostly contributed to the quality of life of families

interviewed. Their general level of satisfaction regarding family relationships was quite high, especially in the categories trust one another, feel a sense of belonging, and support each other during challenging situations. The support received from relatives, friends and neighbors had little relevance from a practical point of view compared to the emotional one (Brown, Hatton, & Emerson, 2013).

Comparing families with a member diagnosed Down syndrome, autism spectrum disorders or other intellectual disabilities, it seems that QoL is higher in the first and second group. Families without disabilities showed significantly high levels of satisfaction in almost all areas, with the exception of the support obtained from disability services, civil and community participation (Brown, Cobigo, & Taylor, 2015). The analysis of overall satisfaction, foreseen in the last section of the tool, showed that in a group of relatives of a person with intellectual disability participants reported different perceptions when thinking to specific domains and when providing a general assessment (Werner, Edwards, Baum, Brown, & Brown, 2009). The presence of non-adaptive behavioral alterations, the degree of necessary supports, values of parents seem to significantly influence the perception of family quality of life in its entirety (Boehm, Carter, & Taylor, 2015).

Moreover, Bertelli, Bianco, Scuticchio and Brown (2011) analyzing the relationship between the scores related to the person with disability and those reported at the family level, found significant correlations only between some areas and underlined the specificity of FQoL perceived by the individual compared to that reported by the members of the family when asked about their own satisfaction. In particular, respondents reported limited levels of support from others, higher levels of family relationships and family health. On the other hand, individual levels showed limited spiritual and physical well-being. Although the relationships between the two areas of quality of life survey are complex, the results suggest the presence of specificity and relationships between the quality of life of the family and of the individual member.

Finally, Edwards, Parmenter, O'Brien, and Brown (2018) recently explored the meaning of social connections, barriers and facilitators in the large environments to family quality of life. Families who reported having rich social networks tended to be supported by friends, communities, and social services that actively reached out and took a strong role in organizing practical and emotional help. This active, well-planned support also appeared to be strengthened by supportive, family-centered programs and policy development that included and respected the voice of families.

The lesson from studies on Quality of Life, Family and intellectual disabilities: moving to an integrated approach

The conceptual paradigm, the levels of description and domains proposed underline a shift in QoL assessment from a framework useful to identify needs of families with disabilities and their members to a resource useful for identifying causes of discomfort, designing and evaluating prevention and rehabilitation interventions where environmental, social and economic considerations are taken into account in the pursuit of a development and an improved quality of life for both the individual and the family.

Both individual and family quality of life approaches have specific and general implications such as the importance of the well-being of individuals and families, the need for ways of assessing wellbeing, and the development of methods to address challenges and needs as they become known. Both are enhanced when basic needs are met and when there is the opportunity for the individual and the family to pursue and achieve goals in major life settings. Such goals include experiencing inclusive education or employment, social inclusion in free time activities; having the family the opportunity to pursue, achieve and enjoy life even when challenges are active (Summers et al., 2005; Brown & Schippers, 2016).

Considering recent studies and following suggestions from Schalock and co-authors recent model, it is then mandatory for an innovative and effective FQoL analysis to give space to perceptions of both individuals and family as a whole.

Assessment tools taking into account at least some of the suggestions outlined from the literature should then integrate the different levels of analysis and refer to both individual and family quality of life perspectives (Boelsma, Schippers, Dane, & Abma, 2018). This will at the same time prevent from a potential paradox in patterns outlined as arising from a non-integrated QoL assessment (Bertelli et al., 2011) and allow a respondent express subjective understandings and meaningful perceptions.

Studies suggest to address specific topics but also to adopt good practices and procedures:

- a. *Take into account both individual and family as a unit.* Individual and family patterns do not overlap in extent and depth. A first part of a sketched interview should be devoted to questions exploring individual experience of QoL, as a single individual and as a functions of the roles played by the individual within the family context. A second part should be devoted to questions related to the family as a whole, with different members being interviewed.

- b. *Adopt a personalized approach focusing on personal characteristics, enhancing resources and overcoming vulnerabilities.* Quantitative and qualitative tools and analyses, principles and concepts developed in addressing Individual and Family Quality of Life in studies on intellectual disability can be used in other areas and may be applicable and useful in a variety of settings to identify and address a wide range of challenges in other areas of experience, also in families dealing with disabilities of different origin (Sgaramella, Nota, & Soresi, 2014).
- c. *Address theoretically based issues and providing information on:*
 - **Wellbeing, Independence and Participation.* Complex time we are currently living require professionals to move beyond intra-individual characteristics opening the view to the context in which he/she lives, to its complexities and challenges.
 - **Opportunities, as well as Initiative and Attainment.* Quality of life of an individual and of his/her family is linked to possibilities and support to reach goals, either in education and employment. Involvement and support from the wider community are, in fact, relevant to enhance capabilities and to improve family quality of life (Migerode, Maes, Buysse, & Brondeel, 2012).
 - **Being, Belonging and Becoming.* An active commitment to personal life and to life goals is enhanced opening the view to the future and to actions aimed at foreseeing and promoting the highest level of life satisfaction in the future.

As recently Ivan Brown and Alice Schippers underlined, “*Identifying the causes, and the means of resolution, of challenges met is relevant to a wide range of families, and needs to be considered by professional and family supporters, whether working in the field of intellectual and developmental disabilities, brain injury, or mental health, or confronting the critical crises that can arise with any individual or family*” (Brown, & Schippers, 2018, pag. 2).

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